

Atlantic Provinces Pediatric Hematology/Oncology Network Réseau d'Oncologie et Hématologie Pédiatrique des Provinces Atlantiques

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Levels of Care Approach for Hematology/Oncology Care of Adolescents and Children within the Atlantic Provinces

LEVELS OF CARE APPROACH—FOR HEMATOLOGY/ ONCOLOGY CARE OF ADOLESCENTS AND CHILDREN WITHIN THE ATLANTIC PROVINCES

INTRODUCTION

In Atlantic Canada, pediatric hematology/oncology care is shared between the pediatric Sub-Specialty care centres and the child/adolescent's home community. The health care professionals in the child/adolescent's home community are especially involved with the complications and side effects of treatment, school issues, emotional and psychological support, resource support, monitoring of growth and development and provision of routine preventative care. In some home communities, health professionals are responsible for administering chemotherapy. Diagnostic investigations [including surgical investigations] will generally occur at the pediatric hematology/oncology Sub-Specialty care centres. Occasionally, supportive care surgery will be performed in other health care centres. Radiotherapy, for study purposes, will always be administered in a Sub-Specialty centre, however radiotherapy closer to home for non-study purposes or palliative care intent, will be considered on a case-by-case basis. The accepted standard for pediatric hematology/oncology care is participation in an applicable clinical research trial or treatment according to the standard arm of a clinical research protocol or equivalent standard. This care is often complex and demanding.

The balance between the benefits and risks of provision of services at a specific locale [home, community health centre, regional health centre or IWK/Janeway] is critical for optimal outcomes of health care. The Levels of Care approach offers an equitable system wherein the expertise and resources of each health centre can be matched with the expertise and resources required for each phase of care [Investigation, treatment, and supportive care].

It is important that secure linkages be established with and among all the health care centres where an individual child/adolescent may receive care. The Levels of Care approach is built on the supposition that, when needed, Sub-Specialty centres will provide expertise and support to the other centres. The Levels of Care approach supports the treatment of children and adolescents with cancer or serious blood disorder in their home communities within defined and accepted standards of care.

This "Approach" document is a framework for resource assessment and a tool to guide decision-making to ensure that pediatric hematology/oncology care is provided in a safe, effective, multi-disciplinary, family-centered manner, and that children and adolescents will have equitable access to effective, quality services as close to home as safely feasible.

APPHON/ROHPPA levels of care were modeled after previously established levels of care systems [British Columbia Children's Hospital, Pediatric Oncology Group of Ontario (POGO), a draft from River Valley Health Region and from Nova Scotia Health Authority Cancer Care Program. It is built on consideration of the following:

- 1. patient safety
- 2. patient volume
- 3. experience/knowledge/education supports available
- 4. resources required and available
- 5. quality care available
- 6. distance and transportation considerations for patients and their family
 - a. [Adapted from the Capital Health District Authority Health Services Integration Cancer Care Planning Team report, 2001].

The above imply consideration of:

- 1. quality
- 2. access
- 3. sustainability [economies of scale]
- 4. retention [of an interdisciplinary health professional team
- 5. affordability [Adapted from Nova Scotia Department of Health]

Quality care is expected to provide care that is:

- 1. safe
- 2. acceptable
- 3. appropriate
- 4. effective
- 5. efficient
- 6. accessible
- 7. supportive
- 8. confidential
- 9. timely
- 10. culturally sensitive
- 11. participatory
- 12. well communicated [Adapted from IWK Health Centre Quality Plan 2007]

DEFINITIONS

Levels of Care:

Levels of Care is an approach that refers to resources [personnel, knowledge/competencies, facilities, and equipment], needed to provide care to pediatric (child/adolescent) hematology oncology patients safely and effectively. Each level builds on the components of the previous Level of Care, plus the additional components added for that level. The six levels of care are outlined below:

1. Home Care:

It is acknowledged that a significant portion of each patient's care will be undertaken by the child/adolescent and family in their home. At varying stages of the child/adolescent's course of treatment and health, the intensity of care received at home will vary.

2. Physician's Office:

Physician office care will encompass ambulatory care including routine physical examination, regular child/adolescent health monitoring, monitoring for therapy complications and side effects, emotional and psychological support, school re-integration, and provision of supportive care. The child/adolescent and family's home community physician is essential to maintaining continuity of care.

3. Basic Level Care:

Basic level care will generally include low intensity, low risk supportive ambulatory care. It also includes immediate stabilization of a critically ill child/adolescent when necessary and provide or initiate emergency treatment before transferring to a site able to provide more complex care.

4. Intermediate Level Care:

Intermediate level care will include ambulatory, low risk inpatient treatment and supportive care plus administration of intermediate level cytotoxic agents [Appendix II].

5. Advanced Level Care:

Advanced level care will include administration of ambulatory/inpatient intermediate and advanced level cytotoxic agents [see Appendix II], as well as supportive care for these patients including prevention and treatment of oncology and hematology complications and emergencies. Advanced sites will also have personnel able to act as resources for sites where basic or intermediate care is delivered.

6. Sub-Specialty Level Care:

[IWK Health Centre, Janeway Children's Health and Rehabilitation Centre] Sub-Specialty level care will include administration of complex cytotoxic agents [see Appendix II], complex monitoring regimes, supportive care for high-risk patients, administration of radiotherapy and related surgical interventions (see Appendix I – Criteria for Care provided at the Sub-Specialty Level. Sub-Speciality Centres will be care, academic and research resources to other health professionals in shared care centres.

It is expected that some health care centres may be able to provide, for example, <u>intermediate</u> level care for treatment and supportive care and <u>advanced</u> level care for investigation. A child/adolescent's care will be negotiated to provide the most practical sharing of care with other centres based on the resources needed by the child/ adolescent /family for that phase of care [investigation, treatment, or supportive care].

<u>Cancer Care</u>: includes all aspects of care pertaining to the child/adolescent with cancer - for example, all anti-cancer treatments, nutrition, supportive therapy, pain control, palliation and family bereavement support as applicable, patient education, coordinating care, referrals to community agencies, and psycho-social care.

<u>Chemotherapy</u>: includes all cytotoxic agents, hormonal and biological agents used in the treatment of cancer.

<u>Child-friendly Environment</u>: includes attention to environmental child safety [e.g. covered wall plugs, child-proof locked cupboards, etc.], area set aside for play and health professionals able to respond to the needs of the young child and family¹.

<u>Child/family-centred Care</u>: includes recognition that each child/adolescent's family is the constant in her or his life, facilitation of child/adolescent/ family and health professional collaboration in health care, respect for child's/adolescent's/family's individuality and encouraging the design of health care delivery systems that are accessible and responsive to child's/adolescent's/family's needs².

Non-Malignant Hematology Care: includes all aspects of care pertaining to diagnosis ranging from inherited and acquired, and includes red blood cell disorders, marrow failure syndromes, disorders of thrombosis and hemostasis, and defects of the phagocyte system.

Phases of Care:

- 1. Investigation phase of care: Phase of care in which child/adolescent is undergoing investigations [e.g., Lab, diagnostic imaging] prior to diagnosis and may include investigations throughout the course of illness.
- 2. **Treatment** phase of Care: Any care given to the child/adolescent with the goal of treating the specific diagnosis.
- 3. **Supportive** phase of care: All care given to child/adolescent and family to support them with complications of the diagnosis and treatment and care given following treatment phase of care including follow up and long term care and/or palliation.

<u>Shared Care</u>: is collaboration of health professionals in Sub-Specialty centres and home community to make it possible for children and adolescents with cancer or a serious blood disorder to receive safe, effective care as close to home as feasible.

<u>Supportive Care Guidelines</u>: are guidelines developed by clinical experts and approved by APPHON/ROHPPA to guide health professionals providing care for pediatric hematology oncology patients. APPHON/ROHPPA expects that all facilities participating in this care will be aware of and follow these guidelines to provide care that is safe and consistent throughout the Atlantic Provinces.

ROLES OF EACH HEALTH DISCIPLINE SPECIFIC TO APPHON/ROHPPA LEVELS OF CARE

It is imperative that as soon as a child/adolescent is suspected of having a malignancy that contact is made with the pediatric hematologist/oncologist on call to discuss further investigations and approach. It is crucial that initial tumour samples be processed appropriately to ensure accurate diagnosis and staging. The improper handling of a pediatric tumour specimen may ultimately result in an inferior outcome for the child/adolescent. In case of inadvertent removal of a mass, each health care facility or organization, where pediatric surgery is carried out, must ensure appropriate health professionals are aware of the proper processing of the tumour tissue [see Appendix V].

