Cancer in Young People in Canada (CYP-C) Data Collection Forms March 2015

1.0 Registration

1.1 Patient Demographics

[This section should be completed only once per patient, but should be updated if new information known (i.e. name change, etc)].

1.2 Child's last name: _____

1.3 Child's first name: _____

1.4 Sex: □Male □Female

1.5 Birth date: _____/_____/_____
(dd /MON/yyyy)

1.6 Age at diagnosis (if birth date is unavailable): _____

1.7 Province of residence at time of diagnosis:

□British Colombia
□Alberta
□Saskatchewan
□Manitoba
□Ontario
□Quebec
□New Brunswick
□Nova Scotia
□Prince Edward Island
□Newfoundland & Labrador
□Yukon
□Northwest Territories
□Nunavut

1.8 Provincial Health Insurance Number: _____

1.9 Postal code of residence at diagnosis: __ __ __ __ __ __

1.10 To which race(s) does the patient belong? *(Check all that apply)*

□ Aboriginal:
- □ First Nations
- □ Métis
- □ Inuit
- □ Aboriginal, not otherwise specified

□ Arab/West Asian (e.g. Arab, Middle Eastern (Lebanese, Arab-Israeli, Palestinian, Jordanian), Iranian, Afghani, Armenian, Turkish, includes ethnic Arab from Morocco, Egypt, Libya, Algeria and Tunisia, etc)

□ Asian:
- □ Chinese
- □ Filipino
- □ Japanese
- □ Korean
- □ South Asian (e.g. East Indian, Pakistani, Bangladeshi, Sri Lankan, Bhutanese, Nepalese)
- □ Southeast Asian (e.g. Vietnamese, Cambodian, Malaysian, Laotian, Thai, etc)

□ Black (e.g. African Canadian, African American, African-Caribbean (e.g. Haitian, Jamaican, Trinidadian), African (e.g. Somali, Nigerian, Angolan, Gambian) (excluding ethnic Arab from Morocco, Egypt, Libya, Algeria and Tunisia))

□ Latin American (Hispanic/Latino, South American (eg. Brazilian, Chilean, Peruvian), Spanish, Portuguese, Mexican, Hispanic Caribbean (Cuban, Porto Rican)))

□ White (e.g. Caucasian, White-European Ancestry, see Data Manual for examples)

□ Other, specify: _____

□ Not available

2.0 Diagnostic Information

2.1 Time to Treatment

(This section is required for each new primary tumour; however, it is not required if entering a revised diagnosis or true disease evolution).

2.1.1 Date of first health care contact for initial symptoms, with a provider listed below:

Date: ____/____/_____
(dd/MON/yyyy)

□ **Not available/unknown**

2.1.2 Which health care professional was contacted on that date?

□ Dentist
□ Emergency room physician
□ Family physician
□ MD (walk in clinic or speciality unknown or not listed here)
□ Neurologist
□ Nurse
□ Optometrist
□ Pediatrician
□ Not available

2.1.3 If alternate health care professional was contacted for initial symptoms, prior to contact or instead of contact with a health care professional listed above, specify the date:

Date: ____/____/_____
(dd/MON/yyyy)

□ Not available/unknown □ Not applicable

2.1.4 Which alternate health care professional was contacted on that date?

□ Chiropractor
□ Homeopath/Naturopath
□ Other, specify: _____
□ Not available

2.1.5 Date first seen by ONCOLOGIST:

Oncologist: Date: ____/____/_____
(dd/MON/yyyy)

□ Not available
□ Did not see an oncologist

2.1.6 Type of oncologist:

□Pediatric Oncologist/Hematologist
□Medical Oncologist/Hematologist
□Radiation Oncologist
□Gynecologic Oncologist
□Surgical Oncologist
□Not available

2.1.7 Institution of oncologist:

□B.C. Children's Hospital
□Alberta Children's Hospital
□Stollery Children's Hospital
□Saskatoon Cancer Centre
□Allan Blair Cancer Centre
□CancerCare Manitoba
□Children's Hospital, LHSC / Children's Hospital of Western Ontario
□McMaster Children's Hospital
□The Hospital for Sick Children
□Kingston General Hospital
□Children's Hospital of Eastern Ontario
□Centre Hospitalier Universitaire de Sainte Justine
□Montreal Children's Hospital
□Centre Hospitalier Universitaire de Sherbrooke
□Centre Hospitalier Universitaire de Québec
□Izaak Walton Killam Health Centre
□Janeway Children's Health & Rehabilitation Center
□Children's Hospital of Winnipeg
□Other, specify: _____
□Not available

2.1.8 Date first seen by SURGEON:

If surgical oncologist selected above (2.1.6), do not count their visit here.

Surgeon: **Date:** ____/____/_____
(dd/MON/yyyy)

□ Not available/unknown
□ Did not see a surgeon

2.1.9 Institution of surgeon:

□B.C. Children's Hospital
□Alberta Children's Hospital
□Stollery Children's Hospital
□Saskatoon Cancer Centre
□Allan Blair Cancer Centre
□CancerCare Manitoba
□ Children's Hospital, LHSC / Children's Hospital of Western Ontario
□McMaster Children's Hospital
□The Hospital for Sick Children
□Kingston General Hospital
□Children's Hospital of Eastern Ontario
□Centre Hospitalier Universitaire de Sainte Justine
□Montreal Children's Hospital
□Centre Hospitalier Universitaire de Sherbrooke
□Centre Hospitalier Universitaire de Québec
□Izaak Walton Killam Health Centre
□Janeway Children's Health & Rehabilitation Centre
□Children's Hospital of Winnipeg
□Other, specify: _____
□Not available

2.1.10 If not seen by an Oncologist or Surgeon, specify the date an alternate specialist was first seen:

Date alternate specialist was first seen:

Date: ____/____/_____
(dd/MON/yyyy)

□ Not available/unknown
□ Did not see an alternate specialist

2.1.11 What type of alternate specialist was seen on that date?

□ Dermatologist
□ Endocrinologist
□ Other, specify: _____
□ Not available

2.1.12 Institution of specialist:

□B.C. Children's Hospital
□Alberta Children's Hospital
□Stollery Children's Hospital
□Saskatoon Cancer Centre
□Allan Blair Cancer Centre
□CancerCare Manitoba
□ Children's Hospital, LHSC / Children's Hospital of Western Ontario
□McMaster Children's Hospital
□The Hospital for Sick Children
□Kingston General Hospital
□Children's Hospital of Eastern Ontario
□Centre Hospitalier Universitaire de Sainte Justine
□Montreal Children's Hospital
□Centre Hospitalier Universitaire de Sherbrooke
□Centre Hospitalier Universitaire de Québec
□Izaak Walton Killam Health Centre
□Janeway Children's Health & Rehabilitation Centre
□Children's Hospital of Winnipeg
□Other, specify: _____
□Not available

2.2 Diagnostic Record

2.2.1 Specify ordinal primary: _____

1= 1st primary (first cancer diagnosis – no prior cancer(s))
2= 2nd primary (2nd cancer diagnosis – one prior cancer)
3= 3rd primary (3rd cancer diagnosis – two prior cancers)
4= 4th primary (4th cancer diagnosis – three prior cancers)

2.2.1.1 If ordinal primary ≥2, **Choose the option that best describes the previous diagnosis of childhood cancer?**

My previous cancer diagnosis was…	
□	Diagnosed **ON or AFTER** Jan 1, 1995 and will be captured by CYPC
□	Diagnosed **ON or AFTER** Jan 1, 1995 and previous primary was not eligible for CYPC, patient information available
□	Diagnosed **ON or AFTER** Jan 1, 1995 and previous primary was not eligible for CYPC, patient information **NOT** available
□	Diagnosed **BEFORE** Jan 1, 1995, patient information available
□	Diagnosed **BEFORE** Jan 1, 1995, patient information **NOT** available

2.2.2 Is this the initial report, a revised diagnosis or a true disease evolution of the diagnosis?

□ Initial report
□ Revised diagnosis
□ Disease evolution

→ *If revised diagnosis or disease evolution, please update sections 2.2 to 2.5.*

2.2.3 Date of definitive diagnostic procedure:
(Procedure which determined the treatment plan)

Date: ____/____/_____
(dd/MON/yyyy)

2.2.4 Definitive diagnosis based on:

□ Histology
□ Radiology
□ Other, specify: _____
□ Not available

2.2.4.1 If histology, diagnostic biopsy only?

□ Yes = *Only a diagnostic biopsy was performed (including bone marrow aspirate and biopsy).*
□ No = *An excision or resection was performed. A Cancer Related surgery should be entered in Section 8.0*
□ Not available

