SJCARES Hospital-Based Cancer Registry

Part of the St. Jude Global Childhood Cancer Analytics Resource and Epidemiological Surveillance System

Data Dictionary and Technical Document

Version 2.2

St. Jude Global
SJCARES | REGISTRY

St. Jude Global

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Suggested Citation

The SJCARES Registry Collaborative Working Group. Department of Global Pediatric Medicine and St. Jude Global, St. Jude Children's Research Hospital (2019). *St. Jude Childhood Cancer Analytics Resource and Epidemiological Surveillance Systems (SJCARES) Hospital-Based Cancer Registry Data Dictionary & Technical Document* (ver 1.6), pp. 145. Available at: https://www.stjude.org/content/dam/en_US/shared/www/clinical/no-index/sjcares-data-dictionary.pdf

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SJCARES ID

Database Description

Database Label:	Patient Number
Definition:	Unique ID (random assignment by system) assigned to each unique patient.
Database Field Number:	1
Required:	Yes

Database Values

Data Type	String
Format	NNNNNNNNN
Maximum Character Length	10
Values	Automatically assigned

Additional Notes

Data Manager Notes:	Unique random number; will serve as key ID. The first eight numbers are unique to the patient and the last number indicates cancer case, which provides an option for second cancers.
Value Notes:	SJ IS to determine format and length. This data is completed once, as soon as the patient is identified for inclusion in the registry. Once submitted, this may not be changed without authorization from the database administrator.
Validation Notes:	To ensure data quality and no duplicative data entry across the registry at your site, logic has been added to determine if patient data are being entered into the tool (or registered) *more than once* or if patients have a secondary cancer that needs to be registered. Please see Appendix VI and the SJCARES Registry Operations Manual for specifics.

Date Created

Database Description

Database Label:	DATE_CREATED
Definition:	This date represents the day on which the SITE created the patient record in the SJCARES Registry.
Database Field Number:	2
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	10
Values	Automatically assigned

Additional Notes

Data Manager Notes:	None
Value Notes:	Automatically assigned. This data is completed once, as soon as the patient is identified for inclusion in the registry. Once submitted, this may not be changed without authorization from the database administrator.
Validation Notes:	DD/MM/YYYY

Site ID

Database Description

Database Label:	Site Number
Definition:	This field identifies which SITE, or unique clinical care facility, registered the patient.
Database Field Number:	3
Required:	Yes

Database Values

Data Type	Int
Format	NNNN
Maximum Character Length	6
Values	GPM to provide list of SJ Global Alliance Partner sites

Additional Notes

Data Manager Notes:	Variable will be used to link across SJCARES modules.
Value Notes:	Auto-populated as SITE of user entering record. This data is completed once, as soon as the patient is identified for inclusion in the registry. Once submitted, this may not be changed without authorization from the database administrator.
Validation Notes:	Auto-populated

First Name

Database Description

Database Label:	FNAME
Definition:	Registered patient's first name.
Database Field Number:	4
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	60
Values	NA

Additional Notes

Data Manager Notes:	St. Jude staff will not have access to this variable field.
Value Notes:	User defined. This data is completed once, as soon as the patient is identified for inclusion in the registry. Once submitted, this may not be changed without authorization from the database administrator.
Validation Notes:	

Last Name

Database Description

Database Label:	LNAME
Definition:	Registered patient's last name.
Database Field Number:	5
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	60
Values	NA

Additional Notes

Data Manager Notes:	St. Jude staff will not have access to this variable field.
Value Notes:	User defined. This data is completed once, as soon as the patient is identified for inclusion in the registry. Once submitted, this may not be changed without authorization from the database administrator.
Validation Notes:	

Middle Name or Alternative Family Name

Database Description

Database Label:	ANAME
Definition:	Registered patient's middle or alternative family name.
Database Field Number:	6
Required:	No

Database Values

Data Type	String
Format	Text
Maximum Character Length	60
Values	NA

Additional Notes

Data Manager Notes:	GPM to provide a list of countries where the label would appear as “Alternate Family Name.” St. Jude staff will not have access to this variable field.
Value Notes:	User defined. Dependent on country-context, to be in line with social or cultural norms. This data is completed once, as soon as the patient is identified for inclusion in the registry. Once submitted, this may not be changed without authorization from the database administrator.
Validation Notes:	

Date of Birth

Database Description

Database Label:	DOB
Definition:	The birth date of the patient.
Database Field Number:	7
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	None
Value Notes:	User defined. This data is completed once, as soon as the patient is identified for inclusion in the registry. Once submitted, this may not be changed without authorization from the database administrator.
Validation Notes:	DD/MM/YYYY and cannot be after any other dates in registry.

Gender

Database Description

Database Label:	SEX
Definition:	The biological difference between male and female, represented by a code.
Database Field Number:	8
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(1) Male
	(2) Female
	(3) Other

Additional Notes

Data Manager Notes:	
Value Notes:	This data is completed once, as soon as the patient is identified for inclusion in the registry. Once submitted, this may not be changed without authorization from the database administrator.
Validation Notes:	Limited to radio button selection.

National ID Number

Database Description

Database Label:	NATID
Definition:	Based on registration system unique to each country but different from Reference ID to link patient to their medical records.
Database Field Number:	9
Required:	Yes

Database Values

Data Type	String
Format	TBD (dependent upon site format)
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Based on registration system unique to each country. Specified by institutions on the worksheet (Appendix III). Some countries may not have such a variable, so this will be hidden in those instances. St Jude staff will not have access to this variable field.
Value Notes:	User defined. What users see will change, based upon country context. This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	

Medical Record Number

Database Description

Database Label:	REFID
Definition:	Unique pseudonymized reference ID linked to a patient identifier at the SITE registering patient. Can be used to link patient to their local records.
Database Field Number:	10
Required:	Yes

Database Values

Data Type	String
Format	TBD (dependent upon site format)
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Reference ID for primary hospital to link to their records such as a medical record number; based on registration system unique to each country. Specified by institutions on the worksheet (Appendix III). St Jude staff will not have access to this variable field.
Value Notes:	User defined. This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	

Address Line 1

Database Description

Database Label:	ADD1
Definition:	The street name and number that identifies the usual physical place of residence (street number and name) of a patient.
Database Field Number:	11
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	St. Jude staff will not have access to this variable field. Site will provide format of standard address locally for visual field label.
Value Notes:	User defined (Appendix III). This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	

Address Line 2

Database Description

Database Label:	ADD2
Definition:	Additional information that identifies the usual physical place of residence of a patient.
Database Field Number:	12
Required:	No

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Hide from SITE-view if not necessary. St. Jude staff will not have access to this variable field. Site will provide format of standard address locally for visual field label.
Value Notes:	User defined (Appendix III). This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	

Address Line 3

Database Description

Database Label:	ADD3
Definition:	Additional information that identifies the usual physical place of residence of a patient.
Database Field Number:	13
Required:	No

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Hide from SITE-view if not necessary. St. Jude staff will not have access to this variable field. Site will provide format of standard address locally for visual field label.
Value Notes:	User defined (Appendix III). This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	

Address Line 4

Database Description

Database Label:	ADD4
Definition:	Additional information that identifies the usual physical place of residence of a patient.
Database Field Number:	14
Required:	No

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Hide from SITE-view if not necessary. St. Jude staff will not have access to this variable field. Site will provide format of standard address locally for visual field label.
Value Notes:	User defined (Appendix III). This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	

City

Database Description

Database Label:	DMCITY
Definition:	The name of the city that identifies the usual physical place of residence of a patient.
Database Field Number:	15
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	50
Values	NA

Additional Notes

Data Manager Notes:	Options will filter based off "Usual Residence Country" selection. St. Jude staff will not have access to this variable field.
Value Notes:	SITES will define and provide their own values (Appendix III). This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	

State/Province

Database Description

Database Label:	DMSTATE
Definition:	The name of the state or province that identifies the usual physical place of residence of a patient.
Database Field Number:	16
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	50
Values	NA

Additional Notes

Data Manager Notes:	Options will filter based off "Usual Residence Country" selection. St Jude staff will not have access to this variable field.
Value Notes:	SITES will define and provide their own values (Appendix III). This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	Limited to defined values

Country

Database Description

Database Label:	DMCNTRY
Definition:	The country in which the registered patient lives or intends to live for six months or more.
Database Field Number:	17
Required:	Yes

Database Values

Data Type	String
Format	AAA
Maximum Character Length	50
Values	https://www.iso.org/iso-3166-country-codes.html

Additional Notes

Data Manager Notes:	Three letter format would be the database value. The country name would be used for entry with an auto-search off full name country list. St Jude staff will not have access to this variable field.
Value Notes:	ISO list. This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	Limited to defined values; include three (3) character code

Race

Database Description

Database Label:	RACEDYN
Definition:	Code the patient's race.
Database Field Number:	18
Required:	Yes

Database Values

Data Type	String
Format	NN
Maximum Character Length	100
Values	GPM to provide a list of options to be filled into a table on the Site Form so that the options are customized per site.

Additional Notes

Data Manager Notes:	Each institution will provide a unique list, on Appendix III, based on the appropriate country census designations.
Value Notes:	Numeric code mapped against drop down list of text variable responses. This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	Limited to select pre-defined values

Ethnic Group

Database Description

Database Label:	ETHNDYN
Definition:	Code the patient's ethnicity.
Database Field Number:	19
Required:	Yes

Database Values

Data Type	String
Format	NN
Maximum Character Length	100
Values	GPM to provide a list of options to be filled into a table on the Site Form so that the options are customized per site.

Additional Notes

Data Manager Notes:	Each institution will provide a unique list, on Appendix III, based on the appropriate country census designations.
Value Notes:	Numeric code mapped against drop down list of text variable responses. This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	Limited to select pre-defined values

Parent/Primary Caregiver Name

Database Description

Database Label:	DMPCNAME
Definition:	First and last name of patient's mother, parent, guardian, or primary caregiver. Refers to the individual who is to be contacted for the patient's follow-up.
Database Field Number:	20
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Adjust in SOP based on death certificate data process locally. St. Jude staff will not have access to this variable field.
Value Notes:	User defined. This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	

Parent/Primary Caregiver Highest Education

Database Description

Database Label:	DMPAREDU
Definition:	The highest level of education achieved by either parent, guardian, or primary caregiver of the patient; again, refers to the individual who is to be contacted for patient follow-up.
Database Field Number:	21
Required:	Yes

Database Values

Data Type	Int
Format	N
Maximum Character Length	1
Values	(1) None (2) 1-8 years (grade school) (3) 9-12 years (high school/O-level), but did not graduate (4) Completed high school/GED/A-levels (5) Training after high school, other than college (vocational/community college) (6) College graduate (7) Post-graduate level (99) Unknown

Additional Notes

Data Manager Notes:	Keep categories but adjust terms based on local schooling labels in each country.
Value Notes:	This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	Limited to defined values

Best Phone Number(s) to Contact Patient/Caregiver

Database Description

Database Label:	DMPHN
Definition:	Best phone number(s) to contact family and/or patient, for the purposes of follow-up. Can include family friends or relatives.
Database Field Number:	22
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Allow for user to choose not applicable and click + sign to enter additional numbers. St. Jude will not have access to this variable field.
Value Notes:	User defined. This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	

Best E-Mail(s) to Contact Patient/Caregiver

Database Description

Database Label:	DMEML
Definition:	Best e-mail address(es) to contact family and/or patient, for the purposes of follow-up. Can include family friends or relatives.
Database Field Number:	23
Required:	No

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Allow for user to choose not applicable and click + sign to enter additional e-mail addresses. St. Jude will not have access to this variable field.
Value Notes:	User defined. This is completed once, as soon as the patient is identified for inclusion in the registry. Update field when applicable.
Validation Notes:	Valid email addresses should have @ symbol.

Date of Initial Onset of Cancer-Related Symptoms

Database Description

Database Label:	DIAGIDAT
Definition:	Date the patient began to experience symptoms and signs related to cancer. If exact date is unknown, enter the approximate date (“XX/XX/YEAR” or “XX/MON/YEAR”).
Database Field Number:	24
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	
Value Notes:	User defined. Complete or answer once, as soon as the data isavailable. May require approximation; if initial date is uncertain, round to first day of the nearest month or select date not found. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	DD/MM/YYYY and cannot be before date of birth or after dates of first cancer-related medical assessment, diagnosis, or treatment; field to be locked from edits.

Date of First Medical Assessment for Cancer Associated Symptoms

Database Description

Database Label:	DIAGFDAT
Definition:	Date the patient first sought primary care for cancer-related symptoms at any hospital/clinic with a healthcare provider prior to admission If exact date is unknown, enter the approximate date (“XX/XX/YEAR” or“XX/MON/YEAR”).
Database Field Number:	25
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	
Value Notes:	User defined. Complete or answer once, as soon as the data isavailable. May require approximation; if date is uncertain, round to first day of the nearest month or select date not found. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	DD/MM/YYYY and cannot be before dates of birth or cancer-related symptom initial onset or after dates of diagnosis or treatment; field to be locked from edits.

Does Patient Have a Confirmed Cancer Diagnosis

Database Description

Database Label:	DIAGCONF
Definition:	Confirmation of a cancer diagnosis, whether clinically or microscopically, by a recognized medical practitioner.
Database Field Number:	26
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(Y) Yes (N) No

Additional Notes

Data Manager Notes:

Value Notes:	User defined. Complete or answer once, as soon as the data isavailable. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	If No, only the data field for Non-Cancer Diagnosis and Referral Sourcewill appear. If Yes, all other questions on the Diagnosis form will appear and are to be answered.

What is the Patient's Non-Cancer Diagnosis

Database Description

Database Label:	DIAGUNCF
Definition:	Open ended, free text annotation of non-cancer diagnosis
Database Field Number:	27
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Open ended opportunity to annotate record of the non-cancer diagnosis
Value Notes:	Free text.
Validation Notes:	If Confirmed Cancer Diagnosis= 0, then this data field should appear.

Date of Diagnosis

Database Description

Database Label:	DIAGDAT
Definition:	Date of initial diagnosis, whether clinically or microscopically confirmed, by a recognized medical practitioner.
Database Field Number:	28
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	
Value Notes:	User defined. Complete or answer once, as soon as the data isavailable. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	DD/MM/YYYY and cannot be before dates of birth, cancer-related symptom initial onset, first cancer-related medical assessment or after treatment; field to be locked from edits.

