CANCER IN YOUNG PEOPLE IN CANADA PROGRAM
PROGRAMME CANCER CHEZ LES JEUNES AU CANADA

Aggregate Level Data Access Requests

Cancer in Young People in Canada/ Cancer Chez les Jeunes au Canada program

The Cancer in Young People in Canada/ Cancer Chez les Jeunes au Canada program (CYP-C /CCJC) is a collaborative effort between the Public Health Agency of Canada (PHAC) and the C^{17} Council.

1. Project title (if applicable):

2. Name, address and affiliation of applicant(s):

Name	
Role	
Address	
Phone	
Email	
Affiliation	
Name	
Role	
Address	
Phone	
Email	
Affiliation	
Name	
Role	
Address	
Phone	
Email	
Affiliation	

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3. Description of data requested (include data elements, years and regions).

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4. Purpose for which the data will be used.

Date Data Requested by: _____

Appendix A - Available Elements

Shaded elements not available for Ontario patients.

1.0 Registration

- 1.4 Sex
- 1.5 Birth Date
- 1.6 Age at diagnosis
- 1.7 Province of residence at time of diagnosis
- 1.9 Postal code of residence at diagnosis
- 1.10 Race(s)

2.0 Diagnostic Information

2.1 Time to Treatment

- 2.1.1 Date of first health care contact
- 2.1.2 Health care professional contacted
- 2.1.3 Date if alternate health care professional first contacted
- 2.1.4 Alternate health care professional contacted
- 2.1.5 Date first seen by oncologist
- 2.1.6 Type of oncologist
- 2.1.7 Institution of oncologist
- 2.1.8 Date first seen by surgeon
- 2.1.9 Institution of surgeon
- 2.1.10 Date of alternate specialist if not seen by an oncologist or surgeon
- 2.1.11 Type of alternate specialist seen
- 2.1.12 Institution of specialist

2.2 Diagnostic Record

- 2.2.1 Ordinal primary
- 2.2.2 Initial report, a revised diagnosis or a true disease evolution?
- 2.2.3 Date of definitive diagnostic procedure
- 2.2.4 Definitive diagnosis basis
- 2.2.4.1 If histology, diagnostic biopsy only?
- 2.2.5 Institution of diagnosis
- 2.2.6 ICDO M code
- 2.2.7 ICDO T code
- 2.2.8 Diagnosis description (ICCC)
- 2.2.9 Site of tumor

2.3 Stage

- 2.3.1 Staging system
- 2.3.2.1 Unilateral disease, stage
- 2.3.2.2 Bilateral disease, stage left
- 2.3.2.2 Bilateral disease, stage right
- 2.3.3 Seer Summary Stage

2.4 Histological Grading and Risk Group

- 2.4.1 Astrocytoma: WHO histological typing
- 2.4.2 Neuroblastoma risk group

2.4.3 Hodgkin's lymphoma risk group
2.4.4 Rhabdomysarcoma risk group
2.4.5 Medulloblastoma risk group
2.4.6 Renal tumor risk group

2.4.7 Acute Lymphoblastic Leukemia

2.4.7.1 Initial white blood cell count
2.4.7.2. Minimal residual disease measured?
2.4.7.3 Disease status of the cerebrospinal fluid at diagnosis
2.4.7.4 Testicular involvement at diagnosis?
2.4.7.5 Immunophenotyping/flow cytometry done at diagnosis?
2.4.7.5.1 If yes, specify phenotype
2.4.7.6 Chromosomal testing done at diagnosis?
2.4.7.6a Translocations
2.4.7.6b Trisomy
2.4.7.6c Other recurrent rearrangements/karyotypes

2.4.8 Acute Myeloid Leukemia

2.4.8.1 Initial white blood cell count
2.4.8.2 Sub-type using either the FAB system
2.4.8.2 Sub-type using either the WHO system
2.4.8.3 Chromosomal testing done at diagnosis?
2.4.3.3a Translocations
2.4.8.3b Inversion
2.4.8.3c Monosomy
2.4.8.3d Other

