**SECTION B: PEDIATRIC CANCER**

1. **Do you have a Pediatric Cancer program?**

**(CAN\_HAVEPROGRAM)**

* Yes
* No – Skip to Section C

**When responding to questions in this section, your hospital must consult with the chief of service (or equivalent) of your Pediatric Cancer program to ensure that answers are accurate and consistent with both the care delivered and the intent of the survey.**

**As data are reviewed, U.S. News may have questions about responses to individual questions or about an entire submission. To ensure communication with the appropriate clinical leader, please provide the following information about the chief of service (or equivalent) for your Pediatric Cancer program.**

**Full name:**

|  |
| --- |
| **(CAN\_DIR\_NAME)** |

**Title:**

|  |
| --- |
| **(CAN\_DIR\_TITLE)** |

**Email:**

|  |
| --- |
| **(CAN\_DIR\_EMAIL)** |

**Preferred phone:**

|  |
| --- |
| **(CAN\_DIR\_PHONE)** |

REQUIRED: IF NAME, TITLE, EMAIL, OR PHONE=BLANK, DISPLAY: “A response is required for [Name/Title/Email/Phone] prior to submitting the survey. Click “OK” to continue with the survey and answer this question later. Click “Change Answer” to provide a response to this question now.”

**B1.1 Are you submitting jointly with a Pediatric Cancer program at another hospital?**

**(CAN\_JOINTSUB)**

* + Yes – Go to Question B1.2
  + No – Skip to Question B2

**B1.2 If yes, what is the name of the Pediatric Cancer program you are reporting jointly with?** Please note that joint submissions must be reviewed and approved before they are allowed. Before submitting your survey, please contact RTI at [PediatricHospSurvey@rti.org](mailto:PediatricHospSurvey@rti.org) to discuss your joint submission request unless you already have received permission to jointly submit data in this specialty. As noted in the instructions for joint reporting, if you are granted permission, only the primary hospital in the joint reporting relationship will be allowed to report data for this specialty.

|  |
| --- |
| **(CAN\_JOINTSUB\_NAME)** |

1. **Please indicate the total number of attending/on-staff physicians (excluding fellows)[[1]](#footnote-2) who *are currently members of the medical staff* in your Pediatric Cancer program in the following categories.** [If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Total Physicians** |  |
| a. | Pediatric hematologists/oncologists (include only board certified/board eligible[[2]](#footnote-3) by the American Board of Pediatrics with subspecialty certification in pediatric hematology-oncology) | \_\_\_\_\_\_\_\_ |  |
|  | **(CAN\_PHYSICIANS\_ONC\_TOT)** |  |  |
| b. | Other attending/on-staff physicians (including but not limited to pediatric general surgeons, pediatric neurosurgeons, and pediatric orthopedists with specific additional involvement in pediatric oncology [e.g., membership in COG, PTCTC or 25% of practice confined to pediatric oncology patients] in your Pediatric Cancer program) | \_\_\_\_\_\_\_\_ |  |
|  | **(CAN\_PHYSICIANS\_OTHER\_TOT)** |  |  |
| c. | Pediatric radiation oncologists (board certified/board-eligible by the American Board of Radiology or American Osteopathic Board of Radiology) | \_\_\_\_\_\_\_\_ |  |
|  | **(CAN\_PHYSICIANS\_RADONC\_TOT)** |  |  |

NOTES: B2x should be whole number only. Do not allow decimals.

***Note: The previous questions are used to determine eligibility for Pediatric Cancer. If you leave any part of these questions blank, your hospital will be considered ineligible for the rankings in Pediatric Cancer.***

1. **Please indicate the total number of nurse practitioners and physician assistants who work in or directly support your Pediatric Cancer program.** [If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Total**  **Staff** |  |
| a. | Nurse practitioners | \_\_\_\_\_\_\_\_ |  |
|  | **(CAN\_NP\_TOT)** |  |  |
| b. | Physician assistants | \_\_\_\_\_\_\_\_ |  |
|  | **(CAN\_PA\_TOT)** |  |  |

NOTES: B3x should be whole number only. Do not allow decimals.

1. **Do you have nurse practitioners, physician assistants, or clinical nurses who serve as case managers[[3]](#footnote-4) for specific disease populations in the following areas? For each category, please also indicate the total number of full-time equivalents (FTEs)[[4]](#footnote-5) devoted to case management activities. [**Due to ongoing nursing shortages, contract nurses should be included in your counts of clinical RNs.]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Yes** | **No** | **FTEs** |
| a. | Hematologic malignancies | **○** | **○** | \_\_\_\_\_ |
|  | **(CAN\_CASEMNGR\_** | **\_HEMA)** | | **\_HEMA\_FTE)** |
| b. | Solid tumors | **○** | **○** | \_\_\_\_\_ |
|  | **(CAN\_CASEMNGR\_** | **\_SOLID)** | | **\_SOLID\_FTE)** |
| c. | Brain tumors | **○** | **○** | \_\_\_\_\_ |
|  | **(CAN\_CASEMNGR\_** | **\_BRAIN)** | | **\_BRAIN\_FTE)** |
| d. | Stem cell transplant | **○** | **○** | \_\_\_\_\_ |
|  | **(CAN\_CASEMNGR\_** | **\_STEM)** | | **\_STEM\_FTE)** |

NOTES: B4x2 is numeric entry (decimals are allowed).

VALIDATE: IF B4x1=Yes AND B4x2=(0 OR BLANK), DISPLAY: “B4x: Please provide a value greater than 0 for FTEs or answer No.”

If B4x2 is not numeric: “B4x2 (FTE): Please enter a numeric value.”

1. **Does your Pediatric Oncology program offer an institutional Code team to immediately address emergencies that may occur with patients receiving care in all of your outpatient cancer treatment clinics?**

**(CAN\_OUTPT\_CODETEAM)**

* Yes
* No

1. **How many unique, new[[5]](#footnote-6) oncology patients (see code list)[[6]](#footnote-7) were seen in your Pediatric Cancer program in the last 2 calendar years?**[If none, please enter 0.]

\_\_\_\_\_\_\_\_ a. New oncology patients in 2023 **(CAN\_NEWPATIENTS\_PREV)**

\_\_\_\_\_\_\_\_ b. New oncology patients in 2024 **(CAN\_NEWPATIENTS\_CURR)**

NOTES: B6x should be whole number only. Do not allow decimals.

1. **Does your pediatric program provide sedation/anesthesia by pediatric specialists[[7]](#footnote-8) for radiation therapy, lumbar punctures, and bone marrow biopsies?**

**(CAN\_SEDATION)**

* Yes
* No

1. **Does your Pediatric program provide access on-site or at an affiliated facility within 25 miles of your children’s hospital to the following diagnostic and/or treatment technologies?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Therapeutic meta-iodo-benzyl-guanidine with I-131 radionuclide (I-131 MIBG)[[8]](#footnote-9) **(CAN\_TRTMNT\_TECH\_MIBG)** | ○ | ○ |
| b. | Functional magnetic resonance imaging (fMRI) **(CAN\_TRTMNT\_TECH\_FMR)** | ○ | ○ |
| c. | Brachytherapy **(CAN\_TRTMNT\_TECH\_BRACH)** | ○ | ○ |
| d. | Stereotactic radiosurgery **(CAN\_TRTMNT\_TECH\_STEREO)** | ○ | ○ |
| e. | Intra-arterial chemotherapy or embolization for solid tumors **(CAN\_TRTMNT\_TECH\_RAD)** | ○ | ○ |
| f. | Radio frequency ablation (RFA) and/or cryoablation for treatment of tumors[[9]](#footnote-10) **(CAN\_TRTMNT\_TECH\_IACE)** | ○ | ○ |
| g. | Proton Beam Therapy **(CAN\_TRTMNT\_TECH\_PROTON)** | ○ | ○ |