Age at Diagnosis

Database Description

Database Label:	AGE
Definition:	Automatically generated based on patient's date of birth and date of diagnosis; age appears in years.
Database Field Number:	29
Required:	Yes

Database Values

Data Type	Int
Format	NN
Maximum Character Length	2
Values	Automatically assigned

Additional Notes

Data Manager Notes:	No user data entry, only available for visual cross-check
Value Notes:	Calculated by combination of patient's birth date and diagnosis date. Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Date of diagnosis cannot be before date of birth. Field locked from edits.

Best Method of Diagnosis Used

Database Description

Database Label:	DIAGMETH
Definition:	Select the best method that was used for diagnostic confirmation of the cancer being reported at any time in the patient's history. The highest in the hierarchy should be selected if multiple diagnostic methods were used (autopsy/death certificate>microscopic verification>exploratory surgery>imaging (CT, MRI)>lab exams>clinical examination).
Database Field Number:	30
Required:	Yes

Database Values

Data Type	Int
Format	N
Maximum Character Length	100
Values	(1) Clinical examination (2) Lab exams (includes tumor markers) (3) Imaging (4) Exploratory surgery (without specimen/biopsy) (5) Microscopic verification (6) Autopsy/death certificate

Additional Notes

Data Manager Notes:	In cases where more than one value can be chosen, the highest in the hierarchy should be selected (Autopsy/death certificate>microscopic verification>exploratory surgery>imaging>lab exams>clinical examination).
Value Notes:	Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Limited to defined values

Topography/Site

Database Description

Database Label:	DIAGTOP
Definition:	Codes for the topography/site of the tumor being reported using ICD-O-3.
Database Field Number:	31
Is Field Required:	Yes

Database Values

Data Type	String
Format	NNN
Maximum Character Length	100
Values	http://www.iacr.com.fr/index.php?option=com_content&view=category&layout=blog&id=100&Itemid=577

Additional Notes

Data Manager Notes:	See cross-check logic in table.
Value Notes:	IARC List. Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Limited to defined values; Must be a valid ICD-O-3 code.

Morphology: Type & Behavior Code

Database Description

Database Label:	DIAGMORP
Definition:	Codes for the histologic type and behavior of the tumor being reported using ICD-O-3.
Database Field Number:	32
Required:	Yes

Database Values

Data Type	String
Format	NNNN[/]N
Maximum Character Length	100
Values	http://www.iacr.com.fr/index.php?option=com_content&view=category&layout=blog&id=100&Itemid=577

Additional Notes

Data Manager Notes:	See cross-check logic in table.
Value Notes:	IARC List. Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Limited to defined values; Must be a valid ICD-O-3 code.

ICCC-3 Extended Classification Code

Database Description

Database Label:	DIAGIECC
Definition:	Automatically generated based on ICD-0-3.
Database Field Number:	33
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	50
Values	https://seer.cancer.gov/iccc/iccc3_ext.html

Additional Notes

Data Manager Notes:	No user data entry, only available for visual cross-check
Value Notes:	Calculated by combination of morphology and topography codes. Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	GPM will provide mapping rules between ICD-O-3 and ICCC3

Laterality of Primary Site

Database Description

Database Label:	TUMLAT
Definition:	Code for the side of a paired organ, or the side of the body on which the reportable tumor originated. This applies to the primary site only.
Database Field Number:	34
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(0) Not a paired SITE
	(1) Right: origin of primary
	(2) Left: origin of primary
	(3) Only one side involved, right or left origin unspecified
	(4) Bilateral involvement at time of diagnosis, lateral origin unknown for a single primary; or both ovaries involved simultaneously, single histology; bilateral retinoblastomas; bilateral Wilms' tumors
	(5) Paired SITE: midline tumor
	(9) Paired SITE, but no information concerning laterality

Additional Notes

Data Manager Notes:	Add logic to hide this variable for tumors without a paired site.
Value Notes:	Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Cross check laterality with topography Code (do not allow bilateral option if Behavior code is in-situ); Limited to defined values. (paired SITE validation from CanReg5 validation rules).

HIV Status

Database Description

Database Label:	DIAGHV
Definition:	Code for the indication of Human Immunodeficiency Virus (HIV)/Acquired Immune Deficiency Syndrome (AIDS). If there is no mention of HIV/AIDS in patient medical record, select "HIV status not assessed or unknown if assessed."
Database Field Number:	35
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(1) HIV positive (2) HIV negative (9) HIV status not assessed or unknown if assessed

Additional Notes

Data Manager Notes:	HIV/AIDS is closely related to some neoplasms (eg. Kaposi sarcoma, lymphomas). If HIV/AIDS is not mentioned in medical record, select (9) and DO NOT assume nor select HIV negative (2).
Value Notes:	Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Limited to defined values.

Date of HIV+ Test

Database Description

Database Label:	DIAGHVDAT
Definition:	Code the date patient was tested for HIV and the result was positive. If exact date is unknown, enter the approximate date ("XX/XX/YEAR" or "XX/MON/YEAR").
Database Field Number:	36
Required:	No

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	
Value Notes:	User defined. Complete or answer once, as soon as the data is available. Update fields when applicable. May require approximation; if exact date is uncertain, round to the first day of the nearest month or enter the approximate year.
Validation Notes:	DD/MM/YYYY and cannot be before date of birth; field should only appear if 'HIV Status'= 1 (HIV Positive) and to be locked from edits.

Referral Source

Database Description

Database Label:	DIAGSRC
Definition:	Codes the earliest source of identifying information for who sent the patient to the hospital or site. For cases identified by a source other than reporting facilities (such as through death clearance or result of an audit), this variable codes the type of source through which the tumor was first identified.
Database Field Number:	37
Required:	Yes

Database Values

Data Type	Int/Float
Format	NN
Maximum Character Length	100
Values	(1) Reporting Hospital (2) Outside Hospital/Clinic (3) Pathology/Diagnostic Lab (4) Radiation Therapy Department/Center (5) General Surgery (6) Neuro Surgery (7) Orthopedics (8) Diagnostic Imaging/Radiology (9) Family Physician/Pediatrician (99) Other Hospital Source, Specify _____

Additional Notes

Data Manager Notes:	When (1) Reporting Hospital is marked, the Place of Diagnosis data elements should all auto-populate, add logic.
Value Notes:	Adapted from NACCRR codes. Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Limited to defined values

Class of Case

Database Description

Database Label:	COC
Definition:	This field distinguishes cases that are usually included in a hospital's treatment and survival statistics from those that are not.
Database Field Number:	38
Required:	Yes

Database Values

Data Type	String
Format	NN
Maximum Character Length	100
Values	(1) New case to center without diagnosis and without treatment
	(2) New case to center with diagnosis but without treatment
	(3) New case to center with diagnosis and non-chemotherapy treatment elsewhere
	(4) New case to center with diagnosis and chemotherapy treatment elsewhere
	(5) New relapse or refractory/ disease case to center

Additional Notes

Data Manager Notes:	Add logic to reduce options based on “referral source”. If “referral source” =1 then class of case choices should be either (1) or (5).
Value Notes:	Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator. Analytical values will include values 1-3.
Validation Notes:	Limited to defined values

Place of Diagnosis – Name

Database Description

Database Label:	DIAGNAME
Definition:	Name of hospital or facility where patient was first clinically diagnosed with a cancer.
Database Field Number:	39
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	
Value Notes:	User defined. Values will not be shown if “referral source” =1 (patient was found in the hospital/reporting institution). Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	

Place of Diagnosis – Country

Database Description

Database Label:	Country
Definition:	Country where patient was first clinically diagnosed with a cancer.
Database Field Number:	40
Required:	Yes

Database Values

Data Type	String
Format	AAA
Maximum Character Length	50
Values	https://www.iso.org/iso-3166-country-codes.html

Additional Notes

Data Manager Notes:	Three letter format would be the database value. The country name would be used for entry with an auto-search off full name country list.
Value Notes:	ISO list. Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Limited to defined values; include three (3) character code

Place of Diagnosis – City

Database Description

Database Label:	City
Definition:	City of facility where patient was first clinically diagnosed with a cancer.
Database Field Number:	41
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	50
Values	NA

Additional Notes

Data Manager Notes:	Options will filter based off "Place of diagnosis Country" selection
Value Notes:	Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	

Place of Diagnosis - State/Province

Database Description

Database Label:	STATEP
Definition:	State or province of facility where patient was first clinically diagnosed with a cancer.
Database Field Number:	42
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	50
Values	NA

Additional Notes

Data Manager Notes:	Options will filter based off "Place of diagnosis Country" selection
Value Notes:	Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Limited to defined value

Place of Diagnosis – Address Line 1

Database Description

Database Label:	DIAGADD1
Definition:	Address of facility where patient was first clinically diagnosed with a cancer.
Database Field Number:	43
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	St. Jude staff will not have access to this variable field. Site will provide format of standard address locally for visual field label. Hide from SITE-view if not necessary.
Value Notes:	User defined. Values will not be shown if “referral source” =1 (patient was found in the hospital/reporting institution). Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	

Place of Diagnosis - Address Line 2

Database Description

Database Label:	DIAGADD2
Definition:	Address of facility where patient was first clinically diagnosed with a cancer.
Database Field Number:	44
Required:	No

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	St. Jude staff will not have access to this variable field. Site will provide format of standard address locally for visual field label. Hide from site-view if not necessary
Value Notes:	User defined. Values will not be shown if “referral source” =1 (patient was found in the hospital/reporting institution). Complete or answer once, as soon as the data is available. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	

Stage

Database Description

Database Label:	STG
Definition:	This item stores the results of clinical stage groupings based on the Toronto Pediatric Cancer Staging guidelines and consensus.
Database Field Number:	45
Required:	Yes

Database Values

Data Type	String
Format	Drop down list with logic based on diagnostic group/subgroup, values and logic for childhood cancer types are reflected in Appendix IV, and in the paper & link provided below.
Maximum Character Length	See Toronto System tables and manual (Appendix IV), endorsed by IARC and provided by Aitken, authors of the paper directly below.
Values	Aitken JF, Youlden DR, Ward LJ, Thursfield VJ, Baade PD, Hallahan AR, Green AC, Valery PC, Gupta S, Frazier AL, 2016. *Childhood cancer staging rules for population registries, based on the Toronto Paediatric Cancer Stage Guidelines.* Cancer Council Queensland: Brisbane, Australia. http://www.iacr.com.fr/index.php?option=com_content&view=article&id=153&Itemid=65

Additional Notes

Data Manager Notes:	Diagnosis-specific based on chart from paper, will link to directly to ICCC3 code. If the cancer diagnosis does not map to a staging system, the value for stage will read “not applicable.”
Value Notes:	Implemented based on Toronto Staging consensus, includes various staging systems appropriate for corresponding diagnoses such as Ann Arbor- for Hodgkin lymphoma, INRGSS- for Neuroblastoma, and TNM- for Osteosarcoma. Complete or answer only once, related to the initial diagnosis, as soon as the data is available within 3 months following completion of the demographic form. Update fields when applicable; certain data may not be edited without authorization from the database administrator.
Validation Notes:	Limited to defined values

Comments- Stage

Database Description

Database Label:	STGCOMM
Definition:	Open ended, free text annotation of cancer staging
Database Field Number:	46
Required:	No

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Open ended opportunity to annotate record
Value Notes:	Free text
Validation Notes:	

Date of Referral to Treatment Institution

Database Description

Database Label:	EXATIDAT
Definition:	Date of when the patient came into the reporting site for the first consultation, inpatient admission or outpatient clinic.
Database Field Number:	47
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	
Value Notes:	User defined.
Validation Notes:	DD/MM/YYYY and cannot be before date of birth, date of cancer symptoms onset, or date of first medical assessment for cancer associated symptoms

Date Curative Treatment Started

Database Description

Database Label:	EXSTDAT
Definition:	Date of the inpatient admission or outpatient clinic at the reporting site to start definitive treatment.
Database Field Number:	48
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	
Value Notes:	User defined. Should be completed one time to capture INITIAL treatment given.
Validation Notes:	DD/MM/YYYY and cannot be before date of birth

Treatment with Curative Intent Given ENTIRELY at your site

Database Description

Database Label:	EXGAH
Definition:	Records whether treatment with curative intent was administered at the reporting site.
Database Field Number:	49
Required:	Yes

Database Values

Data Type	Int
Format	N
Maximum Character Length	100
Values	(0) No
	(1) Yes
	(9) Unknown

Additional Notes

Data Manager Notes:	
Value Notes:	Should be completed one time to capture INITIAL treatment given.
Validation Notes:	Limited to defined values

Reason Curative Treatment Not Given

Database Description

Database Label:	EXRSN
Definition:	Records the reason treatment with curative intent was not administered at the reporting site.
Database Field Number:	50
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	100
Values	(1) Curative treatment planned
	(2) Active surveillance (watchful waiting)
	(3) Definitive control or cure of disease not a feasible a goal
	(4) Failed to start treatment to accomplish cure or definitive control (including upfront treatment abandonment or refusal of curative-intent treatment)
	(5) Patient treated ENTIRELY at another center
	(11) Patient treated PARTIALLY at another center
	(6) Patient treated for palliative purposes as curative treatment not feasible
	(7) Death
	(8) Patient refused any treatment (including palliation)
	(9) Not specified

Additional Notes

Data Manager Notes:	Show if "Treatment with curative intent given" = 0
Value Notes:	Should be completed one time to capture INITIAL treatment(s) given.
Validation Notes:	Limited to defined values. If (5) or (6) selected, require the other facility name, country, city, and address fields to be completed

Type of Palliative Therapies Delivered

Database Description

Database Label:	EXTPT
Definition:	Records whether palliative treatment was administered at the reporting site
Database Field Number:	51
Required:	Yes

Database Values

Data Type	Int
Format	N
Maximum Character Length	100
Values	(1) Palliative anti-cancer therapies given (without curative intent)
	(2) Symptom management only (watchful waiting)
	(3) Unknown type of palliative treatment given

Additional Notes

Data Manager Notes:	Show if "Reason curative treatment not given?" = 6
Value Notes:	Should be completed one time to capture INITIAL treatment(s) given.
Validation Notes:	Limited to list options

Is the Patient Being Treated on a Therapeutic Protocol

Database Description

Database Label:	EXTTPYN
Definition:	Records whether patients are treated on a clinical treatment protocol with a specific reference name and ID.
Database Field Number:	52
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(Y) Yes
	(N) No

Additional Notes

Data Manager Notes:	
Value Notes:	Yes or No. Should be completed one time to capture INITIAL treatment(s) given.
Validation Notes:	Limited to Y/N

Protocol Details or ID

Database Description

Database Label:	EXTP
Definition:	Details of the specific treatment protocol name/ID.
Database Field Number:	53
Required:	Yes

Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Show if "Is the patient being treated on a therapeutic protocol?" = (1) Yes
Value Notes:	User defined. Should be completed one time to capture INITIALtreatment(s) given.
Validation Notes:	

Treatment Data Collected

Database Description

Database Label:	EXCHEMYN, EXRADYN, EXSURYN, EXHEMYN, EXRSTYN, EXPSMYN
Definition:	Records whether patients are initially treated with chemotherapy, external beam radiation, surgery, hematopoietic stem cell transplantation, retinoblastoma-specific treatment types, and pain/symptom management.
Database Field Number:	54
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	Chemotherapy: (Y) Yes (N) No External Beam Radiation: (Y) Yes (N) No Cancer Tumor Directed Surgery: (Y) Yes (N)No Hematopoietic Stem Cell Transplantation: (Y) Yes (N)No Retinoblastoma-Specific Treatments: (Y) Yes (N) No Pain/Symptom Management: (Y) Yes (N) No

Additional Notes

Data Manager Notes:	
Value Notes:	Yes or No. Should be completed one time to capture INITIAL treatment(s) given.
Validation Notes:	Limited to Y/N. Hematopoietic Stem Cell Transplantation field should appear when “Treatment with curative intent given” = 1, Retinoblastoma-Specific Treatment field only appears with the appropriate diagnostic ICCC3 code, and Pain/Symptom Management field should appear when “Treatment with curative intent given” = 0.