2.2.5 Institution of diagnosis:

□B.C. Children's Hospital
□Alberta Children's Hospital
□Stollery Children's Hospital
□Saskatoon Cancer Centre
□Allan Blair Cancer Centre
□CancerCare Manitoba
□ Children's Hospital, LHSC / Children's Hospital of Western Ontario
□McMaster Children's Hospital
□The Hospital for Sick Children
□Kingston General Hospital
□Children's Hospital of Eastern Ontario
□Centre Hospitalier Universitaire Sainte Justine
□Montreal Children's Hospital
□Centre Hospitalier Universitaire de Sherbrooke
□Centre Hospitalier Universitaire de Québec
□Izaak Walton Killam Health Centre
□Janeway Children's Health & Rehabilitation Centre
□Children's Hospital of Winnipeg
□Other, specify: _____
□Not available

2.2.6 ICDO M code: __ __ __ __ / __ **2.2.7 ICDO T code:** C __ __ . __

Paper CRFs only (will be pre-populated by M& T codes in the electronic system)

2.2.8 Diagnosis description (morphology/histology):
(e.g. Malignant lymphoma, large cell, diffuse)

_____
_____
_____

2.2.9 Site of tumor: _____

2.3 Stage

ALL, skip to 2.4.7
AML, skip to 2.4.8
CML, skip to 2.4.9
MDS, skip to 2.4.10

2.3.1 Staging system used:

□ AJCC	□ INSS	□ SSS (MSTS)
□ AJCC/TNM	□ IRSG	□ STS-COG
□ Ann Arbor	□ NWTSG	□ St. Jude/Murphy
□ Chang M-Stage	□ PRETEXT/SIOPEL	□ St. Jude (original) RB
□ Clark's	□ Retinoblastoma Int'l Class	□ St. Jude (modified) RB
□ FIGO	□ Reese-Ellsworth	□ SEER Summary Stage
□ TNM		

□ Other, specify: _____(Enter the system and the stage)
□ Staged according to protocol: If yes,
Protocol Number: _____(Enter the protocol number/name and the stage)
□ Not available

2.3.2 Actual Stage

2.3.2.1 If unilateral disease:
Stage *(definitive stage)***:** _____

2.3.2.2 If bilateral disease (e.g. eye, kidney, adrenal gland, ovary):

Stage left: _____ **Stage right: _____**

□ Not available □ Not available

2.3.3 Select Seer Summary Stage (except ALL, AML, CML or MDS)

□ Localized
□ Regional
□ Distant
□ Not Applicable
□ Not Available

2.4 Histological Grading and Risk Group

(Note: skip to section 2.5 if NOT Astrocytoma, Neuroblastoma, Hodgkin's Lymphoma, Rhabdomyosarcoma, Medulloblastoma or Renal tumor)

2.4.1 Astrocytoma: WHO histological typing

□ I □ II □ III □ IV □ Not available

2.4.2 Neuroblastoma risk group:

□ Low □ Intermediate □ High □ Not available

2.4.3 Hodgkin's lymphoma risk group:

□ Low □ Intermediate □ High □ Not available

2.4.4 Rhabdomyosarcoma risk group:

□ Low □ Intermediate □ High □ Not available

2.4.5 Medulloblastoma risk group:

□ Standard Risk □ High Risk □ Not available

2.4.6 Renal tumor risk group:

□ Very low □ Low □ Standard □ High □ Not available

2.4.7 Acute Lymphoblastic Leukemia (ALL)

[Note: skip to section 2.5 if NOT leukemia or MDS]

2.4.7.1 Initial white blood cell count:

WBC count: _____ **(*10E^9/L)**

□ Not available

2.4.7.2 Was minimal residual disease measured?

□ No, not measured
□ Yes, measured

2.4.7.3 What was the disease status of the cerebrospinal fluid at diagnosis?

□ CNS 1
□ CNS 2
□ CNS 3
□ Not available
□ Not tested

2.4.7.4 Was there testicular involvement at diagnosis?

□Yes
□ No
□ Not available
□ Not applicable

2.4.7.5 Was immunophenotyping/flow cytometry done at diagnosis?

□Yes
□ No
□ Not available

2.4.7.5.1 If yes, specify phenotype:

□ pre B-cell (Acute Lymphoblastic Leukemia, pre-B type)
□ B-cell (Burkitt's Leukemia)
□ T-cell
□ Mixed, specify: _____
□ Other, specify: _____
□ Not available

2.4.7.6 Was chromosomal testing done at diagnosis?

□Yes □ No □ Not available

If yes, please check all those that apply:

2.4.7.6a Translocations:

□ t(1;19)(q23;p13) (*E2A-PBX*)
□ t(4;11)(q21;q23) *(AF4-MLL)*
□ t(5;14)(q35;q32) (TLX3-BCL11B)
□ t(7;10)(q35;q24) *(TcRb-HOX11)*
□ t(7;11)(q35;p11.2) (TcRb-RBTN1)
□ t(7;11)(q35;p13) (TcRb-RBTN2)
□ t(8;14)(q24;q11.2) (*c-MYC-TcRα/δ*)
□ t(8;14)(q24;q32) (*c-MYC-IgH)*
□ t(9;22)(q34;q11) [The Philadelphia chromosome (ABL-BCR)]
□ t(10;11)(p12;q14) (PICALM-MLLT10/CALM-AF10)
□ t(10;14)(q24;q11.2) *(HOX11/TCL3-TcRδ)*
□ t(11;14)(p13;q11.2) *(RBTN2- TcRα/δ)*
□ t(11;14)(p15;q11.2) *(RBTN1- TcRα/δ)*
□ t(11;19)(q23;p13.3) (*MLL-ENL*)
□ t(12;21) (*TEL-AML1* cryptic translocation)
□ other MLL (11q23) rearrangement
□ other *MYC* (8q24) rearrangement

2.4.7.6b Trisomy:

□ Hyperdiploid
□ +4
□ +10
□ +17
□ +21 (trisomy or tetrasomy)

2.4.7.6c Other Recurrent Rearrangements/Karyotypes

□ Amplified NUP214/ABL1 (9q34)
□ dic(9;20)(p13;q11.2)
□ Near haploidy/Hypodiploidy
□ 9p (CDKN2A) deletion
□ RUNX (AML1)(21q22) amplification

□ **Checked and none of the above chromosomal abnormalities were found**

2.4.8 Acute Myeloid Leukemia (AML, ANLL)

2.4.8.1 Initial white blood cell count:

WBC count: _____ **(*10E^9/L)**

□ Not available

2.4.8.2 Please enter the sub-type using <u>either</u> the FAB or WHO system

FAB System

□ M0 Acute myeloblastic leukemia without maturation
□ M1 Acute myeloblastic leukemia with minimal maturation
□ M2 Acute myeloblastic leukemia with maturation
□ M3 Acute promyelocytic leukemia (all variants)
□ M4 Acute myelomonocytic leukemia (all variants)
□ M5 Acute monocytic leukemia
□ M6 Erythroleukemia
□ M7 Acute megakaryocytic leukemia
□ Not available

WHO System

□ AML with recurrent genetic abnormalities
□ AML with multilineage dysplasia
□ AML and myelodysplastic syndromes, therapy related
□ AML not otherwise categorized
□ Not available

2.4.8.3 Was chromosomal testing done at diagnosis?

□ Yes □ No □ Not available

If yes, please check all those that apply:

2.4.8.3a Translocations:

□ t(1;22)(p13;q13) (*OTT-MAL /RBM15-MKL1*)
□ t(6;9)(p23;q34) (DEK-NUP214)
□ t(8;16)(p11;p13) *(MOZ / MYST-CREBBP)*
□ t(8;21)(q22;q22) *(AML1-ETO)*
□ t(9;11)(p21;q23) *(MLL-AF9)*
□ t(9;22)(q34;q11) [The Philadelphia chromosome (ABL-BCR)]
□ t(10;11)(p12;q14) (PICALM-MLLT10/CALM-AF10)
□ t(10;11)(p12;q23) (MLL-MLLT10)
□ t(15;17)(q22;q12~21) (PML/RARα)
□ t(16;16)(p13;q22) *(CBFB-MYH11)*
□ other *MLL* (11q23) rearrangement

2.4.8.3b Inversion:

□ inv(16)(p13q22) *(CBFB-MYH11)*

2.4.8.3c Monosomy:

□ chromosome 5/del(5q)
□ chromosome 7

2.4.8.3d Other:

□ abnormal FLT3 allelic ratio

□ **Checked and none of the above chromosomal abnormalities were found**

2.4.9 Chronic Myeloid Leukemia

2.4.9.1 Was chromosomal testing conducted?

Note: If you select Ph+ve CML (9875/3) as the ICDO M Code (2.2.6), this question will not appear on eCYP as the information is already contained in the M code.

