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Public Health Agency of Canada | Agence de la santé publique du Canada

The Cancer in Young People in Canada (CYP-C)

Project Governance

September 2018

1. Background

Launched in 2009, the CYP-C surveillance system offers an opportunity to study childhood cancer and provides a foundation for planning cancer control programs and policies. The program is a renewal of the federal government's Canadian Childhood Cancer Surveillance and Control program established under the Brighter Futures Initiative in 1992. CYP-C started collecting surveillance data in 2009 from the 17 paediatric oncology centres in Canada and covers cancer cases newly diagnosed in 2001 or later. The surveillance system includes data on demographics (sex, date of birth, race, province, and postal code of residence at diagnosis), diagnostic details (date of diagnosis, type of diagnosis, site, stage, and metastases at diagnosis), treatments (enrolment on clinical trial, treatment plan details, chemotherapy, radiation, surgery, hematopoietic stem cell transplantation (HSCT)), location and timing of care, and outcomes (hospitalizations, complications, relapse, survival) with up to 5 years of follow-up.

The overall goal of the CYP-C program is to improve outcomes for children with cancer through targeted collection of relevant pan-Canadian data. More specific goals include enhancing surveillance of cancer incidence and outcomes, quality improvement through describing variability in practice and results, and clinical research. The CYP-C program also strives to improve clinical care by providing patient-specific data for clinicians and survivors, and to deliver education for potential users of CYP-C data.

The CYP-C represents an extensive collaboration involving all 17 paediatric oncology centres in Canada, the C^{17} Council (C^{17}), provincial and territorial cancer registries, Statistics Canada, the Canadian Partnership against Cancer (CPAC), the Public Health Agency of Canada (PHAC) and non-governmental organizations working on childhood cancers in Canada. External researchers can apply for access to CYP-C data. To date, the CYP-C is a veritable demonstration of working horizontally to bring surveillance and research together and developing the evidence base for childhood cancer control activities

2. Description of CYP-C Data

CYP-C aims to include all children, under the age of 15 years, who were treated at a paediatric oncology centre in Canada with a diagnosis listed in the International Classification of Childhood Cancer, 3rd Edition (ICCC-3). Only those diagnosed in 2001 or later are included. For each child, data are collected for a maximum of five years after diagnosis (or until death). If a child is diagnosed with a subsequent malignancy meeting CYP-C eligibility criteria, data are collected for another five-year period after the diagnosis.

Comparisons of incidence cases in CYP-C to the Canadian Cancer Registry (CCR) have shown that very few paediatric cancer cases (0–14 years) are treated outside these paediatric oncology centres.

3. CYP-C Data Collection and Maintenance

Through expert opinion, a committee drafted the protocol and data collection forms. CYP-C has identified and defined the data elements to be captured and maintained in a national database (Appendix D). There are two broad different methods of data collection for CYP-C:

- In Ontario, the Paediatric Oncology Group of Ontario (POGO) has maintained a population-based registry of incident cancer cases since 1985 (n=5 centres). The Paediatric Oncology Group of Ontario Networked Information System (POGONIS) is an active database and data managers or clinical research associates (CRAs) ensure key information is collected using hospital chart review, internal hospital information and direct connections with the patient's health care team. Information is then shared with the PHAC through a data sharing agreement.
- In paediatric oncology centres outside of Ontario (n=12 centres), data are abstracted directly from patient medical charts by data managers or CRAs and entered into a secure electronic data entry and management tool.

Data quality checks are performed on both data from CYP-C and POGONIS by the data manager in the Surveillance System and Data Management Unit (SSDM) at PHAC. If there are discrepancies, issues are jointly resolved between the CRAs at the centres, POGO and PHAC. Data from POGONIS and all other centres are collated and maintained on a secure server at PHAC.

To promote high quality data, the CRAs outside Ontario meet monthly by teleconference and face-to-face annually for training and review of cases. CRAs in Ontario are also invited to attend the teleconferences and may attend the meetings. Their attendance is expected to increase with CYP-C 2.0 (update to the current data approach) implementation as the data will be better harmonized between CYP-C and POGONIS.