Initial Curative Treatments Given

Database Description

Database Label:	EXTX
Definition:	Records the initial type of treatment with curative intent administered at the reporting site.
Database Field Number:	55
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	255

Values

Chemotherapy:	External Beam Radiation:
Allopurinol	Head
Asparaginase	Neck
Bleomycin	Chest
Carboplatin	Abdomen
Cisplatin	Pelvis
Cyclophosphosphamide	Extremity
Cytarabine	Spine
Dacarbazine	Other
Dactinomycin	
Daunorubicin	
Doxorubicin	Surgery:
Etoposide	Gross-total resection plus removal of adjacent structures
G-CSF (or Filgrastim)	
Ifosfamide	Gross-total resection but limited to a single organ

Imatinib (or other TKI)

Leucovorine

Mercaptopurine

Mesna

Methotrexate

Paxlitaxel

Steroids

Thioguanine

Vinblastine

Vincristine

Other_____

Sub-total resection
Palliative surgery not directed at tumor

Hematopoietic Stem Cell Transplantation:

Autologous stem cells

Matched related stem cells

Matched unrelated stem cells

Unmatched related stem cells

Retinoblastoma Specific Treatments:

Laser

Cryotherapy

Brachytherapy

Intra-arterial

Intraocular/Local Chemotherapy

Additional Notes

Data Manager Notes: Show if "Treatment with curative intent given" = 1. Add logic and dynamic coding to link ICCC3 diagnostic codes to appropriate chemotherapy options. Add logic to show “RB-specific treatment” choices only for retinoblastoma.

Value Notes: Should be completed one time to capture INITIAL treatment(s) given.

Validation Notes:

Initial Palliative Treatments Given

Database Description

Database Label:	EXTX
Definition:	Records the initial palliative treatment types administered at the reporting site.
Database Field Number:	56
Required:	Yes

Database Values

Data Type	Code-Number	
Format	N	
Maximum Character Length	2	
Values	Chemotherapy:	External Beam Radiation:
	Allopurinol	Head
	Asparaginase	Neck
	Bleomycin	Chest
	Carboplatin	Abdomen
	Cisplatin	Pelvis
	Cyclophosphosphamide	Extremity
	Cytarabine	Spine
	Dacarbazine	Other
	Dactinomycin	
	Daunorubicin	
	Doxorubicin	Surgery:
	Etoposide	Gross-total resection plus removal of adjacent structures
	G-CSF (or Filgrastim)	
	Ifosfamide	Gross-total resection but limited to a single topographical location
	Imatinib (or other TKI)	Sub-total resection

Leucovorine

Mercaptopurine

Mesna

Methotrexate

Paxlitaxel

Steroids

Thioguanine

Vinblastine

Vincristine

Other_____

Palliative surgery not directed at tumor

Pain / Symptom Management:

Opiates

Psychiatric Medications (i.e. antipsychotics, antidepressants, etc.)

Traditional Medicines

Homeopathic/Alternative Therapies (i.e. acupuncture, massage therapy, etc.)

Psychosocial Interventions

Additional Notes

Data Manager Notes: Show if "Treatment with curative intent given" = 0. Add logic and dynamic coding to link ICCC3 diagnostic codes to appropriate chemotherapy options.

Value Notes: Should be completed one time to capture INITIAL treatment(s) given.

Validation Notes:

Remission

Database Description

Database Label:	FURELTXT
Definition:	Record of the patient's cancer remission or inactive disease status.
Database Field Number:	57
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(Y) Yes (N) No

Additional Notes

Data Manager Notes:	
Value Notes:	Should be obtained at each evaluation, i.e. CR, PR, etc. To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	Limited to defined values

Date of Remission

Database Description

Database Label:	FURELDAT
Definition:	The date remission (inactive disease or no evidence of disease) was achieved.
Database Field Number:	58
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	Add logic to require completion of “Date of remission” if “Patient presented with remission” =1.
Value Notes:	User defined. When applicable, to be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations. If relapse, date of actual relapse should be recoded. If no relapse, date of most recent disease evaluation should be recorded.
Validation Notes:	DD/MM/YYYY and cannot be before dates of birth, diagnosis, referral, starting treatment, nor before the date of relapse/recurrence

Still in Remission

Database Description

Database Label:	FURELTXT
Definition:	Record of whether or not the patient is still in remission or inactive disease status since the last follow-up timepoint.
Database Field Number:	59
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(Y) Yes (N) No

Additional Notes

Data Manager Notes:	
Value Notes:	Should be obtained at each evaluation, i.e. CR, PR, etc. To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	Limited to defined values. If this data field (still in remission) =1, then add logic that no more diseases-related questions be asked on the current form. If this data field (still in remission) =2, then prompt relapse/recurrence data field to appear.

Relapse or Recurrence

Database Description

Database Label:	FURELTXT
Definition:	Record of the patient's relapse or recurrence status since the last follow-up timepoint.
Database Field Number:	60
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(Y) Yes (N) No

Additional Notes

Data Manager Notes:	
Value Notes:	Should be obtained at each evaluation, i.e. CR, PR, etc. To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	Limited to defined values

Date of Relapse or Recurrence

Database Description

Database Label:	FURELDAT
Definition:	The date relapse/recurrence occurred.
Database Field Number:	61
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	Add logic to require completion of “Date of relapse” if “Patient presented with relapse/recurrence” =1.
Value Notes:	User defined. When applicable, to be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations. If relapse, date of actual relapse should be recoded. If no relapse, date of most recent disease evaluation should be recorded.
Validation Notes:	DD/MM/YYYY and cannot be before dates of birth, diagnosis, referral, starting treatment

Additional Treatment Given ENTIRELY at Your Site Since Last Data Entry

Database Description

Database Label:	FUPPRYN
Definition:	Specify if the patient has had any treatment since the last time data was entered and if so, select the types of treatment (curative, palliative, or both) given in the interval since last update to registry
Database Field Number:	62
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(Y) Yes ▪ Curative treatment given ▪ Palliative treatment given (N) No (U) Unknown

Additional Notes

Data Manager Notes:	Add logic to allow user to select both (1) Curative treatment given and (2) Palliative treatment given, when applicable.
Value Notes:	To be completed at 6 months following the treatment form, and every calendar year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	Limited to defined values

Treatment Types Since Last Follow-Up

Database Description

Database Label:	EXCHEMYN, EXRADYN, EXSURYN, EXHEMYN, EXRSTYN, EXPSMYN
Definition:	Records whether patients were treated with chemotherapy, external beam radiation, surgery, hematopoietic stem cell transplantation, retinoblastoma-specific treatment types, and pain/symptom management since the last time data was entered (during the follow-up period).
Database Field Number:	63
Required:	Yes

Database Values

Data Type	Code-Number
Format	N
Maximum Character Length	1
Values	Chemotherapy: (Y) Yes (N) No External Beam Radiation: (Y) Yes (N) No Cancer Tumor Directed Surgery: (Y) Yes (N) No Hematopoietic Stem Cell Transplantation: (Y) Yes (N) No Retinoblastoma-Specific Treatments: (Y) Yes (N) No Pain/Symptom Management: (Y) Yes (N) No

Additional Notes

Data Manager Notes:	
Value Notes:	Yes or No. To be completed at 6 months following the treatment form, and every calendar year until one of the milestones is met (>5 years cancer survivorship, death, or lost to follow-up).
Validation Notes:	Limited to Y/N. Hematopoietic Stem Cell Transplantation field should appear when “Additional treatment at follow-up” = 1 and curative treatment given is selected, Retinoblastoma-Specific Treatment field only appears with the appropriate diagnostic ICCC3 code, and Pain/Symptom Management field should appear when “Additional treatment at follow-up” = 1 and palliative treatment given is selected.

Reason Curative Treatment Not Given at Follow-Up, Reason

Database Description

Database Label:	FUTXRSN
Definition:	Select why curative therapy not pursued during follow-up period.
Database Field Number:	64
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	100
Values	(1) Treatment planned (2) Active surveillance (watchful waiting) (3) Definitive control or cure of disease not a feasible a goal (4) Missed at least 4 weeks of curative therapy to extent that impacts ability to control disease (treatment abandonment) (5) Patient treated ENTIRELY at another center (11) Patient treated PARTIALLY at another center (6) Patient treated for palliative purposes as curative treatment not feasible (7) Death (8) Patient in remission without relapse (9) Patient refused any treatment (including palliation) (10) Not specified

Additional Notes

Data Manager Notes:	Show if "Additional treatment at follow-up" = 0
Value Notes:	To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	Limited to defined values. If (5) or (6) selected, require the other facility name, country, city, and address fields to be completed

Type of Palliative Therapies Delivered at Follow-Up

Database Description

Database Label:	FUTPT
Definition:	Types of palliative treatments provided if curative treatment not pursued.
Database Field Number:	65
Required:	Yes

Database Values

Data Type	Int
Format	N
Maximum Character Length	100
Values	(1) Palliative anti-cancer therapies given (without curative intent)
	(2) Symptom management only (watchful waiting)
	(3) Unknown type of palliative treatment given

Additional Notes

Data Manager Notes:	Show if “Additional treatment at follow-up” = 1, and palliative treatment given is checked and "Reason curative treatment not given at follow-up?" =6
Value Notes:	To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	Limited to list options

Curative Treatments Given During Follow-Up Period

Database Description

Database Label:	EXTX
Definition:	At each follow-up, please select all treatments with curative intent given in the interval since the last registry update.
Database Field Number:	66
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	255

Values

Chemotherapy:	External Beam Radiation:
Allopurinol	Head
Asparaginase	Neck
Bleomycin	Chest
Carboplatin	Abdomen
Cisplatin	Pelvis
Cyclophosphosphamide	Extremity
Cytarabine	Spine
Dacarbazine	Other
Dactinomycin	
Daunorubicin	
Doxorubicin	Surgery:
Etoposide	Gross-total resection plus removal of adjacent structures
G-CSF (or Filgrastim)	
Ifosfamide	Gross-total resection but limited to a single topographical location

Imatinib (or other TKI)
Leucovorine
Mercaptopurine
Mesna
Methotrexate
Paxlitaxel
Steroids
Thioguanine
Vinblastine
Vincristine
Other_____

Sub-total resection

Hematopoietic Stem Cell Transplantation:

Autologous stem cells
Matched related stem cells
Matched unrelated stem cells
Unmatched related stem cells

Retinoblastoma Specific Treatments:

Laser
Cryotherapy
Brachytherapy
Intra-arterial
Intraocular/Local Chemotherapy

Additional Notes

Data Manager Notes: Show if "Additional treatment at follow-up" = 1 and curative treatment given is checked. Add logic to show “local therapy” choices only for retinoblastoma. Add logic and dynamic coding to link ICCC3 diagnostic codes to appropriate chemotherapy options.

Value Notes: To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.

Validation Notes:

Palliative Treatments Given During Follow-Up Period

Database Description

Database Label:	EXTX
Definition:	At each follow-up, please select all types of palliative treatment (chemotherapy, radiation, surgery, or symptom management) given in the interval since the last registry update.
Database Field Number:	67
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	255

Values

Chemotherapy:

- Allopurinol
- Asparaginase
- Bleomycin
- Carboplatin
- Cisplatin
- Cyclophosphosphamide
- Cytarabine
- Dacarbazine
- Dactinomycin
- Daunorubicin
- Doxorubicin
- Etoposide
- G-CSF (or Filgrastim)

External Beam Radiation:

- Head
- Neck
- Chest
- Abdomen
- Pelvis
- Extremity
- Spine
- Other

Surgery:

- Gross-total resection plus removal of adjacent structures
- Gross-total resection but limited to a

Ifosfamide

Imatinib (or other TKI)

Leucovorine

Mercaptopurine

Mesna

Methotrexate

Paxlitaxel

Steroids

Thioguanine

Vinblastine

Vincristine

Other_____

single organ

Sub-total resection

Palliative surgery not directed at tumor

Pain / Symptom Management:

Opiates

Psychiatric Medications (i.e. antipsychotics, antidepressants, etc.)

Traditional Medicines

Homeopathic/Alternative Therapies (i.e. acupuncture, massage therapy, etc.)

Psychosocial Interventions

Additional Notes

Data Manager Notes: Show if "Additional treatment at follow-up" = 1, and palliative treatment given is checked. Add logic and dynamic coding to link ICCC3 diagnostic codes to appropriate chemotherapy options.