1. **This question has been removed from the survey.**
2. **Does your Pediatric Cancer program offer the following dedicated clinical care programs with an identifiable medical leader or director? To be eligible, clinics must be offered at least quarterly.**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
|  | Pediatric clinical brain tumor program[[10]](#footnote-11) **(CAN\_CLINICALCARE\_TUMOR)** | ○ | ○ |
|  | Pediatric solid tumor program[[11]](#footnote-12) that includes limb-sparing surgery[[12]](#footnote-13) for bone tumors **(CAN\_CLINICALCARE\_BONE)** | ○ | ○ |
|  | Pediatric clinical leukemia/lymphoma program[[13]](#footnote-14) **(CAN\_CLINICALCARE\_LEUK)** | **○** | **○** |
|  | A comprehensive, long-term survivors program[[14]](#footnote-15) **(CAN\_CLINICALCARE\_LONG)** | **○** | **○** |
| e. | Histiocytosis program[[15]](#footnote-16) **(CAN\_CLINICALCARE\_HISTIO)** | **○** | **○** |
|  |  |  |  |

1. **Does your Pediatric Cancer program offer the following programs and/or supporting staff?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Complementary and alternative medicine (CAM) or holistic healthcare program for pediatric cancer patients (providing adjunct services such as massage therapy, music therapy, pet therapy, etc.) **(CAN\_SUPPORTING\_STAFF\_HOLISTIC)** | ○ | ○ |
| b. | Pediatric cancer child life specialists **(CAN\_SUPPORTING\_STAFF\_CHILDLIFE)** | ○ | ○ |
| c. | Psychosocial support program including psychologists and/or psychiatrists with oncology expertise **(CAN\_SUPPORTING\_STAFF\_PYCHO)** | **○** | **○** |
| d. | Social work support for the pediatric cancer program **(CAN\_SUPPORTING\_STAFF\_SOCIAL)** | **○** | **○** |
| e. | School program led by certified teachers which focus on the specialized educational needs of hospitalized pediatric patients undergoing cancer care **(CAN\_SUPPORTING\_STAFF\_SCHOOL)** | **○** | **○** |
| f. | Dedicated school intervention program with certified teachers and integrated neuropsychological evaluation focused on school re-entry issues and the cognitive effects of cancer therapy **(CAN\_SUPPORTING\_STAFF\_NEURO)** | **○** | **○** |
| g. | An APHON chemotherapy/biotherapy provider course and safe handling policies and procedures in any unit of the hospital where oncology patients receive chemotherapy or biotherapy **(CAN\_SUPPORTING\_STAFF\_APHON)** | ○ | ○ |
| h. | Adolescent and Young Adult (AYA) support program for patients in active treatment and follow-up separate from a long-term survivorship program.[[16]](#footnote-17) **(CAN\_SUPPORTING\_STAFF\_AYA)** | ○ | ○ |
|  | Cancer genetics/hereditary program[[17]](#footnote-18) **(CAN\_CLINICALCARE\_GENETICS)** | **○** | **○** |
|  | Sibling targeted support services **(CAN\_CLINICALCARE\_SIBLING)** | **○** | **○** |
|  | Bereavement support for families **(CAN\_CLINICALCARE\_BEREAVE)** | **○** | **○** |
|  | Molecular oncology/targeted therapy program[[18]](#footnote-19) **(CAN\_CLINICALCARE\_MOLECULAR)** | ○ | ○ |
|  | On-site inpatient pediatric rehabilitation unit with individualized dedicated cancer rehabilitation programming[[19]](#footnote-20) **(CAN\_CLINICALCARE\_REHAB)** | ○ | ○ |

**B11.1 What percentage of eligible[[20]](#footnote-21) direct clinical care RNs who are employed and contracted to work in your Pediatric Cancer program have a national oncology certification (certified pediatric hematology-oncology nurse (CPHON) or certified pediatric oncology nurse (CPON)) or certified bone marrow transplant nurse (BMTCN)?**

**(CAN\_SUPPORTING\_STAFF\_CPON)**

* < 25%
* 25-49%
* 50-74%
* 75-100%

**B11.2 Did at least 50% of your patients who started chemotherapy in 2024, have a formal initial psychosocial assessment/distress screening either before the initiation of therapy or within 4 weeks of starting therapy?**

**(CAN\_SUPPORTING\_STAFF\_PSYC)**

* Yes
* No

**B11.3 Does your Pediatric Cancer program have a parent advisory committee that meets at least twice a year?**

**(CAN\_PARENT\_ADVISORY)**

* Yes
* No

**B11.4** **Does your Pediatric Cancer program offer a fertility preservation program[[21]](#footnote-22) that includes**

**sperm banking and oocyte preservation?**

**(CAN\_CLINICALCARE\_FERT)**

* Yes – go to B11.5
* No – go to B12

**B11.5 If “yes” to B11.4, is a pediatric and adolescent gynecology (PAG) specialist consulted on an ongoing basis for the fertility preservation program?**

**(CAN\_CLINICALCARE\_PAG)**

* Yes
* No

1. **Does your Pediatric Cancer program have multidisciplinary morbidity and mortality conferences[[22]](#footnote-23) at least quarterly for cancer patients at your institution?**

**(CAN\_MM\_CONFD)**

* Yes
* No

1. **This question has been removed from the survey.**
2. **Does your Pediatric Cancer program promote ease of access to care through any of the following?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Offering on-site direct oncology-specific patient care (not just emergency care) from hematology/oncology providers during nights[[23]](#footnote-24) and weekends[[24]](#footnote-25) **(CAN\_EASYACCESS\_EVENINGS)** | **○** | **○** |
| b. | A coordinated outreach program[[25]](#footnote-26) that enables cancer patients to receive community-based follow-up care or treatment **(CAN\_EASYACCESS\_COMMUNITY)** | **○** | **○** |
| c. | Multidisciplinary clinics, allowing patients to see multiple care providers in a single visit **(CAN\_EASYACCESS\_MULTIDISC)** | **○** | **○** |

1. **Does your Pediatric Cancer program provide the following in support of chemotherapy treatment?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Dedicated pediatric chemotherapy pharmacy[[26]](#footnote-27) **(CAN\_CHEMOSUPPORT\_CHEMPHARM)** | **○** | **○** |
| b. | Pediatric oncology pharmacist with training and experience in pediatric chemotherapy **(CAN\_CHEMOSUPPORT\_CHEMCERT)** | **○** | **○** |
| c. | Pharmacists specifically assigned to participate in daily inpatient rounds with the pediatric cancer treatment team **(CAN\_CHEMOSUPPORT\_PHARM)** | **○** | **○** |
| d. | The APHON Chemotherapy/Biotherapy Provider training course for nurses administering chemotherapy **(CAN\_CHEMOSUPPORT\_TRAINING)** | **○** | **○** |

1. **How are most chemotherapy ordered in your Pediatric Cancer program? Select the response that coincides with the majority of your program’s orders.**

**(CAN\_CHEMORDERS)**

* Hand-written
* Written using word processing or spreadsheet software with or without a protocol-driven template
* CPOE as part of electronic medical record
* CPOE as part of electronic medical record with plan-driven orders (i.e., order sets, treatment plans, templates) and formal multiple co-signatures/review required

1. **Does your Pediatric Cancer program have a stem cell transplant unit with pediatric nurses and physicians specially trained in transplant?**

**(CAN\_STEMUNIT)**

* + Yes
* No

1. **Does your hospital offer the following pediatric stem cell transplant services? If yes, how many of each of the following types of transplants for malignant diseases were done in the last 3 calendar years?** [Please report each transplant in only one row.]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Yes** | **No** | **Transplants**  **2022-2024** |
|  | Autologous stem cell transplantation | **○** | **○** | **\_\_\_\_\_** |
|  | **(CAN\_TRANSPLANT\_** | **AUTO)** | | **AUTO\_COUNT)** |
|  | Allogeneic matched (related or unrelated) or Haploidentical (half-matched) donor transplantation | **○** | **○** | **\_\_\_\_\_** |
|  | **(CAN\_TRANSPLANT\_** | **ALLOGENEIC)** | | **ALLOGENEIC\_COUNT)** |
|  | Cellular therapy[[27]](#footnote-28) including infusions of CAR-T, viral specific T-cells, mesenchymal stem cells, or NK cells | **○** | **○** | **\_\_\_\_\_** |
|  | **(CAN\_TRANSPLANT\_** | **CELL)** | | **CELL\_COUNT)** |

NOTES: B18x2 should be whole number only. Do not allow decimals.