□ Yes
□ No
□ Not available

If yes:

2.4.9.1a Translocations:

□ t(9;22)(q34;q11) *[The Philadelphia chromosome (ABL-BCR)]*

□ **Checked and none of the above chromosomal abnormalities were found**

2.4.10 Myelodysplastic Syndrome (MDS)

2.4.10.1 Initial white blood cell count:

WBC count: _____ **(*10E^9/L)**

□ Not available

2.4.10.2 Please enter the sub-type using **either** the FAB or WHO system

FAB System

□ Refractory anemia (RA)
□ Refractory anemia with ringed sideroblasts (RARS)
□ Refractory anemia with excess blasts (RAEB)
□ Refractory anemia with excess blasts in transformation (RAEB-T)
□ Chronic myelomonocytic leukemia (CMML)
□ Juvenile myelomonocytic leukemia (JMML)
□ Not available

WHO System

□ Refractory anemia (RA)
□ Refractory anemia with ringed sideroblasts (RARS)
□ Refractory cytopenia with multilineage dysplasia (RCMD)
□ Refractory cytopenia with multilineage dysplasia and ringed sideroblasts (RCMD-RS)
□ Refractory anemia with excess blasts-1 (RAEB-1)
□ Refractory anemia with excess blasts-2 (RAEB-2)
□ MDS associated with isolated del(5q)
□ Myelodysplastic syndrome, unclassified (MDS-U)
□ Not available

2.4.10.3 Was chromosomal testing conducted at diagnosis?

□ Yes
□ No
□ Not available

If yes:

2.4.10.3a Monosomy:

□ chromosome 7

□ **Checked and none of the above chromosomal abnormalities were found**

2.5 Extent of Disease at Diagnosis

Includes all types of cancer:
– Leukemia/lymphoma: if CSF is positive and/or testes are involved, please be sure to check off as a metastatic site(s)
– If CNS metastasis: indicate if CSF, spinal cord and/or brain are involved (select all that apply)

2.5.1 Was there metastasis at diagnosis?

□Yes □No □Not available

↓

If yes:

2.5.2 Metastatic sites (check all general sites that apply):

□Abdomen (NOS)
□Adrenal gland-bilateral
□Adrenal gland-left/right
□Bladder
□Bone marrow
□Bone-multiple
□Bone-single
□Brain
□Breast
□Cerebrospinal fluid (CSF)
□Eye-bilateral
□Eye-left/right
□Head and neck (NOS)
□Heart
□Kidney-bilateral
□Kidney-left/right
□Large bowel
□Liver
□Lung-bilateral
□Lung-left/right
□Lymph nodes-distant
□Lymph nodes-local/regional
□Mediastinum
□Meninges
□Muscular tissue (NOS)
□Ovary – left/right
□Ovary - bilateral
□Pancreas
□Pelvis/Inguinal region (NOS)
□Peritoneal
□Pituitary gland
□Pleura
□Skin
□Small bowel
□Spinal cord
□Spleen
□Testes – left/right
□Testes – bilateral
□Thyroid
□Uterus
□Other, specify:_____
□Not available

2.6 Organ Transplantation

2.6.1 Did the patient previously receive an organ or hematopoietic cell transplant prior to malignancy?

- □ Yes
- □ No
- □ Not available

If yes:

2.6.2 Date transplant was received:

Date: _____
(dd/MON/yyyy)

2.6.3 Type of transplant received:

- □ Heart
- □ Hematopoietic cells
- □ Kidney
- □ Liver
- □ Lung
- □ Pancreas
- □ Other, specify: _____
- □ Not available

2.7 Predisposing and Genetic Conditions

2.7.1 Does the patient have a predisposing condition/co-morbidity which led to the modification of therapy?

- Yes
- No
- Not available

2.7.2 Does the patient have a known genetic condition, diagnosed prior to or at the time of the cancer diagnosis?

- Yes
- No
- Not available

If yes:

2.7.2.1 Did the child have a consult with an geneticist?

- Yes
- No
- Not available/unknown

2.7.3 Does the child have one of the following:

2.7.3.1 Nephroblastomatosis:

Left:	Yes	No	Not available/unknown
Right:	Yes	No	Not available/unknown

2.7.3.2 Beckwith-Wiedemann Syndrome:

- Yes
- No
- Not available/unknown

2.7.3.3 Neurofibromatosis:

Type I :	Yes	No	Not available/unknown
Type II:	Yes	No	Not available/unknown

2.7.3.4 Li-Fraumeni Syndrome:

- Yes
- No
- Not available/unknown

3.0 Patient Contact and Status

(Capture data from diagnosis until 5 years post diagnosis)

3.1 Patient Contact and Status

3.1.1 For the 1995-2000 cohort, data current up to: ____/_____/____

(dd/MON/yyyy)

Year of Follow Up	Year 1	Year 2	Year 3	Year 4	Year 5
3.1.2 Start date:	Date of diagnosis	Date of diagnosis + 1 year	Date of diagnosis + 2 years	Date of diagnosis + 3 years	Date of diagnosis + 4 years
3.1.3 End date:	Date of diagnosis + 1 year	Date of diagnosis + 2 years	Date of diagnosis + 3 years	Date of diagnosis + 4 years	Date of diagnosis + 5 years
3.1.4 What was their status <u>at the end</u> of the period?					
Alive, with disease	☐	☐	☐	☐	☐
Alive, no evidence of disease	☐	☐	☐	☐	☐
Alive, disease status unknown	☐	☐	☐	☐	☐
Dead	☐	☐	☐	☐	☐
3.1.5 Was there any contact within period above?					
Yes	☐	☐	☐	☐	☐
No	☐	☐	☐	☐	☐
3.1.6 If yes, enter date of last contact:					
What was the date of last contact?	___/____/___	___/____/___	___/____/___	___/____/___	___/____/___
3.1.7 If no contact, enter details below:					
Monitor only (no follow-up needed in the time period)	☐	☐	☐	☐	☐
Moved out of country	☐	☐	☐	☐	☐
Patient not seen / no contact	☐	☐	☐	☐	☐

3.2 Patient Information Summary

Year of Follow Up	**Year 1**		**Year 2**		**Year 3**		**Year 4**		**Year 5**	
3.2.1 Start date:	Date of diagnosis		Date of diagnosis + 1 year		Date of diagnosis + 2 years		Date of diagnosis + 3 years		Date of diagnosis + 4 years	
3.2.2 End date:	Date of diagnosis + 1 year		Date of diagnosis + 2 years		Date of diagnosis + 3 years		Date of diagnosis + 4 years		Date of diagnosis + 5 years	
3.2.3 Section	**Details Entered**	**3.2.4a Date** dd/MON/yyyy	**Details Entered**	**3.2.4b Date** dd/MON/yyyy	**Details Entered**	**3.2.4c Date** dd/MON/yyyy	**Details Entered**	**3.2.4d Date** dd/MON/yyyy	**Details Entered**	**3.2.4e Date** dd/MON/yyyy
Protocol/Treatment plan details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Chemotherapy treatment details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Surgery details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Radiotherapy details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Hematopoeitic cell transplantation details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Hospitalization details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Complications details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Revised diagnosis details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Relapse details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Second or subsequent primary (new malignancy) details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Patient transfer in or transfer out of your centre	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___
Death details	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___	☐ Yes ☐ No	___/___/___

4.0 Height and Weight

Enter height and weight taken at diagnosis and once per year thereafter. If multiple weights in a given year, use the date closest to the anniversary of diagnosis.