Determining an accurate diagnosis and staging significantly influence long-term outcome, therefore, the standard of practice for pediatric oncology is immediate consultation with the Sub-Specialty pediatric oncology centre to develop the plan for investigation as soon as the diagnosis of a malignancy is considered. All children and adolescents in the Atlantic Provinces will have their diagnostic/ staging investigations done at the Sub-Specialty care centres. The results of these investigations are communicated to the home community care team through the pediatric hematologist/oncologist or family care coordinator's (FCC) initial discharge letter.

It is expected that after the child/adolescent's diagnosis and treatment plan is established, communication, negotiation and documentation for shared care around the course of treatment within each health care discipline will be initiated by the Sub-Specialty health care team and maintained between the home community and the Sub-Specialty centre by each respective discipline throughout the child/adolescent's entire course of treatment and follow-up.

Health professionals must comply with all appropriate federal, provincial, institutional, and Children's Oncology Group [COG] study guidelines for record keeping and documentation.

For all patients, an appropriate primary contact person[s] must be identified at each location where the child/adolescent may receive care. In most circumstances, this would involve a designated person in the disciplines of medicine and nursing, and linkages for pharmacy, nutrition, and psychosocial support.

All health professionals involved in the health care of a child/adolescent with cancer or serious blood disorder will have appropriate contact numbers [including phone and fax numbers].

Pediatric Hematologist/Oncologist:

- Develops a comprehensive treatment plan for each child/ adolescent
- Oversees and directs all chemotherapy regardless of the site of delivery.
- Verifies and signs chemotherapy orders for each patient as applicable
- Is readily available for monitoring complications and for consultation to respond to any questions or to provide additional information as needed
- Participates in and supports educational endeavours for pediatricians/family physicians/ health professionals as needed
- Maintains contact by phone initially with the community pediatrician (or family physician) and provides, on a timely basis, a full discharge summary (or comparable information), protocol information and clear guidelines for care
- Appropriately communicates pertinent patient information to the pediatrician (or family physician) after each visit to the Sub-Specialty centre and clearly indicates the current plan of care (including interval, duration, and assessment of therapy) and identifies specific monitoring/follow-up expected of the pediatrician (or family physician). The method of communication will depend on the urgency for exchange of information, but formal documentation of the information sharing is essential.
- Obtains "Consent for Shared Treatment" and other documentation as might be required by the Children's Oncology Group (COG).
- Provides 24/7 on call coverage for this patient population.

Pediatrician and/or Family Physician:

- Has experience in the care of children/adolescents with cancer
- If not experienced, but willing to care for a child /adolescent with cancer, commits to gaining additional education, information, and support for that care. Education may be provided through 'just in time' telephone consultation as care for individual child/adolescent proceeds. [Note: it is recommended that delivery of cancer care be limited to a small number of physicians to maintain expertise]
- Through an understanding of the child/ adolescent's treatment protocol and roadmap, supervises the portion of the treatment received when the child/adolescent is under her/ his care
- Through an understanding of the chemotherapy [systemic and/or intrathecal] to be administered and knowledge of possible side effects, provides the appropriate monitoring required
- Administers or supervises administration of chemotherapy, provides on-site or immediate response for agents with risk of hypersensitivity and/or extravasation (for Intermediate and Advanced Levels of Care)
- Recognizes and responds to emergency situations such as extravasation and anaphylaxis (for Intermediate and Advanced Care) or fever and neutropenia (for Basic, Intermediate and Advanced Levels of Care)

- Manages chemotherapy-related toxicity within their scope of experience or on the advice
 of the pediatric hematologist/oncologists as applicable, and as dictated by the resources
 available, or appropriately transfers the care of the child/adolescent
- Identifies personal learning needs in relation to providing care to a child/adolescent with cancer and/or serious hematological disorder and their family and participates in applicable pediatric hematology and oncology continuing education; attendance at the annual APPHON/ROHPPA conference, other APPHON/ROHPPA education sessions, and available pediatric hematology or oncology education modules is encouraged and can be arranged.
- Provides documentation of the care delivered locally to the Sub-Specialty care centre, including the results of laboratory tests and imaging, as well as the treatments administered, particularly any chemotherapeutic agents
- Communicates and documents all visits including purpose of visit, assessment, interventions, and outcomes, and forwards the documentation needed for protocol-driven care by mail or fax to the IWK [1-902-470-7208] or Janeway Pediatric Hematologist/Oncologist Fax [1-709-777-4941]
- Contacts pediatric oncologist if questions or problems arise or if patient requires admission or transfer to hospital
- Obtains institutional "Consent for Shared Treatment" and other institutional documentation as required
- Provides any additional documentation that may be required by COG

Nurse:

- Using expertise and/or specialized training, the nurse providing care to the pediatric hematology and/or oncology population identifies personal learning needs and develops and maintains the nursing standards & competencies of their facility's assessed level of care as delineated in the documents "Practice Standards and Competencies for Nurses Providing Pediatric Cancer Care in Atlantic Canada" and "Practice Standards and Competencies for Nurses Providing Pediatric Non-malignant Hematology Care in Atlantic Canada" [Appendix III] Note: In locations where the number of children and adolescents with cancer and serious hematological disorders is small, it is recommended that the delivery of care be limited to a small number of nurses to maintain expertise; if there are nurses who are not experienced, but willing to care for a child/adolescent there must be a commitment to gaining additional education, information and support to provide that care. Education may be provided through 'just in time' telephone consultation as care for individual child/adolescent proceeds, and participation in education sessions and other learning opportunities
- Provides documentation required for shared care
- Participates in applicable pediatric hematology and oncology continuing education including the Association of Pediatric Hematology/Oncology Nurses (APHON) Chemotherapy Biotherapy Provider course, attendance at the annual APPHON/ROHPPA conference, and other APPHON/ROHPPA education sessions is encouraged
- Completes and maintains Chemotherapy Administration Standards and Competencies [Appendix IV]
- Designation as a certified oncology nurse [Certified Pediatric Hematology/Oncology Nurse (CPHON/CPON), or Certified Oncology Nurse (Canadian)/CON(C)] is encouraged
- A case manager at the Sub-Specialty centre (Family Care Coordinator [FCC] at the IWK
 and Provincial Pediatric Oncology Nurse Coordinator at the Janeway) is a registered
 nurse with expertise in the treatment and supportive care of pediatric
 hematology/oncology patients. They act as the key contact for patients and families as
 well as health professionals in the shared care facilities. The case manager provides

the applicable community health professionals with a summary of relevant patient and family information, protocol information and clear guidelines for nursing care. Ongoing communication and documentation of each Sub-Specialty care visit will be provided to the home community and will include purpose of visit, assessment, interventions and outcomes, as well as plan of treatment and supportive care

- At the IWK, case managers will be readily available for consultation as needed from 0800 hours to 1600 hours 1-902-470-8819 Monday to Friday, and at the Janeway from 0800 hours to 1600 hours at 1-709-777-4668 Monday to Friday. At all other times, the pediatric hematologist/oncologist on call may be contacted through the switchboard at 1-902-470-8888 at the IWK, and 1-709-777-6300 at the Janeway
- A Clinical Nurse Specialist [CNS] provides support to the family while the child is an inpatient in the Sub-Specialty facility. The CNS also works with the case managers to assist with support in hospital, community, and school for very complex cases.
- A Nurse Practitioner [NP] works collaboratively to manage the health needs of Hematology/Oncology patients and families (especially in the inpatient setting) who are receiving treatment at the Sub-Specialty Centre. The NP does comprehensive health assessments, diagnoses, and treats health problems, prescribes treatments, and orders and interprets appropriate screening and diagnostic tests. The NP provides consistency in patient care coverage and works with patients who require complex, multi-skilled, collaborative and comprehensive care.
- A Pediatric Oncology Patient Navigator (New Brunswick) is a pediatric nurse with education and experience in children's cancer, who works closely with the healthcare teams at the IWK and home community. They are a source of support and information, and link patients and families to many other resources (social, financial, informational, and psychological) in their home communities. Working with the schools and health care teams they coordinate transitions back to home.
- The home community nurses maintain regular contact with the appropriate case manager and provide comprehensive and accurate data on all visits including purpose of visit, assessment, interventions, and outcomes, and contacts the case manager if questions or problems arise. They also coordinate the details of the care in the shared care settings, including treatment, routine monitoring, and supportive care.