WARNING: IF B18x1=“Yes” AND B18x2=(0 OR BLANK), DISPLAY: “B18x: Please check your responses. You marked that you offer these services, but reported no transplants.”

1. **As of January 1, 2025, is your hospital recognized by any of the following?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Accredited as an autologous or allogeneic stem cell transplant facility[[28]](#footnote-29) by the Foundation for the Accreditation of Cellular Therapy (FACT) **(CAN\_RECOG\_FACT)** | **○** | **○** |
| b. | Recognized as a transplant center by the National Marrow Donor Program (NMDP) **(CAN\_RECOG\_NMDP)** | **○** | **○** |
| c. | Member of the Pediatric Transplant and Cellular Therapy Consortium (PTCTC) **(CAN\_RECOG\_PTCTC)** | **○** | **○** |

1. **Does your Pediatric Cancer program submit data to the Center for International Blood & Marrow Transplant Research (CIBMTR) or the Stem Cell Therapeutic Outcomes Database (SCTOD)?**

**(CAN\_SCTOD)**

* + Yes – Go to Question B20.1
  + No – Skip to Question B21

**B20.1 Based on the data submitted to the CIBMTR and the SCTOD[[29]](#footnote-30) for your center, how many unique patients < 20 years of age received allogeneic (cord blood/bone marrow/peripheral) stem cell transplants—sibling-matched or other—*for malignant disease* from your Pediatric Cancer program in calendar years 2020-2024? Across those 5 years, how many of these patients[[30]](#footnote-31) died within 100 days, of all causes other than disease progression, following stem cell transplant in each of the categories?** [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Patients from 2020-2024** |
| a. | Patients receiving sibling-matched (HLA-identical) allogeneic-related transplants **(CAN\_ALLOGENEIC\_TRANSPLANTS)** | \_\_\_\_\_\_\_\_\_\_ |
| b. | Patients who died within 100 days (all causes other than disease progression) who received sibling-matched (HLA-identical) allogeneic-related transplants **(CAN\_ALLOGENEIC\_DEATHS100)** | \_\_\_\_\_\_\_\_\_\_ |
| c. | Patients receiving matched unrelated allogeneic transplants (excluding sibling-matched)  **(CAN\_OTHERALLO\_TRANSPLANTS)** | \_\_\_\_\_\_\_\_\_\_ |
| d. | Patients who died within 100 days (all causes other than disease progression) who received matched unrelated allogeneic transplants (excluding sibling-matched) **(CAN\_OTHERALLO\_DEATHS100)** | \_\_\_\_\_\_\_\_\_\_ |

NOTES: B20.1x should be whole number only. Do not allow decimals.

VALIDATE: IF B20.1b > B20.1a, DISPLAY: “Patients who died within 100 days (B20.1b) cannot be greater than patients receiving sibling-matched allogeneic-related transplants (B20.1a).”

IF B20.1d > B20.1c, DISPLAY: “Patients who died within 100 days (B20.1d) cannot be greater than patients receiving all other allogeneic transplants (B20.1c).”

1. **Does your hospital track central line associated blood stream infections (CLABSI) rates for pediatric oncology/stem cell transplant inpatient units[[31]](#footnote-32) (whether separate or embedded in a larger oncology unit) using current NHSN criteria?**

**(CAN\_MALIGDIS)**

* + Yes – Skip to Question B22
  + No – Go to Question B23

1. **Please report your overall CLABSI rate (excluding MBI-CLABSI) per 1,000 central line days for the pediatric oncology/stem cell transplant inpatients in the last calendar year.** [Calculate as follows: (a.) Determine the number of CLABSI events (excluding MBI-CLABSI) according to current NHSN criteria.[[32]](#footnote-33) (b.) Determine the total number of central line days[[33]](#footnote-34) in 2024. (c.) Clicking “Save” will calculate the rate by dividing CLABSI events by central line days and multiplying by 1,000. Responses will be rounded to 2 decimals.]

\_\_\_\_\_\_\_\_ a. CLABSI events **(CAN\_STEMCELL\_EVENTS)**

\_\_\_\_\_\_\_\_ b. Central line days **(CAN\_STEMCELL\_DAYS)**

\_\_\_\_\_\_\_\_ c. CLABSI rate **(CAN\_STEMCELL\_CLASBI)**

NOTES: B22a and B22b should be whole number only. Do not allow decimals.

B22c is an autocalculation and decimals are allowed.

WARNING: If B21=Yes AND B22b = (0 OR BLANK), DISPLAY, “B22 (central line days): Please provide a value greater than 0 or answer No to B21.”

VALIDATE: IF B22a > B22b DISPLAY, “B22: The number of CLABSI events cannot be greater than the number of central line days.”

AUTOCALC: B22c = [(B22a / B22b) \*1000]

**B22.1 Does your hospital’s 2024 NHSN report include a standardized infection ratio (SIR) for CLABSI for your pediatric oncology/stem cell transplant inpatients?**

**(CAN\_SIR\_REPORT)**

* + Yes – Go to Question B22.2
  + No – Skip to Question B23

**B22.2 Please report your NHSN-generated CLABSI standardized infection ratio (SIR), SIR p-value, and 95% confidence intervals (CI) in the last calendar year 2024 for pediatric oncology/stem cell transplant inpatients.** This information is readily available for facilities reporting CLABSI data to NHSN. Regenerate datasets in NHSN before running the report in NHSN Analysis. Also note that if your pediatric cancer program reports separately from your bone marrow transplant unit for CLABSI infections, but is located at the same address, you should combine the two programs in NHSN before generating your numbers in the NHSN Analyses tool. [Please note that all hospitals wishing to receive credit for this question will be required to upload a screenshot of their NHSN report with the SIR information when submitting their survey.]

\_\_\_\_\_\_\_\_ a. Predicted CLABSI events(numPred) **(CAN\_SIR\_EXPECTED)**

\_\_\_\_\_\_\_\_ b. CLABSI standardized infection ratio (SIR) **(CAN\_SIR\_RATE)**

\_\_\_\_\_\_\_\_ c. SIR p-value(SIR\_pval) **(CAN\_SIR\_PVALUE)**

\_\_\_\_\_\_\_\_ d. Lower 95% confidence interval (sir95ci) **(CAN\_SIR\_LOWER)**

\_\_\_\_\_\_\_\_ e. Upper 95% confidence interval (sir95ci) **(CAN\_SIR\_UPPER)**

NOTES: B22.2x is numeric entry (decimals are allowed).

VALIDATE: IF B22.2e < B22.2d OR DISPLAY: “B22.2d & B22.2e: Please check your confidence interval bounds as the upper interval limit should be greater than the lower interval limit.”

IF B22.2b > B22.2e OR B22.2b < B22.2d DISPLAY, “B22.2b: The CLABSI SIR estimate should be between the two confidence interval bounds. Please double check your responses.”

If B22.2x is not numeric: “B22.2x: Please enter a numeric value.”

