The overarching objective of Canadian Brain Tumor Registry (CBTR) Project is to enhance the Canadian Cancer registry (CCR) and brain tumor research capacity by providing surveillance data on all primary brain tumours (an additional 40% being non-malignant) diagnosed between 2010-2014 to the neurooncology community in an effort to accelerate the research impact of these data. This population-based data will be used to describe cancer burden and trends, design cancer programs and support clinical and population research. Currently, Brain Canada and partners are funding Aim 1 and 2 of the proposed initiative. Project aims and progress towards all aims are summarized below.

Project Aims

Aim 1: Obtain data on non-malignant brain tumours by supplementing registry activities in two provinces. Participating regional registries (AB, BC) will identify and record non-malignant tumors retrospectively.

Aim 2: A first Canadian surveillance report on all primary brain tumours from 5 participating provinces will be compiled and documented. Brain tumour data will be collected from participating registries (ON, MB, QB, BC, AB).

Aim 3: A consensus will be achieved on standards for collecting brain tumour specific registry and clinical data to facilitate surveillance, epidemiological and clinical research.

Aim 4: Develop guidelines for the systematic collection of molecular data in the CCR.

Aim 5: Demonstrate the feasibility of using the surveillance data infrastructure to support clinically relevant research.

Year 1 Progress

Aims 1 and 2:

In Alberta the cancer registry (ACR) was updated with non-malignant brain tumours diagnosed since 2010. This involved reviewing 942 new benign cases identified from an external database (Discharge Admission Database); those that were confirmed primary brain tumours were added to the cancer registry. We are now conducting a quality control project to assess the completeness and quality of this new information. This new

Alberta data will be included in a submission to the CCR in their annual call for data in March 2018. It should be noted that the cost of conducting this new case review was substantially higher than originally budgeted because the numbers of cases were higher than anticipated, requiring more staff time. All primary brain tumour cases occurring in Alberta are now being routinely recorded in the Registry and will be available through the CCR without further external funding.

Data collection in BC started in June 2017, later than originally envisioned due to the delay in the project start date. We anticipate that 2000 new cases will be identified, reviewed and added, as appropriate, to the BC cancer registry for inclusion in the March 2018 CCR call for data. Future registration of all primary brain tumours in BC will be continued as routine practice.

Once Alberta and BC have submitted their new cases to the CCR, we anticipate that four of our five collaborating registries will have complete brain tumour data from 2010-2015. We are awaiting confirmation from Quebec. A research associate, Emily Hastings will be joining this project in August to assist with the creation of a surveillance report (Aim 2) and facilitate collaborative research.

In an effort to coordinate and standardize data collection activities we held a face to face meeting of western collaborators on May 5, 2017 at University of Alberta. This information exchange and discussion of case ascertainment and coding practices identified two larger issues: 1) the need for clarity around a Canadian brain tumor case definition, and 2) the need for coding guidelines to assist in standardized decisions at each registry level. To address the first issue, Angela Eckstrand (AB) is using ACR and CBTRUS data to help us better understand variation in organizational (Canadian Council of Cancer Registries (CCCR) and CBTRUS) definitions of primary brain tumors and how that might impact Canadian estimates of incidence rates. To address the second issue, Cathy MacKay (BC) is drafting a guidance document in collaboration with Cindy Nikiforuk (AB) that will be used in prospective data collection. This document will be

discussed and revised to reflect practices in all collaborating registries, prior to disseminating recommendations to the CCCR.

We elected to have a working group meeting in conjunction with the Brain Tumour Epidemiology Consortium meetings in Banff, June 27-29, 2017. This meeting involved 17 collaborators: all research and registry investigators, clinicians, representatives from Brain Tumour Foundation of Canada and the Public Health Agency of Canada were invited. The intent of this was to create a sense of teamwork and develop project tasks focused on each aim (below), while increasing collaborator knowledge about the field of brain tumour epidemiology. This was the first time some of the team members had met and the level of enthusiasm for moving the project forward was infectious and rewarding.

Aim 3 and 4:

Our working group meeting in June, included presentations from all participants relevant to aims 3 and 4. Discussions allowed us to learn from each other and to develop a consensus around goals for the next year as shown below. A high level of enthusiasm was expressed towards accomplishing these objectives.

Aim 5: Demonstration Project

The intent of this aim is to provide an example of using cancer registry data to address a clinical question. Through conference calls with Jay Easaw and Marchall Pitz we reached a consensus that the original question proposed was no longer relevant so a new question (What evidence do we have from observational data regarding grade 2 and 3 glioma patient outcomes comparing the use of TMZ versus the PVC regimen?) was framed. This proposal was discussed and approved in principle at the working group meeting. We are now preparing a detailed research protocol and beginning the ethics application process for this project.

Goals for year 2:

Aim 1:

- Finish data collection and quality control studies in AB and BC.

- Complete guidelines for standard data collection for presentation to CCCR
- Engage clinicians in the reporting process in their province by demonstrating surveillance data can be used to address clinically relevant questions

Aim 2:

- Have data infrastructure in place for all five collaborating provinces which will allow us to conduct preliminary analysis of tables for a surveillance report
- Work with Public Health Agency of Canada in establishing an agreement for the creation of data tables for a surveillance report
- Expand research around quality control and data quality in all provinces
- Facilitate interprovincial data sharing for new research projects

Aim 3:

- Stimulate clinical and population research using surveillance data
- Develop recommendations for harmonizing data access for cross provincial collaboration
- Facilitate research projects through team discussions at regular conference call meetings

Aim 4:

- Develop position papers on standardized procedures for capturing molecular diagnostics in cancer registry systems as routine practice
- Support CBTRUS (Carol Kruchko) around ICD-0 changes that will facilitate incorporating these markers into current registry systems
- Engage Statistics Canada in a discussion around prioritizing and capturing molecular markers and treatment data.

Aim 5:

- Demonstrate the use of surveillance data to find solutions to a real world example of research need
- Develop a protocol for demonstration project and finish data collection and analysis.