Data completeness and currency are key to meeting CYP-C's goals. A maximum lag time of 2 years in data currency in CYP-C should be met by all data providers. Given the five-year follow-up of all cases, updates will provide a continuous stream of information for each case until it is closed.

PHAC has custody of the national CYP-C dataset. Each centre and POGO remain the data custodians of their own respective dataset.

4. Access to CYP-C Data

The CYP-C data are available for research related to childhood cancer. Researchers can obtain access to CYP-C data by taking all the following steps:

1) Submit an application including a research proposal describing their objectives and rationale, methods, justifications for each data element requested, knowledge translation plan, and timelines for completion and data retention;
2) Obtain institutional research ethics board approval(s);
3) Receive the approval of the CYP-C Data Use and Publication Committee;
4) Receive the approval of POGO and the Public Health Agency of Canada's program and privacy authorities;
5) Enter into a CYP-C Data Confidentiality Agreement

Applications are assessed on the basis of scientific merit (including alignment of study methodology with research objectives), feasibility, relevance to childhood cancer, timelines, and specific privacy safeguards proposed. Data access can only occur within Canada; however, applications from researchers with international affiliations will be considered provided that they do not involve removal of data from Canada.

5. The Research Champion Program

Providing education for potential CYP-C users and training the next generation of CYP-C leaders are important goals of the program. CYP-C Research Champions may be in a clinical, research or public health role, must be affiliated with a Canadian institution or organisation and must have some knowledge of research methodology. Young investigators are encouraged, but investigators of any seniority are eligible to be Research Champions.

The goals of the program are:

- To increased knowledge of CYP-C across Canada
- To enhance utilization of CYP-C
- To provide opportunities for academic advancement through co-authorship on research publications and presentations
- To identify and train the next generation of leaders in CYP-C
- To provide opportunities for mentorship and collaboration across Canada

The CYP-C Research Champions are provided a monthly educational webinar related to management of CYP-C data and an annual face-to-face training session. They are also provided an opportunity to participate in PHAC-directed research publications.

6. Dissemination strategy

Health system leaders including cancer agency leads (current members of CAPCA) and child health leads for each of the 17 pediatric cancer centers will be engaged proactively as partners as is currently the process for CPAC's System Performance Reports. This process aims to maximize the effective impact of these national level data and interjurisdictional comparisons. Communication strategies will be developed to include all relevant stakeholders, the public and media. CPAC will identify opportunities for including some CYP-C data based content in future reports, including the analysis of data by mutual agreement of the Management Committee and CPAC.

7. Transparency

The CYP-C partners are committed to transparency as an operating principle. Transparency of the CYP-C is served by posting CYP-C materials, with confidential and personal information removed, on the Public Health Agency of Canada's website. These materials may include the following:

- terms of reference
- committee membership
- summaries of information contained in any of the committee's members' summaries of expertise, experience, and affiliations and interest's forms
- biographies of members

- public records of decision
- records of Confidentiality Agreement form completion
- processes for obtaining CYP-C data
- records of CYP-C data usage.

8. Roles and Responsibilities

CYP-C is a partnership between PHAC, C^{17} Council and CPAC.

- PHAC's mandate is to conduct high quality surveillance — through obtaining and producing quality data and translating it into timely, relevant and accessible information to enable public health action. It is the data custodian, provides financial support and focuses on the development and dissemination of public health surveillance information.
- The C^{17} Council is an organization composed of the institutionally appointed heads of the seventeen paediatric hematology, oncology, and HSCT centres across Canada. Its mission is to improve health outcomes and quality of life for children and adolescents in Canada with cancer and blood disorders. The C^{17} Council represents the Canadian paediatric oncology centres' perspectives and is responsible for bidirectional communication of status, products, updates and opportunities related to CYP-C.
- CPAC is an independent organization funded by the federal government to accelerate action on cancer control for all Canadians. The CPAC is a collaborative organization dedicated to helping reduce the impact of cancer on Canadians. CPAC will focus on contributing to and implementing strategies for knowledge mobilization including selection of the data to be presented, targeted communications to stakeholders and the use of creative formats to maximize impact. CPAC will be responsible for producing some reports, including the analysis of data by mutual agreement of the Management Committee and CPAC.