Pharmacist:

- Through an understanding of the child/adolescent's treatment protocol, provides support for the provision of their care
- Understands the medications being used and their side effects provides monitoring required and ensures that appropriate supportive care measures are in place to avoid, minimize or manage such effects
- Provides pharmaceutical care and clinical support (drug information, drug therapy monitoring and review, discharge planning, patient teaching, etc.) as staff and resources permit
- Ensures all personnel involved in preparation and handling of chemotherapy have appropriate training and education; encourages or mandates specialized training, (e.g., chemotherapy preparation and order verification courses) where available to ensure competence, accuracy and safety
- Provides documentation required for shared care
- Assumes responsibility for procurement, storage, safe handling, preparation, dispensing, and disposal of chemotherapy according to established standards and guidelines
- Identifies personal learning needs in relation to providing care to children/adolescents with cancer and/or serious blood disorders and their families, and participates in appropriate

- pediatric hematology/ oncology related continuing education programs; attendance at the annual APPHON/ROHPPA conference, other APPHON/ROHPPA education sessions, and available pediatric hematology or oncology education modules is encouraged
- Sub-specialty clinical pharmacists develop and verify accuracy of pre-printed order sets as outlined by the treatment protocols and reflective of each individual patient's health care needs

In addition, at the Sub-Specialty Centres:

- An in-depth knowledge of COG protocols is required.
- PharmD/clinical pharmacy specialist with understanding of current standards/evidence-based practice.
- Clinical pharmacy technician.
- The pharmacist will initiate contact by phone with pharmacist in community and will
 provide a summary of relevant patient and family information and identify medication
 needs and drug- related issues.
- The pharmacist will provide information on chemotherapy including chemotherapy orders, protocol roadmap and information (for Intermediate and Advanced Levels of Care) and will be accessible for consultation as needed.
 - 1. All involved pharmacists will maintain records of medications issued and contact other pharmacists involved when clarifications are needed.
 - 2. Sub-Specialty centre and home community pharmacist will document all therapy recommendations.

Psychosocial:

Psychosocial Oncology is a specialty in cancer care concerned with understanding and treating the social, psychological, emotional, spiritual, quality-of-life and functional aspects of cancer, from prevention through palliation and bereavement. It is a whole-person approach to cancer care that addresses a range of very human needs that can improve quality of life for children/adolescent and families affected by cancer³

• Psychosocial professionals include Child Life Specialist, Psychologist, Psychiatrist, Spiritual Care Provider/Chaplain, Social Worker, as applicable.

Child Life Specialist:

- Assesses the child's response to hospitalization and illness
- Supports continued growth and development while hospitalized through group and individual programming
- Provides emotional/behavioural preparation for medical procedures and treatments and facilitates coping with health care experiences
- Provides education about specific diseases and treatment in age appropriate language for patients and their siblings
- Advocates for a child/adolescents and families psychological needs and has access to appropriate educational literature for staff and families
- Educates multidisciplinary team members about the developmental/emotional impact of hospitalization and stress; includes supervising students, volunteers and child life interns
- Identifies personal learning needs in relation to providing care to children/adolescents
 with cancer and/or serious blood disorder and their family, and participates in
 appropriate continuing education programs; attendance at the annual
 APPHON/ROHPPA conference, other APPHON/ROHPPA education sessions, and
 available pediatric hematology or oncology education modules is encouraged

 Has received certification as a Certified Child Life Specialist from the Child/adolescent Life Council and has membership in Child/adolescent Life Council

Psychiatrist:

- Specializes in the prevention, diagnosis and treatment of mental, addictive and emotional disorders and. has additional training in the diagnosis and treatment of developmental, behavioural, emotional and mental disorders of childhood and adolescence
- Able to understand the biological, psychological and social components of illness
- Is qualified to order diagnostic laboratory tests and to prescribe medications
- Evaluates and treats psychological and interpersonal problems
- May intervene with individuals and families who are coping with stress crises and other problems of living with cancer and non-malignant hematology disorders
- Provides consultation on a wide range of issues inherent in pediatric oncology, including coping with pediatric cancer, pain and symptom management, medication compliance, neuropsychological effects of disease and therapy, sibling and family relations, bereavement, and care of the dying child/adolescent
- Some of these responsibilities cross over with other psychosocial oncology professionals Identifies personal learning needs in relation to providing care to children/adolescents with cancer and/or serious blood disorder and their family, and participates in appropriate pediatric hematology/ oncology related continuing education programs

Psychologist:

- Addresses the relationship between children's/adolescent's physical, cognitive, social, and emotional functioning and their physical wellbeing, including maintenance of health, promotion of positive health behaviours, and treatment of chronic or serious medical conditions
- Identifies personal learning needs in relation to providing care to children/adolescents
 with cancer and/or serious blood disorder and their family, and participates in
 appropriate pediatric hematology/ oncology related continuing education programs;
 attendance at the annual APPHON/ROHPPA conference, other APPHON/ROHPPA
 education sessions, and available pediatric hematology or oncology education
 modules is encouraged and
- Is a licensed or registered clinical child psychologist

Social Work:

- At time of diagnosis completes a psychosocial assessment for each family
- Provides social work interventions based on psychosocial assessment
- Shares the assessment with appropriate psychosocial liaison(s) in home community (if available and with family's consent)
- Sub-Specialty centre provides ongoing social work expertise in counselling, advocacy and resource for families with cancer by phone or other means when no appropriate community liaison available
- Has access to appropriate educational literature at all levels of care
- Appropriate educational literature shall be maintained by Sub-Specialty social worker

- Identifies personal learning needs in relation to providing care to children/adolescents with cancer and/or serious blood disorder and their family, and participates in appropriate pediatric hematology/oncology related continuing education programs, attendance at the annual APPHON/ROHPPA conference, other APPHON/ROHPPA education sessions, and available pediatric hematology or oncology education modules is encouraged
- Has an active membership in the Association of Pediatric Oncology Social Workers (APOSW) at the Sub-Specialty Level of Care

Spiritual Care Provider/Chaplain:

- Joins with the patient/family in the midst of their lived experience and journey with them over the complete continuum of care
- Focuses primarily on being available to the patient/family in their spiritual, religious and emotional needs
- Focuses on religious resource and advocacy, spiritual distress, helping to build hope, exploring meaning of life concerns, end of life care and bereavement support Identifies personal learning needs in relation to providing care to children/adolescents with cancer and/or serious blood disorder and their family, and participates in appropriate pediatric hematology/ oncology related continuing education programs; attendance at the annual APPHON/ROHPPA conference, other APPHON/ROHPPA education sessions, and available pediatric hematology or oncology education modules is encouraged

Allied Health Professional [radiology and laboratory technologists, physiotherapists, occupational and respiratory therapists]:

- Access, on-site or through other means of communication, to allied health professionals is considered essential to support children/adolescents with cancer and their families (for all Levels of Care)
- Note: it is recommended that delivery of cancer care be limited to a small number of professionals to maintain expertise; if not experienced, but willing to care for a child/adolescent, commits to gaining additional education, information and support for that care
- Identifies personal learning needs in relation to providing care to children/adolescents with cancer and/or serious blood disorder and their family, and participates in appropriate pediatric hematology/oncology related continuing education program
- With signed patient consent to sharing of information maintain contact by phone or other
 means with appropriate professional liaison in community/ Sub-Specialty centre as
 available and provides a summary of relevant patient and family information and
 discusses clear guidelines and/or recommendations for care. If an appropriate local
 liaison is not available, the Sub-Specialty centre will continue to provide relevant services.

Dietician:

- Provides nutritional support through a general understanding of the drugs being used and their side effects and required monitoring
- Provides expertise in the nutritional assessment and appropriate nutritional interventions for children/adolescents receiving care for cancer or non-malignant blood disorders
- With signed patient consent to sharing of information maintain contact by phone or other means with appropriate professional liaison in community/ Sub-Specialty centre as

- available and provides a summary of relevant patient and family information and discusses clear guidelines and/or recommendations for care
- Identifies personal learning needs in relation to providing care to children/adolescents with cancer and/or serious blood disorder and their family, and participates in appropriate pediatric chematology/ oncology related continuing education programs; attendance at the annual APPHON/ROHPPA conference, other APPHON/ROHPPA education sessions, and available pediatric hematology or oncology education modules is encouraged.

HOME CARE

It is understood that each level builds on the criteria from the previous level[s].

Care includes administration of oral cytotoxic agents that may be self-administered or administered at home by a caregiver and do not require hospital services. The requirements and the intensity of care received at home will vary with each child/adolescent and family.

PHYSICIAN'S OFFICE

(Family physician and/or community Pediatrician)

It is understood that each level builds on the criteria from the previous level[s].