1. **This question has been removed from the survey.**

**B23.1. This question has been removed from the survey.**

**B23.2 Does your Pediatric Cancer program participate in the Solutions for Patient Safety or other formal consortia for pediatric cancer-related organized quality improvement?**

**(CAN\_QUALITY\_NETWORK)**

* + Yes, Solutions for Patient Safety – Skip to Question B23.4
  + Yes, other formal consortia – Go to Question B23.3
  + No – Skip to Question B23.4

**B23.3. If “yes, other formal consortia” to B23.2, please provide the name of the consortia that your Pediatric Cancer program participates in.**

|  |
| --- |
| **(CAN\_QUALITY\_NETWORK\_TEXT)** |

**B23.4 Does your Pediatric Cancer program have a quality committee with an identified medical leader/director that meets at least monthly?**

**(CAN\_QUALITY\_COMMITTEE)**

* + Yes
  + No

1. **Does your Pediatric Cancer program participate in any of the following organized clinical research networks?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Children’s Oncology Group (COG)[[34]](#footnote-35) **(CAN\_RESEARCH\_COG)** | **○** | **○** |
| b. | National Cancer Institute (NCI) Phase 1/Pilot Consortium **(CAN\_RESEARCH\_NCICONSORT)** | **○** | **○** |
| c. | National Cancer Institute (NCI) designated cancer center[[35]](#footnote-36)(CAN\_RESEARCH\_NCICENTER) | **○** | **○** |
| d. | Other cancer-related organized clinical research network(s) (such as Pediatric Brain Tumor consortium, New Approaches to Neuroblastoma Therapy, Sarcoma Alliance for Research through Collaboration, Department of Defense Neurofibromatosis Consortium, Therapeutic Advances for Childhood Leukemia and Lymphoma, and other formal consortia) **(CAN\_RESEARCH\_OTHER)** | **○** | **○** |

**B24.1 If “no” to B24c, is your Pediatric Cancer program a consortium partner[[36]](#footnote-37) or affiliate[[37]](#footnote-38) of a National Cancer Institute (NCI) designated cancer center?**

**(CAN\_RESEARCH\_NCIAFFIL)**

* + Yes, a consortium partner of an NCI designated cancer center
  + Yes, an affiliate of an NCI designated cancer center
  + No

1. **Did your Pediatric Cancer program have Phase I or Phase II[[38]](#footnote-39) clinical trials available to patients during the last 2 calendar years?** [Only include trials that were open and enrolled at least one patient during this timeframe.]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Yes** | **No** |  |
| a. | Phase I clinical trials | **○** | **○** |  |
|  | **(CAN\_PHASEI\_STUDY)** |  | |  |
| b. | Phase II clinical trials | **○** | **○** |  |
|  | **(CAN\_PHASEII\_STUDY)** |  | |  |

1. **Did your Pediatric Cancer program participate[[39]](#footnote-40) in Investigator-Initiated Phase I and/or Phase II clinical trials where the PI is at your hospital or do they participate[[40]](#footnote-41) in other therapeutic bench-to-bedside translational research trials (not including cooperative groups such as COG or other consortiums) in any of the following areas in the past calendar year?** [Note that each trial can only be counted once in the categories below. Also, please only include studies that were open and enrolled at least one patient during this timeframe.]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Yes** | **No** |  |
| a. | Leukemia/lymphoma only | **○** | **○** |  |
|  | **(CAN\_TRIALS\_LEUKEMIA** |  | |  |
| b. | Solid tumors only | **○** | **○** |  |
|  | **(CAN\_TRIALS\_SOLID)** |  | |  |
| c. | CNS tumors only | **○** | **○** |  |
|  | **(CAN\_TRIALS\_CNS)** |  | |  |
| d. | Transplants only | **○** | **○** |  |
|  | **(CAN\_TRIALS\_NEURO)** |  | |  |
| e. | Trials that are not disease specific | **○** | **○** |  |
|  | **(CAN\_TRIALS\_AVEGF)** |  | |  |

**B26.1. This question has been removed from the survey.**

1. **Please indicate the number of unique pediatric patients treated[[41]](#footnote-42) (e.g., chemotherapy, radiation therapy, biological therapy, surgery) in your Pediatric Cancer program in the last calendar year with the following diagnoses. Please also indicate the number of operative episodes[[42]](#footnote-43) related to their cancer diagnosis that occurred in the last calendar year, if applicable. Include all patients who are newly diagnosed, transfers, relapsed, or still in active treatment but diagnosed in a previous survey year.** Please use provided code lists with diagnosis codes to identify unique patients. Operative episodes must have both a diagnosis and procedure code.[If none, please enter 0.]

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Unique**  **Patients** | **Operative Episodes** |
| a. | Leukemia (see code) | \_\_\_\_\_\_\_\_ |  |
|  | **(CAN\_LEUKEMIA\_** | **PATIENTS)** |  |
| b. | Brain tumors/Central Nervous System – malignant (see code list) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_BRAINTUMOR\_** | **PATIENTS)** | **OPERATIONS)** |
| c. | Neuroblastoma (see code list) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_BLASTOMA\_** | **PATIENTS)** | **OPERATIONS)** |
| d. | Bone tumors (see code list) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_BONETUMORS\_** | **PATIENTS)** | **OPERATIONS)** |
| e. | Soft tissue sarcomas (see code list) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_SARCOMA\_** | **PATIENTS)** | **OPERATIONS)** |
| f. | Wilms' tumor (see code list) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_WILMSTUMOR\_** | **PATIENTS)** | **OPERATIONS)** |
| g. | Liver tumors (see code list) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_LIVERTUMOR\_** | **PATIENTS)** | **OPERATIONS)** |
| h. | Retinoblastoma (see code list) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_RETINO\_** | **PATIENTS)** | **OPERATIONS)** |
| i. | Extracranial germ cell tumors (see code list) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_CELLTUMORS\_** | **PATIENTS)** | **OPERATIONS)** |
| j. | Lymphoma (see code list) | **\_\_\_\_\_\_\_\_** |  |
|  | **(CAN\_LYMPHOMA\_** | **PATIENTS)** |  |

NOTES: B27x1 and B27x2 should be whole number only. Do not allow decimals. Allow up to 3 digits.

**B27.1 Are patients with thyroid cancer being treated by your Pediatric Cancer program having thyroidectomies performed by a high-volume thyroid surgeon (>25 thyroid resections per year) either in your institution or by transfer agreement?**

**(CAN\_THYROID\_RESECTION)**

* + Yes
  + No

**B27.2 How many patients received radical nephrectomy, prior to chemotherapy, for Wilms tumor between 2022-2024? Of this group how many underwent lymph node sampling during the procedure (see code list)?**

\_\_\_\_\_\_\_\_ a. Number of patients receiving radical nephrectomy for Wilms tumor **(CAN\_WILLS\_RADNEPH)**

\_\_\_\_\_\_\_\_ b. Number of patients undergoing lymph node sampling **(CAN\_WILLS\_SAMPLING)**

* Not applicable **(CAN\_WILLS\_NA)**

NOTES: B27.2x should be whole number only. Do not allow decimals.

N/A should be mutually exclusive (i.e. cannot be selected with other responses).

1. **What percentage of patients who completed cancer treatment in 2019-2021 received care through your formal long-term survivor program[[43]](#footnote-44) between 2022-2024?** [Note that eligibility rules may vary by institution.]

**(CAN\_AFTERTRTMNT)**

* + <25%
  + 25-49%
  + 50-74%
  + 75-100%
  + Not applicable **(CAN\_AFTERTRTMNT\_NA)**

NOTES: N/A should be mutually exclusive (i.e. cannot be selected with other responses).

