



# **MARATHON OF HOPE CANCER CENTRES NETWORK CONSORTIUM TERMS OF REFERENCE Atlantic Cancer Consortium**

## **1. INTRODUCTION**

The Marathon of Hope Cancer Centres Network (MOHCCN) unites cancer researchers, clinicians, patients, administrators and other partners across Canada to advance precision medicine research and improve cancer outcomes. The Network facilitates sharing of knowledge and of molecular, clinical and health data and promotes the application of advanced technologies such as genomics, imaging and artificial intelligence (AI) in cancer research and care. Anchored by five regional consortia across all ten provinces, the Network supports national collaboration, aligns investments and drives innovation in cancer care.

Founding consortia from British Columbia, Ontario and Québec initially formed the Network in 2017, with consortia from the Prairie and Atlantic provinces joining subsequently in 2022 and 2023, respectively. Each consortium demonstrated capability in precision oncology research through approved pilot projects funded by the Terry Fox Research Institute and partner foundations.

## **2. PURPOSE AND OBJECTIVE**

This document outlines the terms of reference that govern the activities, responsibilities and governance structure of a Consortium. As the Network continues to grow, the primary purpose of the Consortium is to facilitate collaboration among participating cancer centres in their province(s) to achieve the following objectives:

- i. Foster interdisciplinary and inter-institutional collaborations.
- ii. Facilitate knowledge sharing and dissemination of best practices, enhancing the relevance, quality and consistency of MOHCCN data.
- iii. Align Consortium activities with the Network's broader goals and strategic priorities.

## **3. MEMBERSHIP AND GOVERNANCE**

### **3.1. Membership**

The Consortium consists of representatives from participating cancer centres within a province/region. Each member cancer centre designates at least one representative to serve on the Consortium.



### **3.2. Secretariat**

The Atlantic Cancer Consortium (ACC)'s leadership group - which consists of one co-lead each from Newfoundland and Labrador (NL), Nova Scotia (NS), and New Brunswick (NB), who are supported by the project manager - is designated as the ACC's Secretariat. This group meets regularly and will help coordinate efforts across the Atlantic provinces to invite and provide strategic support and guidance to new Member Sites.

The Secretariat's key responsibilities include onboarding of new members, determining the best strategies for resource sharing, facilitating personnel training, developing workplans, managing case sequencing and bioinformatics analyses, and ensuring effective communication within the consortium and with external stakeholders.

### **3.3. Leadership and Governance**

The ACC is led by Consortium Leads representing Newfoundland and Labrador, Nova Scotia and New Brunswick. The Consortium Leads hold the overall responsibility of planning, managing and running the program's day-to-day activities, and meet weekly to review progress of the overall program and of each node, review timelines and finances, identify, propose and approve any required changes and identify solutions to problems as they arise during the course of the program.

The Consortium creates its own governance structure and may appoint councils and committees as needed. Committees may provide oversight and guidance and may help plan, develop and implement policies and guidelines supporting different aspects of program governance. Committee members can include principal investigators, research scientists, clinicians, project managers, technicians, bioinformaticians, post-doctoral fellows, trainees, community representatives and others.

#### Executive Council

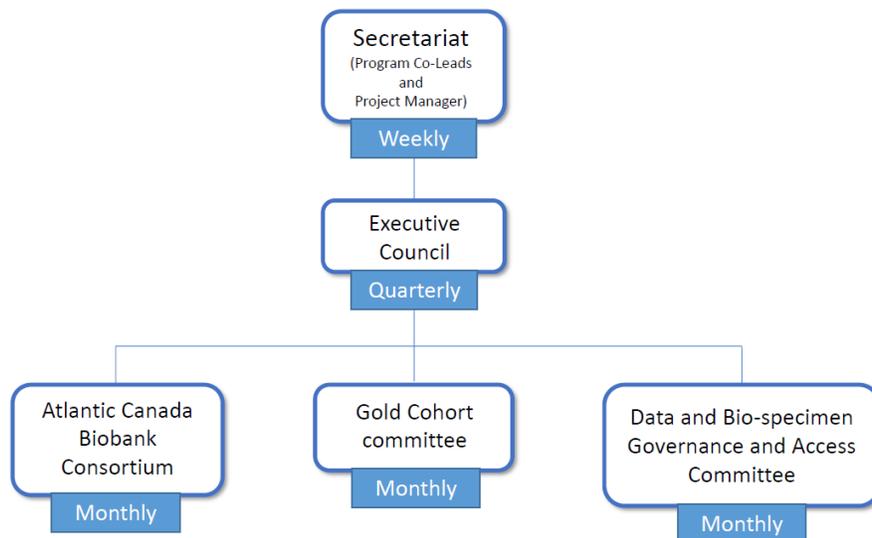
The ACC Executive Council consists of the TFRI Atlantic Node Leader, the Beatrice Hunter Cancer Research Institute (BHCRI) Scientific Director, the four Provincial Leads, the Chief Data Officer, the Biobank Consortium Lead and one community representative. The Executive Council is ultimately responsible for the conduct of the ACC, and is responsible for adhering to timelines and achieving the program's proposed milestones. The council oversees the project's progress, allocation of funds, institutional commitments and sharing agreements, approves any changes to finances or the governance framework and is responsible for conflict resolution.