Oversight for the CYP-C program is provided by three groups: the CYP-C Partners Group, the CYP-C Advisory Committee and the CYP-C Management Committee.

The CYP-C Partners Group meets weekly and makes day-to-day decisions on behalf of the program and performs preliminary work required to present questions about process or direction to the Management and Advisory Committees. Its focus includes CYP-C data quality, data currency, report creation and education. (Terms of Reference can be found in Appendix A)

The CYP-C Advisory Committee (CYP-C AC) will help guide and promote the program and ensure key stakeholders have an opportunity to understand and inform CYP-C direction and decisions. In its capacity as an advisory committee, it will have no decision making authority (beyond the decisions required to make recommendations) or policy making responsibilities. (Terms of Reference can be found in Appendix B)

The CYP-C Management Committee (CYP-C MC) meets monthly and with input from the CYP-C AC, makes decisions on behalf of the program. It is responsible for providing oversight for data currency and quality, providing clarifications or changes to the data elements, facilitating merger between POGONIS and directly entered CYP-C data, determination of report content and frequency, reviewing research proposals and approving all CYP-C products such as reports. It also develops and promotes the Research Champions role. All activities are undertaken with a view to ensue representation from all 17 centres and from a variety of role types including nurses, researchers, CRAs, epidemiologists, pharmacists and other allied health staff. (Terms of Reference can be found in Appendix C)

Appendix A – Terms of Reference for the CYP-C Partners Group

1. Purpose

Make day-to-day decisions on behalf of the program and perform preliminary work required to present questions about process or direction to the Management and Advisory Committees. Focus also includes CYP-C data quality, data currency, report creation and education

2. Membership, as appointed by their respective organizations:
   (1) C^{17} representative;
   (2) C^{17} Surveillance Coordinator;
   (3) PHAC CYP-C Program Manager;
   (4) PHAC CYP-C Database Manager;
   (5) POGO representative (ex officio);
   (6) CPAC representative; and
   (7) CYP-C Management Committee Chair

3. Roles and Responsibilities
   By consensus, establishes an annual work plan for CYP-C and sets the agenda for CYP-C Management Committee meetings on behalf of the C^{17} Council's member organizations, the Canadian Partnership Against Cancer, and the Public Health Agency of Canada. In situations where consensus cannot be reached by the appointed members, the members will have recourse to escalate the matter to the executive management of their respective organizations.

   Meets weekly to discuss a mutually agreed upon agenda.

Appendix B – Terms of Reference for the CYP-C Advisory Committee (CYP-C AC)

1. Background

Beyond the CYP-C Partners Group (i.e., C^{17}, PHAC and CPAC), there are a range of stakeholders with an interest in national enhanced childhood cancer surveillance. The CYP-C Partners Group recognize the potential benefits of creating an opportunity for these stakeholders to understand and inform CYP-C direction and decisions. These stakeholders include, but are not limited to, Provincial/Territorial Cancer Agencies, Provincial/Territorial Cancer Registries, cancer charities, and patient advocacy organizations.

Date Terms of Reference finalized (or amended): *September 13, 2018*

2. Mandate

The CYP-C AC will help guide and promote the program and ensure key stakeholders have an opportunity to understand and inform CYP-C direction and decisions. It will provide guidance to the CYP-C Partners Group on issues relating to childhood cancer surveillance. It will have no decision making authority (beyond the decisions required to make recommendations) or policy making responsibilities.

The CYP-C AC will carry out its mandate in the following manner:

- Provide advice and make recommendations to the CYP-C Partners Group through routine meetings
- Sub-Committees may be established to address specific childhood cancer surveillance areas/issues.
- The CYP-C AC meets twice annually. Ongoing advice may also be provided through targeted teleconferences, email, etc
- CYP-C AC members may participate in sub-committees based on their expertise and interest. Sub-committees will review and address technical, scientific, clinical and public health aspects and when appropriate, prepare recommendations to be discussed by the CYP-C AC. Chair of the sub-committees must be members of the CYP-C AC.