It is expected that the child/adolescent family's general practitioner will continue to be involved with care. Because of the complexity or care during active treatment many physicians will be involved with the care of the child/adolescent. Maintaining communication among all care givers will be key to optimal outcomes for the child/adolescent and family.

1. Treatment Phase of Care

Required Criteria:

- A physician (family physician or pediatrician) able to manage the care of a child/adolescent with a serious hematological disease. Care may include early recognition, ongoing assessment, and monitoring in consultation with a qualified subspecialty physician, pharmacist or nurse.
- A physician (family physician or pediatrician) able to support dose adjustment of oral
 cytotoxic agents by a managing physician, in consultation with a qualified sub-specialty
 pediatric hematologist/oncologist, pharmacist or Registered Nurse.

2. Supportive Phase of Care

Required Criteria:

- Able to anticipate and recognize common therapy-related toxicities, assess for, and provide care according to supportive care guidelines
- Able to provide appropriate immunizations and subcutaneous injections when required
- Able to access resources to address a child/adolescent's difficulty adhering to treatment protocol.
- Has a designated person within office for purposes of communication [this person may be the physician her/himself]

- Able to recognize and secure an appropriate means to address the psychosocial support of the child/adolescent and family
- Able to make appropriate referrals to community health resources

BASIC LEVEL CARE

It is understood that each level builds on the criteria from the previous level[s].

In a Basic Level Facility, care may include assessment, monitoring and support of dose adjustment of oral cytotoxic agents by a managing physician, in consultation with a qualified subspecialty pediatric hematologist/oncologist, sub-specialty pediatric oncology pharmacist or subspecialty Registered Nurse with the Beyond Entry Level Competency in dose modification of oral chemotherapy, but does not include administration of parenteral cytotoxic agents. Personnel must be able to initiate and stabilize emergent care (such as febrile neutropenia or bleeds) prior to transfer. The presence of appropriate resources and expertise at a facility **may** permit selected chemotherapy to be administered after approval by the hematologist/oncologist and sub-specialty health professionals, discussion at sub-specialty medical rounds, in collaboration with the APPHON/ROHPPA Levels of Care Coordinator and formal agreement of the responsibility between the centres.

The criteria that are either required or recommended for a BASIC level facility for all three phases of care: **Investigation**, **Treatment** and **Supportive Care** are listed below:

Basic Level Facility Required (✓) Recommended (*)	For Supportive Care (SC)	For Treatment (T)	For Investigation (I)
Physical Facilities			
Child friendly area to isolate child from nosocomial infections.	\checkmark	\checkmark	\checkmark
Personnel			
A family physician or pediatrician in the home community willing to manage the care of a child/adolescent with cancer or a serious haematological disorder which includes:			

Basic Level Facility Required (✓) Recommended (*)	SC	-	-
A physician or pediatrician able to support families in giving accurate oral chemotherapy doses according to the appropriate toxicity/ therapeutic guidelines after consultation with a pediatric hematologist/oncologist, pediatric oncology pharmacist or a sub-specialty oncology Registered Nurse with the Beyond Entry Level Competency in dose modification for oral chemotherapy		√	
A physician or pediatrician to provide ongoing assessment for side-effects or complications of common chemotherapy-related toxicities (e.g. bleeds and febrile neutropenia). (Note that side effects come from all chemotherapy they are taking not just oral.)	√	√	
Health professionals able to provide pediatric care and monitoring such as immunizations, subcutaneous injections, insertion of nasogastric tube, GCSF administration and vital signs monitoring.		✓	
Physician or nurse with 24/7 coverage in emergency department to stabilize patients with oncological emergencies such as febrile neutropenia, initiate treatment and arrange for transfer as necessary.		√	✓
If pediatric palliative care is to be provided, a physician willing to provide care in consultation with local or sub-specialty experts as needed.	✓		
Health and/or psychosocial professionals able to provide family support and assist with arrangements for transfer as required.	√	√	✓
Community Resources for Palliative Care in place	\checkmark		
Pharmacy			
Ready access to pharmacy with antibiotics, anti-emetics, pain medications and other drugs required for provision of basic level care.	√	√	√
Equipment Resources			
24/7 Emergency Department services with basic resuscitation equipment. Basic investigations to ensure child can be transferred safely.	\checkmark	√	√
Lab/DI			
Blood products available for emergent purposes. Able to identify where to find the <i>Guideline to process Initial Malignant Specimens Found Unexpectedly</i> . Able to obtain blood samples from children and transport blood samples to lab for testing if not available on site.	\checkmark	✓	√
Education Certification			
Commitment to 'just in time' education related to pediatric hematology/oncology	√	√	

Basic Level Facility Required (✓) Recommended (*)	SC	Τ	_
Communication Links			
Identification of a primary contact able to forward necessary documentation to the tertiary centre	✓	√	\checkmark

INTERMEDIATE LEVEL CARE

It is understood that each level builds on the criteria from the previous level[s].

At the intermediate level of care a pediatrician will be the designated physician managing the care of a child/adolescent with cancer or a serious hematological disorder in the home area. If a pediatrician is not available; in rare circumstances and on an individual basis an exception could be made. In those cases, a family physician able to care for the child/adolescent with cancer or serious hematological disorder, and committed to gaining additional education, information and support for that care may be the designated physician.

- At the <u>Investigation</u> phase of care personnel at an Intermediate Facility are expected to collaborate with a sub-specialty centre to determine interventions to be done prior to transfer and the timing of transfer.
- <u>Treatment</u> may include administration of any oral cytotoxic agent and Intermediate level parenteral cytotoxic agents [per Appendix II]. This includes chemotherapy that can be given on an outpatient basis or given over less than a 6-hour period including hydration and may require premedication or hypersensitivity monitoring. The presence of appropriate resources and expertise at a facility may permit selected chemotherapy not normally included at an Intermediate level to be administered after approval by the hematologist/oncologist and subspecialty health professionals, discussion at sub-specialty medical rounds, in collaboration with the APPHON/ROHPPA Levels of Care Coordinator and formal agreement of responsibility between centres.
- An Intermediate level facility is not obligated to deliver every cytotoxic agent within their assessed level if it is not felt to be safe.
- For <u>Supportive Care</u> the Intermediate level facility must be able to provide low risk inpatient care for treatment, disease complications and therapy related toxicities, e.g., interventions with intravenous medications, intravenous hydration, blood products, administration of IVIG and enteral nutrition
- Able to treat patients presenting in ED with febrile neutropenia in collaboration with a pediatric hematologist/ oncologist.

The criteria that are either required or recommended for an Intermediate level facility for all three phases of care: **Investigation, Treatment** and **Supportive Care** are listed below:

Intermediate Level Facility Required (✓) Recommended (*)	For Supportive Care	For Treatment	For Investigation
Physical Facilities			
Child friendly area to isolate child from nosocomial infections. [ED/ambulatory care]	\checkmark	√	√
Pediatric Inpatient unit (may be shared) with isolation rooms	\checkmark	\checkmark	
Controlled quiet environment for chemotherapy administration		\checkmark	
Personnel			
A pediatrician (or GP in certain circumstances) able to manage the care of a child/adolescent with cancer or a serious haematological disorder in collaboration with a pediatric hematologist/oncologist and this includes:		✓	√
Supervision of chemotherapy administration and provision of onsite or immediate response for agents with risk of hypersensitivity reactions and/or extravasation		✓	
Managing the supportive care of a child with cancer or a serious hematologic disorder e.g. treating low risk febrile neutropenia. (FN)	\checkmark		
Patients requiring antibiotic monotherapy for FN may be admitted with consultation with a pediatric hematologist/oncologist. A plan to transfer less stable patients requiring double or triple therapy to an advanced or tertiary center.			
Nurses with competencies to access CVADs 24/7	\checkmark	\checkmark	
Nurses with APPHON/ROHPPA established competencies to care for this patient population at the Intermediate level [Appendix III and IV]	\checkmark	\checkmark	
All nurses giving Chemotherapy to this population must have completed the APHON Pediatric Chemotherapy Biotherapy Provider Course		\checkmark	
There must be at least one APHON Provider RN on staff to provide oversite in nursing care in order to admit a patient for supportive care	\checkmark		
Pharmacist/s on site with understanding of chemotherapy and treatment protocols/ roadmaps, able to provide chemotherapy order verification. Able to work collaboratively with the tertiary centre pharmacists and seek just in time learning as needed.		✓	
Pharmacist/s or pharmacy technician/s with direct supervision by pharmacist/s, competent in safe handling, preparation, dispensing and disposal of chemotherapy agents.		\checkmark	
Pharmacists and/or nurses able to provide drug information, monitoring, clinical support and patient teaching.		$\sqrt{}$	
Health and/or psychosocial professionals able to provide family support and assist with arrangements for transfer as required.			✓