2.4.9 Chronic Myeloid Leukemia

2.4.9.1 Chromosomal testing conducted?
2.4.9.1a Translocations

2.4.10 Myelodysplastic Syndrome

2.4.10.1 Initial white blood cell count
2.4.10.2 Sub-type using either the FAB or WHO system
2.4.10.3 Chromosomal testing conducted at diagnosis?
2.4.10.3a Monosomy

2.5 Extent of Disease at Diagnosis

2.5.1 Metastasis at diagnosis?
2.5.2 Metastatic sites

2.6 Organ Transplantation

2.6.1 Previous organ or hematopoietic cell transplant prior to malignancy
2.6.2 Date transplant was received
2.6.3 Type of transplant received

2.7 Predisposing and Genetic Conditions

- 2.7.1Predisposing condition/co-morbidity?
- 2.7.2 Known genetic condition?
- 2.7.2.1 Consult with a geneticist?
- 2.7.3.1 Nephroblastomatosis left?
- 2.7.3.1 Nephroblastomatosis right?
- 2.7.3.2 Beckwith-Wiedemann Syndrome?
- 2.7.3.3 Neurofibromatosis Type I?
- 2.7.3.3 Neurofibromatosis Type II?
- 2.7.3.4 Li-Fraumeni Syndrome?

3.0 Patient Contact and Status

- 3.1.2 Annual period start date
- 3.1.3 Annual period end date
- 3.1.4 Status at the end of the period
- 3.1.5 Contact within period?
- 3.1.6 If yes, date of last contact
- 3.1.7 Details if no contact

4.0 Height and Weight

- 4.1 Date for height
- 4.2 Height
- 4.3 Date for weight
- 4.4 Weight

5.0 Protocol/Treatment Plan Information

- 5.1 Treatment plan used
- 5.2 Reason if not registered on a clinical trial
- 5.3 If registered on or following a protocol: type of protocol
- 5.4 Protocol number
- 5.5 Treatment arm
- 5.6 If non-COG trial, protocol name
- 5.7 Date treatment began
- 5.8 Protocol/treatment plan status
- 5.9 If protocol/treatment completed OR terminated early, specify date
- 5.10 Reason if protocol/treatment terminated early

6.0 Chemotherapy List

- 6.2 Treatment agents used

7.0 Chemotherapy Details

- 7.1 Agent name
- 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

8.0 Surgery Details

8.1.1 Cancer related surgery type

8.1.2 Partial or complete tumor resection

8.1.3 Date of cancer related surgery

8.2.1 Secondary surgery type

8.2.2 Date of secondary surgery

9.0 Radiation Details

9.2 Start date

9.3 End date

9.4 Intent of radiation

9.5 Type of radiation

9.5.1 Systemic therapy type

9.5.2 Systemic dose of radiation

9.5.3 Unit of measurement

9.6 Radiation site

9.7 Total radiation dose

9.8 Number of fractions

9.9 Multiple fractions per day?

9.10 Boost dose given?

9.11 Type of boost radiation

9.12 Boost site

9.13 Total dose to boosted area

9.14 Number of boost fractions

10.0 Hematopoietic Cell Transplantation Details

10.2 Date of transplant

10.3 Transplant centre

10.4 Source of hematopoietic cells

10.5 Non-cord blood graft type

10.5.1 Degree of match/mismatch of non-cord blood grafts

10.6 Cord blood grafts

10.7 T-cell depletion?

10.8 Date the pre-HCT conditioning regimen started

10.9 Type of transplant related irradiation received

10.9.1 Lung shielding?

10.10 Total radiation dose

10.11 Number of fractions

10.12 Multiple fractions per day?

10.13 Radiation start date

10.14 Radiation end date

10.15 Chemotherapy used as part of the preparative regimen?

10.16 Non-myeloablative transplant?

11.0 Hospitalizations

11.1 Date of admission

11.2 Date of discharge

11.3 Location

11.4 Reason for admission
12.0 Complications
12.2 Complication type
12.3 Grade
12.4 Date
13.0 Relapse Details
13.1 Date of relapse
13.2 Relapse at the primary site?
13.3 Metastasis at relapse?
13.3.1 If yes, specify metastatic site
13.4 Additional treatment given?
14.0 Other Therapies
14.1 Other therapy
14.2 Date of procedure(s)
15.0 Death
15.1 Date of death
15.2 Cause of death
15.3 Source of death information