Value Notes: To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.

Validation Notes:

Last Known Vital Status

Database Description

Database Label:	FULKA
Definition:	Specifies the vital status of the patient at the last date of last contact.
Database Field Number:	68
Required:	Yes

Database Values

Data Type	Int
Format	N
Maximum Character Length	100
Values	(1) Dead
	(2) Alive
	(4) Not seen since last follow up
	(8) Unknown

Additional Notes

Data Manager Notes:	
Value Notes:	To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	Limited to defined values

Date of Death

Database Description

Database Label:	FUDTHDAT
Definition:	The date of death.
Database Field Number:	69
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	Show if “Last known vital status” = 1. Evaluate whether >5-year milestone is met- prompt user to end data collection.
Value Notes:	User defined. To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	DD/MM/YYYY and cannot be before dates of birth, diagnosis, referral, starting Treatment, nor before the prior follow-up date

Date of Last Follow-Up

Database Description

Database Label:	FUDAT
Definition:	The date of last contact with the patient.
Database Field Number:	70
Required:	Yes

Database Values

Data Type	Date
Format	Site can choose to display as DD/MM/YYYY or MM/DD/YYYY
Maximum Character Length	1
Values	NA

Additional Notes

Data Manager Notes:	Show if “Last known vital status” = 2 or 3. Evaluate whether >5-year milestone is met- prompt user to end data collection.
Value Notes:	User defined. To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	DD/MM/YYYY and cannot be before dates of birth, diagnosis, referral, starting Treatment, nor before the prior follow-up date

Source of Vital Status or Method of Contact

Database Description

Database Label:	FUMETH
Definition:	Specifies the source of information regarding the patients' vital status.
Database Field Number:	71
Required:	Yes

Database Values

Data Type	Int
Format	N
Maximum Character Length	100
Values	(1) Medical record
	(2) Phone call
	(3) E-Mail
	(4) Fax
	(5) Letter/post
	(6) Outside clinician
	(7) Death certificate
	(9) Other_____

Additional Notes

Data Manager Notes:	
Value Notes:	To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	Limited to list options. Add logic to require specification if (9) is selected

Does the Patient's Contact Information Need to be Updated

Database Description

Database Label:	FUCNT
Definition:	Confirmation of an update(s) to the patient's contact information for the purposes of follow-up. Check one or more of the appropriate method of contact boxes (address, phone, email) to enter the updated data.
Database Field Number:	72
Required:	Yes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(Y) Yes ▪ Address ▪ Phone ▪ Email (N) No

Additional Notes

Data Manager Notes:	St. Jude staff will not have access to this variable field.
Value Notes:	To be completed at 6 months following the treatment form, and every year until one of the following milestones is met: patient reaches >5 years of cancer-free survival, death, or patient is lost to follow-up as defined using the most recent SIOP recommendations.
Validation Notes:	Add logic to require data be entered for at least one of the methods of contact if yes is selected to indicate contact information updates. Logic similar to that on the demographics form for the address, phone, and email are to be added.

Cause of Death

Database Description

Database Label:	FUCODLBL, FUCODP, FUCODS, FUCODT, FUCODQ
Definition:	Official cause of death information as coded from the death certificate or best available information in the *WHO application of ICD-10 codes for low-resource settings initial cause of death collection* document. Cancer-related deaths are linked to ICCC3 extended classification codes. Primary cause of death refers to the disease or injury which initiated the sequence of morbid events leading directly to death.
Database Field Number:	73
Required:	Yes

Database Values

Data Type	String
Format	Drop down list with logic based on clinical condition groups, ICD-10 and ICCC3 codes, values can be referenced in tables and appendices on website below.
Maximum Character Length	1
Values	http://www.who.int/healthinfo/civil_registration/ICD_10_SMoL.pdf {each will have a drop-down list} Primary Secondary Tertiary Quaternary

Additional Notes

Data Manager Notes:	Show if "Last known vital status" = 1
Value Notes:	ICD10 Code, ICCC3 Extended Classification Code
Validation Notes:	Limited to defined values. Add logic to require specification if ‘other’ isselected

Place of Death- Country

Database Description

Database Label:	Country
Definition:	Code for the country where patient died and where certificate of death is filed.
Database Field Number:	74
Required:	Yes

Database Values

Data Type	String
Format	AAA
Maximum Character Length	50
Values	https://www.iso.org/iso-3166-country-codes.html

Additional Notes

Data Manager Notes:	Show if "Last known vital status" = 1
Value Notes:	
Validation Notes:	Limited to defined values

Place of Death- Location

Database Description

Database Label:	FUPODL
Definition:	Code for the specific place where patient died and where certificate of death is filed.
Database Field Number:	75
Required:	Yes

Database Values

Data Type	Int
Format	N
Maximum Character Length	100
Values	(1) Home
	(2) Hospital
	(3) Hospice facility
	(4) Other
	(5) Unknown

Additional Notes

Data Manager Notes:	Show if "Last known vital status" = 1
Value Notes:	Value= (4) “Other” can include vehicular accidents, edifices that are not otherwise listed.
Validation Notes:	Limited to defined values

Comments- Follow-Up

Database Description

Database Label:	FUCOMM
Definition:	Open ended, free text annotation of cancer relapse/recurrence, remission, treatment, case finding activities, and follow-up
Database Field Number:	76
Required:	No

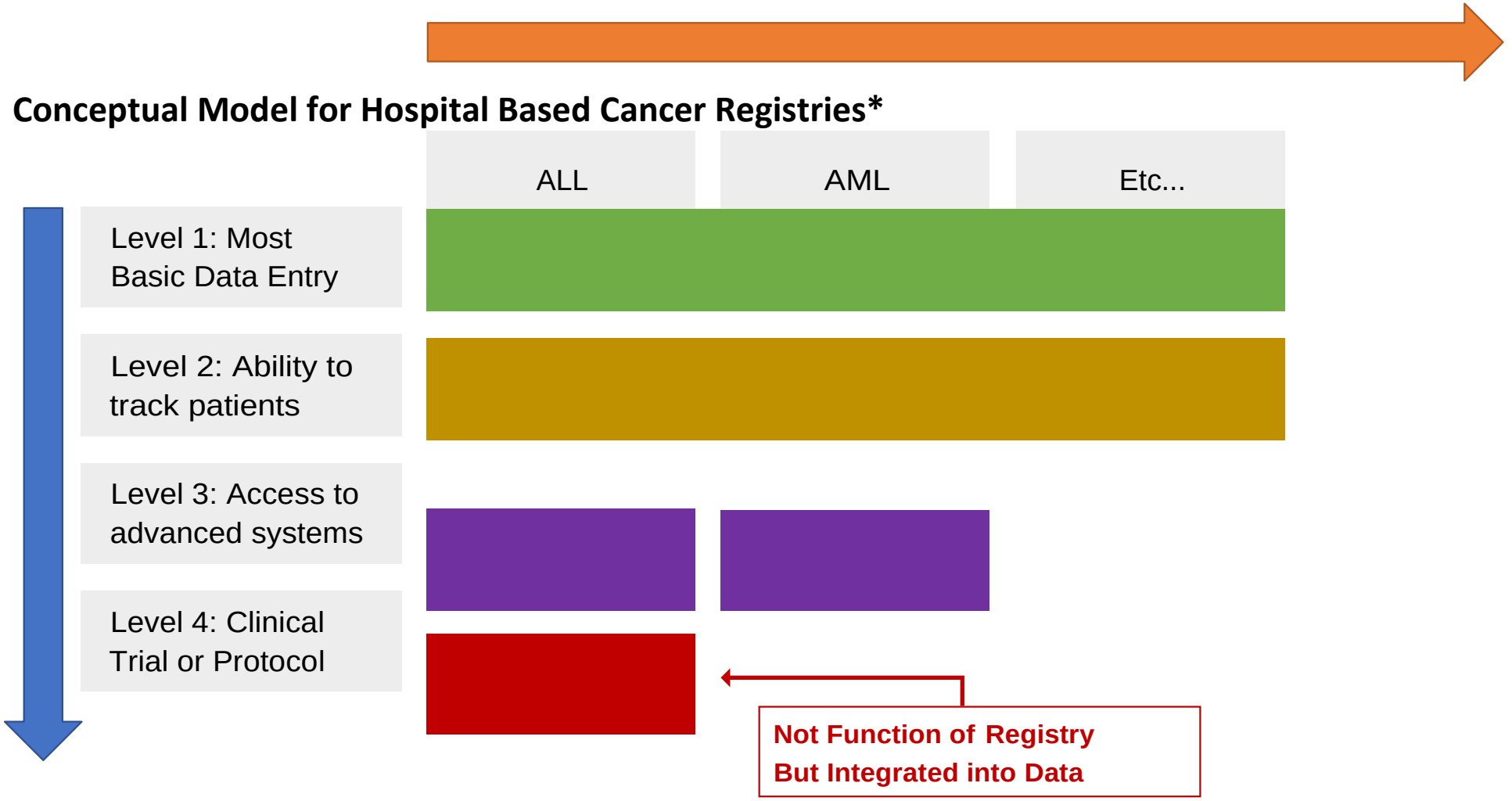
Database Values

Data Type	String
Format	Text
Maximum Character Length	255
Values	NA

Additional Notes

Data Manager Notes:	Open ended opportunity to annotate record
Value Notes:	Free text
Validation Notes:	

Conceptual Model for Hospital Based Cancer Registries*



*This technical document represents variables for Levels 1 and 2, future expansion feasible based on regional and institutional needs.

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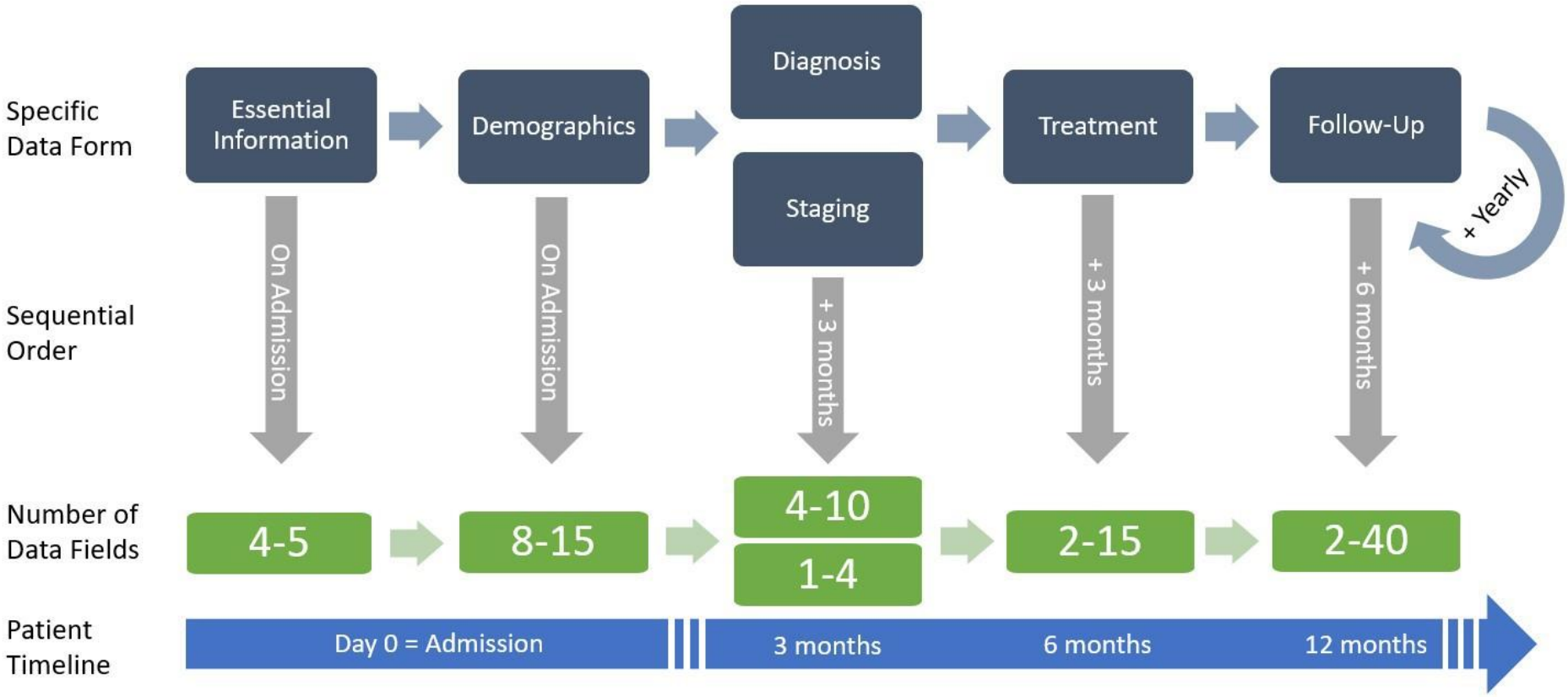
Pathway for Data Capture



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Appendix III: Customizable Country-Specific Site Worksheet Example

Site Worksheet

Instructions: *Please complete this data collection worksheet for inclusion in the registry. The information will be used to customize the registry with field choices relevant to your site. Once submitted, data in this form may not be changed without joint authorization from the database administrator and St. Jude Global.*

Hospital Site Identification:

Hospital Site Name _____

Time Zone _____

Please complete the following information by writing out the hospital site address exactly how an address would be written in your country or region. Please use labels to describe each line.

Site Address (**example**) **St Jude Children's Hospital (name)** _____
262 Danny Thomas Place (street) _____
Mail Stop 721 (street) _____
Memphis, Tennessee 38105 (city, state, zip code) _____
_____

Please complete the information directly below for your hospital site Registry team, your team must include at minimum one MD Monitor and one Data Entry Specialist.
MD Monitor*- the individual who would be responsible for oversight of registry data quality at their hospital site (should be a physician****). Data Entry Specialist****- the individual responsible for entering data into all Registry forms.*

Name _____
Professional Title(s): □ MD/Licensed Clinical Physician □ RN/Practicing Nurse □ Neither
Registry Team Role: □ MD Monitor □ Data Entry Specialist
Email_____
Phone Number _____

Name _____
Professional Title(s): □ MD/Licensed Clinical Physician □ RN/Practicing Nurse □ Neither
Registry Team Role: □ MD Monitor □ Data Entry Specialist
Email_____
Phone Number _____

Demographics Information:

Instructions: *Complete this data by answering a few questions regarding National and Ref ID numbers, addresses, racial and ethnic groups within your country or region.*

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Appendix III: Customizable Country-Specific Site Worksheet Example

National ID Number

In the U.S., the National ID Number would be a patient's social security number with this format: XXX-XX-XXXX. For your country/region, please provide your recommendation for this data element with an example.