3. Membership –

The CYP-C AC members and ex-officio members are selected by and represent their sponsoring agency/organization who have been selected to provide a broad range of expertise on the many aspects of childhood cancer and/surveillance.

a. Members:

- CAPCA Representative
- CCCR Representative
- Canadian Cancer Society Representative
- Indigenous Representative
- Parent and/or Patient Advocate

b. Ex officio Members:

- C^{17}:
    - Executive Director
    - Chair

- CPAC representative
- POGO Representative
- PHAC:
    - Executive Director, Center for Surveillance and Research or her delegate (e.g., Chief, Maternal Child Youth Health Team)
- CYP-C Management Committee Chair

The CYP-C AC Chair is appointed by the CYP-C Partners Group.
The CYP-C Partners Group in consultation with the CYP-C AC Chair may adjust the number of members as necessary, to ensure the appropriate range of knowledge, expertise, experience and perspectives.

Membership will have knowledge, expertise and experience in the following areas, collectively:

a) Scientific or technical knowledge in childhood cancer and childhood cancer/public health surveillance
b) Specialized expertise in childhood cancer and childhood cancer/public health surveillance
c) Recognition as a leader in the field of in childhood cancer and childhood cancer/public health surveillance
d) Significant experience in areas relevant to childhood cancer and childhood cancer/public health surveillance, such as paediatric oncology; as well as public health, epidemiology and biostatistics (analytical experience)
e) Organizational experience representing practitioners who provide oncology care as well as representing public health in Canada
f) First-hand personal experience as consumers/users of paediatric oncology surveillance information
g) First-hand business knowledge as data custodians or providers
h) Specialized expertise in knowledge translation and government policy
i) Any other relevant background that will bring useful input to the CYP-C AC and complement the knowledge, expertise and experience of other members

Membership should include, but is not limited to, people with the following backgrounds:

- Scientists, researchers, academics and individuals with specialized expertise
- Health professionals including those with practical and clinical experience
- Experts professionally recognized in their fields
- Consumers of paediatric oncology surveillance information

The Secretariat for this committee will be provided by the C^{17} Surveillance Coordinator who will attend all CYP-C AC meetings.

c. Term of Membership

To help ensure a range of expertise, experience and perspectives, organisations will be asked to appoint their representatives to the CYP-C AC for a period of 3 years. Membership will be reviewed on an annual basis by the Chair and the CYP-C Partners Group to ensure continuity. Should the CYP-C AC membership increase substantially, the Chair and the CYP-C Partners Group will consider implementing a systematic rotation of membership.

The Chair is appointed by the CYP-C Partners Group for 3 years, with the option of renewal for another 2 years. The performance of the Chair will be reviewed by the CYP-C Partners Group annually to ensure that all duties are being fulfilled and to ensure systematic rotation of responsibility.

d. Resignation Process

A member may resign from the CYP-C AC by providing written notice to the Secretariat and Chair. It is preferable for a member to provide 14 days' notice of the intent to resign. The letter should state the effective date of the resignation.

e. Reasons for Termination

The CYP-C Partners Group may end a member's appointment for a variety of reasons including: the member's term is complete; the mandate of the CYP-C AC has been completed; the CYP-C AC's mandate has changed, thus requiring a different membership, etc. The CYP-C Partners Group may also end an appointment if a member has not acted in accordance with the Terms of Reference. Examples include if a member breaches his/her confidentiality obligations, or misses multiple meetings without a satisfactory reason. The CYP-C Partners Group will notify a member in writing about the termination and will provide the member the reason why the appointment is being concluded and the date of termination.

4. Roles and Responsibilities of Members

Members of the CYP-C AC have a responsibility to the CYP-C Partners Group to consider all input received that is related to the mandate of the external advisory body. Voting members may include provincial and territorial employees who are chosen for their expertise and are not representing their province or territory.