**B28.1 What percentage of patients alive in 2024 with these diagnoses (see code list) and who received cranial radiation, total body irradiation, or intracranial surgery (see code list for procedures) in 2021-2023 had documentation of a formal neuropsychological evaluation conducted since the completion of therapy?**

**(CAN\_NEUROPSYCH\_EVAL)**

* + <25%
  + 25-49%
  + 50-74%
  + 75-100%

**B28.2 What percentage of school-age (6-18 years of age) patients[[44]](#footnote-45) diagnosed with these diagnoses (see code list) in 2022 were formally assessed for school intervention services performed by or in consultation with your Pediatric Cancer program since diagnosis and before the end of the last calendar year?**

**(CAN\_SCHOOL\_EVAL)**

* + <25%
  + 25-49%
  + 50-74%
  + 75-100%

**B28.3 What percentage of pediatric brain tumor patients (from B27b) were enrolled in a formal, comprehensive neuro-oncology clinic for their care coordination?**

\_\_\_\_\_\_\_\_ **% (CAN\_BRAIN\_NEUROCLINIC)**

NOTES: B28.3 is numeric entry (decimals are allowed).

VALIDATE: 0 ≤ B28.3 ≤ 100. ELSE DISPLAY: “B28.3: Please enter a numeric value between 0 and 100.”

1. **Does your pediatric cancer program offer the following pain control programs?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | Pediatric pain service consult **(CAN\_PAINSERVICE)** | **○** | **○** |
| b. | Pediatric outpatient pain management services **(CAN\_OUTPATIENT)** | **○** | **○** |

**B29.1 Does your hospital offer a pediatric palliative care program[[45]](#footnote-46) on-site?**

**(CAN\_PALLIATIVE)**

* + Yes – Go to Question B29.2
  + No – Skip to Question B31

**B29.2 Does your palliative care program have at least one FTE physician with board certification, or who is board eligible, in Hospice and Palliative Medicine?**

**(CAN\_PALLIATIVE\_BOARD)**

* + Yes
  + No

1. **Does your institution have a policy of conducting palliative care consultations 30 days or more prior to death?**

**(CAN\_ADVREFRACT)**

* + Yes
  + No

1. **This question has been removed from the survey.**

**B31.1 This question has been removed from the survey.**

1. **Did your hospital track seasonal influenza vaccination for patients with the following ICD-10 codes (see code list) on active chemotherapy (patients who received chemotherapy after April 1, 2024) in your Pediatric Cancer program between October 1, 2024 and December 31, 2024?**

**(CAN\_TRCK\_CHEMO\_FLUVAC)**

* + Yes
  + No

1. **This question has been removed from the survey.**
2. **How many unique patients were newly diagnosed and treated by your Pediatric Cancer program for each of the following diagnoses between January 1, 2015 and December 31, 2019?** [Note hospitals should only include patients who were newly diagnosed and received initial treatment at your center; do not include referrals for relapsed or refractory disease.] [If none, please enter 0.]

|  |  |  |
| --- | --- | --- |
|  |  | **Patients diagnosed and treated** |
| a. | Acute lymphocytic leukemia (ALL) – All subtypes and risk levels, ages 2 to < 10 years at diagnosis (see code list) **(CAN\_ALL\_TREATED)** | \_\_\_\_\_\_\_\_ |
| b. | Acute myeloid leukemia (AML) – All subtypes and risk levels (see code list) **(CAN\_AML\_TREATED)** | \_\_\_\_\_\_\_\_ |
| c. | Neuroblastoma - Stage L1 (as defined by International Risk Group Staging System) or COG stages I-II, ≥ 18 months of age[[46]](#footnote-47) (see code list) **(CAN\_NEUROBLATOMAII\_TREATED)** | \_\_\_\_\_\_\_\_ |
| d. | Neuroblastoma - NMYC amplified INR L2 or COG stage 3 AND INR stage M and COG stage 4, > 18 months of age[[47]](#footnote-48) **(CAN\_NEUROBLASTOMAIV\_TREATED)** | \_\_\_\_\_\_\_\_ |
| e. | Medulloblastoma – Ages 5 to < 18 years at diagnosis with standard risk[[48]](#footnote-49) (see code list) **(CAN\_MEDULLO\_TREATED)** | \_\_\_\_\_\_\_\_ |

NOTES: B34x should be whole number only. Do not allow decimals.

1. **Of the patients reported in B34, please report the number of patients with each of the following statuses at 5 years from date of diagnosis?** [NOTE: Sum of row must match number of patients from B34]. [If none, please enter 0.]

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Patients known to be alive[[49]](#footnote-50)** | **Patients known to be deceased[[50]](#footnote-51)** | **Patient status unknown** |
| a. | Acute lymphocytic leukemia (ALL) – All subtypes and risk levels, ages 2 to < 10 years at diagnosis | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_ALL\_** | **ALIVE)** | **DEAD)** | **UNKNOWN)** |
| b. | Acute myeloid leukemia (AML) – All subtypes and risk levels | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_AML\_** | **ALIVE)** | **DEAD)** | **UNKNOWN)** |
| c. | Neuroblastoma - Stage L1 (as defined by International Risk Group Staging System) or COG stages I-II, > 18 months of age[[51]](#footnote-52) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_NEUROBLASTOMAII\_** | **ALIVE)** | **DEAD)** | **UNKNOWN)** |
| d. | Neuroblastoma - NMYC amplified INR L2 or COG stage 3 AND INR stage M and COG stage 4, > 18 months of age[[52]](#footnote-53) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_NEUROBLASTOMAIV\_** | **ALIVE)** | **DEAD)** | **UNKNOWN)** |
| e. | Medulloblastoma – Ages 5 to < 18 years at diagnosis with standard risk[[53]](#footnote-54) | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ | \_\_\_\_\_\_\_\_ |
|  | **(CAN\_MEDULLO\_** | **ALIVE)** | **DEAD)** | **UNKNOWN)** |

NOTES: B35x1, B35x2, and B35x3 should be whole number only. Do not allow decimals.

WARNING: IF B34a IS NOT MISSING AND (B35a1=MISSING AND B35a2=MISSING AND B35a3=MISSING), DISPLAY: “B35a: You reported a total number of unique patients in B34a but did not report numbers for each patient status in B35a.”

IF B34b IS NOT MISSING AND (B35b1=MISSING AND B35b2=MISSING AND B35b3=MISSING), DISPLAY: “B35b: You reported a total number of unique patients in B34b but did not report numbers for each patient status in B35b.”

IF B34c IS NOT MISSING AND (B35c1=MISSING AND B35c2=MISSING AND B35c3=MISSING), DISPLAY: “B35c: You reported a total number of unique patients in B34c but did not report numbers for each patient status in B35c.”

IF B34d IS NOT MISSING AND (B35d1=MISSING AND B35d2=MISSING AND B35d3=MISSING), DISPLAY: “B35d: You reported a total number of unique patients in B34d but did not report numbers for each patient status in B35d.”

IF B34e IS NOT MISSING AND (B35e1=MISSING AND B35e2=MISSING AND B35e3=MISSING), DISPLAY: “B35e: You reported a total number of unique patients in B34e but did not report numbers for each patient status in B35e.”

IF B35x1 IS NOT MISSING & (B35x2=MISSING OR B35x3=MISSING), DISPLAY: “B35x: Please check your responses. You provided the number of patients alive but did not provide the number of patients deceased and/or patients with status unknown.”

IF B35x2 IS NOT MISSING & (B35x1=MISSING OR B35x3=MISSING), DISPLAY: “B35x: Please check your responses. You provided the number of patients deceased but did not provide the number of patients alive and/or with status unknown.”

IF B35x3 IS NOT MISSING & (B35x1=MISSING OR B35x2=MISSING), DISPLAY: “B35x: Please check your responses. You provided the number of patients with status unknown but did not provide the number of patients alive and/or deceased.”