Recommendation (e.g. health insurance, taxnumber)? _____

Please Provide Example/Format (do not use a real one) _____

Ref ID Number

In the U.S., the Ref ID Number would be a patient's medical record number with varying hospital formats. For your country/region, please provide an example.

Name of Reference ID Number at your site/in your country _____

Please Provide Example/Format (do not use a real one) _____

Home Address

Please complete the following information by writing out a residential or home address exactly how an address would be written in your country or region. Use labels to describe each line and use the example provided above for site address.

_____

_____

_____

_____

_____

_____

_____

Please provide local and/or regional terms for postal code and state/province. For example, the term for postal code in the United States is 'zip code' and in France is 'postal code.'

Postal Code _____

State/Province _____

St. Jude Global
SJCARES REGISTRY

Appendix III: Customizable Country-Specific Site Worksheet Example

*Please provide the format for a phone number in your country/region. For example: In the USA, phone numbers are +1-***-###-#### (+1=country code, * = area code and # = phone number)*

Phone Number _____

Race and Ethnicity

Please list the appropriate racial and ethnic groups represented in your country in this table. Please refer to your country's bureau or ministry of statistics for standardized listings of racial and ethnic groups.

Race	Ethnic Groups

Cancer Staging Information:

Instructions: *Complete this data by answering the questions regarding how you would stage at your hospital site, please check the appropriate box. Again, this information will be used to customize your answer choices on the registry.*

How is Retinoblastoma staged?
□ International Retinoblastoma Staging System (IRSS)
□ International Classification for Intraocular Retinoblastoma (ICIR)

How is Wilms Tumor/Nephroblastoma staged?
□ Children's Oncology Group/National Wilms Tumor Study Group (COG/NWTSG)
□ SIOP

Comments: *Please make any additional comments below and on the back of this page.*

Appendix IV: Toronto Childhood Cancer Staging Manual

Aitken JF, Youlden DR, Moore AS, Baade PD, Ward LJ, Thursfield VJ, Valery PC, Green AC, Gupta S, Frazier AL. *Childhood cancer staging for population registries according to the Toronto Childhood Cancer Stage Guidelines*. Cancer Council Queensland and Cancer Australia: Brisbane, Australia; 2017. Available at https://cancerqld.blob.core.windows.net/content/docs/childhood-cancer-staging-for-population-registries.pdf.

Introduction

The following information is presented to provide guidance for collecting internationally consistent information on childhood cancer stage by cancer registries, which is essential for epidemiologic analysis, international benchmarking, and meaningful comparisons of childhood cancer incidence and outcomes. The tumor/node/metastasis (TNM) system is the standard staging system for most adult cancers; however, it is inadequate for documenting the extent of disease in children. Disease-specific staging systems have been developed for childhood cancers, but for many diagnostic groups two or more systems are in clinical use and there is no internationally uniform standard for population-based cancer registration.

A consensus meeting was convened in 2014 by the Union for International Cancer Control (UICC), the Dana-Farber Cancer Institute, Boston, MA, and the Hospital for Sick Children, Toronto, to address the lack of consistent information on childhood cancer staging in population registries. For each subset of the major childhood cancer diagnostic groups/subgroups, meeting participants reviewed all disease-specific cancer staging systems currently in use and recommended the one most suitable for use by population-based cancer registries. The recommended staging systems are listed as the *Toronto Paediatric Cancer Stage Guidelines*. The *Guidelines* recommend disease-specific staging systems for acute lymphoblastic leukemia, acute myeloid leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma, neuroblastoma, Wilms tumor, rhabdomyosarcoma, non-rhabdomyosarcoma soft tissue sarcoma, osteosarcoma, Ewing sarcoma, retinoblastoma, hepatoblastoma, germ cell tumors (testicular cancer and ovarian cancer), medulloblastoma, and ependymoma.

Presented below are detailed descriptions of the staging systems recommended in the *Guidelines,* which have been endorsed by IARC and the UICC TNM-Prognostic Factors Project and have been programmed into the hospital-based SJCARES Registry to assist cancer registries to collect internationally consistent and comparable information on childhood cancer stage at diagnosis by using available medical records. **The authors have granted permission to publish the Childhood Cancer Staging Manual as Appendix 4 in the SJCARES Registry* (see footnote to Appendix 4).**

***We thank Joanne Aitken, Danny Youlden, Lindsay Frazier, Sumit Gupta, and other authors and affiliated experts for their willingness to collaborate and share this important information.

Table 1: The Toronto Paediatric Cancer Stage Guidelines[1]

Diagnostic group/subgroup	**Tier 1 staging system** (for low resource settings)	**Tier 2 staging system** (for high resource settings)
Acute lymphoblastic leukaemia[3]	CNS negative CNS positive	CNS1 CNS2 CNS3
Acute myeloid leukaemia[4]	CNS negative CNS positive	CNS negative CNS positive
Hodgkin lymphoma[5]	Ann Arbor-stage IA/B Ann Arbor-stage IIA/B Ann Arbor-stage IIIA/B Ann Arbor-stage IVA/B	Ann Arbor-stage IA/B Ann Arbor-stage IIA/B Ann Arbor-stage IIIA/B Ann Arbor-stage IVA/B
Non-Hodgkin lymphoma[6]	Limited Advanced	St Jude/Murphy-stage I St Jude/Murphy-stage II St Jude/Murphy-stage III St Jude/Murphy-stage IV
Neuroblastoma[7]	Localized Locoregional Metastatic INRGSS-MS disease	INRGSS-localized L1 INRGSS-locoregional L2 INRGSS-metastatic M INRGSS-MS disease
Wilms tumour[8, 9]	Localized Metastatic	Stage I/y-stage I Stage II/y-stage II Stage III/y-stage III Stage IV
Rhabdomyosarcoma[2]	Localized Metastatic	TNM stage 1 TNM stage 2 TNM stage 3 TNM stage 4
Non-rhabdomyosarcoma soft tissue sarcoma[2]	Localized Metastatic	TNM stage 1 TNM stage 2 TNM stage 3 TNM stage 4

Cancer Council Queensland and Cancer Australia provide permission to publish the Toronto Guidelines Childhood Cancer Staging Manual as Appendix 4 of the SJCARES Hospital-Based Cancer Registry. This work was supported by Cancer Australia to improve national data for childhood cancers as part of the *Investing in Medical Research – Fighting Childhood Cancer* initiative.

Table 1 (cont.): The Toronto Paediatric Cancer Stage Guidelines[1]

Diagnostic group/subgroup	**Tier 1 staging system** (for low resource settings)	**Tier 2 staging system** (for high resource settings)
Osteosarcoma[2]	Localized Metastatic	Localized Metastatic
Ewings sarcoma[2]	Localized Metastatic	Localized Metastatic
Retinoblastoma[10]	Localized	IRSS Stage 0 IRSS Stage I IRSS Stage II
	Regional	IRSS Stage III
	Metastatic	IRSS Stage IV
Hepatoblastoma[2]	Localized Metastatic	Localized Metastatic
Testicular cancer[2]	Localized Regional Metastatic	TNM stage I TNM stage II TNM stage III
Ovarian cancer[11]	Localized	FIGO stage I
	Regional	FIGO stage II FIGO stage III
	Metastatic	FIGO stage IV
Medulloblastoma and other CNS embryonal tumours[12]	Localized	M0
	Metastatic	M1 M2 M3 M4
Ependymoma[12]	Localized	M0
	Metastatic	M1 M2 M3 M4

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1. Acute lymphoblasticleukaemia

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

1a1 - Precursor cell leukaemias: 9811-9818, 9835-9836, 9837*

* Updated for haematopoietic codes based on *WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues*.[14]

ICD-O-3 site codes:[15]

C000-C809

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Acute lymphoblastic leukaemia
Tier 1 and Tier 2 are based on the extent of central nervous system (CNS) involvement. Tier 2 is the Children's Oncology Group (COG) staging system.[3]

Definitions and notes
<u>CSF reports</u> - If RBC <1/µL, record as RBC = 0. - If WBC <1/µL, record as WBC = 0. - If blasts are referred to as "occasional" or "seen" or similar wording, assume blasts are present. - If there is no mention of blasts, assume blasts are absent. <u>Clinical signs of CNS involvement are defined as</u> - Radiologic evidence of intracranial, intradural mass - Cranial nerve palsy (e.g. facial weakness, ptosis), brain/eye involvement or hypothalamic syndrome. Extra-ocular orbital masses, severe headaches and eye swelling (in the absence of signs of cranial nerve involvement) are not sufficient to constitute CNS involvement.

<table>
<tr><th colspan="2">Staging criteria for acute lymphoblastic leukaemia</th></tr>
<tr><th>TIER 1</th><th>TIER 2</th></tr>
<tr><td>CNS-

• No clinical signs of CNS involvement
and no blasts in CSF</td><td>CNS1

• No clinical signs of CNS involvement
And no blasts in CSF</td></tr>
<tr><td rowspan="2">CNS+

• Clinical signs of CNS involvement

or

• blasts in CSF</td><td>CNS2

• No clinical signs of CNS involvement
and blasts in CSF
and either:

WBC < 5/µL CSF

or

WBC ≥5/µL CSF *and* RBC ≥ 10/µL CSF
and WBC/RBC in CSF ≤ 2x WBC/RBC in blood</td></tr>
<tr><td>CNS3

• Clinical signs of CNS involvement

or

• Blasts in CSF
and WBC ≥ 5/µL CSF
and either:

RBC < 10/µL CSF

or

RBC ≥ 10/µL CSF
and WBC/RBC in CSF > 2x WBC/RBC in blood</td></tr>
</table>

Database entry codes for acute lymphoblastic leukaemia			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
CNS-	CNS-	**CNS1**	CNS1
CNS+	CNS+	**CNS2**	CNS2
		CNS3	CNS3
Unknown	X	**Unknown**	X

2. Acute myeloidleukaemia

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

1b - Acute myeloid leukaemias: 9840, 9861, 9865-9867, 9869-9874, 9891, 9895-9898, 9910-9911, 9920, 9931*

* Updated for haematopoietic codes based on *WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues*.[14]

ICD-O-3 site codes:[15]

C000-C809

Acute myeloid leukaemia
Tier 1 and Tier 2 are identical and are based on whether there is central nervous system (CNS) involvement.[4]

Definitions and notes
Traumatic and nontraumatic lumbar puncture - If RBC in CSF < 10/μL then lumbar puncture is "nontraumatic". - If RBC in CSF ≥ 10/μL then lumbar puncture is "traumatic". CSF reports - If blasts are referred to as "occasional" or "seen" or similar wording, assume blasts are present. - If there is no mention of blasts, assume blasts are absent. Clinical signs of CNS involvement are defined as - Radiologic evidence of intracranial, intradural mass - Cranial nerve palsy (e.g. facial weakness, ptosis), brain/eye involvement or hypothalamic syndrome. Extra-ocular orbital masses, severe headaches and eye swelling (in the absence of signs of cranial nerve involvement) are not sufficient to constitute CNS involvement.

Staging criteria for acute myeloid leukaemia	
TIER 1	**TIER 2**
CNS- • Lumbar puncture nontraumatic (see Definitions and notes) *and* no blasts in CSF *and* no clinical signs of CNS involvement	**CNS-** • Lumbar puncture nontraumatic (see Definitions and notes) *and* no blasts in CSF *and* no clinical signs of CNS involvement
CNS+ • Lumbar puncture traumatic or • Lumbar puncture nontraumatic *and* blasts in CSF or • Clinical signs of CNS involvement	**CNS+** • Lumbar puncture traumatic or • Lumbar puncture nontraumatic *and* blasts in CSF or • Clinical signs of CNS involvement

Database entry codes for acute myeloid leukaemia			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
CNS-	CNS-	**CNS-**	CNS-
CNS+	CNS+	**CNS+**	CNS+
Unknown	X	**Unknown**	X

3. Hodgkin lymphoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

2a - Hodgkin lymphoma: 9650-9655, 9659, 9661-9665, 9667

ICD-O-3 site codes:[15]

C000-C809

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Hodgkin lymphoma
Tier 1 and Tier 2 are identical and follow the Ann Arbor staging system.[5]

Definitions and notes
Nodal regions, extra-lymphatic organs or sites Staging requires assessment of - the number of nodal regions involved, by anatomical location (i.e., above or below the diaphragm). Nodal regions are listed in Figures 1a and 1b. - the number of extra-lymphatic organs or sites involved, by anatomical location (i.e., above or below the diaphragm). Constitutional symptoms The suffix A or B is added to the stage according to the absence or presence of defined constitutional symptoms, as follows: A = no constitutional symptoms are recorded, or the medical record states there are no constitutional symptoms B = medical record states there are constitutional symptoms Constitutional symptoms are: • *Fevers.* Unexplained fever with temperature above 38 degrees C (100.4 degrees F). • *Night sweats.* Drenching sweats (e.g. those that require change of bedclothes). • *Weight loss.* Unexplained weight loss of more than 10% of usual body weight in the 6 months prior to diagnosis.