Intermediate Level Facility Required (✓) Recommended (*)	SC	Т	_
Access to social worker and/or psychologist able to provide psycho-social support	√	√	
Dietician on site with applicable expertise able to provide nutritional assessment, monitoring and support, including enteral feeds, in liaison with tertiary dietician.		✓	
Personnel			
Pharmacists with understanding in supportive care guidelines	*		
Access to physiotherapy, occupational therapist and respiratory therapist able to collaborate with tertiary colleagues to deliver pediatric care as required.		*	
Pharmacy			
Hospital pharmacy available on site with access to pediatric specific resuscitation drugs and	√	\checkmark	√
Level appropriate chemotherapy (Appendix II) and supportive agents [and IV Phosphate and Magnesium]	\checkmark	\checkmark	
Equipment Resources			
Class II biological hood externally vented, chemo precautions equipment; chemo spill kit readily available; appropriate pumps for chemotherapy administration; rapid access to resuscitation, anaphylaxis and extravasation treatment drugs and equipment		✓	
24 /7 on site ED with pediatric appropriate resuscitation equipment, medications, and dosing and on-site physician; applicable supportive care guidelines and pre-printed orders	✓	√	
Lab/DI			
Guidelines for 'Processing initial malignant specimens found unexpectedly' readily available (on website)	\checkmark		\checkmark
Lab: CBC/diff, BUN, Na, K, creatinine, glucose stat [within 1 hour] if needed; PT PTT, access to fibrinogen test results within two days if needed; uric acid, Ca, Phos, Mg, AST, ALT, bilirubin total and direct, amylase within 24 hours; creatinine clearance.	√	✓	√
Microbiology: aerobic and anaerobic bacterial cultures.	\checkmark	\checkmark	
Blood bank: FFP, CMV safe, irradiated PRBC onsite; access to cryo and on site if caring for at risk patient; CMV safe irradiated platelets within 24 hrs; access to appropriate blood product filters, factor concentrates, IVIG, VZIG.		√	
Blood bank: Access to CMV safe, irradiated platelets and PRBC within 24 hours			\checkmark
Diagnostic Imaging: equipment and personnel able to obtain and interpret pediatric ECGs, chest x-rays, abdominal films, and ultra-sounds – able to adjust to deliver lower doses of radiation for diagnostic imaging tests to pediatric patients.	*	*	*
Able to transmit ECG images to tertiary centre.	$\sqrt{}$	\checkmark	

Intermediate Level Facility Required (✓) Recommended (*)	SC	Τ	-
Communication Links			
Identification of a primary contact - able to forward necessary documentation to the appropriate tertiary centre contact; Designated physician, nursing and pharmacist contact persons at the intermediate centre; contact numbers for other appropriate disciplines; phone and access to fax.	\checkmark	✓	
Institutional Support:			
All Chemotherapy orders originate at the Sub-Specialty Centre		√	
Able to provide institutional policies for chemotherapy ordering, preparation, administration, disposal, management of spills, etc. even if they are borrowed from another institution.		✓	

ADVANCED LEVEL CARE

It is understood that each level builds on the criteria from the previous level[s].

At the advanced level of care, a pediatrician will be the designated physician managing the care of a child/adolescent with cancer or a serious hematological disorder in the home area.

Treatment may include administration of any Intermediate and Advanced level cytotoxic agents [Appendix II]. This includes chemotherapy requiring greater than a 6-hour period to administer including hydration and support, and pre or post hydration requiring overnight admission. It will also include administration of intrathecal cytotoxic agents by a pediatrician (with this expertise) and procedural sedation service provided by an anesthetist. The presence of appropriate resources and expertise at a facility may permit selected chemotherapy not normally included at an Advanced level to be administered after approval by the hematologist/oncologist, sub-specialty health professionals, discussion at sub-specialty medical rounds, in consultation with the APPHON/ROHPPA Levels of Care Coordinator and formal agreement of responsibility between centres. An Advanced level facility is not obligated to deliver every cytotoxic agent within their assessed level if it is not felt to be safe.

The criteria that are either required or recommended for an Advanced level facility for all three phases of care: **Investigation**, **Treatment** and **Supportive Care** are listed below:

Advanced Level Facility Required (✓) Recommended (*)	For Supportive Care	For Treatment	For Investigation
Physical Facilities			
A pediatric inpatient unit with isolation rooms [dedicated pediatric unit preferred].	\	\	
Intensive Care Unit capable of stabilizing a critically ill child/adolescent for transportation to a sub-specialty centre.	✓	√	✓
Personnel			
Pediatricians prepared to manage the care of a child with cancer or a serious hematologic disorder, in collaboration with a pediatric hematologist/oncologist including:		\checkmark	√
Treating febrile neutropenia. The need to transfer unstable patients to a tertiary centre shall be considered on a case-by-case basis	✓		
Treating varicella zoster with IV Acyclovir, in collaboration with a pediatric hematologist/oncologist and/or infectious disease specialist	√		
Managing common complications and oncologic emergencies such as metabolic disturbances or hemorrhagic complications, etc.	✓	√	

Advanced Level Facility	SC	_	_
Required (✓) Recommended (*)			
Onsite supervision of administration of advanced level chemotherapy and ability to provide immediate response and clinical support for hypersensitivity reactions and/or extravasation		✓	
Pediatricians able to administer intrathecal (IT) chemotherapy in consultation with a pediatric oncologist at the sub-specialty centre, as required		✓	
Anesthetist to provide deep sedation/ anesthesia resources to perform LP's and IT chemotherapy administration		√	
Pediatrician on call 24/7	\checkmark	\checkmark	\checkmark
Nurses with APPHON/ROHPPA established competencies to care for this patient population at the advanced level (Appendix III and IV)	√	√	
On-site pharmacist/s able to provide monitoring and consultation about the treatment plan, in collaboration with the Sub-Specialty Centre		\checkmark	
Nurses able to provide one-on-one care, if needed, or arrange transport.	\checkmark		
Social worker and/or psychologist available to provide applicable psychosocial support.	√	✓	\checkmark
Available dietician with applicable expertise in nutritional support of children/adolescents with cancer or haematological disorder Including parenteral feeds, in collaboration with dietician at the sub-specialty centre		✓	
Access to physiotherapy, occupational therapy and respiratory therapist with pediatric experience.	√	√	
Personnel			
Access to a child life specialist (Recommended for Holistic Care)	*	*	*
Pharmacy			
Able to provide pediatric total parenteral nutrition.	\checkmark		
Pharmacy onsite with access to advanced level chemotherapy agents		√	
Equipment and Resources			
24/7 onsite Emergency Department with advanced pediatric appropriate resuscitation equipment, an onsite physician, and access to an on-cal pediatrician 24/7.			
applicable supportive care guidelines and pre-printed orders	✓		
Diagnostic Imaging:			
Nuclear medicine facilities for glomerular filtration rate (GFR) (preferred) or creatinine clearance.	✓		\checkmark

Advanced Level Facility Required (✓) Recommended (*)	၁၄	L	
Wall motion ejection fraction (WMEF) or echocardiogram to determine left ventricular function	√	√	<u> </u>
Experience in pediatric CT scanning, able to adjust to deliver lower doses of radiation for pediatric patients.	*	√	*
Lab:			
Access to bacterial culture on site and fungal culture results in a timely manner	\checkmark	\checkmark	√
Blood Bank: access to CMV safe, irradiated platelets and PRBC for transfusion within 12 hours.	√	\checkmark	\checkmark
Education/Certification			
Commitment to ongoing education related to pediatric hematology oncology	\checkmark	\checkmark	
Experience and education applicable to advanced level of care.	\checkmark	\checkmark	
Communication links			
Designated contact persons for dietician, child life specialist, social work and/or psychology at the advanced centre		*	
Institutional Support			
Local Institutional policies for oral and parenteral chemotherapy ordering, preparation administration, disposal, management of spills etc.		<u> </u>	

SUB-SPECIALTY LEVEL CARE

It is understood that each level builds on the criteria from the previous level[s].

A Sub-Specialty centre must be a Principal Investigator Institution within the Children's Oncology Group⁴Treatment at the Sub-Specialty facility includes administration of any level cytotoxic agents [Appendix II]. This level initiates all new chemotherapy protocols/regimens at diagnosis and relapse, and new chemotherapy cycles of a protocol, also all phase I and II drugs as restricted by NIH/NCI.