Diagnosis and Anniversary Dates (pre-populated electronically)	**4.1 Date for Height** (dd/MON/yyyy)	**4.2 Height** (cm)	**Not Available**	**4.3 Date for Weight** (dd/MON/yyyy)	**4.4 Weight** (kg)	**Not Available**	**BMI***
___/___/____	___/___/____	_____ cm	□	___/___/____	_____ kg	□	
___/___/____	___/___/____	_____ cm	□	___/___/____	_____ kg	□	
___/___/____	___/___/____	_____ cm	□	___/___/____	_____ kg	□	
___/___/____	___/___/____	_____ cm	□	___/___/____	_____ kg	□	
___/___/____	___/___/____	_____ cm	□	___/___/____	_____ kg	□	
___/___/____	___/___/____	_____ cm	□	___/___/____	_____ kg	□	

* BMI will be computed by program

5.0 Protocol/Treatment Plan Information

(Note: Please fill out a separate page for each protocol/treatment plan)

Treatment Plan #_____

5.1 Treatment Plan Used:

- □ Registered on a clinical trial that is REB Approved
- □ Individualized treatment
- □ Palliative care
- □ Standard of care
  - □ Following a protocol
  - □ Standardized regimen
  - □ Observation alone
  - □ Surgery alone
  - □ Surgery and radiation
  - □ Radiation alone
- □ Other, specify: _____
- □ Not available

5.2 If not registered on a clinical trial, please give reason:

- □ Language barrier, trial not offered
- □ No available trial at the time
- □ Not eligible for any available trial
- □ Physician choice
- □ Refused therapy
- □ Refused to participate in proposed trial
- □ Other, specify: _____
- □ Not available

5.3 If registered on or following a protocol:

Type of protocol:

- □ COG protocol (incl. former POG, CCG, IRSG, NWTSG and joint COG protocols (e.g.COG/PBMTC, etc.))
- □ Dana Farber Cancer Institute (DFCI) ALL Consortium
- □ Pediatric Blood and Marrow Transplant Consortium (PBMTC)
- □ Institutional protocol
- □ Other group protocol
- □ Not available

5.4 Protocol number: _____

□Not applicable

5.5 Treatment arm: _____

□Not applicable

5.6 If non-COG trial, protocol name:

_____

_____

□Not applicable

5.7 Date treatment began:

(Note: Use the date systemic chemotherapy began for leukemics, NOT intrathecal.)

Date: _____/_____/_____
(dd/MON/yyyy)

□ Not available

5.8 Protocol/Treatment Plan Status:

□ Completed as planned
□ Terminated early
□ In progress
□ Not applicable (e.g. observation only, palliative care)

5.9 If protocol/treatment completed OR terminated early, specify date:

Date: _____/_____/_____
(dd/MON/yyyy)

□ Not available

5.10 If protocol/treatment plan terminated early, reason treatment plan not completed

□ Death
□ Physician preference
□ Progression/no response
□ Refusal to continue
□ Relapse
□ Revised diagnosis
□ Other, specify: _____
□ Not available
□ Second malignancy
□ Stem cell transplant
□ Study terminated
□ Study violation
□ Toxicity

□ Use multiple pages as required. Check box if multiple pages used.

6.0 Chemotherapy List

6.1 Were treatment agents used?

□ Yes □ No (if no, please skip to section 8.0 surgery details)

6.2 If yes, check all agents that apply:

Includes monoclonal antibodies and Biological Effect Modifiers (eg. G-CSF). Does NOT include chemotherapy used as part of the preparative regimen prior to hematopoietic cell transplant.

Agents highlighted in Grey require the completion of the Chemotherapy Details form

6.2 Chemotherapeutic Agent	Check if administered	Chemotherapy Details Completed
17-AAG, demethoxygeldanamycin	□	
Alemtuzumab, Campath	□	
Alisertib (MLN8237)	□	
Aminocamptothecin (9-AC, 9-aminocamptothecin)	□	
Amifostine	□	
Amsacrine, Acridinyl anisidide, m-AMSA	□	
Antilymphocyte globulin (ALG)/ Antithymocyte globulin (ATG/ATGAM)	□	
Anti-rejection drugs (Sirolimus, Tacrolimus, MMF)	□	
Arsenic trioxide (Trisinox)	□	
Asparaginase E-Coli (L-Asp), Elspar, Kidrolase	□	
Asparaginase Erwinia (Erwinase)	□	
Asparaginase Peg	□	
Azacytidine (Aza-C) 5-AZA, 5-AC, 5-azacytidine)	□	
Bcl-2 antisense, Oblimersen, Genasense, Augmerosen	□	
Bevacizumab (Avastin)	□	
Bleomycin, Blenoxane, Bleo*	□	□
Bortezomib (Velcade)	□	
Brentuximab vedotin (SGN-35)	□	
Bryostatin 1	□	
Busulphan, Busulfan, (Myleran)*	□	□

Carboplatin, CBDCA, Paraplatin, Carboplatinum*	☐	☐
Carmustine (BCNU), Bis-Chloroethyl-Nitrosourea, BiCNU*	☐	☐
Ch14.18	☐	
Chlorambucil, Leukeran	☐	
CI-958	☐	
CI-980	☐	
Cisplatin, CDDP, Platinol, Cisplatinum, Cis-diamminedicloro-platinum II, P*	☐	☐
Cixutumumab	See IMC-A12	
Cladribine, CdA, Leustatin	☐	
Clofarabine, Clolar	☐	
Colony stimulating factors/Erythropoietin (e.g. G-CSF, Eprex, Aransep)	☐	
Cyclophosphamide, Cytoxan, CTX, Procytox*	☐	☐
Cyclosporin	☐	
Cytarabine, Ara-C, Cytosar, Cytosine arabinoside (IM, sub q, PO OR IV <500mg/m^2 per dose)	☐	
Cytarabine, Ara-C, Cytosar, Cytosine arabinoside* (IT ONLY)	☐	☐ (IT)
Cytarabine, Ara-C, Cytosar, Cytosine arabinoside* (ONLY IV ≥500mg/m^2 per dose)	☐	☐ (IV ≥500mg/m^2)
Dacarbazine (DTIC), Dimethyl Trazenoimidazole Carboxamide	☐	
Dactinomycin (DACT), Actinomycin D, Cosmogen, Act-D	☐	
Dasatinib (BMS-354825)	☐	
Daunomycin, Daunorubicin, Cerubidine, DNR*	☐	☐
Decitabine, Dacogen	☐	
Depsipeptide (DEP)	☐	
Dexamethasone (Decadron)	☐	
Dexrazoxane, Zinecard, Cardioxane	☐	
Docetaxel (Taxotere)	☐	
Dolastatin 10 (D10)	☐	
Doxorubicin, Adriamycin, ADR*	☐	☐
Doxorubicin-pegylated liposomal (DOXIL), PLD*	☐	☐
Ecteinascidin 743 (ET 747)	☐	
Epirubicin, Pharmorubicin, Ellence*	☐	☐

Epratuzumab	☐	
Erlotinib, Tarceva, OSI-774	☐	
Etoposide (VP16), VePesid, ETOP*	☐	☐
Fenretinide (FEN)	☐	
Flavopiridol (FLAV)	☐	
Fludarabine, FAMP, Fludara	☐	
Fluorouracil (5-FU, Adrucil, Efudex, Fluoroplex, 5-fluorouracil)	☐	
Gamma globulin (IVIG, IgG)	☐	
Gefitinib, Iressa, ZD1839	☐	
Gemcitabine (Gemzar)	☐	
Gemtuzumab (Mylotarg)	☐	
Glucocorticoids (corticosteroids)	☐	
Homoharringtonine, HHT, Ceflatonin	☐	
Hu14.18-IL2	☐	
Hydrocortisone (IT ONLY)*	☐	☐
Hydroxyurea, Hydroxycarbamide, Hydrea	☐	
Ibritumomab tiuxetan	☐	
Idarubicin, Idamycin, 4-Demethoxydaunorubicin*	☐	☐
Ifosfamide, Isophosphamide, IFOS, Ifex, Holoxan*	☐	☐
IMC-A12 (Cixutumumab)	☐	
IVIG	See Gamma globulin	
Imatinib (Gleevec), IMAT	☐	
Interferon	☐	
Interleukin	☐	
Irinotecan (CPT-11), Camptosar	☐	
Isotretinoin, 13-cis-Retinoic Acid	☐	
Ixabepilone	☐	
Lenalidomide, Revlimid	☐	☐
Lestaurtinib (CEP-701)	☐	
Lomustine (CCNU), CeeNU, Chloroethyl-Cyclohexyl-Nitrosurea*	☐	☐
Mechlorethamine, Nitrogen Mustard, HN2, Mustargen*	☐	☐