Other responsibilities include, to:

a) be available and prepared to participate in CYP-C AC meetings, including face-to-face and Internet meetings; email exchanges; conference calls; and, videoconferencing
b) participate in the discussions on the external advisory body's recommendations, advice, or report to PHAC
c) participate in working groups established to address specific technical areas/issues

a. Chair

A member of the CYP-C AC who serves as the Chair has additional responsibilities, including, to:

a) Chair CYP-C AC meetings
b) Invite members to make a presentation at a meeting, when relevant and appropriate
c) Facilitate a full and frank discussion among CYP-C AC members in fulfillment of the external advisory body's mandate, including in formulating its recommendations, advice, or report to PHAC
d) Seek consensus on the CYP-C AC advice among all external advisory body members, and if there is not agreement, ensure that this diversity of opinion is noted in the meeting records or report
e) Ensure the preparation of the meeting records or report and the delivery of the CYP-C AC's advice to the CYP-C Partner's Group
f) Support in any other way, the fulfillment of the external advisory body's mandate.

b. Secretariat

The Secretariat is housed in the C[17]offices. It is the administrative liaison between CYP-C AC members and the CYP-C Partners Group and is a resource for members. The Secretariat works closely with the Chair, the CYP-C Partners Group and other working groups and communicates the CYP-C AC advice to the CYP-C Partners Group.

In addition, the responsibilities of the Secretariat include to:

a) Coordinates the member appointment process
b) Prepares materials for CYP-C AC members and meetings, observers, and others, and coordinates the timing of their distribution
c) Assists with the work of the CYP-C AC, as required
d) Provides administrative support to CYP-C AC members
e) Supports public access to information regarding the CYP-C AC, as appropriate
f) Acts as a liaison between PHAC and the advisory committee members, including seeking input from PHAC's scientific, technical, programs, and policies subject-matter experts
g) Assists the Chair in carrying out his/her responsibilities
h) Carries out any additional duties as appropriate to support the CYP-C AC
i) Undertakes any tasks delegated to it by the PHAC

c. Affiliations and Interests

CYP-C AC members are expected to conduct themselves in an appropriate manner, i.e., the use of their positions cannot be reasonably construed to be for their private gain or that of any other person, company, or organization. Members must refrain from any real or perceived conflict of interest and declare any perceived conflict of interest at the beginning of each meeting.

As a condition of appointment, CYP-C AC members will be required to submit a Summary of Expertise, Experience and Affiliations and Interests Declaration Form (the Disclosure Form) to the Secretariat before commencing membership on the CYP-C AC and must disclose in the Disclosure Form any circumstances that may place, or be seen to place the member in a real, apparent or potential conflict of interest. Interests that are required to be declared include significant financial interests, business and professional interests and intellectual interests.

Members must update the Disclosure Form in writing whenever their situation changes. The CYP-C Partners Group will review Disclosure Forms and on an ongoing basis, at least on an annual basis, as well as any time the CYP-C AC mandate is changed.

Disclosure should be made at the earliest possible time, and, in any event, prior to any discussion and decision-making on the subject matter. In situations where conflict of interest or the appearance thereof arises in the course of the work of the CYP-C AC the individual member involved must declare the existence of the conflict of interest and may be required to disqualify himself/herself from participation in the discussions on that subject matter, or from further participation on the CYP-C AC depending on the circumstances.

Any disclosure and measures taken in connection with a real, potential or apparent conflict of interest should be recorded in the record of any meeting in which the disclosure is made or measures taken.

Completed Disclosure Forms will be treated as confidential information and will be kept on file by C[17]. However, as a condition of membership, CYP-C AC members will allow the CYP-C partners to publish on

its Website a Summary of Expertise, Experience, and Affiliations and Interests Declaration, which will be based on the completed Declaration Form. The CYP-C AC members will be asked to review the content of the Summary for accuracy before its release.

d. Confidentiality

The Chair and members of the CYP-C AC (as well as any observers or invitees if applicable) will be required to sign confidentiality agreements. The CYP-C AC members are expected to hold in confidence and not disclose any confidential information obtained as a result of their participation on the CYP-C AC except as permitted under the terms of the confidentiality agreement. Confidential documents will be identified and designated appropriately.