The Sub-Specialty centre provides pediatric surgery for diagnostic, therapeutic and supportive care and provides radiation, both therapeutic and palliative. The Sub-Specialty facility is also able to provide complex monitoring and supportive care [Appendix I].

The criteria that are either required or recommended for Sub-Specialty facility for all three phases of care: **Investigation**, **Treatment** and **Supportive Care** are listed below:

Sub-Specialty Level Facility Required (✓) Recommended (*)	For Supportive Care	For Treatment	For Investigation
Description/Physical Facilities			
Availability or access to full spectrum of investigations required for an accurate and timely diagnosis			√
In-patient and ambulatory care areas with negative and positive isolation capabilities	\checkmark	\checkmark	
Physical Facilities			
Sub-Specialty care Pediatric Emergency Department services with pediatric appropriate resuscitation equipment available on- site 24/7	✓	\checkmark	✓
Pediatric Intensive Care Unit; pediatric operating rooms	✓	\checkmark	
Personnel			
Pediatric hematologist/oncologists who develop a comprehensive treatment plan for each child/adolescent, available 24/7	<	✓	\checkmark
Pediatric expertise/specialists in general surgery	\checkmark	\checkmark	\checkmark
Pediatric orthopedic surgery, neurosurgery, plastic surgery, nephrology, urology, and availability of anesthetists and surgeons with expertise in the management of children and adolescents with cancer or serious blood disorder		✓	
Radiation oncologists with experience and expertise in the treatment of children and adolescents with cancer	√	√	
Pediatric pathologists, hematopathologists, neuropathologists			\checkmark
Pediatric diagnostic imaging specialists			\checkmark
Pediatric nurses with additional education and expertise in the management of children/adolescents with cancer or non-malignant hematologic disorder	\checkmark	√	✓
Registered Nurses (RNs) with APPHON/ROHPPA established competencies to care for this patient population at the Sub-specialty level (Appendix III and IV)		\checkmark	
Family Care Coordinators or Provincial Pediatric Oncology Nurse Coordinator (RNs)to act as key contacts and case managers for each patient diagnosed with an oncological or hematological disorder		\checkmark	
Pediatric psychologists	√	\checkmark	\checkmark
Pediatric neuropsychologists	\checkmark		

Sub-Specialty Level Facility Required (✓) Recommended (*)	SC	-	_
Social workers who have membership in the Association of Pediatric Oncology Social Workers (APOSW) and who have additional education and expertise in the management of children and adolescents with cancer or serious blood disorder	√	✓	✓
School intervention/education support personnel,	\checkmark		
Pediatric sub-specialists in nephrology*, anesthesiology**, rehabilitation*, clinical genetics*, dermatology*, immunology*, infectious diseases*, rheumatology*, gastroenterology*, neurology*, endocrinology*, and psychiatry*	✓		
Clinical pharmacists** with expertise in anti-neoplastic agents and therapies for serious hematologic disorders	\checkmark	\checkmark	
Dieticians** with expertise in the nutritional requirements of children and adolescents with cancer or serious hematologic disorder	\checkmark	√	
Physical therapists**, occupational therapists** and respiratory therapists** with expertise in pediatric oncology and hematologic disorders	\checkmark	\checkmark	
Home health care professionals* with the ability to provide supportive care to children and adolescents with cancer or serious hematologic disorder	\checkmark		
Clinical research associates** with expertise in data management support of cooperative research		\checkmark	
Certified child life specialists who have membership in the Child Life Council (required for holistic care)	\checkmark	√	✓
Pharmacy			
Medications for a broad range of treatment and supportive care	\checkmark		
Expertise in chemotherapy agents and therapies for serious hematologic disorders. Pharmacy capable of accurately and safely preparing, dispensing, and documenting administration and disposal of investigational medications.		✓	
Equipment and Resources			
Hematopoietic stem cell transplant service*		\checkmark	
Regularly held Tumour Boards** to discuss treatment planning		\checkmark	
Data collection and transfer systems** to support clinical research trials		√	
Membership in an international cooperative clinical trials group**		\checkmark	
Radiation therapy equipment designed for state-of-the-art treatment of children and adolescents*, including rotational linear accelerator*, dedicated radiation simulator or CT simulator*, anesthetic resources for sedation when needed		✓	
Services for dialysis for children and adolescents*	$\sqrt{}$		

Sub-Specialty Level Facility Required (✓) Recommended (*)	SC	-	_
Services for cytopheresis and plasmapheresis*	\checkmark		
Provision of psychosocial and supportive care as per treatment plan**	\checkmark		
Pain management program and guidelines**	\checkmark		
Rehabilitative services**	\checkmark		
Palliative care/ bereavement follow-up services**	\checkmark		
Long-term follow-up and transition services*	\checkmark		
Pediatric dental services*	\checkmark		
Procedural deep and conscious sedation services provided by an anesthetist*	√		
Lab/Diagnostic Imaging			
Diagnostic Imaging with pediatric expertise for US, CT scanning, nuclear medicine, MRI, angiography, and interventional radiology	\checkmark	\checkmark	\checkmark
Clinical laboratories with expertise in the assessment and diagnosis of pediatric hematology/oncology disorders including cell flow cytometry, bone marrow aspirate and biopsy histological analysis, immunohistochemistry, cytogenetic analysis, hemoglobinopathy diagnosis by protein and molecular methods, specialized coagulation testing, specialized analysis of immune function, microbiology/virology services and clinical chemistry expertise in monitoring antibiotic, antineoplastic and immunosuppressant drug levels, blood gas, routine chemistry, hematology and coagulation assays on small samples, immediate interpretation of infectious organisms stains, histopathology	✓	√	✓
Anatomic pathology services with ability to perform and interpret rapid frozen sections, ability to appropriately prepare tissue for complex investigations			✓
Pediatric expertise in audiology, EEG, and ECG testing and interpretation	\checkmark	√	\checkmark
Education/Certification			
Tertiary education qualifications and maintenance of ongoing education to support the expertise required in sub-specialty care; support of educational endeavors for other health professionals as needed.		✓	✓
Communication Links			
Established community links. Designated contact persons for all involved disciplines; able to forward necessary communication to appropriate health professional in the community in timely manner		✓	✓
Institutional support			
Local institutional policies for chemotherapy ordering, preparation, transporting, administration, disposal, management of spills, management of body fluids, etc.		✓	

APPENDIX I

Criteria for Care Provided at the Sub-specialty Level

All pediatric oncology patients should have their diagnosis and treatment plans established at a sub-specialty level facility. Patients usually receive their initial treatments at the sub-specialty facility before treatment with a shared care center is established. In addition, a pediatric patient must have care at a sub-specialty site if:

- Child less than 1 year of age.
- Children/adolescents diagnosed with Acute Lymphoblastic Leukemia on a 3-drug induction: hospitalize or keep near the sub-specialty level facility until day 8 and peripheral circulating blasts cleared; then, consider sending home if the patient is stable [afebrile for least 48 hours, with negative cultures and no mucositis or other foci of infection] and there are services within 45 minutes of home at an advanced level facility; otherwise, stay close to the sub-specialty level facility until count recovery.
- Children/adolescents diagnosed with Acute Lymphoblastic Leukemia on a 4-drug induction (or re-induction if post relapse) hospitalize until day 8 and no peripheral circulating blasts; keep near the sub-specialty level facility until day 15; then, consider sending home if the patient is stable [afebrile for at least 48 hours, with negative cultures and no mucositis or other foci of infection] and there are services within 45 minutes of home at an advanced level facility; otherwise keep close to the sub-specialty level facility until count recover. All patients with relapsed disease receiving re-induction chemotherapy.
- Children/adolescents with serious co-morbidities/organ dysfunction.
- Post-bone marrow transplant children/adolescents; allogenic less than 100 days post and autologous less than 60 days post.
- Children/adolescents who have experienced toxicity beyond that which is expected may need to initiate subsequent treatment at a sub-specialty level facility.
- Children/adolescents on severely myelosuppressive protocols [expected greater than 7-10 days of severe neutropenia].
- Any agent requiring drug serum level monitoring. Biological or chemotherapeutic agents which require the resources of a sub-specialty centre (e.g., some phase I and phase II agents).
- All investigational agents
- Patients receiving continuous 24-hour chemotherapy/biotherapy infusions require care by an APHON provider. Therefore, 24-hour infusions will generally be given at a sub-specialty centre, however, if there is no special monitoring (i.e., levels, study requirements) these infusions maybe considered on a case-by-case basis for Advanced centres with overnight presence of APHON providers.
- Children/adolescents with complex chemotherapy regimens, monitoring requirements or supportive care needs.
- All children with underlying immunodeficiency including Down's syndrome, Common Immune Variable Deficiency (CVID) etc.
- Children/families requiring concurrent psychosocial services not available at a regional centre.