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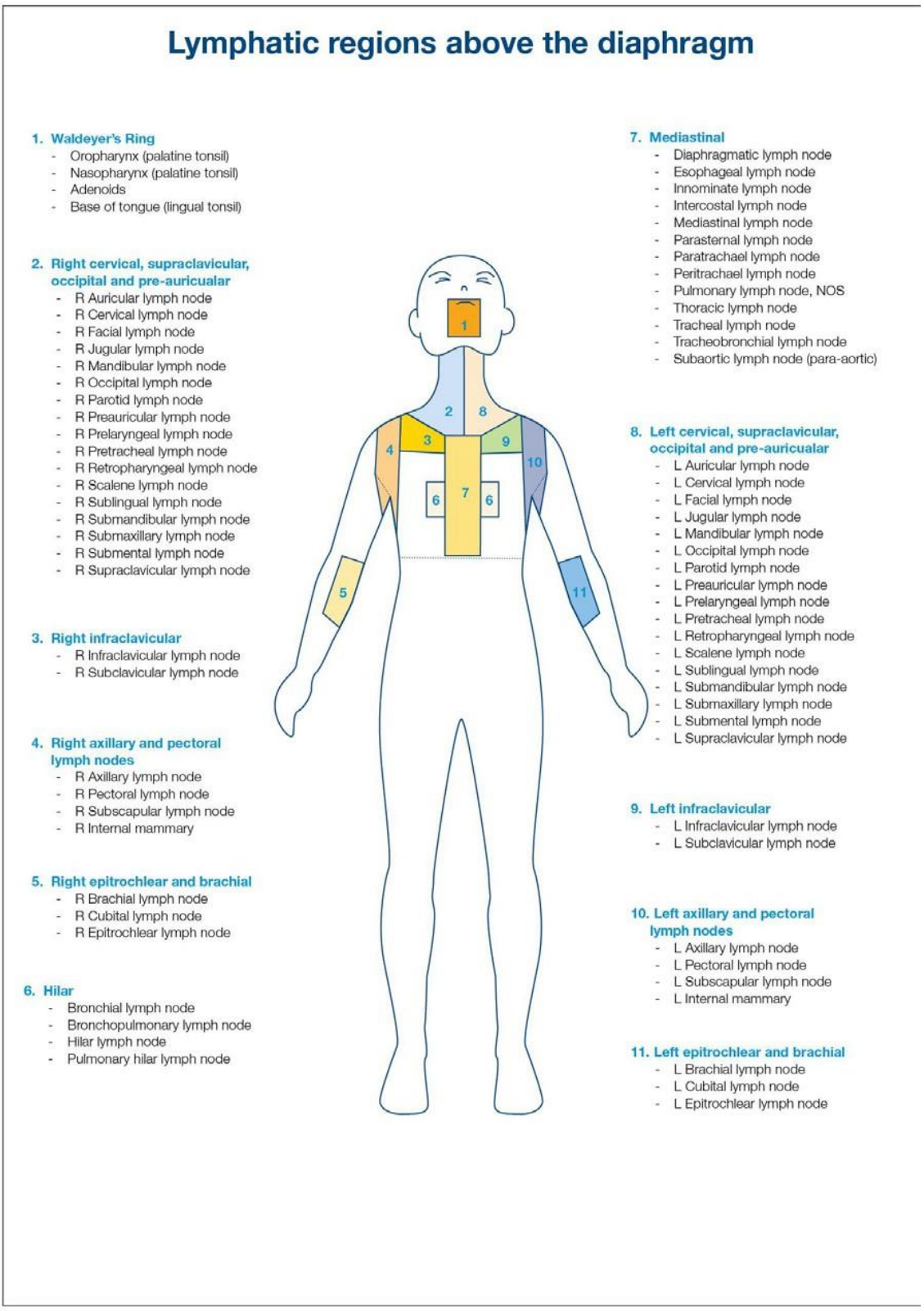

Figure 1a: Lymphatic regions above the diaphragm for the staging of Hodgkin's and Non-Hodgkin's Lymphoma

Cancer Council Queensland and Cancer Australia provide permission to publish the Toronto Guidelines Childhood Cancer Staging Manual as Appendix 4 of the SJCARES Hospital-Based Cancer Registry. This work was supported by Cancer Australia to improve national data for childhood cancers as part of the *Investing in Medical Research – Fighting Childhood Cancer* initiative.

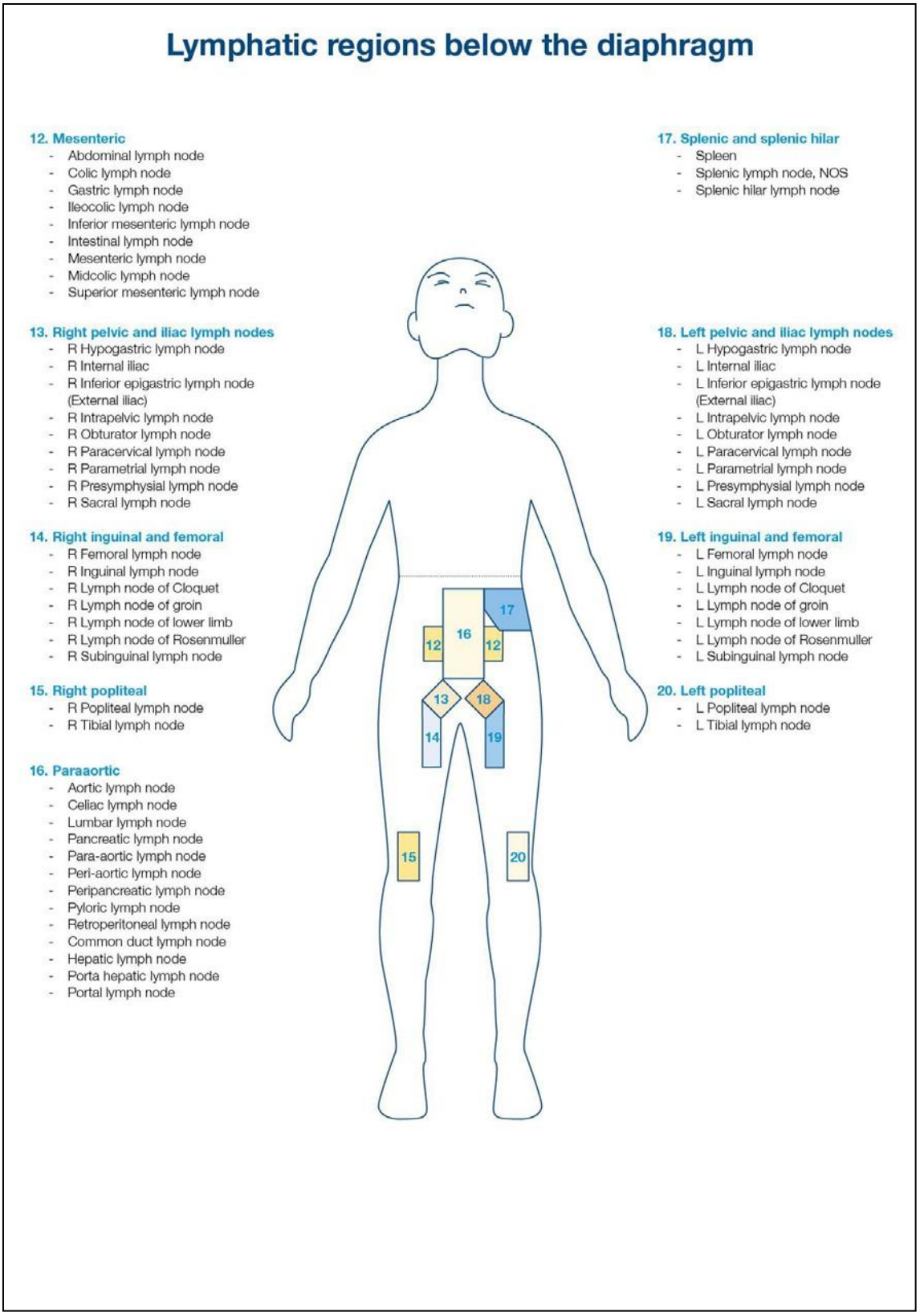

Figure 1b: Lymphatic regions below the diaphragm for the staging of Hodgkin's and Non-Hodgkin's Lymphoma

Cancer Council Queensland and Cancer Australia provide permission to publish the Toronto Guidelines Childhood Cancer Staging Manual as Appendix 4 of the SJCARES Hospital-Based Cancer Registry. This work was supported by Cancer Australia to improve national data for childhood cancers as part of the *Investing in Medical Research – Fighting Childhood Cancer* initiative.

Staging criteria for Hodgkin lymphoma	
Note: The suffix **A** or **B** is added to the stage according to the absence or presence of defined constitutional symptoms, as follows: A = no constitutional symptoms are recorded, or the medical record states there are no constitutional symptoms B = medical record states there are constitutional symptoms Constitutional symptoms are: • *Fevers.* Unexplained fever with temperature above 38 degrees Celsius (100.4 degrees F). • *Night sweats.* Drenching sweats (e.g. those that require change of bedclothes). • *Weight loss.* Unexplained weight loss of more than 10% of usual body weight inthe 6 months prior to diagnosis.	
TIER 1	**TIER 2**
Stage I • Involvement of a single lymph node region or • Involvement of a singleextra-lymphatic organ or site, without lymph node involvement.	**Stage I** • Involvement of a single lymph node region or • Involvement of a singleextra-lymphatic organ or site, without lymph node involvement.
Stage II • Involvement of two or more lymph node regions on the SAME side (either above or below) of the diaphragm or • Localized involvement of a single extra-lymphatic organ or site in association with regional lymph node involvement (i.e. local extension from a lymph node area into a nearby organ), *with or without* involvement of other lymph node regions on the SAME side (either above or below) of the diaphragm.	**Stage II** • Involvement of two or more lymph node regions on the SAME side (either above or below) of the diaphragm or • Localized involvement of a single extra-lymphatic organ or site with associated regional lymph node involvement (i.e. local extension from a lymph node area into a nearby organ), *with or without* involvement of other contiguous lymph node regions on the SAME side (either above or below) of the diaphragm.
Stage III • Involvement of lymph node regions on BOTH sides (above and below) of the diaphragm. This may be accompanied by: - extra-lymphatic extension in association with adjacent lymph node involvement (i.e. local extension from a lymph node area into a nearby organ) and/or - involvement of spleen.	**Stage III** • Involvement of lymph node regions on OPPOSITE sides (above and below) of the diaphragm. This may be accompanied by: - extra-lymphatic extension in association with adjacent lymph node involvement (i.e. local extension from a lymph node area into a nearby organ) and/or - involvement of spleen.

Stage IV • Diffuse or disseminated involvement of one or more extra-lymphatic organs with or without associated lymph node involvement or • Isolated extra-lymphatic organ involvement in the absence of adjacent regional lymph node involvement, but in conjunction with disease in distant site(s). or • Any involvement of liver, bone marrow, lungs (except by direct extension from another site) or CSF.	**Stage IV** • Diffuse or disseminated (multifocal) involvement of one or more extra-lymphatic organs with or without associated lymph node involvement or • Isolated (non-contiguous) extra-lymphatic organ involvement in the absence of adjacent regional lymph node involvement, but in conjunction with disease in distant site(s). or • Any involvement of liver, bone marrow, lungs (except by direct extension from another site) or CSF.

Database entry codes for Hodgkin lymphoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Stage IA	1A	**Stage IA**	1A
Stage IB	1B	**Stage IB**	1B
Stage IIA	2A	**Stage IIA**	2A
Stage IIB	2B	**Stage IIB**	2B
Stage IIIA	3A	**Stage IIIA**	3A
Stage IIIB	3B	**Stage IIIB**	3B
Stage IVA	4A	**Stage IVA**	4A
Stage IVB	4B	**Stage IVB**	4B
Unknown	X	**Unknown**	X

4. Non-Hodgkin lymphoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

2b1* – Precursor cell lymphoma: 9727-9729

2b2 – Mature B-cell lymphomas (except Burkitt lymphoma): 9670-9671, 9673, 9675,9678-9680, 9684, 9688-9691, 9695, 9698-9699, 9731-9735, 9737-9738, 9761-9762, 9764-9766, 9769, 9970; 9823**

2b3 – Mature T-cell and NK-cell lymphomas: 9702, 9705, 9714, 9716, 9717, 9724, 9767-9768; 9827**

2b4 – Non-Hodgkin lymphoma NOS: 9591, 9760

2c – Burkitt lymphoma: 9687

* Morphology codes 9811-9818 and 9837 are not included with 2b1, but are included with acute lymphoblastic leukaemia.

** Updated for haematopoietic codes based on *WHO Classification of Tumours of Haematopoietic and Lymphoid Tissues*.[14]

ICD-O-3 site codes:[15]

C000-C809 (unless otherwise specified and excluding cutaneous lymphomas, C44_)

Non-Hodgkin lymphoma
Tier 2 follows the St Jude/Murphy staging system.[6]

Definitions and notes
Nodal regions, extra-lymphatic organs or sites Staging requires assessment of - the number of nodal regions involved, by anatomical location (i.e., above or below the diaphragm). Nodal regions are listed in Figures 1a and 1b (pages 20, 21). - the number of extra-lymphatic organs or sites involved, by anatomical location (i.e., above or below the diaphragm).

Staging criteria for non-Hodgkin lymphoma	
TIER 1	**TIER 2**
Limited • No involvement of CNS or bone marrow.	**Stage I** • Involvement of a single tumour mass or nodal area, excluding the abdomen and mediastinum.
	Stage II • A single tumour (extranodal) with regional node involvement or • Two or more nodal areas on the SAME side (either above or below) of the diaphragm or • Two or more single (extranodal) tumours, with or without regional node involvement, on the SAME side (either above or below) of the diaphragm or • A completely resected primary gastrointestinal tract tumour with or without involvement of associated mesenteric nodes only.
	Stage III • Tumours (extranodal) or nodal areas on OPPOSITE sides (above and below) of the diaphragm or • Any primary intrathoracic tumours (mediastinal, hilar, pulmonary, pleural, or thymic). or • Extensive* (unresectable) primary intra-abdominal disease or • Any paraspinal or epidural tumours regardless of other tumour sites.
Advanced • Involvement of CNS and/or bone marrow	**Stage IV** • Initial CNS and/or bone marrow involvement.

* Extensive disease typically exhibits spread to para-aortic and retro-peritoneal areas by implants and plaques in mesentery or peritoneum, or by direct infiltration of structures adjacent to the primary tumour. Ascites may be present, and complete resection of all gross tumour is not possible.

Database entry codes for non-Hodgkin lymphoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Limited	L	**Stage I**	1
		Stage II	2
		Stage III	3
Advanced	A	**Stage IV**	4
Unknown	X	**Unknown**	X

5. Neuroblastoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

4a – Neuroblastoma and Ganglioneuroblastoma; 9490, 9500

ICD-O-3 site codes:[15]

C000-C809

Neuroblastoma
Tier 2 follows the International Neuroblastoma Risk Group Staging System (INRGSS).[7] Tier 1 criteria are simplified proxies of Tier 2 that do not require assessment of image-defined risk factors for use in settings where cross-sectional imaging is not available.