The C[17] Surveillance Coordinator will mark information according to the level to which it is protected under the Policy on Government Security (www.tbs-sct.gc.ca/pol/doc-eng.aspx?id=16578).

The Chair will ensure that everyone participating in the meeting, telephone discussion, email exchange, or in another form of communication has received clear instructions on the confidentiality of the proceedings.

e. Security clearance

Members are not required to undergo a security clearance as a condition for appointment to this committee.

f. Legal Assistance and Indemnification

PHAC undertakes to provide volunteer members with protection against civil liability provided the volunteer member acts in good faith, within the scope of the CYP-C AC mandate, does not act against the interests of the Crown and does not have available to him/her such protection.

The volunteer member shall give prompt notice to PHAC of any claim, action, suit or proceeding brought against the member. If the volunteer member is eligible for protection against civil liability, PHAC must consent to the legal counsel selected to represent the volunteer member and any associated costs, or PHAC will not provide coverage to defend the claim, action, suit or proceeding. PHAC will, at its own expense, participate in the conduct of the defense of any such claim, action, suit or proceeding, and any negotiations for the settlement of the same. PHAC shall not be liable to indemnify the member for payment of any settlement, unless it has consented to the settlement.

g. Travel and expenses

Members serve as volunteers and are not remunerated for their services. Members will be reimbursed for expenses incurred on approved travel to attend CYP-C AC meetings, such as transportation and accommodation, in accordance with Government of Canada policies, including the Treasury Board's Directive on the Management of Expenditures on Travel, Hospitality and Conferences https://www.tbs-sct.gc.ca/pol/doc-eng.aspx?id=27228

5. Media and communications

All media requests related to the CYP-C AC should be directed to PHAC Communications and responses will be coordinated by PHAC.

When appropriate, the PHAC or other CYP-C partners may request the Chair or a member of the CYP-C AC to address a question raised by the media. The media request must first be directed to the Agency's Communications Directorate or the Secretariat, and the Agency must decide to ask a member of the CYP-C AC to respond to the question. The Agency will provide guidance to the member on how to address the question.

If committee members are asked a question by the media that relates to the mandate of the CYP-C AC, committee members may respond to the question in their personal/professional capacity (for example, an academic professor may speak about his/her research). Committee Members must avoid expressing any opinions on behalf of the CYP-C AC or PHAC, or providing information that would be considered Confidential Information under the Confidentiality Agreement. Committee members may also, in their personal/professional capacity, speak to information that has been published by PHAC, CYP-C and/or CYP-C researchers. If asked by the media to discuss the CYP-C AC or discuss how the CYP-C AC has examined certain issues, committee members should refer the media to PHAC Communications or the Secretariat.

6. Management and Administration

a. Meetings

The CYP-C AC will have regular meetings to discuss key and emerging issues relating to childhood cancer surveillance.

i. Meeting frequency and location

It is anticipated that two meetings a year will be held, of which one will be a face-to-face full committee meeting and one will be a teleconference. Efforts will be made to hold the meeting in conjunction with an existing meeting (e.g., C^{17} or CCCR) for cost savings measures as this meeting will be included in the funding provided by PHAC. All travel is according to the Treasury Board Guidelines. Additional meetings of the CYP-C AC may be held on an as-needed basis at the discretion of the Partners Group, in consultation with the Chair.

Working groups may meet more frequently by teleconference, when necessary.

ii. Meeting Attendance and invitations

Meetings may be limited to CYP-C AC members only or may be opened to other CYP-C Partners Group staff, presenters, and observers by invitation. Meeting invitations will be sent out by the Secretariat.

iii. Meeting agendas

The Partners Group, in consultation with the Chair and with input from the members, sets the meeting agenda, including identifying questions and issues for discussion. The Secretariat will strive to canvass members for relevant agenda items in a timely manner, and at least two weeks before regularly scheduled meetings.

Members will generally receive the agenda, briefing material and presentations one week before a meeting.