#### Operational oversight

The following committees ensure oversight of specific operations:



- The *Atlantic Canada Biobank Consortium (ACBC)* includes biobanks in Halifax, Moncton, Saint John and St. John's. The ACBC is responsible for biospecimen and clinical data collection. The ACBC works with the Data and Biospecimen Governance and Access Committee (DBGAC) to provide oversight regarding specimen sharing.
- The *Data and Biospecimens Governance and Access Committee (DBGAC)* oversees issues regarding privacy, ethics, biospecimen access and data sharing. The DBGAC is responsible for the creation and implementation of a coherent inter-institution framework within the ACBC to develop a strong and collaborative biobanking activity in the Atlantic region. This committee is composed of the biobank site leads, bioinformatics site leads, a representative from the Executive Council and an ethics/legal expert. The committee is chaired by a Chief Data Officer and a biobank lead elected by the committee. The committee also liaises with MOHCCN working groups to ensure harmony with MOHCCN national standards.
- The *Gold Cohort Committee* oversees contributing cohorts and projects. Membership includes cohort leads and co-leads and biobank coordinators who facilitate biospecimen collection and processing. A major duty of this committee is to ensure that cohorts do not overlap.



### 3.4. Management and Operations

#### Project Manager(s)

The Project Manager(s) (PM) report(s) to the Consortium Leads and liaise(s) with the Executive Council and other team members to coordinate meetings, monitor budgets, create and maintains records and generate and disseminate progress and finance reports for the ACC, funders and other stakeholders. The PM also facilitates internal and external program-related



communication and works with various committees to ensure any required processes are developed, implemented and adhered to.

### Project Coordinator

The Project Coordinator(s) (PC) report(s) to the Consortium Leads and liaise(s) with ACC team members to coordinate meetings, prepare meeting agendas and packages and document and distribute meeting minutes. The PC also assists the PM in formulating reports and ensuring effective communication within the team.

### Document Management

The PM, under the direction of the Consortium Leads, maintains all documents required for tracking of projects and reporting to TFRI. The PM also maintains minutes and all other documents relating to ACC committees and meetings. ACC members are also required to maintain documents/records related to their cohort/program activities and to report to the Consortium Leads on a timely basis and as required during the course of the program.

### Meetings

The Consortium Lead(s) and the Project Manager(s) meet on a weekly basis to discuss initiatives and day-to-day activities, provide status updates, review upcoming work, set priorities, adjust plans and follow up on action items.

The Executive Council members meet quarterly to track ACC milestones, review budget, funding status and expenses, make informed decisions and resolve any conflicts within the consortium.

The Gold Cohort Committee meets monthly, serving as a platform for all cohort leads/co-leads to provide updates on the status of their cohorts, discuss challenges, and present queries related to their budget, match funds, and other relevant issues. Core facility members also participate to provide updates on the samples they are managing for each site. The overarching purpose is to achieve strategic alignment and ensure the consortium's goals are met in a timely fashion.

The ACBC meets monthly for biobank leads and coordinators to provide updates on their specimen collection, discuss any challenges they are facing in accruing quality samples, and ensure that all specimens are being collected and processed uniformly across all ACC sites.

The DBGAC meets monthly to discuss access to biospecimens, clinical data and molecular data generated by ACC researchers/investigators. The committee also ensure that data generation and ingestion comply with the MOHCCN policy and standards.



### **3.5. New Member Sites**

The Secretariat is responsible for overseeing the process of inviting and onboarding for new Member Sites to join the consortium. This process is initiated with potential site(s) or member(s) contacting the Project Manager with the request to join. Upon receipt, applications are carefully reviewed by the Secretariat, and decisions are made through a consensus-based approach. Successful institutions or members will then be formally invited to join the consortium.

## **4. ROLES AND RESPONSIBILITIES**

### **4.1. Collaboration**

Consortia are expected to promote regional collaboration between Member Sites, and members are expected to work together to advance Network activities within their region.

### **4.2. Technology Sharing**

Members agree to share relevant data and information that would help move MOHCCN deliverables forward. This could include processes related to case generation (sequencing pipeline), clinical data collection (electronic data capture systems) and data deposition (CanDIG instance), while adhering to data privacy and security regulations.

### **4.3. Project Development**

The Consortium may develop and oversee specific projects or quality improvement initiatives to achieve its objectives.

### **4.4. Advocacy**

The Consortium may advocate for policies and resources that support its goals and objectives at the regional, provincial, and national levels.

### **4.5. Knowledge Exchange**

Members will actively participate in knowledge exchange activities to share best practices, innovations, and research findings.