Definitions and notes

Patients with multifocal primary tumours should be staged according to the greatest extent of disease as defined in the IDRF table.

Image-defined risk factors

Staging requires assessment of whether or not patients have none (Stage L1) or one or more (Stage L2) of the image-defined risk factors (IDRF) listed below. These are identified in reports of imaging at diagnosis, prior to any surgical resection.

- *Ipsilateral tumour extension within two body compartments*
  Neck-chest, chest-abdomen, abdomen-pelvis

- *Neck*
  Tumour encasing carotid and/or vertebral artery and/or internal jugular vein
  Tumour extending to base of skull
  Tumour compressing the trachea

- *Cervico-thoracic junction*
  Tumour encasing brachial plexus roots
  Tumour encasing subclavian vessels and/or vertebral and/or carotid artery
  Tumour compressing the trachea

- *Thorax*
  Tumour encasing the aorta and/or major branches
  Tumour compressing the trachea and/or principal bronchi
  Lower mediastinal tumour, infiltrating the costo-vertebral junction between T9 and T12

- *Thoraco-abdominal*
  Tumour encasing the aorta and/or vena cava

- *Abdomen/pelvis*
  Tumour infiltrating the porta hepatis and/or the hepatoduodenal ligament
  Tumour encasing branches of the superior mesenteric artery at the mesenteric root
  Tumour encasing the origin of the coeliac axis, and/or of the superior mesenteric artery
  Tumour invading one or both renal pedicles
  Tumour encasing the aorta and/or vena cava
  Tumour encasing the iliac vessels
  Pelvic tumour crossing the sciatic notch

- *Intraspinal tumour extension whatever the location provided that:*
  More than one third of the spinal canal in the axial plane is invaded and/or the perimedullary eptomeningeal spaces are not visible and/or the spinal cord signal is abnormal

- *Infiltration of adjacent organs/structures*
  Pericardium, diaphragm, kidney, liver, duodeno-pancreatic block, and mesentery

Staging criteria for neuroblastoma			
TIER 1		**TIER 2**	
Localized	Localized tumour not involving vital structures and confined to one body compartment	**Stage L1**	Localized tumour that does not involve any vital structures as defined by the list of IDRFs (i.e. there are no IDRFs) and the tumour must be confined within one body compartment, neck, chest, abdomen, or pelvis. An intraspinal tumour extension that does not fulfil the criteria for an IDRF is consistent with stage L1.
Locoregional	Locoregional tumour with spread	**Stage L2**	Locoregional tumour with one or more IDRFs. The tumour may be ipsilaterally contiguous within body compartments (ie, a left sided abdominal tumour with left-sided lung, bone or pleura involvement should be considered stage L2). However, a clearly left sided abdominal tumour with right-sided lung, bone or pleura (or vice versa) involvement is defined as metastatic disease.
Metastatic	Distant metastatic disease (except stage MS)	**Stage M**	Distant metastatic disease (ie, not contiguous with the primary tumour) except as defined for stage MS. Nonregional (distant) lymph node involvement is metastatic disease. However, an upper abdominal tumour with enlarged lower mediastinal nodes or a pelvic tumour with inguinal lymph node involvement is considered locoregional disease. Ascites and/or a pleural effusion, even with malignant cells, do not constitute metastatic disease unless they are remote from the body compartment of the primary tumour.
MS	Metastatic disease confined to skin, liver, and/or bone marrow in a patient less than 18 months (547 days). .	**Stage MS**	Metastatic disease confined to skin, liver, and/or bone marrow, in a patient less than 18 months (547 days). MIBG scintigraphy must be negative in bone and bone marrow.

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Database entry codes for neuroblastoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Stage L1**	L1
Locoregional	LR	**Stage L2**	L2
Metastatic	M	**Stage M**	M
MS	MS	**Stage MS**	MS
Unknown	X	**Unknown**	X

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6. Wilms tumour

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

6a1 – Nephroblastoma; 8959, 8960

ICD-O-3 site codes:[15]

C649

Wilms tumour
Two principle staging systems exist for Wilms Tumour.[8, 9] Both systems are based on findings at surgery (except for stage IV which is based on presence of distant metastases at diagnosis). The COG/National Wilms Tumour Study Group (NWTSG) staging system is based on findings at surgery for patients who have not received chemotherapy prior to surgery. The SIOP staging system is based on findings at surgery for patients who have received chemotherapy prior to surgery. The recommended staging system incorporates both systems; "y" designates SIOP stage (for patients who have received neo-adjuvant chemotherapy). It is noted that giving chemotherapy before surgery will shrink the tumour and will likely "downstage" the patient.

Definitions and notes
In cases of bilateral disease - the presence of synchronous disease should be noted - for purpose of staging, only the most advanced kidney should be recorded. At diagnosis, if diagnostic imaging reports on the status of the liver, lung, bone, brain and other sites and mention the words "suspicious", "highly suspicious", "possible" or "highly suspected", record as metastatic disease (stage IV) regardless of upfront surgery or chemotherapy.

Staging criteria for Wilms tumour based on findings at surgery for patients who <u>have not</u> received chemotherapy prior to surgery (Children's Oncology Group (COG) protocol)	
TIER 1	**TIER 2**
Localized Tumour confined to area of origin	**Stage I** Tumour is limited to the kidney and completely excised: • Renal capsule intact, not penetrated by tumour • No tumour invasion of veins or lymphatics of renal sinus • No nodal or haematogenous metastases • No prior biopsy • Negative margins
	Stage II Tumour extends beyond kidney but completely resected: • Tumour penetrates renal capsule • Tumour in lymphatics or veins of renal sinus • Tumour in renal vein with margin not involved • No nodal or haematogenous metastases • Negative margins
	Stage III Residual tumour or nonhaematogenous metastases confined to abdomen: • Involved abdominal nodes • Peritoneal contamination or tumour implant • Tumour spillage of any degree occurring before orduring surgery • Gross residual tumour in abdomen • Biopsy of tumour (including fine-needle aspiration) prior to removal of kidney • Resection margins involved by tumour
Metastatic Distant metastases present at diagnosis	**Stage IV** Haematogenous metastases or spread beyond abdomen <u>at diagnosis</u>

Staging criteria for Wilms tumour based on findings at surgery for patients who <u>have</u> received chemotherapy prior to surgery (International Society of Paediatric Oncology (SIOP) protocol)	
TIER 1	**TIER 2**
Localized Tumour confined to area of origin	**Stage y-I** Tumour limited to kidney and completely resected: • Renal capsule may be infiltrated by tumour, buttumour does not reach the outer surface • Tumour may protrude or bulge into the pelvic system or ureter, but does not infiltrate • Vessels of renal sinus not involved
	Stage y-II Tumour extends beyond kidney but completely resected: □ Tumour penetrates renal capsule into perirenal fat □ Tumour infiltrates the renal sinus and/or invades blood and lymphatic vessels outside renal parenchyma but is completely resected □ Tumour infiltrates adjacent organs or vena cava but is completely resected
	Stage y-III Incomplete excision of the tumour (gross or microscopic extension beyond the resection margins): • Involved abdominal lymph nodes, including necrotic tumour or chemotherapy-induced changes • Tumour rupture before or intraoperatively • Tumour has penetrated the peritoneal surface • Tumour thrombi present at resection margins • Surgical biopsy prior to resection (does notinclude needle biopsy)
Metastatic Distant metastases present at diagnosis	**Stage IV** Haematogenous metastases or spread beyond abdomen <u>at diagnosis</u>.

Database entry codes for Wilms tumour			
Children's Oncology Group (COG) protocol (prechemotherapy)			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Stage I**	1
		Stage II	2
		Stage III	3
Metastatic	M	**Stage IV**	4
Unknown	X	**Unknown**	X

Database entry codes for Wilms tumour			
International Society of Paediatric Oncology (SIOP) protocol (postchemotherapy)			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Stage y-I**	y1
		Stage y-II	y2
		Stage y-III	y3
Metastatic	M	**Stage IV**	4
Unknown	X	**Unknown**	X

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7. Rhabdomyosarcoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

9a – Rhabdomyosarcomas: 8900-8905, 8910, 8912, 8920, 8991

ICD-O-3 site codes:[15]

C000-C809

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Rhabdomyosarcoma
Tier 2 follows a modified TNM classification incorporating anatomic site of disease. [2]

Definitions and notes

Favourable and unfavourable anatomic sites of disease

Favourable anatomic sites:
- orbit
- head and neck (excluding parameningeal tumours),
- genitourinary sites (excluding bladder and prostate tumours)

Unfavourable anatomic sites:
- bladder
- prostate
- extremity
- cranial
- parameningeal
- trunk
- retroperitoneum
- all other sites not noted as favourable

T – Tumour size

T0 = no evidence of primary tumour

T1 = tumour confined to a single anatomic site

T1a = tumour ≤ 5cm in greatest dimension

T1b = tumour > 5cm in greatest dimension

T2 = extension beyond anatomic site

T2a = tumour ≤ 5cm in greatest dimension

T2b = tumour > 5cm in greatest dimension

Tx = primary tumour cannot be assessed

N - Regional nodes

N0 = regional lymph nodes not involved

N1 = regional lymph nodes involved

Nx = regional lymph nodes cannot be assessed (especially sites that preclude lymph node evaluation)

M - Metastases

M0 = no distant metastasis

M1 = distant metastasis

Staging criteria for rhabdomyosarcoma			
TIER 1		**TIER 2**	
Localized	Tumour confined to the area of origin including the regional lymph nodes.	**Stage I**	Favourable sites: orbit, head and neck (excluding parameningeal tumours) and genitourinary sites (excluding bladder and prostate tumours) and Any T Any N M0
		Stage II	Unfavourable site and T1a, T2a N0 M0
		Stage III	Unfavourable site and T1a, T2a N1 M0 T1b, T2b Any N M0
Metastatic	Distant metastases present	**Stage IV**	Any site Any T Any N M1

Database entry codes for rhabdomyosarcoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Stage I**	1
		Stage II	2
		Stage III	3
Metastatic	M	**Stage IV**	4
Unknown	X	**Unknown**	X

8. Non-rhabdomyosarcoma soft tissue sarcoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

9b – Fibrosarcomas, peripheral nerve sheath tumors, and other fibrous neoplasms: 8810, 8811, 8813–8815, 8821, 8823, 8834–8835, 8820, 8822, 8824–8827, 9150, 9160, 9491, 9540–9571, 9580

9d – Other specified soft tissue sarcomas: 8587, 8710–8713, 8806, 8830–8833, 8836, 8840–8842, 8850–8858, 8860–8862, 8870, 8880, 8881, 8890–8898, 8921, 8963, 8982, 8990, 9040–9044, 9120–9125, 9130–9133, 9135, 9136, 9141, 9142, 9161, 9170–9175, 9180, 9210, 9220, 9231, 9240, 9251, 9252, 9260, 9364, 9365, 9373, 9581

9e – Unspecified soft tissue sarcomas: 8800-8805

ICD-O-3 site codes:[15]

C00.0–C39.9, C44.0–C76.8, C80.9 (unless otherwise specified)

Non-rhabdomyosarcoma soft tissue sarcoma
Tier 2 follows a modified TNM classification incorporating tumour grade.[2]

Definitions and notes
<u>T - Tumour</u> T0 No evidence of primary tumour T1 Tumour ≤ 5cm in greatest dimension T2 Tumour > 5cm and ≤ 10cm in greatest dimension T3 Tumour >10cm and ≤ 15cm in greatest dimension T4 Tumour >15cm in greatest dimension Tx Primary tumour cannot be assessed <u>N - Regional lymph nodes</u> N0 = regional lymph nodes not involved N1 = regional lymph nodes involved Nx = regional lymph nodes cannot be assessed (especially sites that preclude lymph node evaluation) <u>M - Metastases</u> M0 = no distant metastasis M1 = metastasis present <u>G – Grade</u> G1 = grade 1 (low/well differentiated) G2 = grade 2 (intermediate/moderately differentiated) G3 = grade 3 (high/poorly/undifferentiated) Gx = grade cannot be assessed

Staging criteria for non-rhabdomyosarcoma soft tissue sarcoma			
TIER 1		**TIER 2**	
Localized	Tumour confined to the area of origin including regional lymph nodes.	**Stage I**	Any T N0 M0 G1 or Gx
		Stage II	T1 N0 M0 G2 or G3
		Stage III	T2 or T3 or T4 N0 M0 G2 or G3 *or* Any T N1 M0 Any G (G1, G2, G3 or Gx)
Metastatic	Distant metastases present	**Stage IV**	Any T Any N M1 Any G (G1, G2, G3, Gx)

Database entry codes for non-rhabdomyosarcoma soft tissue sarcoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Stage I**	1
		Stage II	2
		Stage III	3
Metastatic	M	**Stage IV**	4
Unknown	X	**Unknown**	X

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9. Osteosarcoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

8a – Osteosarcoma: 9180-9187, 9191-9195, 9200

ICD-O-3 site codes:[15]

C400-C419, C760-C768, C809

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Osteosarcoma
Only two stages are recommended (localized or metastatic) for both Tier 1 and Tier 2.[2]

Definitions and notes
"Skip lesions", "skip metastases" or "seeding" in the same bone as the primary tumour are considered localized and not metastatic; if in a different bone to the primary tumour these are considered metastatic.

Staging criteria for osteosarcoma			
TIER 1		**TIER 2**	
Localized	Tumour confined to the area of origin including regional lymph nodes	**Localized**	Tumour confined to the area of origin including regional lymph nodes
Metastatic	Distant metastases present	**Metastatic**	Distant metastases present

Database entry codes for osteosarcoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Localized**	L
Metastatic	M	**Metastatic**	M
Unknown	X	**Unknown**	X

10. Ewing sarcoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

8c1 – Ewing Tumour and Askin Tumour of Bone: 9260, 9365

8c2 – pPNET of Bone: 9363-9364

ICD-O-3 site codes:[15]

C400-C419, C760-C768, C809 (unless otherwise specified)

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Ewing sarcoma
Only two stages are recommended (localized or metastatic) for both Tier 1 and Tier 2.