Melphalan, L-PAM, Alkeran, L-sarcolysin*	☐	☐
Mercaptopurine (6-MP, Purinethol, 6-mercaptopurine)	☐	
Methotrexate, MTX, amethopterin (IM, sub q, PO OR IV <500mg/m^2 per dose)	☐	
Methotrexate, MTX, amethopterin* (IT ONLY)	☐	☐ (IT)
Methotrexate, MTX, amethopterin* (ONLY IV ≥500mg/m^2 per dose)	☐	☐ (IV ≥500mg/m^2)
MGI 114, Irofulven, HMAF	☐	
Mitomycin C (MMC)	☐	
Mitotane, Lysodren	☐	
Mitoxantrone, Novantrone, DHAD, Dihydrochloride*	☐	☐
MMF → Anti-rejection drugs	☐	
Motexafin gadolinium, Xcytrin, Gadolinium Texaphyrin (GD-Tex)	☐	
Nelarabine (Arranon, AraG)	☐	
Nilotinib (AMN107, Tasigna)	☐	
Nimotuzumab	☐	
O6-Benzylguanine	☐	
Oxaliplatin, Eloxatin*	☐	☐
Paclitaxel, Taxol	☐	
Palivizumab (Synagis)	☐	
Pemetrexed, Alimta	☐	
Prednisone (Methylprednisone, Prednisolone)	☐	
Procarbazine, PCB, Natulan, Matulane*	☐	☐
PXD101	☐	
Pyrazolodacridine (PA)	☐	
Raltitrexed, Tomudex, ZD1694	☐	
Rebeccamycin Analogue	☐	
Rituximab, Rituxan	☐	
Sirolimus → See Anti-rejection drugs	☐	
Sorafenib, BAY 43-9006, Nexavar	☐	
Suberoylanilide hydroxamic acid (SAHA)	☐	
Sunitinib (Sutent, SU11248)	☐	

Tacrolimus → Anti-rejection drugs	☐	
Tamoxifen, Tam, Nolvadex	☐	
Temozolomide, TMZ, Temodal	☐	
Temsirolimus (CCI-779)	☐	
Teniposide (Vumon) VM-26*	☐	☐
Thalidomide (Thalomid)	☐	
Thioguanine (6-TG, Lanvis, 6-thioguanine)	☐	
Thiotepa, TESPA, Triethylene Thiophosphoramide*	☐	☐
Tiazofurin (TR)	☐	
Tipifarnib, FTI, R115777	☐	
Tirapazamine	☐	
Topotecan (Hycamtin)	☐	
Tositumomab (Bexxar)	☐	
Trastuzumab, Herceptin, Her2	☐	
Tretinoin, ATRA, all-trans-Retinoic acid, Vesanoid	☐	
Tumour vaccine	☐	
Vinblastine, Velbe, Velban, VLB	☐	
Vincristine, Leurocristine, Oncovin, VCR	☐	
Vindesine, DAVA, Eldisine	☐	
Vinorelbine, Navelbine	☐	
Vorinostat	☐	
Other, specify: _____	☐	

7.0 Chemotherapy Details

Complete this information for each agent that the patient received and was grey-shaded on the Chemotherapy List (Section 6.0).

PLEASE NOTE THAT THE e-CYP SYSTEM DEFAULTS TO:
7.4 Type of Dose: Total Dose ***7.6 Unit of Dose: mg*** ***7.7 Route of Administration (unless specified otherwise): IV.***

7.0 Chemotherapy Details Chart							
7.1 Agent Name (pre-populated electronically)	**7.2 Date Agent First Administered**	**7.3 Date Agent Last Administered**	**7.4 Type of Dose**	**7.5 Dose**	**7.6 Unit of Dose**	**7.7 Route of Administration**	**7.8 Total Dose Current until this date**
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m^2		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m^2		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m^2		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m^2		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____

7.1 Agent Name (pre-populated electronically)	7.2 Date Agent First Administered	7.3 Date Agent Last Administered	7.4 Type of Dose	7.5 Dose	7.6 Unit of Dose	7.7 Route of Administration	7.8 Total Dose Current until this date
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m²		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m²		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m²		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m²		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m²		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____
	___/____/____	___/____/____	□ **Total dose** □ Individual dose □ Total dose/m²		□ **mg** □ g □ microg □ U □ IU	□ **IV** □ IC □ IM □ IT □ PO □ Sub Q □ N/A □ IA	___/____/____

□ **Check box if multiple pages were used.**

8.0 Surgery Details

8.1 Was surgery ever performed?

□ Yes □ No (if no, please skip to section 9.0 Radiation Details)

If yes, enter information for all surgeries *used as a form of treatment*. Check all that apply.

Includes: excisional biopsies.
Excludes: incisional biopsies, bone marrow aspirates, lumbar punctures, or central lines.
Use multiple pages as required.

CANCER TREATMENT RELATED SURGERY					
			8.1.3 Date of Cancer Related Surgery		
Check if yes	**8.1.1 Cancer related surgery type:** (excludes procedures for diagnostic purposes)	**8.1.2 Partial or complete tumor resection**	**Date** (dd/MON/yyyy)	**Date** (dd/MON/yyyy)	**Date** (dd/MON/yyyy)
□	Amputation	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Excision, partial		____/_____/____	____/_____/____	____/_____/____
□	Excision, complete		____/_____/____	____/_____/____	____/_____/____
□	Limb salvage surgery	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - adrenal - unilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - adrenal - bilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - bowel	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - eye - unilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - eye - bilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____

CANCER TREATMENT RELATED SURGERY					
			8.1.3 Date of Cancer Related Surgery		
Check if yes	**8.1.1 Cancer related surgery type:** (excludes procedures for diagnostic purposes)	**8.1.2 Partial or complete tumor resection**	**Date** (dd/MON/yyyy)	**Date** (dd/MON/yyyy)	**Date** (dd/MON/yyyy)
□	Organ resection - kidney - unilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - kidney - bilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - liver	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - lung - unilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - lung - bilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - ovary - unilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - ovary - bilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - testis - unilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - testis - bilateral	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection - thyroid	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Organ resection – uterus	□ Partial □ Complete	____/_____/____	____/_____/____	____/_____/____
□	Resection, gross total (neurosurgery only)		____/_____/____	____/_____/____	____/_____/____
Ventriculostomy		Include under “Shunt insertion” under secondary surgeries (8.2.1)			

8.2 Enter information for all secondary surgeries.

Secondary surgeries are those that are not used as a form of treatment but may be used to deliver care, diagnose or treat complications that may arise as a result of therapy. The intent of this section is to capture utilization of resources.

SECONDARY SURGERIES				
		8.2.2 Date of Secondary Surgery		
Check if yes	**8.2.1 Secondary surgery type**	**Date** (dd/MON/yyyy)	**Date** (dd/MON/yyyy)	**Date** (dd/MON/yyyy)
☐	Allograft repair	____/_____/____	____/_____/____	____/_____/____
☐	Amputation	____/_____/____	____/_____/____	____/_____/____
☐	Gastrostomy	____/_____/____	____/_____/____	____/_____/____
☐	Laparoscopy (diagnostic)	____/_____/____	____/_____/____	____/_____/____
☐	Laparotomy (diagnostic)	____/_____/____	____/_____/____	____/_____/____
☐	Ostomy - colostomy	____/_____/____	____/_____/____	____/_____/____
☐	Ostomy - ileostomy	____/_____/____	____/_____/____	____/_____/____
☐	Ostomy - urostomy	____/_____/____	____/_____/____	____/_____/____
☐	Reconstructive surgery (excludes limb salvage)	____/_____/____	____/_____/____	____/_____/____
☐	Shunt insertion/ventriculostomy	____/_____/____	____/_____/____	____/_____/____
☐	Shunt revision	____/_____/____	____/_____/____	____/_____/____
☐	Shunt removal	____/_____/____	____/_____/____	____/_____/____
☐	Splenectomy	____/_____/____		
☐	Transplant – heart	____/_____/____	____/_____/____	____/_____/____
☐	Transplant – kidney	____/_____/____	____/_____/____	____/_____/____
☐	Transplant – liver	____/_____/____	____/_____/____	____/_____/____
☐	Transplant – lung	____/_____/____	____/_____/____	____/_____/____
☐	Transplant – pancreas	____/_____/____	____/_____/____	____/_____/____
☐	Transplant – other, specify:	____/_____/____	____/_____/____	____/_____/____

☐ **Check this box if multiple pages used.**

9.0 Radiation Details

9.1 Was radiotherapy ever given?

□ Yes □ No (if no, please skip to section 10.0 HCT)

*If yes, enter each radiation treatment used since diagnosis (**exclude radiation therapy given as part of a preparative regimen for hematopoietic cell transplantation**)*

Note: If more than one site was irradiated within one treatment plan, enter all site locations. If more than one radiation treatment plan was used, use multiple sheets to capture these separate treatments.