VALIDATE: B35a1+B35a2+B35a3 MUST EQUAL B34a, ELSE DISPLAY: “Sum of patients alive, deceased or status unknown in B35a must total the value in B34a.”

B35b1+B35b2+B35b3 MUST EQUAL B34b, ELSE DISPLAY: “Sum of patients alive, deceased or status unknown in B35b must total the value in B34b.”

B35c1+B35c2+B35c3 MUST EQUAL B34c, ELSE DISPLAY: “Sum of patients alive, deceased or status unknown in B35c must total the value in B34c.”

B35d1+B35d2+B35d3 MUST EQUAL B34d, ELSE DISPLAY: “Sum of patients alive, deceased or status unknown in B35d must total the value in B34d.”

B35e1+B35e2+B35e3 MUST EQUAL B34e, ELSE DISPLAY: “Sum of patients alive, deceased or status unknown in B35e must total the value in B34e.”

1. **How many manuscripts focused on quality improvement (QI) topics have been published by pediatric hematology/oncology faculty or fellows in the last 2 calendar years?**

**(CAN\_QI\_PUBLISH)**

* 0
* 1-2
* >= 3

1. **How many peer-reviewed publications have been published by your program’s pediatric hematology/oncology faculty or fellows in the last 2 calendar years?** [Note that you may include QI manuscripts published in peer-reviewed journals reported in B36.]

**(CAN\_PEER\_PUBLISH)**

* 0
* 1-2
* >= 3

**The following are being collected for information purposes only. They will not be factored into the rankings this year.**

**B38. In B28.1 we asked for the percentage of living patients with these diagnoses (see code list) and received cranial radiation, total body irradiation, or intracranial surgery (see code list for procedures) who were 1 to 3 years post-treatment in the last calendar year who had documentation of a formal neuropsychological evaluation conducted since the completion of therapy. In patients with what other cancer diagnoses do you routinely perform formal neuropsychological screening?**

|  |
| --- |
| **(CAN\_NEUROPSYCH\_SCRN)** |

**B39. What percentage of your hemoglobin SS/S-Beta 0 thalassemia patients (see code list) who are < 5 years old are prescribed penicillin prophylaxis (or the equivalent when patient is allergic to penicillin) in the past calendar year?**

\_\_\_\_\_\_\_\_**% (CAN\_HEMOPEN)**

* Not applicable **(CAN\_HEMOPEN\_NA)**

NOTES: B39 is numeric entry (decimals are allowed).

N/A should be mutually exclusive (i.e. cannot be selected with other responses).

VALIDATE: 0 ≤ B39 ≤ 100. ELSE DISPLAY: “B39: Please enter a numeric value between 0 and 100.”

**B40. What percentage of your hemoglobin SS/S-Beta 0 thalassemia patients (see code list) who are ages 2 years to 16 years inclusive received primary stroke screening with transcranial doppler ultrasound (see procedure code) in the past calendar year? Exclude patients on chronic transfusion.**

**(CAN\_HEMODOPP)**

* < 25%
* 25-49%
* 50-74%
* 75-100%
* Not applicable **(CAN\_HEMODOPP\_NA)**

NOTES: N/A should be mutually exclusive (i.e. cannot be selected with other responses).

**B41. In the past calendar year, what percentage of your hemoglobin SS/S-Beta 0 thalassemia patients (see code list) ages 1 year or older (those who have turned 1 year old by at least July 1, 2024) were prescribed hydroxyurea? Exclude patients on chronic transfusion.**

**(CAN\_HEMOHYDRO)**

* < 25%
* 25-49%
* 50-74%
* 75-100%
* Not applicable **(CAN\_HEMOHYDRO\_NA)**

NOTES: N/A should be mutually exclusive (i.e. cannot be selected with other responses).

**B42. Did your hospital track seasonal influenza vaccination for active sickle cell patients (see code list) seen in your Pediatric Cancer program between October 1, 2024 and December 31, 2024?**

**(CAN\_SIKL\_FLUVAC)**

* Yes
* No

**B43. Did your hospital track pneumococcal vaccination for active sickle cell patients (see code list) seen in your Pediatric Cancer program in the last calendar year?**

**(CAN\_SIKL\_PNEVAC)**

* Yes
* No

**B44. Does your Hematology/Oncology Program treat sickle cell patients?**

**(CAN\_SIKL\_PRGM)**

* + Yes - Go to B44.1
  + No - Go to B45

**B44.1 This question has been removed from the survey.**

**B44.2 Which of the following resources are available to your sickle cell patients?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | On-site apheresis service **(CAN\_SIKL\_APHERESIS)** | **○** | **○** |
| b. | Day hospital/Observation unit to care for patients with fever and/or pain on evenings and weekends **(CAN\_SIKL\_OBSUNIT)** | **○** | **○** |
| c. | On-site transcranial doppler ultrasound imaging **(CAN\_SIKL\_TCDOPP)** | **○** | **○** |
| d. | Inpatient pain consultation service **(CAN\_SIKL\_PAINCONSULT)** | **○** | **○** |
| e. | Integrative pain clinic **(CAN\_SIKL\_PAINCLINIC)** | **○** | **○** |
| f. | Available gene therapy trials (on-site or through formal agreement with outside center) **(CAN\_SIKL\_GENETHER)** | **○** | **○** |

**B45. Does your Pediatric Hematology/Oncology Program include a hemostasis program?**

**(CAN\_HEMO\_PRGM)**

* + Yes - Go to B46
  + No - Go to Chief of Service Approval

**B46. Is your hemostasis program a federally designated Hemostasis and Thrombosis center by**

**Maternal and Child Health?**

**(CAN\_HEMO\_FEDDES)**

* + Yes
  + No

**B47. Please list the number of patients with the following diagnoses (see code list) who received**

**comprehensive hematology care through your hemostasis programs in the calendar year**

**2024?**

1. \_\_\_\_ Hemophilia A (factor VIII deficiency) **(CAN\_HEMO\_A)**
2. \_\_\_\_ Hemophilia B (factor IX deficiency) **(CAN\_HEMO\_B)**
3. \_\_\_\_ von Willebrand disease **(CAN\_HEMO\_VWD)**

NOTES: B47x should be whole number only. Do not allow decimals.

**B48. What percentage of severe hemophilia patients who received care from your hemostasis**

**Program in the calendar year 2024 are on primary prophylaxis[[54]](#footnote-55)?**

\_\_\_\_\_\_\_\_**% (CAN\_HEMO\_PROPHY)**

* Not applicable **(CAN\_HEMO\_PROPHY\_NA)**

NOTES: B48 is numeric entry (decimals are allowed).

N/A should be mutually exclusive (i.e. cannot be selected with other responses).

VALIDATE: 0 ≤ B48 ≤ 100. ELSE DISPLAY: “B48: Please enter a numeric value between 0 and 100.”

**B49. Is your hemostasis program actively involved in any of the following bleeding disorder**

**clinical research networks?**

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | **Yes** | **No** |
| a. | American Thrombosis and Hemostasis Network (ATHN) **(CAN\_HEMO\_ATHN)** | **○** | **○** |
| b. | Centers for Disease Control (CDC) **(CAN\_HEMO\_CDC)** | **○** | **○** |
| c. | Other **(CAN\_HEMO\_NTWRK\_OTH)** | **○** | **○** |

NOTES: If B49c=yes, go to B49.1.