For teleconferences and other similar meetings, members must make every effort to ensure that a secure line is used and that no one else can listen to the proceedings unless the person has been previously approved by the Chair and Secretariat.

iv. Deliberations and Reports

Yearly reports of the CYP-C AC are required. Advice and guidance from the CYP-C AC will be provided to the CYP-C Partners Group in the form of formal reports, meeting minutes and/or records of proceedings. Such documents summarize the proceedings to effectively reflect the advice offered. Remarks are not attributed to individuals in the records of proceedings. Records of proceedings will be prepared by the Secretariat and circulated to members for review and confirmation. Minutes/records of proceedings may be posted on PHAC's website.

b. Review

CYP-C Partners Group and the Chair will review the mandate, activities, terms of reference, and relevance of CYP-C AC and sub-committees; at least every two years to ensure that it continues to meet ongoing needs.

Recommendations for improvement will be considered on an ongoing basis. PHAC retains the prerogative to disband the CYP-C AC following any such review.

Appendix C – Terms of Reference for the CYP-C Management Committee (CYP-C MC)

1. Background

The Public Health Agency of Canada (PHAC) conducts national enhanced childhood cancer surveillance through the Cancer in Young People in Canada (CYP-C) surveillance program. Since its inception in 2009, a steering committee (now called the advisory committee), a management committee and a sub-committee of the management committee (CYP-C working group which is being converted to the Partners Group) have supported the program.

Date Terms of Reference finalized (or amended): *September 13, 2018*

2. Mandate

The CYP-C MC makes decisions on behalf of the program based upon PHAC, C^{17} and CPAC perspectives. It will also implement recommendations from the CYP-C AC. It is responsible for providing oversight for data currency and quality, providing clarifications or changes to the data elements, facilitating merger between POGONIS and directly entered CYP-C data, reviewing research proposals and approving all CYP-C products such as reports. It also develops and promotes the Research Champions role. All activities are undertaken with a view to ensure representation from all 17 centres and from a variety of role types including nurses, researchers, CRAs, pharmacists and other allied health staff. Decisions will be made by consensus and, should there be no consensus, by majority vote. This committee meets monthly by teleconference and face-to-face annually.

Ad hoc working groups will be created as needed. Ad hoc groups will be led by a member of the CYP-C MC and appointment will be by the CYP-C MC Chair.

3. Membership

Members are specifically chosen to provide: (1) regional representation across Canada; (2) role representation (physicians, allied health, epidemiologists, and data management); and (3) disease specific expertise.

- C^{17} Surveillance Coordinator
- C^{17} representative
- CPAC representative
- POGO representative
- 3 Pediatric oncologists
- Epidemiologist
- 2 clinical research associates/database managers
- Allied health professional (e.g., nurse or pharmacist)

- PHAC:
    - Chief, Maternal Child Youth Health Team
    - CYP-C Program Manager
    - Chief, Surveillance System and Database Management;

The incoming CYP-C MC Chair will be selected by the CYP-C Partners Group and the outgoing CYP-C MC Chair. The Chair will have the appropriate pediatric oncology, public health and research expertise and knowledge to carry out the necessary work and steer this Committee.

C^{17} and CPAC will be asked to appoint their representatives to the CYP-C MC for a period of 3 years. Membership will be reviewed on a regular basis by the Chair and the CYP-C Partners Group to ensure continuity.

4. Meetings

The CYP-C MC will meet regularly to discuss the operational issues relating to childhood cancer surveillance.

4.1. Meeting frequency and location

It is anticipated that a monthly meeting will be held. Additional meetings of the CYP-C MC may be held on an as-needed basis at the discretion of the CYP-C Partners (C^{17}, PHAC and CPAC), in consultation with the Chair.

Working groups may meet more frequently by teleconference, when necessary.

4.2. Meeting Attendance and invitations

Meetings may be limited to CYP-C MC members only or may be opened to other CYP-C Partners Group staff, presenters, and observers by invitation. Meeting invitations will be sent out by the Secretariat.

4.3. Meeting agendas

Meeting agendas are set by the Chair in consultation with the CYP-C Partners Group, including identifying questions and issues for discussion. Members will generally receive the agenda, briefing material and presentations two days before a meeting.

4.4. Quorum and Voting

The CYP-C MC must have quorum when making recommendations or providing advice to the CYP-C Partners Group. Quorum is one half of the members plus one. The Chair must be present to have quorum.