9.2 Start date: ____/____/_____
dd/MON/yyyy

9.3 End date: ____/____/_____
dd/MON/yyyy

(Include the dates of the boost in the above timeframe)

9.4 Intent of radiation:

□ Curative
□ Palliative
□ Other, specify: _____
□ Not available

9.5 Type of radiation:

□ Brachytherapy
□ Conformal (3DCRT)
□ Conventional external beam
□ Electron
□ IMRT/Tomotherapy
□ Other, specify: _____
□ Not available
□ Intra-operative
□ Proton
□ Stereotactic (gamma-knife, cyber knife)
□ Systemic (includes radioactive iodine, High-dose MIBG)**

9.5.1 Systemic Therapy

□ Radioactive iodine
□ High-dose MIBG
□ Other, specify_____

9.5.2 Systemic Dose of Radiation

_____
□ Not available

9.5.3 Unit of Measurement:

□ mCi □ MBq □GBq
□ Not available

****Note: If entering systemic therapy, complete sections 9.1-9.5.3. After that-skip to section 10.**

9.6 Radiation site: Select all that apply

Specify general site: e.g. kidney = abdomen (left or right)

- □ Abdomen – hemi
- □ Abdomen/flank – left
- □ Abdomen/flank – right
- □ Abdomen – whole
- □ Brain: infratentorial
- □ Brain: partial
- □ Brain: supratentorial
- □ Brain: whole
- □ Chest wall – left
- □ Chest wall – right
- □ Craniospinal
- □ Face
- □ Inverted Y nodes
- □ Limb – lower – left
- □ Limb – lower – right
- □ Limb – upper – left
- □ Limb – upper – right
- □ Liver
- □ Lymph nodes - abdominal
- □ Lymph nodes - axilla
- □ Lymph nodes - head and neck
- □ Lymph nodes - inguinal/femoral
- □ Other, specify: _____
- □ Lymph nodes - Mediastinum/hilar
- □ Lymph nodes - pelvic
- □ Lymph nodes - other
- □ Lung-bilateral
- □ Lung-left
- □ Lung-right
- □ Mantle nodes
- □ Mediastinum
- □ Nasopharynx
- □ Neck
- □ Orbit – Left
- □ Orbit – Right
- □ Parotid
- □ Pelvis
- □ Scalp
- □ Skull
- □ Spleen
- □ Spine- cervical
- □ Spine- lumbar
- □ Spine- thoracic
- □ Spine- whole
- □ Testis
- □ Not available

9.7 Total radiation dose: _____cGy (excluding boost)

□ Not available

9.8 Number of fractions: _____

□ Not available

9.9 Multiple fractions per day?

- □ Yes
- □ No
- □ Not available

9.10 Was a boost dose given?

□ Yes
□ No
□ Not available

9.11 Type of boost radiation:

□ Brachytherapy
□ Conformal (3DCRT)
□ Conventional external beam
□ Electron
□ IMRT/Tomotherapy
□ Other, specify: _____
□ Not available
□ Intra-operative
□ Proton
□ Stereotactic (gamma-knife, cyber knife)
□ Systemic (includes radioactive iodine, High-dose MIBG)

9.12 Boost site: Select all that apply

□ Brain: infratentorial
□ Brain: partial
□ Brain: posterior fossa
□ Brain: supratentorial
□ Chest wall – left
□ Chest wall – right
□ Face
□ Flank/abdomen – left
□ Flank/abdomen – right
□ Limb – lower – left
□ Limb – lower – right
□ Limb – upper – left
□ Limb – upper – right
□ Lung-left
□ Lung-right
□ Mediastinum
□ Nasopharynx
□ Neck
□ Pelvis
□ Scalp
□ Skull
□ Spine- cervical
□ Spine- lumbar
□ Spine- thoracic
□ Testis
□ Other, specify:_____
□ Not available

9.13 Total dose to boosted area: (dose from 9.7 + boost dose)

_____**cGy**
□ Not available

9.14 Number of boost fractions: (does not include fractions from 9.8)

_____
□ Not available

□ **Use multiple pages as required. Check box if multiple pages used.**

10.0 Hematopoietic Cell Transplantation Details

10.1 Was a hematopoietic cell transplant ever performed?

□ Yes □ No (if no, please skip to section 11.0 Hospitalizations)

*If yes, enter each hematopoietic cell transplant given since diagnosis (**includes conditioning regimen**)*

10.2 Date of transplant: _____/_____/_____

dd/MON/yyyy

Date of actual transplant, not pre-hematopoietic transplant radiation or chemo conditioning.

10.3 Transplant centre :

□B.C. Children's Hospital
□Alberta Children's Hospital
□Children's Hospital of Winnipeg
□Montreal Children's Hospital
□Centre Hospitalier Universitaire de Sainte Justine
□The Hospital for Sick Children
□Other, specify code: _____
□Not available

10.4 Source of Hematopoietic Cells (include all that are applicable):

□Bone marrow
□Cord blood
□Peripheral blood stem cells

10.5 Non-cord blood graft type:

□ Allogeneic- matched sibling donor
□ Allogeneic- mismatched sibling donor
□ Allogeneic- matched unrelated donor
□ Allogeneic- mismatched unrelated donor
□ Allogeneic- matched relative other than parent or sibling
□ Allogeneic- mismatched relative other than parent or sibling
□ Allogeneic- matched parent
□ Allogeneic- mismatched parent
□ Autologous
□ Syngeneic
□ Other, specify:_____
□ Not available
□ Not applicable

10.5.1 Specify degree of match/mismatch of non-cord blood grafts:

□ Fully matched (8/8, high resolution; HLA-A, B, C, DRB1)
□ Partly matched (≤7/8 high resolution: HLA-A, B, C, DRB1)
□ Haploidentical
□ Not available
□ Not applicable

10.6 Cord blood grafts:

□ Umbilical Cord Blood, fully (6/6) matched
□ Umbilical Cord Blood 5/6 Mismatched
□ Umbilical Cord Blood 4/6 Mismatched
□ Umbilical Cord Blood <4/6 Mismatched
□ Double Cord Blood Transplant
□ Not available
□ Not applicable

10.7 Was there T-cell depletion? (allogeneic transplants only)

□ Yes □ No □ Not applicable □ Not available

10.8 Date the pre-HCT conditioning regimen (irradiation or drugs) started?

Date: ____/____/_____
(dd/MON/yyyy)

10.9 Type of transplant related irradiation received:

□No irradiation
□Total body irradiation
□Other, specify: _____
□Not available

10.9.1 Was there lung shielding?

□ Yes
□ No
□ Not available

10.10 Total radiation dose: _____cGy

10.11 Number of fractions: _____

10.12 Multiple fractions per day?

□ Yes □ No □ Not available

10.13 Radiation start date: ____/____/_____
dd/MON/yyyy

10.14 Radiation end date: ____/____/_____
dd/MON/yyyy

10.15 Was chemotherapy used as part of the preparative regimen?

□ Yes □ No □ Not available

Note: This area does not include any GVHD or supportive care drugs given near or post HCT. However, please include the use of these drugs in the Chemotherapy list. (e.g. Anti-rejection drugs: Sirolimus, Tacrolimus, MMF or Cyclosporin)

Agents highlighted in Grey require the completion of a separate Chemotherapy Details form.