**B49.1. Please list the other bleeding disorder clinical research networks your hemostasis program is actively involved in.**

|  |
| --- |
| **(CAN\_HEMO\_NTWRK\_OTH2)** |

**B50. This question has been removed from the survey.**

**B51. Which of the following resources are available to your hemostasis patients?**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Yes** | **No** |  |
| a. | On-site lab able to perform clotting factor assays same day **(CAN\_HEMO\_LAB)** | **○** | **○** |  |
| b. | Musculoskeletal ultrasound as part of comprehensive clinic **(CAN\_HEMO\_ULTRASOUND)** | **○** | **○** |  |

**CHIEF OF SERVICE APPROVAL**

To have this section of the survey accepted for scoring, the Service Chief for your Pediatric Cancer program must acknowledge that they have reviewed all responses and approve of the submission. To do this you will need to download, complete, and upload the approval form by the date of the final survey submission. Has the approval form for your Pediatric Cancer program been completed and uploaded to the Pediatric Hospital Survey website?

* Yes, the form as been submitted **(CAN\_DIR\_APPROVE)**
* No, the form has not been submitted. Please complete and upload the form before proceeding.

**COMMENTS FOR SECTION B:**

If needed, you may provide clarifications to the responses you provided to the questions asked in this section only. All other comments, suggestions or questions should be sent to [PediatricHospSurvey@rti.org](mailto:PediatricHospSurvey@rti.org).