The CYP-C MC is encouraged to reach a consensus on decisions to implement whenever possible. When a consensus is not possible, the decision will be made by majority rule and the meeting record will reflect the diversity of opinions.

4.5. Deliberations and Reports

Yearly reports of the CYP-C MC are required. Advice and guidance from the CYP-C AC will be provided to the CYP-C Partners Group in the form of formal reports, meeting minutes and/or records of proceedings. Remarks are not attributed to individuals in the records of proceedings. Records of proceedings will be prepared by the Secretariat and circulated to members for review and confirmation. Minutes/records of proceedings may be posted on the CYP-C Partners' websites.

5. Review

CYP-C Partners Group and the Chair will review the mandate, activities, terms of reference, and relevance of CYP-C MC and sub-committees; at least every two years to ensure that it continues to meet ongoing needs.

Recommendations for improvement will be considered on an ongoing basis. Each partner retains the prerogative to disband the CYP-C MC following any such review.

Appendix D – CYP-C Data Elements

1.0 REGISTRATION
- 1.1 PATIENT DEMOGRAPHICS

2.0 DIAGNOSTIC INFORMATION
- 2.1 TIME TO TREATMENT
- 2.2 DIAGNOSTIC RECORD
- 2.3 STAGE
- 2.4 HISTOLOGICAL GRADING AND RISK GROUP
- 2.5 EXTENT OF DISEASE AT DIAGNOSIS
- 2.6 ORGAN TRANSPLANTATION
- 2.7 PREDISPOSING AND GENETIC CONDITIONS

3.0 PATIENT CONTACT AND STATUS
- 3.1 PATIENT CONTACT AND STATUS

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 IF NOT REGISTERED ON A CLINICAL TRIAL
- 5.3 TYPE OF PROTOCOL
- 5.4 PROTOCOL NUMBER
- 5.5 TREATMENT ARM
- 5.6 IF NON-COG TRIAL
- 5.7 DATE TREATMENT BEGAN
- 5.8 PROTOCOL/TREATMENT PLAN STATUS
- 5.9 DATE PROTOCOL/TREATMENT COMPLETED OR TERMINATED EARLY
- 5.10 REASON PROTOCOL/TREATMENT COMPLETED OR TERMINATED EARLY

6.0 CHEMOTHERAPY LIST
- 6.2 TREATMENT AGENTS USED

7.0 CHEMOTHERAPY DETAILS
- 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 TO CURRENT DATE

8.0 SURGERY DETAILS
- 8.1 WAS SURGERY EVER PERFORMED
- 8.2 INFORMATION FOR ALL SECONDARY SURGERIES

9.0 RADIATION DETAILS
- 9.1 WAS RADIOTHERAPY EVER GIVEN
- 9.2 RADIATION START DATE
- 9.3 RADIATION END DATE
- 9.4 INTENT OF RADIATION
- 9.5 TYPE OF RADIATION
- 9.6 RADIATION SITE
- 9.7 TOTAL RADIATION DOSE
- 9.8 NUMBER OF FRACTIONS
- 9.9 MULTIPLE FRACTIONS PER DAY
- 9.10 WAS A 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 HEMATOPOETIC CELLS
- 10.5 NON-CORD BLOOD GRAFT TYPE
- 10.6 CORD BLOOD GRAFT
- 10.7 T-CELL DEPLETION
- 10.8 DATE PRE-HCT CONDITIONING REGIMEN STARTED
- 10.9 TYPE OF TRANSPLANT-RELATED IRRADIATION
- 10.10 TOTAL RADIATION DOSE
- 10.11 NUMBER OF FRACTIONS
- 10.12 MULTIPLE FRACTIONS
- 10.13 RADIATION START DATE
- 10.14 RADIATION END DATE
- 10.15 WAS CHEMOTHERAPY USED AS PART OF THE PREPARATIVE REGIMEN
- 10.16 NON-MYELOABLATIVE TRANSPLANT

11.0 HOSPITALIZATIONS (Inpatient only)
- 11.1 DATE OF ADMISSION