Agent *Select all that apply*	**Check if administered**	**Chemotherapy details completed**
Alemtuzumab, Campath	□	
Antilymphocyte globulin (ALG)/ Antithymocyte globulin (ATG/ATGAM)	□	
Busulphan, Busulfan, (Myleran)*	□	□
Carboplatin, CBDCA, Paraplatin, Carboplatinum*	□	□
Carmustine (BCNU), Bis-Chloroethyl-Nitrosourea, BiCNU*	□	□
Cisplatin, CDDP, Platinol, Cisplatinum, Cis-diamminedicloro-platinum II, P*	□	□
Cyclophosphamide, Cytoxan, CTX, Procytox*	□	□
Cytarabine, Ara-C, Cytosar, Cytosine arabinoside (IM, sub q, PO OR IV <500mg/m^2 per dose)	□	
Cytarabine, Ara-C, Cytosar, Cytosine arabinoside* (IT ONLY)	□	□ (IT)
Cytarabine, Ara-C, Cytosar, Cytosine arabinoside* (ONLY IV ≥500mg/m^2 per dose)	□	□ (IV ≥500mg/m^2)
Etoposide (VP16), VePesid, ETOP*	□	□
Fludarabine, FAMP, Fludara	□	
Ifosfamide, Isophosphamide, IFOS, Ifex, Holoxan*	□	□
Melphalan, L-PAM, Alkeran, L-sarcolysin*	□	□
Mitoxantrone, Novantrone, DHAD, Dihydrochloride*	□	□
Thiotepa, TESPA, Triethylene Thiophosphoramide*	□	□

10.16 Was this a non-myeloablative transplant (also known as mini-transplant or reduced intensity transplant)?

□ Yes □ No □ Not available

PLEASE NOTE: DONOR LYMPOCYTE INFUSIONS ARE CAPTURED IN SECTION 14.0

□ **Use multiple pages as required. Check box if multiple pages used.**

11.0 Hospitalizations (inpatient only)

Enter each in-patient hospitalization & reason for admission. Include all hospitalizations (including the one in which diagnosis was made) but DO NOT include day care admissions. The first admission date can be before the date of definitive diagnosis; however, it cannot be before the date of first health care contact for initial symptoms.

Category	Description
A	Cancer related (diagnosis, staging, treatment) or any complication due to cancer or treatment that precipitates or prolongs hospitalization
C	Hematopoietic cell transplantation related
D	Non-cancer related
E	Not available

11.1 Date of Admission (dd/MON/yyyy)	11.2 Date of Discharge (dd/MON/yyyy)	11.3 Location Specify hospital code: (Drop-down list)	11.4 Reason for Admission (check all that apply)				
			A		C	D	E
____/____/____ ☐ Not available	____/____/____ ☐ Not available		☐		☐	☐	☐
____/____/____ ☐ Not available	____/____/____ ☐ Not available		☐		☐	☐	☐
____/____/____ ☐ Not available	____/____/____ ☐ Not available		☐		☐	☐	☐
____/____/____ ☐ Not available	____/____/____ ☐ Not available		☐		☐	☐	☐
____/____/____ ☐ Not available	____/____/____ ☐ Not available		☐		☐	☐	☐
____/____/____ ☐ Not available	____/____/____ ☐ Not available		☐		☐	☐	☐
____/____/____ ☐ Not available	____/____/____ ☐ Not available		☐		☐	☐	☐
____/____/____ ☐ Not available	____/____/____ ☐ Not available		☐		☐	☐	☐

☐ **Use multiple pages as required. Check box if multiple pages used.**

12.0 Complications

The following complications listed are the only complications that CYP-C is capturing. Please refer to the Data Manual for descriptions and reference to grading system if applicable. **Please note that for data abstraction, Common Terminology Criteria for Adverse Events (CTCAE) version 3 should be used for all complications up to the end of 2010. Complications starting on or after January 1, 2011 should be abstracted with CTCAE version 4.**

12.1 Did the patient experience a major complication?

12.1 Check if yes	12.2 Complication Type	12.3 SELECT GRADE	12.4 Date (dd/MON/yyyy)
Auditory			
☐	Hearing loss	3 4	____/_____/____
		3 4	____/_____/____
Blood/Bone Marrow			
☐	Bone marrow cellularity; [CTC 3.0] Hypocellular [CTC 4.0]	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
☐	Transfusion		
Cardiac			
☐	Arrhythmia (under cardiac disorders in CTC 4.0)	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
☐	Left ventricular dysfunction[CTC 3.0] Heart failure [CTC 4.0]	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
Endocrine			
☐	Diabetes mellitus	☐ Present	____/_____/____
☐	Diabetes insipidus (deficiency of antidiuretic hormone or low ADH)	☐ Present	____/_____/____
☐	Growth Hormone Deficiency	☐ Present	____/_____/____
☐	Hyperthyroidism	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
☐	Hypothyroidism	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
☐	Primary Ovarian Failure	☐ Present	____/_____/____
☐	Adrenal insufficiency, Hypoadrenalism	3 4 5	____/_____/____

12.1 Check if yes	12.2 Complication Type	12.3 SELECT GRADE	12.4 Date (dd/MON/yyyy)
	(Addison)	3 4 5	____/_____/____
		3 4 5	____/_____/____
Hemorrhage			
☐	Hemorrhage, specify site: ☐ CNS ☐ GI ☐ GU ☐ Pulmonary/Respiratory ☐ Other, specify: _____	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
Infection			
☐	Infection	4 5	____/_____/____
		4 5	____/_____/____
		4 5	____/_____/____
Serology			
☐	Diagnosed with Hepatitis B	☐ Present	____/_____/____
☐	Diagnosed with Hepatitis C	☐ Present	____/_____/____
Musculoskeletal/Soft Tissue			
☐	Fibrosis (stiffening)	3 4	____/_____/____
		3 4	____/_____/____
☐	Osteonecrosis (avascular necrosis)	3 4	____/_____/____
		3 4	____/_____/____
☐	Prosthesis problem (use Local complication – device/prothesis-related in CTC 3.0) (use injury, poisoning and procedural complications in other, page 106 of CTC 4.0)	3 4	____/_____/____
		3 4	____/_____/____
Neurology			
☐	Cerebrovascular ischemia or stroke	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
☐	Learning disability (use Cognitive disturbance under CTC 3.0 and CTC 4.0 [no grade 4 in CTC 4.0])	3 4	____/_____/____
		3 4	____/_____/____
☐	Leukoencephalopathy	3 4 5	____/_____/____
☐	Seizures	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____

12.1 Check if yes	12.2 Complication Type	12.3 SELECT GRADE	12.4 Date (dd/MON/yyyy)
Ocular			
☐	Vision Loss/Blindness See Data Manual for rules	4	____/_____/____
Pulmonary			
☐	Fibrosis	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
Renal			
☐	Fanconi syndrome (Under renal –urinary electrolyte wasting in CTC 3.0)	3	____/_____/____
☐	Glomerular filtration rate (GFR) [CTC 3.0] (Under metabolic in CTC 3.0) Chronic Kidney Disease [CTC 4.0]	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
Vascular			
☐	Thrombosis/embolism[CTC 3.0] Thromboembolic event [CTC 4.0]	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____
☐	Thrombosis/embolism, vascular access-related [CTC 3.0] Vascular access complication [CTC 4.0]	3 4 5	____/_____/____
		3 4 5	____/_____/____
		3 4 5	____/_____/____

☐ **Checked and none of the above complications were found.**

12.1 Check if yes	12.2 Complication Type	12.3 SELECT GRADE	12.4 Date (dd/MON/yyyy)
Hematopoietic Cell Transplantation Complications			
☐	ACUTE Graft vs. Host disease, specify organs affected: ☐ Gastrointestinal Tract ☐ Liver ☐ Skin ☐ Other, specify (eg. Lungs): ____________	3 4	____/_____/____
☐	ACUTE Graft vs. Host disease, specify organs affected: ☐ Gastrointestinal Tract ☐ Liver ☐ Skin ☐ Other, specify (eg. Lungs): ____________	3 4	____/_____/____
☐	ACUTE Graft vs. Host disease, specify organs affected: ☐ Gastrointestinal Tract ☐ Liver ☐ Skin ☐ Other, specify (eg. Lungs): ____________	3 4	____/_____/____
☐	CHRONIC Graft vs. Host disease	2 3	____/_____/____
		2 3	____/_____/____
☐	Thrombotic microangiopathy (Not present in CTC 4.0)	☐ Present ☐ Suspected and treated	
☐	Hepatic sinusoidal obstruction syndrome (Veno-Occlusive Disease of the liver)	☐ Present ☐ Suspected and treated	
☐	Idiopathic pneumonitis syndrome	☐ Present ☐ Suspected and treated	
☐	CMV- viremia	☐ Present	____/_____/____
☐	CMV- colitis	☐ Present ☐ Suspected and treated	
☐	CMV- hepatitis	☐ Present ☐ Suspected and treated	