|  |
| --- |
| **(CAN\_COMMENTS)** |

1. Attending/on-staff physicians include those who have completed their training in their particular medical specialty, are actively providing clinical care to patients, and are currently considered a member of the “medical staff” at the hospital. This may include physicians employed by the hospital, an affiliated university, or some other entity as long as the physician is considered part of the medical staff at the hospital. [↑](#footnote-ref-2)
2. The American Board of Pediatrics no longer recognizes the commonly employed term "board eligible". For the purposes of the rankings, a "board eligible" hematology-oncology specialist will refer to someone who has completed their fellowship in an ACGME accredited program within the past 7 years but who has not yet become board certified. [↑](#footnote-ref-3)
3. Case managers are nurse practitioners, physician assistants, or clinical nurses who work to coordinate the care of patients in your pediatric cancer program. This involves helping to track and navigate patients through various types of care prescribed by the program, identifying needs for additional services, and may involve the delivery of some clinical care. The role of case manager is differentiated from the normal delivery of care by the fact that patients are assigned and followed over an extended period of time by these staff in your pediatric cancer care program. [↑](#footnote-ref-4)
4. To calculate nurse practitioner, physician assistant, and clinical nurse FTEs, please take the percentage of typical case management effort provided to the program and divide by 100. This resulting decimal will be the FTE. For example, NP Smith spends 65% of her time in clinical care and 35% in case management activities; the case management FTE for NP Smith would be 0.35 FTE (i.e., 35/100=0.35). [↑](#footnote-ref-5)
5. Count a patient as new if he or she did not receive any medical services from a physician or other health care provider in your Pediatric Cancer program in the 36 months prior to the patient’s first visit in the reporting year. Do not count patients who come in for consultation and evaluation who ultimately seek treatment elsewhere. You may count any patient (newly diagnosed or relapsed) who comes to your center to participate in clinical trials, or to receive anti-cancer therapy of any type; however, you should exclude long-term follow-up patients who would otherwise qualify under the 36-month window as they do not represent “new” patients to your center. [↑](#footnote-ref-6)
6. If your hospital participates in a tumor registry, we encourage you to pull these data from those records. [↑](#footnote-ref-7)
7. A pediatric specialist is one who is trained in sedation through competencies and spends at least 30% of their time providing sedation for children. See ACOS Optimal Resources for more information: <https://www.facs.org/quality-programs/about/optimal-resources-manual>. [↑](#footnote-ref-8)
8. I-131MIBG is a functional imaging and treatment agent used to help locate, diagnose and treat tumors of adrenergic tissues, such as neuroblastoma and pheochromocytoma. For this question, we are ONLY interested in therapeutic use of I-131 MIBG to treat cancer. [↑](#footnote-ref-9)
9. Radio frequency ablation (RFA) and/or cryoablation for treatment of tumors must be performed by an interventional radiologist with expertise in pediatric tumor treatment. To be counted, the interventional radiologist must perform at least 50 pediatric interventional procedures (of any type) annually. [↑](#footnote-ref-10)
10. This program brings together a multidisciplinary team of specialists to deliver the most effective treatment to ensure the optimal functioning and quality of life for children with brain tumors. To be eligible, a program must have at least one of each of the following as part of the team: pediatric neurooncologist, neurosurgeon, pediatric neuroradiologist, pediatric interventional neuroradiologist, radiation oncologist, pediatric neurologist, pediatric endocrinologist, neuropathologist, psychologist (or neuropsychologist), pediatric physiatrist, and interventional radiologist with pediatric expertise. [↑](#footnote-ref-11)
11. This program brings together a multidisciplinary team of specialists to deliver the most effective treatment to ensure the optimal functioning and quality of life for children with bone and soft tissue sarcomas. To be eligible, a program must have at least one of each of the following as part of the team: oncologist, surgeon, radiologist, radiation oncologist, pediatric bone marrow transplant specialist, immunotherapy specialist, pediatric physiatrist, and pathologist. [↑](#footnote-ref-12)
12. A limb-sparing (otherwise known as limb-salvage) surgery involves removing a malignant (cancerous) bone or soft tissue tumor without amputation, and replacing the bone and/or joint with an allograft (bone graft), endoprothesis (artificial devices), or composite (combining allograft and endoprothesis). Soft tissue and muscle transfers to cover and close the site and restore motor power also are part of this procedure. [↑](#footnote-ref-13)
13. This program brings together a multidisciplinary team of specialists and national certification to deliver the most effective treatment for children with leukemia and lymphoma. To receive credit, program must have access to on-site allogeneic hematopoietic stem cell transplantation program. They must have at least one of each of the following as part of the team: pediatric oncologist specializing in leukemia and lymphoma, pediatric bone marrow transplant specialist, on-site hematopathologist, nuclear medicine specialist and access to PET/CT. [↑](#footnote-ref-14)
14. This program is designed to follow and monitor the health of patients in the cancer program who survive beyond the 5-year survival window for cancer outcome monitoring. To be eligible, a program must have a multidisciplinary team with at least one pediatric endocrinologist, social worker, psychologist (or neuropsychologist), and specialist pediatric physiatrist, each of who have clinical activities focused on survivorship. In addition, the program must have access to the patient’s primary care provider for ongoing coordination of their care. [↑](#footnote-ref-15)
15. This program brings together a multidisciplinary team of specialists to deliver the most effective treatment for children with histiocytoses (LCH, JXG, RDD etc.). To be eligible, a program must have at least one of each of the following as part of the team: pediatric oncologist, radiation oncologist, orthopaedic surgeon, pathologist, and a pediatric endocrinologist. [↑](#footnote-ref-16)
16. Program must include physicians and other support staff skilled in working with adolescents and young adults. The program should include a variety of services including supportive counseling, group therapy, fertility counseling, spiritual counseling, and vocational counseling. [↑](#footnote-ref-17)
17. To answer “Yes,” the program must include a clinical geneticist and a genetic counselor. [↑](#footnote-ref-18)
18. This program brings together a multidisciplinary team of specialists to achieve the most effective incorporation of molecular diagnostic tests including next generation sequencing in patient care to ensure accurate diagnosis, identification of cancer predisposition and implementation of a precision approach to treatment selection. To be eligible, a program must have at least one of each of the following as part of the team: pediatric pathologist, genomics expert (molecular pathologist, ABMGG-certified laboratory geneticist or PhD-level expert in genomics and/or bioinformatics), pediatric oncologist and an ABGC-certified genetics counselor. The program must have developed a rational and standard approach to molecular testing in a clinical lab (on site or elsewhere) for both tumor and germline for each of the major pediatric oncology disease types (hematologic malignancies, brain tumors and extra-cranial solid tumors) which includes pre-test education or consent, a determination of the diagnoses / disease statuses to be tested, the testing laboratory or laboratories to be utilized and how financial burden to the patient is mitigated. Results of testing must be routinely reviewed in a case-discussion format such as tumor board. [↑](#footnote-ref-19)
19. To answer “yes”, the program must be part of a Commission on Accreditation of Rehabilitation Facilities (CARF) Pediatric Specialty Program certified contiguous unit. Footnote to list requirements of program which should include each of the following rehabilitation professionals: (1) physicians with subspecialty certification in Pediatric Rehabilitation Medicine, (2) physical therapists, (3) occupational therapists, (4) speech and language pathologists, (5) recreation therapists, and (6) school integration and (7) reentry coordinators that develop cancer rehabilitation programming unique to the functional deficits acquired by the patient and facilitate safe and effective transition to home and the community. [↑](#footnote-ref-20)
20. For this question, eligible nurses include those who have an active unencumbered RN license, with a minimum 24 months RN experience within 48 months prior to application. This experience should include 2,000 hours of pediatric hematology-oncology/BMT nursing practice within 48 months prior to application. Due to ongoing nursing shortages, float and contract nurses may be included in your counts this year. [↑](#footnote-ref-21)
21. These programs must offer interventions to preserve fertility of BOTH male and female patients newly-diagnosed with cancer before undergoing treatments which may damage, reduce, or inhibit the ability to reproduce in the future. [↑](#footnote-ref-22)
22. These are regularly scheduled conferences to provide a forum for faculty and trainees to explore the management of cases which resulted injury or death, near misses, or near misses without harm. They are also a requirement of all fellowship programs of the Accreditation Council for Graduate Medical Education (ACGME). [↑](#footnote-ref-23)
23. Nights are defined as any time between 5pm and 5am. [↑](#footnote-ref-24)
24. Weekends are defined as any time between 5pm on Friday and 5am Monday morning. [↑](#footnote-ref-25)
25. Coordinated outreach programs provide care in the community using a combination of resources from your hospital as well as external providers to provide follow-up care or treatment for cancer patients. [↑](#footnote-ref-26)
26. This may include either a separate pharmacy focused on pediatric chemotherapy or a special unit within the hospital’s pharmacy services that focuses exclusively on pediatric chemotherapy. [↑](#footnote-ref-27)
27. Do NOT include donor lymphocyte infusions (DLIs). [↑](#footnote-ref-28)
28. Please note that we verify responses based on information from FACT: https://accredited.factglobal.org/. If your hospital is an autologous or allogeneic transplant facility, but not listed on this site, please provide an explanation in the comments section. Please note that we do not give credit for being affiliated with a pediatric transplant facility. [↑](#footnote-ref-29)
29. If your center is interested in using data obtained from CIBMTR, instructions can be found within the Data Back to Centers (DBtC) application on the CIBMTR Portal at the following link: <https://portal.cibmtr.org/dbtc2/Docs/survey.aspx>. You need to be an authorized user of the Portal in order to access this information. Please use data from the Stem Cell Therapeutic Outcomes Database (SCTOD) available from the Center for International Blood & Marrow Transplant Research (CIBMTR). [↑](#footnote-ref-30)
30. Patients should be reported for the five year period. To answer, identify cases where a patient received a stem cell transplant for a malignant disease and they were < 20 years of age at the time of transplant. Note that patients should only be counted for their first transplant within the time period. Then determine how many died within 100 days following transplant. [↑](#footnote-ref-31)
31. Include only hospital associated cases for oncology inpatients as per NHSN criteria. Do not include outpatient clinic or home care patients. [↑](#footnote-ref-32)
32. For the most recent NHSN definitions, see the following 2018 definitions for CLABSI rates: <https://www.cdc.gov/nhsn/pdfs/pscmanual/4psc_clabscurrent.pdf> [↑](#footnote-ref-33)
33. According to NHSN guidelines, a patient with one or more central lines on a given day equals 1 central line day. If central lines days associated with temporary and permanent catheters are collected separately (as per NHSN guidelines for oncology and SCT), combine these numbers for this denominator. [↑](#footnote-ref-34)
34. See <http://www.childrensoncologygroup.org>. [↑](#footnote-ref-35)
35. Please note that we verify cancer center status with NCI: <http://www.cancer.gov/researchandfunding/extramural/cancercenters/find-a-cancer-center>. If your hospital is an NCI designated cancer center, but not listed on this site, please provide an explanation in the comments section. [↑](#footnote-ref-36)
36. Recognized by the NCI as a consortium partner of an NCI designated cancer center. [↑](#footnote-ref-37)
37. Have a formal contractual agreement with an NCI designated cancer center as an affiliate in which resources are dedicated to the pediatric program. [↑](#footnote-ref-38)
38. Please count a “Phase I/II” study as Phase I. Also, if a patient is enrolled in more than one clinical trial at a time, please count them only once in your response on the survey. [↑](#footnote-ref-39)
39. Your hospital must be actively involved in the research to answer yes. Referring patients to other locations that do this research is not sufficient for receiving credit. [↑](#footnote-ref-40)
40. By participate, we mean serve as a PI, Co-PI or active investigator, and not serving only as a referral source. [↑](#footnote-ref-41)
41. You may include expectant observation but exclude those seen for off-therapy long-term follow-up. This is also referred to as Expectant Management by NCI in cancer care; for more information please see <https://www.cancer.gov/publications/dictionaries/cancer-terms/def/expectant-management>. [↑](#footnote-ref-42)
42. The intended focus of this question is on treatment activities involving operating room or outpatient surgery procedures that seek to remove or treat tumors (either brain or other solid tumors) in patients seen by your pediatric cancer program. Do NOT include operative episodes that were only for central venous catheter placement/removal, shunt placement/revisions, biopsies (of tumors, involved nodes, or bone marrow), lumbar punctures in brain tumor patients (for disease status monitoring), or other procedures not involved in treating or removing tumors. [↑](#footnote-ref-43)
43. A formal long-term survivor program is defined as a program that monitors the health of patients in the cancer program who survive beyond the 3-year survival window for cancer outcome monitoring. The program must have access to the patient’s primary care provider for ongoing coordination of their care. Note that both in-person and telehealth patient visits are acceptable. [↑](#footnote-ref-44)
44. Include all patients – both those in active treatment and those in follow-up or survivorship. [↑](#footnote-ref-45)
45. A palliative care program is organized and staffed for children nearing the end of life or living with lifespan-limiting conditions. The program’s purpose is to minimize pain and discomfort, provide emotional and spiritual support for children and their families, assist with financial guidance and social services, and support decision making. Programs must include at least one physician providing direct patient care; a nurse coordinator; and a social worker, certified child-life specialist, or pastoral counselor. All program staff must have training in palliative care. [↑](#footnote-ref-46)
46. Age at time of diagnosis. [↑](#footnote-ref-47)
47. Age at time of diagnosis. [↑](#footnote-ref-48)
48. Standard risk is defined as patients >3 years of age with <1.5cm residual tumor after resection and absence of metastases. [↑](#footnote-ref-49)
49. You may count as “known to be alive” if you have had confirmation within 6 months of the 5-year mark or more recently. [↑](#footnote-ref-50)
50. The intent of this question is to identify patients deceased due to disease or therapy-related complications and does not include other causes of mortality that do not reflect the outcomes of the cancer program. Therefore, you may exclude patients known to be deceased due to accidental mortality, (such as car accidents). [↑](#footnote-ref-51)
51. Age at time of diagnosis. [↑](#footnote-ref-52)
52. Age at time of diagnosis. [↑](#footnote-ref-53)
53. Standard risk is defined as patients >3 years of age with <1.5cm residual tumor after resection and absence of metastases. [↑](#footnote-ref-54)
54. Primary prophylaxis includes both ongoing and peri-procedural prophylaxis. [↑](#footnote-ref-55)