APPENDIX II

Chemotherapy/Biotherapy Agents Given at Each Level of Care

Any agents not appearing on this list will be assessed and categorized by the IWK/Janeway Hematology/Oncology Groups as required. This list does not include oral chemotherapy which are at the discretion of the treating oncologist).

All agents that are identified as investigational in a clinical trial must be administered at the IWK/Janeway, even if they appear on this list.

Agent	Intermediate Level Hospital	Advanced Level Hospital	Sub-Specialty Level Centre
Alemtuzumab	No	No	Yes
Anti-thymocyte globulin (ATG)	No	No	Yes
Arsenic Trioxide	Yes	Yes	Yes
Asparaginase (E.Coli) [Pegaspargase/Calaspargase]	Yes*	Yes*	Yes
Asparaginase (Erwinaze/Rylaze)	Yes	Yes	Yes
Azacitidine	Yes	Yes	Yes
Bendamustine	Yes	Yes	Yes
Bevacizumab	Yes*	Yes*	Yes
Bleomycin	Yes	Yes	Yes
Blinatumomab	No	Yes***	Yes
Bortezomib	No	Yes	Yes
Brentuximab vedotin	Yes*	Yes*	Yes
Carboplatin	Yes	Yes	Yes
Carmustine	Yes	Yes	Yes
Cisplatin	No	Yes	Yes
Cladribine	Yes	Yes	Yes
Cyclophosphamide (low dose less than or equal to 1000 mg/m²)	Yes	Yes	Yes
Cyclophosphamide (high dose greater than 1000 mg/m²)	No	Yes	Yes
Cytarabine (low dose)	Yes	Yes	Yes
Cytarabine (high dose greater than or equal to 1000 mg/m ²	No	No	Yes
Cytarabine Intrathecal	No	Yes	Yes
Dacarbazine	Yes	Yes	Yes
Dactinomycin	Yes	Yes	Yes
Daratumumab	No	No	Yes
Daunorubicin	Yes	Yes	Yes
Doxorubicin	Yes	Yes	Yes
Dinutuximab	No	No	Yes
Etoposide	No	Yes*	Yes
Etoposide Phosphate	Yes	Yes	Yes
Fludarabine	No	No	Yes
Gemcitabine	Yes	Yes	Yes

Gemtuzumab ozogamicin	No	No	Yes
Idarubicin	Yes	Yes	Yes
Ifosfamide	No	Yes	Yes
Interferon alfa-2b	Yes	Yes	Yes
Inotuzumab ozogamicin	No	No	Yes
Irinotecan	Yes	Yes	Yes
Methotrexate (low dose)	Yes	Yes	Yes
Methotrexate (high dose greater than or equal to 1000 mg/m²)	No	No	Yes
Methotrexate intrathecal	No	Yes	Yes
Mitoxantrone	Yes	Yes	Yes
Nelarabine	No	No	Yes
Nivolumab	Yes*	Yes*	Yes
Rituximab	Yes*	Yes*	Yes
Temsirolimus	Yes	Yes	Yes
Tocilizumab	No	No [%]	Yes
Topotecan	Yes	Yes	Yes
Vinblastine	Yes	Yes	Yes
Vincristine	Yes	Yes	Yes
Vinorelbine	Yes	Yes	Yes

The delivery of all chemotherapy outside of the IWK/Janeway should occur with the agreement of the pediatric oncologist and the local center. Intermediate and Advanced level care hospitals/pediatricians may choose to decline administration of any chemotherapy agent if they believe that they are unable to safely administer and supervise the chemotherapy delivery for whatever reason.

^{*} Give first dose at sub-specialty level center
*** In consultation with sub-specialty level center

[%] dependent on indication

APPENDIX III

Practice Standards and Competencies for the Registered Nurse Providing Pediatric Cancer Care and Non-malignant Hematology Care in Atlantic Canada

Practice Standards and Competencies for Oncology:

www.apphon-

rohppa.com/en/system/files/documents/APPHON LOC oncology nursing practice standards and competencies June.2007 %20final%5B1%5D.pdf

Practice Standards and Competencies for Hematology:

www.apphon-

rohppa.com/en/system/files/documents/APPHON LOC hematology nursing.practice standard s and competencies July.2008 final%5B1%5D.pdf

Contact Information

Atlantic Provinces Pediatric Hematology Oncology Network/ Réseau d'Oncologie et Hématologie Pédiatrique des Provinces Atlantiques (APPHON/ROHPPA) c/o:

IWK Health Centre 5850/5980 University Avenue PO Box 9700 Halifax NS B3K 6R8 (902) 470-7429

or

Janeway Children's Hospital and Rehabilitation Center 4J371-300 Prince Phillip Drive St John's NL A1B 3V6 (709) 777-1887 or (709) 777-4303

APPENDIX IV

Chemotherapy Administration Standards and Competencies

Purpose

To ensure competency of the Registered Nurse administering pediatric chemotherapy in the Atlantic Provinces.

Background

The Canadian Association of Nurses in Oncology/L'Association Canadienne des Infirmières en Oncologie (CANO/ACIO) (2001) describes the nursing roles (Generalist Nurse; Specialized Oncology Nurse; and Advanced Oncology Nurse), and the core competencies required (2001, 2006, and 2011) to provide the care all patients with cancer are entitled according to stated standards. Whether from a generalist or a specialist nurse, patients are entitled to knowledgeable and skilled care, including administration of chemotherapy. CANO/ACIO (2001) also notes that children with cancer are "a population that requires specific attention and a body of knowledge in Atlantic Provinces Pediatric Hematology/Oncology pediatric oncology nursing". The Network/Réseau d'Oncologie Hématologie Pédiatriques des Provinces (APPHON/ROHPPA) (2007) delineates the competencies required to provide the nursing care required by this pediatric population in the Atlantic Provinces.

The Association of Pediatric Hematology/Oncology Nurses (APHON)] states that safe, competent, and consistent administration of chemotherapy and biotherapy to children and adolescents requires specific knowledge and specialized skills (2007, 2011). APHON has developed and maintained a curriculum for pediatric oncology Registered Nurses (RNs), with the overall objective to establish international education and practice standards. The APHON Standard of Practice is: chemotherapy and biotherapy administered to children and adolescents should be provided by RNs who have completed the APHON Chemotherapy and Biotherapy Provider Course and a clinical practicum (APHON, 2011).

CANO/ACIO has developed a *National Strategy For Chemotherapy Administration* (Toolkit) that includes standards and competencies for a RN working in oncology. Additional work is being done to complete an educational resource list for oncology RN's. This document is for both pediatric and adult based practice. In Canada, CAPHOL (Canadian Association of Pediatric Hematology/Oncology Leaders) and CCPHOD (Council of Canadian Pediatric Hematology/Oncology Directors) have made recommendations requiring chemotherapy administration to children and adolescents be provided by RNs who have completed the APHON Chemotherapy and Biotherapy Provider Program.

Therefore, APPHON/ROHPPA chemotherapy administration standards and requirements will reflect both CANO's and APHON's standards and requirements.

Standard:

Chemotherapy and biotherapy administered to children and adolescents in the Atlantic Provinces will be provided by Registered Nurses who have completed the APHON Chemotherapy and Biotherapy Provider Program, have demonstrated clinical competency, and maintained knowledge and competency according to APPHON/ROHPPA specifications.