### **4.6. Reporting**

Consortium members are expected to work together to provide to TFRI cohesive bi-annual reports on the Consortium's overall activities and progress using templates provided. Individual cohorts or projects within the Consortium are also expected to provide to TFRI reports specific to their own activities and progress using templates provided. These reports, or elements of them, will also be shared with other relevant stakeholders.



## **5. PROJECTS**

### **5.1. New Cohorts**

Members may suggest the addition of new cohorts at any time. A written proposal of no more than 3 pages, including figures and tables, must be submitted to the Project Manager by email ([accprojman@mun.ca](mailto:accprojman@mun.ca)). The proposal will be circulated to the Consortium Leads and the Atlantic Cancer Biobank Consortium leads for approval. Approval will be contingent on availability of samples to fulfill the MOHCCN Gold Cohort criteria for whole-genome and transcriptome sequencing and the ability to provide matching funds.

### **5.2. Pan-Canadian Projects**

Pan-Canadian projects may be conducted at Member Sites that do not contribute other (cohort) cases to MOHCCN. The Project Manager is responsible for coordinating with participating sites within the Consortium to submit financial reports and update the data dashboard for Pan-Canadian projects with an Atlantic component. The Consortium may provide logistical support on a case-by-case basis.

### **5.3. Research Ethics and Other Considerations**

Each cohort, project or biospecimen-contributing biobank is responsible for ensuring compliance with their appropriate Research Ethics Board. Ethics protocols must include the ability to use and share data according to MOHCCN requirements. Member Sites and Secretariat Institutions may provide further guidance as appropriate.

#### Participant identification and eligibility

Patient participants can include but are not limited to those with primary, recurrent or metastatic disease.

#### *Inclusion criteria:*

- Able and willing to have (or have already undergone) a biopsy or resection of tumour or metastatic site.
- Able and willing to sign (or have already signed) informed consent for tissue/fluid collection, recording of clinical data, and broad use of tissues for future research including genetic studies through either one of the affiliated consortium Biobanks or affiliated projects.

#### *Exclusion criteria:*

- Unable or unwilling to sign informed consent. Exceptions may be made in cases where an REB waiver has been obtained.



Ethics approval must be obtained by each cohort/project lead/co-lead from their local health and research ethics board.

To have samples from Biobank NL sequenced at Centre for Translational Genomics (CTG) local REB approval must be obtained (i.e. at the cohort/project lead's site).

To have samples from Vitalité or Horizon Health sequenced, approval must be obtained directly from these institutions' REBs.

To have samples from NS Health/Dalhousie Biobank sequenced, a request must be made to the Biobank. Sequencing and data sharing to the MOHCCN are covered under the Biobank's HREB. To access the data, the cohort/project lead must have local REB approval for their study and request access from the ACC Data and Biospecimens Governance and Access Committee.

Access to data for secondary analysis may be requested via the Data and Biospecimens Governance and Access Committee.

## **6. DATA**

### **6.1. Genomic Data Generation**

Genomic data are generated at the Atlantic Cancer Research Institute (ACRI) in Moncton, NB and at the Centre for Translational Genomics in St. John's, NL. Sequencing data are analyzed using a standardized protocol for alignment, variant calling, and annotation at the Centre for Analytics, Informatics, and Research (CAIR) at Memorial University in St. John's NL by the Bioinformatics Core of the ACC. All data are collected and processed to MOHCCN standards as outlined in the MOHCCN Gold Cohort Policy.

### **6.2. Clinical Data Collection**

Each biobank is responsible for collecting and/or coordinating the collection of clinical data to complete the MOHCCN Clinical Data Model, in collaboration with the project/cohort in which the patient is included. Due to jurisdictional and institutional differences in clinical data access, each Member Site may have different processes for clinical data collection, curation and ingestion.

### **6.3. Data Ingestion and Sharing**

MOHCCN Gold Cohort data, including genomic and clinical data, must be ingested into CanDIG according to the timelines laid out in the MOHCCN Data Access and Use Policy. The ACC operates a single CanDIG node at CAIR. Clinical data collected by the biobanks at a Member Institution will transfer data exported from their local database to CAIR by secure file



transfer, facilitated by the Bioinformatics Core, for ingestion into CanDIG. Upon ingestion, the transferred clinical data files will be deleted by the Bioinformatics Core.

## **7. DURATION**

### **7.1. Term**

The Consortium's terms of reference are valid indefinitely unless amended or dissolved by its members.

### **7.2. Amendment Process**

Any amendments to these terms of reference must be discussed at a Consortium meeting and then voted on by the Secretariat. The terms of reference and any amendments will be shared with Network Council and made available on the MOHCCN website.

### **7.3. Review Period**

These terms of reference shall be subject to periodic review, at a minimum of every two years, to ensure alignment with the evolving needs and objectives of the MOHCCN and its members across the country.

Approved by Atlantic Cancer Consortium leads:

Sherri Christian  
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Date: **March 20, 2025**

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Associate Professor, Dalhousie University, Halifax, NS

Date: March 20, 2025

Anthony Reiman  
Principal Investigator, Horizon Health, Saint John, NB

Date: **March 21, 2025**