12.1 Check if yes	12.2 Complication Type	12.3 SELECT GRADE	12.4 Date (dd/MON/yyyy)
☐	CMV- pneumonitis	☐ Present ☐ Suspected and treated	
☐	Other CMV Disease: _____	☐ Present ☐ Suspected and treated	
☐	Epstein Barr Virus Viremia	☐ Present	____/_____/____
☐	Epstein Barr Virus Post-Transplant Lymphoproliferative Disorder **This diagnosis may qualify as a second malignancy, see CYPC eligibility and if eligible, enter into section 2.0**	☐ Present ☐ Suspected and treated	
☐	Adenovirus - viremia	☐ Present	____/_____/____
☐	Adenovirus - colitis	☐ Present ☐ Suspected and treated	
☐	Adenovirus - hepatitis	☐ Present ☐ Suspected and treated	
☐	Adenovirus - pneumonitis	☐ Present ☐ Suspected and treated	
☐	Other Adenovirus Disease: _____	☐ Present ☐ Suspected and treated	
Hemorrhagic cystitis - Hemorrhagic cystitis – Captured under Hemorrhage - GU			

☐ **Checked and none of the above complications were found.**

13.0 Relapse Details

Use a separate CRF for each relapse. *Note: Includes all types of cancer relapse as defined according to their protocol/treatment criteria. Before a relapse can occur, a patient would have had a complete response to treatment.*

13.1 Date of relapse: _____/_____/_____
(dd/MON/yyyy)

☐ Not available

13.2 Was the relapse at the primary site?

☐Yes ☐No ☐Not available

13.3 Were there metastases at relapse?

☐Yes ☐No (local relapse only) ☐Not available

↓

13.3.1 If yes, specify metastatic sites (check all general sites that apply):

☐Abdomen (NOS)
☐Adrenal gland-bilateral
☐Adrenal gland-left/right
☐Bladder
☐Bone marrow
☐Bone-multiple
☐Bone-single
☐Brain
☐Breast
☐Cerebrospinal fluid (CSF)
☐Eye
☐Head and neck (NOS)
☐Heart
☐Kidney-bilateral
☐Kidney-left/right
☐Large bowel
☐Liver
☐Lung-bilateral
☐Lung-left/right
☐Lymph nodes-distant
☐Lymph nodes-local/ regional
☐Mediastinum
☐Meninges
☐Muscular tissue (NOS)
☐Ovary – left/right
☐Ovary - bilateral
☐Pancreas
☐Pelvis/Inguinal region (NOS)
☐Peritoneal
☐Pituitary gland
☐Pleura
☐Skin
☐Small bowel
☐Spinal cord
☐Spleen
☐Testes – left/right
☐Testes – bilateral
☐Thyroid
☐Uterus
☐Other, specify:_____
☐Not available

13. 4 Was additional treatment given to this patient after their relapse?

☐Yes ☐No ☐Not available

If yes, please complete: Chemotherapy List, Chemotherapy Details, Surgery, HCT, etc. as required.

14.0 Other Therapies

14.1 Did the patient have any of the following alternative treatments (please check all that apply)?

☐ Yes ☐ No (if no, please skip to section 15.0 Death Details)

Check if yes	14.1 Other Therapy	14.2a Date of Procedure (dd/MON/yyyy)	14.2b Date of Procedure (dd/MON/yyyy)	14.2c Date of Procedure (dd/MON/yyyy)
☐	Cryotherapy	_____/_____/_____	_____/_____/_____	_____/_____/_____
☐	Laser therapy	_____/_____/_____	_____/_____/_____	_____/_____/_____
☐	Radio frequency ablation	_____/_____/_____	_____/_____/_____	_____/_____/_____
☐	High intensity focused ultrasound	_____/_____/_____	_____/_____/_____	_____/_____/_____
☐	Donor lymphocyte infusion	_____/_____/_____	_____/_____/_____	_____/_____/_____
☐	Homeopathic/ Naturopathic/ Herbal treatments/ Medicine Man therapy	_____/_____/_____ Provide estimated start date of the first therapy in this category		
☐	Transarterial chemo-embolization	_____/_____/_____	_____/_____/_____	_____/_____/_____

☐ **Use multiple pages as required. Check box if multiple pages used.**

15.0 Death

15.1 Has the patient died?

□ Yes, date of death:

____/_____/_____
(dd/MON/yyyy)

□ Yes, date not available
□ No
□ Unknown

15.2 Cause of death:

□ Died of disease/complications/toxicity related to disease/treatment
□ Died of other causes
□ Unknown

15.3 Source of death information:

□ Hospital chart (Protocol chart/Outpatient chart/Research chart/Research database/etc.)

□ Registration document (Vital Statistics, Cancer Registry)

□ Other, specify: _____

16.0 Patient Transfer

To be completed only if patient is *permanently* transferred from one CYP-C centre to another CYP-C centre.

Note: If patient was only temporarily transferred (e.g. for a specific procedure, transplant, etc.) *do not complete this form.* If the patient has been transferred to a non-CYP-C centre (regional hospital, adult cancer centre, etc.), your centre is still responsible for the collection of CYP-C data on this patient and therefore the patient cannot be transferred. Continue to complete data collection.

During your review of CYP-C charts if you realize that the patient was transferred either from your centre or to your centre, contact should be made with the other centre's CRA to ensure that only one CYP-C record is created. The diagnosing institution should be responsible to complete their portion of the 60 month follow-up and then request the official transfer.

The date of official transfer should be the first date that the patient is seen at the receiving centre.

Procedure:

1. Sending institution, complete page 2 and send via fax or mail along with the completed forms to the receiving institution.

2. Receiving institution, complete page 3 and fax back to sending institution to confirm conditional acceptance of the patient transfer.

- The receiving institution must have current IRB approval for the study.

- Data submission, corrections or modifications that are required for data generated prior to the transfer will be the responsibility of the sending institution. However, after the official transfer has been made, only the receiving institution will have write-access to this data. The sending institution must notify the receiving institution of any changes as the receiving institution will be responsible for making changes to the database.

- The transferred record retains its original and unique CYP-C number even after it has been transferred to another participating CYP-C centre.

Database Procedure:

1. Sending institution will request a transfer in the database.
    a. Inputs *receiving institution* and *date of transfer*.

2. Receiving institution will be notified of the transfer request
    a. They will have access to review the chart and ensure that the information has been inputted and is up to date
    b. After a period of time they will have the option to accept or reject the transfer.

CYP-C# _____

TRANSFER FORM

Today's Date _____

Patient's First Name _____ Patient's Last Name _____

Patient's Date of Birth _____ Patient's Gender _____ CYP-C # _____

Sending Institution

- ☐ B.C. Children's Hospital
- ☐ Alberta Children's Hospital
- ☐ Stollery Children's Hospital
- ☐ Saskatoon Cancer Centre
- ☐ Allan Blair Cancer Centre
- ☐ CancerCare Manitoba
- ☐ Children's Hospital, LHSC / Children's Hospital of Western Ontario
- ☐ McMaster Children's Hospital
- ☐ The Hospital for Sick Children
- ☐ Kingston General Hospital
- ☐ Children's Hospital of Eastern Ontario
- ☐ Centre Hospitalier Universitaire de Ste. Justine
- ☐ Montreal Children's Hospital
- ☐ Centre Hospitalier Universitaire de Sherbrooke
- ☐ Centre Hospitalier Universitaire de Québec
- ☐ Izaak Walton Killam Health Centre
- ☐ Janeway Children's Health and Rehabilitation Centre

CRA : _____

Telephone Contact Number: _____

Fax Number: _____

Email Address: _____

Requested Date of Transfer: (date first seen at receiving centre)

_____

Is data submission current on this patient? ☐ Yes ☐ No

Transfers cannot take place unless data is current to the date of transfer.

You are responsible for all data prior to the transfer date, including performance monitoring and audit. Please send a copy of all the completed forms to the receiving centre.

Signature of Sending Institution CRA _____ Date _____

CYP-C# _____

TRANSFER FORM

Receiving Institution

- □ B.C. Children's Hospital
- □ Alberta Children's Hospital
- □ Stollery Children's Hospital
- □ Saskatoon Cancer Centre
- □ Allan Blair Cancer Centre
- □ CancerCare Manitoba
- □ Children's Hospital, LHSC / Children's Hospital of Western Ontario
- □ McMaster Children's Hospital
- □ The Hospital for Sick Children
- □ Kingston General Hospital
- □ Children's Hospital of Eastern Ontario
- □ Centre Hospitalier Universitaire de Ste. Justine
- □ Montreal Children's Hospital
- □ Centre Hospitalier Universitaire de Sherbrooke
- □ Centre Hospitalier Universitaire de Québec
- □ Izaak Walton Killam Health Centre
- □ Janeway Children's Health and Rehabilitation Centre

CRA: _____

Telephone Contact Number: _____

Fax Number: _____

Email Address: _____

You will be responsible for all data from the date of transfer, including performance monitoring and audit).

Signature of Receiving Institution CRA _____ Date _____