Staging criteria for Ewing sarcoma			
TIER 1		**TIER 2**	
Localized	Tumour confined to the area of origin including regional lymph nodes.	**Localized**	Tumour confined to the area of origin including regional lymph nodes.
Metastatic	Distant metastases present	**Metastatic**	Distant metastases present

Database entry codes for Ewing sarcoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Localized**	L
Metastatic	M	**Metastatic**	M
Unknown	X	**Unknown**	X

11. Retinoblastoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

5 – Retinoblastoma: 9510-9514

ICD-O-3 site codes:[15]

C692

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Retinoblastoma
Tier 2 follows the International Retinoblastoma Staging System (IRSS).[10] Tier 2 stage is determined after enucleation and is therefore a pathological classification.

Definitions and notes
In cases of bilateral disease: - the presence of synchronous disease should be noted - for purpose of stage, only the most advanced eye should be recorded.

Staging criteria for retinoblastoma			
TIER 1		**TIER 2**	
Localized	Intraocular	**Stage 0**	The tumour is confined to the globe. Enucleation has not been performed. (The patient is treated "conservatively" with either focal therapies or chemotherapy.)
		Stage I	Enucleation with negative margins
		Stage II	Enucleation with microscopic residual disease
Regional	Orbital extension or regional lymph nodes	**Stage III**	Regional extension: involvement of the orbit and/or preauricular or cervical lymph node extension
Metastatic	Distant metastases present	**Stage IV**	Distant metastatic disease

Database entry codes for retinoblastoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Stage 0**	0
		Stage I	1
		Stage II	2
Regional	R	**Stage III**	3
Metastatic	M	**Stage IV**	4
Unknown	X	**Unknown**	X

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12. Hepatoblastoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

7a – Hepatoblastoma: 8970

ICD-O-3 site codes:[15]

C220

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Hepatoblastoma
Only two stages are recommended (localized or metastatic) for both Tier 1 and Tier 2.[2]

Staging criteria for hepatoblastoma			
TIER 1		**TIER 2**	
Localized	Tumour confined to the liver including regional lymph nodes	**Localized**	Tumour confined to the liver including regional lymph nodes
Metastatic	Distant metastases present	**Metastatic**	Distant metastases present

Database entry codes for hepatoblastoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Localized**	L
Metastatic	M	**Metastatic**	M
Unknown	X	**Unknown**	X

13. Testicular cancer

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

10c – Malignant gonadal germ cell tumours: 9060–9065, 9070–9073, 9080–9085, 9090, 9091, 9100, 9101

ICD-O-3 site codes:[15]

C620-C629

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Testicular cancer
Tier 2 follows a modified TNM classification.[2]

Definitions and notes for Tier 2	
T - Tumour	
The extent of primary tumour is usually classified after radical orchiectomy, and for this reason, a pathologic stage is assigned.	
pTx	Primary tumour cannot be assessed
pT0	No evidence of primary tumour (e.g. histologic scar in testis)
pT1	Tumour limited to the testis and epididymis without vascular/lymphatic invasion; tumour may invade into the tunica albuginea but not the tunica vaginalis
pT2	Tumour limited to the testis and epididymis with vascular/lymphatic invasion, or tumour extending through the tunica albuginea with involvement of the tunica vaginalis
pT3	Tumour invades the spermatic cord with or without vascular/lymphatic invasion
pT4	Tumour invades the scrotum with or without vascular/lymphatic invasion
* Note: Except for pT4, extent of primary tumour is classified by radical orchiectomy. Tx is used if radical orchiectomy has not been performed.	
N - Regional nodes	
Nx	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1	Metastasis with a lymph node mass 2cm or less in greatest dimension; or multiple lymph nodes, none more than 2cm in greatest dimension.
N2	Metastasis with a lymph node mass more than 2cm but not more than 5cm in greatest dimension; or multiple lymph nodes, any one mass greater than 2cm but not more than 5cm in greatest dimension
N3	Metastasis with a lymph node mass more than 5cm in greatest dimension

Definitions and notes for Tier 2	
pN - Pathologic regional nodes	
pNx	Regional lymph nodes cannot be assessed
pN0	No regional lymph node metastasis
pN1	Metastasis with a lymph node mass 2cm or less in greatest dimension and five or fewer positive nodes, none more than 2cm in greatest dimension
pN2	Metastasis with a lymph node mass more than 2cm but not more than 5cm in greatest dimension; or more than five nodes positive, none more than 5cm; or evidence of extranodal extension of tumour
pN3	Metastasis with a lymph node mass more than 5cm in greatest dimension
M – Distant metastasis	
M0	No distant metastasis
M1	Distant metastasis

Staging criteria for testicular cancer			
TIER 1		**TIER 2**	
Localized	Tumour confined to the testes	**Stage I**	Any T N0 M0
Regional	Tumour extension to regional lymph nodes: - Interaortocaval - Para-aortic (periaortic) - Paracaval - Preaortic - Precaval - Retroaortic - Retrocaval - Along spermatic cord	**Stage II**	Any T N1, N2, N3 M0
Metastatic	Distant metastases present	**Stage III**	Any T Any N M1

Database entry codes for testicular cancer			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Stage I**	1
Regional	R	**Stage II**	2
Metastatic	M	**Stage III**	3
Unknown	X	**Unknown**	X

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14. Ovarian cancer

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

10c – Malignant gonadal germ cell tumours: 9060–9065, 9070–9073, 9080–9085, 9090, 9091, 9100, 9101

ICD-O-3 site codes:[15]

C569

Ovarian cancer
Tier 2 follows the FIGO staging system.[11]

Staging criteria for ovarian cancer			
TIER 1		**TIER 2**	
Localized	Tumour confined to ovaries	**Stage I**	Tumour confined to ovaries (one or both)
Regional	Tumour involves one or both ovaries with pelvic extension and/or spread to the peritoneum outside the pelvis and/or retroperitoneal lymph nodes	**Stage II**	Tumour involves one or both ovaries with pelvic extension (below the pelvic brim)
		Stage III	Tumour involves one or both ovaries with cytologically or histologically confirmed spread to the peritoneum outside the pelvis and/or metastasis to the retroperitoneal lymph nodes
Metastatic	Distant metastatic disease excluding peritoneal metastases	**Stage IV**	Distant metastasis (excludes peritoneal metastases)

Database entry codes for ovarian cancer			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**Stage I**	1
Regional	R	**Stage II**	2
		Stage III	3
Metastatic	M	**Stage IV**	4
Unknown	X	**Unknown**	X

15. Medulloblastoma and otherCNS embryonal tumours

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

3c1 – Medulloblastomas: 9470-9472, 9474, 9480*

3c2 – PNET: 9473*

3c3 – Medulloepithelioma: 9501-9504*

3c4 – Atypical teratoid/rhabdoid tumour: 9508*

3e3 – Only pineoblastoma is included: 9362*

* Includes tumours with non-malignant behaviour for all morphology codes shown.

ICD-O-3 site codes:[15]

C700-C729, C753

Medulloblastoma
Tier 2 follows the M staging system.[12]

Staging criteria for medulloblastoma			
TIER 1		**TIER 2**	
Localized	Localized disease	**M0**	No visible disease on imaging (MRI brain and spine) beyond primary site of disease and no tumour cells in the cerebrospinal fluid (CSF)
Metastatic	Disease beyond local site (e.g., other lesions in brain or spine, tumour cells in CSF or distant metastases	**M1**	Tumour cells in the CSF
		M2	Visible metastasis in brain
		M3	Visible metastasis in spine or Visible metastasis in cervicomedullary (junction)
		M4	Metastasis outside of the central nervous system

Database entry codes for medulloblastoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**M0**	M0
Metastatic	M	**M1**	M1
		M2	M2
		M3	M3
		M4	M4
Unknown	X	**Unknown**	X

Cancer Council Queensland and Cancer Australia provide permission to publish the Toronto Guidelines Childhood Cancer Staging Manual as Appendix 4 of the SJCARES Hospital-Based Cancer Registry. This work was supported by Cancer Australia to improve national data for childhood cancers as part of the *Investing in Medical Research – Fighting Childhood Cancer* initiative.

16. Ependymoma

ICCC-3 diagnostic group/subgroup and morphology codes:[13]

3a1 – Ependymomas: 9383, 9391-9394*

* Includes tumours with non-malignant behaviour for all morphology codes shown.

ICD-O-3 site codes:[15]

C710-C729

Cancer Council Queensland and Cancer Australia provide permission to publish the Toronto Guidelines Childhood Cancer Staging Manual as Appendix 4 of the SJCARES Hospital-Based Cancer Registry. This work was supported by Cancer Australia to improve national data for childhood cancers as part of the *Investing in Medical Research – Fighting Childhood Cancer* initiative.

Ependymoma
Tier 2 follows the M staging system.[12]

Staging criteria for ependymoma			
TIER 1		**TIER 2**	
Localized	Localized disease	**M0**	No visible disease on imaging (MRI brain and spine) beyond primary site of disease and no tumour cells in the cerebrospinal fluid (CSF)
Metastatic	Disease beyond local site (e.g., other lesions in brain or spine, tumour cells in CSF or distant metastases	**M1**	Tumour cells in the CSF
		M2	Visible metastasis in brain
		M3	Visible metastasis in spine or Visible metastasis in cervicomedullary (junction)
		M4	Metastasis outside of the central nervous system

Database entry codes for ependymoma			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
Localized	L	**M0**	M0
Metastatic	M	**M1**	M1
		M2	M2
		M3	M3
		M4	M4
Unknown	X	**Unknown**	X

Appendix V: Additional SJCARES Registry Staging Elements

Acute Lymphoblastic Leukemia (ALL)- CNS Presence

Database entry codes for acute lymphoblastic leukemia (ALL)			
TIER 1		**TIER 2**	
Stage	**Code**	**Stage**	**Code**
CNS-	CNS-	**CNS1**	CNS1
CNS+	CNS+	**CNS2** **CNS3**	CNS2 CNS3
Additional required Staging Tier: What's the patient's peripheral white blood cell (WBC) count? Enter recorded values in µl or check the "Not Reported" box.			

Hodgkin Lymphoma (HL)- Ann Arbor Designation

Staging criteria for Hodgkin lymphoma (HL)
Note: The suffix **A** or **B** is added to the stage according to the absence or presence of defined constitutional symptoms, as follows: A = no constitutional symptoms are recorded, or the medical record states there are no constitutional symptoms B = medical record states there are constitutional symptoms which are: • *Fevers.* Unexplained fever with temperature above 38 degrees Celsius (100.4 degrees F). • *Night sweats.* Drenching sweats (e.g. those that require change of bedclothes). • *Weight loss.* Unexplained weight loss of more than 10% of usual body weight inthe 6 months prior to diagnosis.
E= Involvement of a single extra-nodal site that is contiguous or proximal to the known nodal site
S= Splenic involvement

Retinoblastoma- International Classification for Intraocular Retinoblastoma (ICIR)

Risk classifications for retinoblastoma	
Risk Group A **(Very low risk)**	• Small intraretinal tumors away from foveola and disc • All tumors are 3 mm or smaller in greatest dimension, confined to the retina and • All tumors are located further than 3 mm from the foveola and 1.5 mm from the optic disc
Risk Group B **(Low risk)**	• All remaining discrete tumors confined to the retina • All other tumors confined to the retina not in Group A • Tumor-associated subretinal fluid less than 3 mm from the tumor with no subretinal seeding
Risk Group C **(Moderate risk)**	• Discrete local disease with minimal subretinal or vitreous seeding • Subretinal fluid, present or past, without seeding involving up to one-fourth of the retina • Local fine vitreous seeding may be present close to discrete tumor • Local subretinal seeding less than 3 mm (2 DD) from the tumor
Risk Group D **(High risk)**	• Diffuse disease with significant vitreous or subretinal seeding • Tumor(s) may be massive or diffuse • Subretinal fluid present or past without seeding, involving up to total retinal detachment • Diffuse or massive vitreous disease may include "greasy" seeds or avascular tumor masses • Diffuse subretinal seeding may include subretinal plaques or tumor nodules
Risk Group E **(Very high risk)**	• Presence of any one or more of the following poor prognosis features: o Tumor touching the lens o Tumor anterior to anterior vitreous face involving ciliary body or anterior segment o Diffuse infiltrating retinoblastoma o Neovascular glaucoma o Opaque media from hemorrhage o Tumor necrosis with aseptic orbital cellulites o Phthisis bulbi
IMPORTANT NOTE: ICIR risk classifications DO NOT correlate with Tier 1 and Tier 2 IRSS Staging	

Appendix VI: Duplicate Patient Checks & Secondary Cancers

Database Description

If patients with the same first and last name, date of birth, and gender are entered on the **Essential Information Form,** programming, questions, and logic are all in place (described below) to ensure that duplicative patient data is not being entered and/or distinguish secondary cancers.

Required:	Yes, under conditions noted in the Validation Notes

Database Values

Data Type	String
Format	N
Maximum Character Length	1
Values	(1) Are you attempting to report a second cancer in a patient who was previously registered? □ (Y) Yes □ (N) No (2) These cases will now be linked in the Registry and a new SJCARES ID will be assigned for the patient's second cancer. Confirm or Cancel? □ Confirm □ Cancel (3) Confirm the SJCARES ID represents different persons. □ (Y) Yes □ (N) No

Additional Notes

Data Manager Notes:	
Value Notes:	This data is completed once, as soon as the patient is identified for inclusion in the registry OR as soon as a secondary cancer case is identified in an already registered patient. Once submitted, this may not be changed without joint authorization from the database administrator, hospital site(s), and St Jude.
Validation Notes:	Limited to radio button selections. Values are programmed to show only if patient data points from the Essential Information form- first name, last name, date of birth, and gender- match across the Registry site database. Programmed data point matching is automated and blinded- St Jude cannot see these data points. If (1)= No, then (3) should appear. If (1)= Yes, then (2) should appear, if (2)= Confirm then create a new, unique SJCARES ID for the secondary cancer and if (2)= Cancel then (3) should appear. If (3)= Yes, allow the registration of the patient cancer case to continue by moving through the Registry forms and data fields and if (3)= No, lock the ability to create a new SJCARES ID.