Competency Requirements

- **1.a** The nurse will demonstrate **knowledge competency** by successful completion of the APHON Pediatric Chemotherapy and Biotherapy Provider Course *The Pediatric Chemotherapy and Biotherapy Curriculum*. The RN will be termed a Pediatric Chemotherapy and Biotherapy Provider (APHON, 2011).
- **1.b** The nurse will demonstrate **continuing knowledge competency** by:
 - Reviewing the APHON Biannual renewal updates provided by APHON
 - Maintaining his/her status as an APHON Pediatric Chemotherapy and Biotherapy Provider with renewal every 2-3 years as required by APHON via an online written exam
 - Participating in continuing education specific to care of a child or adolescent with cancer including administration of chemotherapy and biotherapy is recommended. This could include, but is not limited to, participation in oncology related in-services, workshops, conferences, committees and associations, completion of oncology certification or oncology related university credits, and completion of self-learning projects such as oncology related self-learning packages, and video or article reviews.
- 2.a The nurse will demonstrate initial clinical competency in administering chemotherapy by: Successful demonstration of at least three supervised chemotherapy administrations, to a child, adolescent, or adult. A Chemotherapy Administration refers to the whole process of providing chemotherapy to a patient. This includes patient assessment, education, checking, administering, and safe handling of the agent as well as the ongoing monitoring of the patient while the medication is infusing.
 - Clinical competency must be reflective of the level of care the nurse will provide at his/her institution (APPHON/ROHPPA, 2012), and local institutional policies. The APPHON/ROHPPA Pediatric Chemotherapy Administration Clinical Competency Checklist must be completed in entirety to assess initial chemotherapy/biotherapy administration competencies. Additional learning opportunities may be required to meet all clinical competencies.
 - A nurse who will administer **peripheral vesicants**, either by IV infusion or IV push, must have an **additional supervision** of a peripherally administered vesicant.

Supervision must be by a *competent chemotherapy administration supervisor* at the nurse's institution (or a designated provincial supervisor). A **Competent chemotherapy administration supervisor** is an RN who has completed the APHON Pediatric Chemotherapy Biotherapy Provider course **and** has demonstrated current clinical and knowledge competency based on the *APPHON/ROHPPA Pediatric Chemotherapy Administration Standards and Competencies for Practice and Education* and has at least 2 years of chemotherapy administration experience. Competency will be assessed using the APPHON/ROHPPA *pediatric chemotherapy administration clinical competency checklist*.

Note: It is recognized that some centres have institutional policies that limit who may administer any peripheral or any intravenous push antineoplastic medications or may require extra supervisions of the nurse.

- **2.b** The nurse will demonstrate **continuing clinical competency** by:
 - Completing an annual administration to a child, adolescent, or adult (only if trained for adult chemotherapy administration) supervised by a competent chemotherapy provider or administration supervisor using the APPHON/ROHPPA pediatric chemotherapy administration competency checklist.
 - Each nurse will maintain a record of administrations and achieve a minimum of 20 administrations in a 2-year period, preferably at regular intervals. Administrations may be to a child, adolescent, **or adult** (only if trained for adult chemotherapy administration).
 - Both the nurse and her manager (or designate) should keep copies of the competency records.

Grandfather clause – In the past, RNs with previous pediatric chemotherapy administration education have not been required to complete the APHON Provider course. This clause is no longer in effect. APPHON/ROHPPA has met their goal of having all RNs administering chemotherapy/biotherapy to children/adolescents complete the APHON provider course.

If a nurse has been unable to maintain the demonstration of clinical skills due to low chemotherapy administration volume or other reasons, they may again demonstrate clinical competency by successful completion of at least three supervised chemotherapy administrations. Clinical competency must be shown reflective of the level of care the nurse will provide at his/her institution (APPHON/ROHPPA, 2012), and local institutional policies.

Dose adjustment of oral chemotherapy is a Beyond Entry Level Competency. **Only nurses at a sub-specialty level who have completed the BELC learning program** and have maintained the BELC certification, [or a pediatric oncologist, sub-specialty oncology clinical pharmacist, sub-specialty oncology clinical nurse specialist (Janeway Children's Health and Rehabilitation Centre, St. John's) or sub-specialty oncology nurse practitioner (IWK Health Centre, Halifax)], may make oral dose modifications.

Competency Documentation: Health Centers that provide pediatric chemotherapy administration are expected to maintain documentation of the APHON provider status/renewal and competency achievement/maintenance of all staff who administers chemotherapy.



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Guidelines for the Handling & Processing of Potentially Malignant Specimens from Pediatric Patients

APPHON/ROHPPA supportive care guidelines have been developed by appropriate Atlantic Provinces health professional specialists (physicians, pharmacists, nurses, and other health professionals) using evidence-based or best practice references. Format and content of the guidelines will change as they are reviewed and revised on a periodic basis. Care has been taken to ensure accuracy of the information. However, any physician or health professional using these guidelines will be responsible for verifying doses and administering medications and care according to their own institutional formularies and policies and acceptable standards of care. Unofficial document if printed. To ensure that this printed is the latest version, please check website http://www.apphon-rohppa.com.

1. PURPOSE:

To ensure appropriate handling and processing of **malignant or potentially malignant** pathology specimens from pediatric patients at institutions other than pediatric tertiary care centres.

2. RATIONALE:

There are important differences when handling pediatric specimens in comparison to the standard practices for adult cancer specimens.

The initial handling and processing of pediatric specimens (diagnostic biopsies or primary resections) is crucial to ensure collection of fresh tissue samples for diagnostic, prognostic, and predictive testing; and/or enrollment in clinical trials.

3. PROCESS:

Whenever possible, if malignancy is in the differential diagnosis of a mass lesion in a child or adolescent, **referral to a tertiary-care children's hospital is advised**. Pediatric surgeons and oncologists can help arrange timely work-up and biopsy.

If a biopsy procedure is to be carried out at a site without pediatric pathology services, consultation between local surgeon and/or pathologist with a pediatric pathologist is strongly recommended to discuss appropriate handling of the specimen. If the local pathology laboratory cannot provide appropriate tissue handling of potentially malignant specimens, then surgery should be referred to a site with pediatric pathology services.

Local pathologists should be aware of standard tissue handling recommended by and carried out in pediatric pathology laboratories. In particular, fresh **sampling** of lesional tissue for frozen storage is required.

Specific specimen handling instructions:

- 1. Specimen must be sent fresh/dry (**NOT in formalin or any other fixative**) to the pathology laboratory from the operating room, with cold ischemic time kept to a minimum (less than 15 minutes).
 - a. The laboratory must ensure timely receipt and handling of the specimen by a pathologist or appropriately supervised delegate.
- Touch prep and/or frozen section may be considered by the pathologist to help guide specimen triage or to determine adequacy of sample. Frozen sections may be considered if they will influence intra-operative decisions.
- 3. A portion of the fresh lesional tissue **must be frozen** in a cryovial or another clean sealed receptacle.
 - a. Adjunct methods like liquid nitrogen can be used to aid flash-freezing but are not required.
 - b. Labelled specimen should be placed immediately in a negative 70°C to negative 80°C freezer
 - c. If ultra-low temperature freezer is not available, specimen should be placed on dry ice or in a negative 20°C freezer until it can be transferred to colder storage as soon as possible.
 - d. The amount of tissue reserved for freezing depends on total quantity of lesional tissue available. For example, if multiple core biopsies are received, one entire core should be reserved for freezing. For larger specimens, multiple 0.5 to 1 g aliquots can be stored in separate cryovials. Even if lesional tissue is extremely limited, every effort should be made to save at least one small sample frozen.

- 4. **Optional** sampling of fresh tissue can be considered, depending on specific case, differential diagnosis, and quantity.
 - a. Microbiology cultures: should be considered for all lymph node specimens or whenever infection is in the differential diagnosis; bacterial, mycobacterial, and/or fungal cultures can be performed on fresh sterile samples per local laboratory protocols.
 - b. Cytogenetics (karyotype and/or FISH): karyotype no longer ordered routinely, but preservation of some fresh tissue in RPMI or other culture media may provide options for diagnostic FISH in some cases.
 - c. Flow cytometry: should be considered for all potential lymphomas; handle per local laboratory's protocols.
 - d. Electron microscopy: no longer used routinely; a very small sample (1-2 mm³) can be fixed in glutaraldehyde if available.
- 5. After procuring mandatory sample for freezing the priority is for adequate tissue for microscopic work-up. Tissue can be transferred to an adequate volume of **formalin for fixation for routine processing** and paraffin embedding according to local laboratory standards. Ideal fixation time for most specimens is 24-48 hours.
 - a. It is advisable to divide lesional tissue into multiple blocks in case an entire block is required for diagnostic testing or donation to clinical trials group.

Questions to be referred to:

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- The APPHON-ROHPPA Levels of Care Working Group
- The Cancer Care Nova Scotia Pediatric Site Team
- The IWK Health Centre Hematology/ Oncology Interdisciplinary Council
- Site visit to the Dr. Everett Chalmers Regional Hospital
- The Cancer Care Nova Scotia Levels of Care Steering Committee
- Site visit to Sydney, NS
- The Psychosocial Committee of APPHON/ROHPPA
- The APPHON/ROHPPA Levels of Care Standards Review Working Group [2008]