Comparing Pediatric Brain Tumour Physician Databases with the Alberta Cancer Registry

by

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A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Science
in Epidemiology

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Abstract

There is a concern that brain tumours are underreported in the Alberta Cancer Registry (ACR), yet no studies have been performed to investigate this issue. This perception of underreporting has led to the data from the ACR not always being utilized or trusted by physicians, researchers, or operational planners, with them instead relying on physician databases for information on brain tumours.

This study has three main objectives:

i. Evaluate case ascertainment of pediatric brain tumour cases present in physician databases and captured by the ACR.
ii. Compare overall pediatric brain tumour case ascertainment of the ACR and the pediatric physician databases.
iii. Compare the demographic, diagnostic, and treatment information between the physician database and ACR.

Overall, the ACR captured 197 of 205 cases (96%) recorded in the physician databases. Case ascertainment was higher in Edmonton (99%) compared to Calgary (92%). Using the North American Association of Central Cancer Registries (NAACCR) certification criteria to assess case ascertainment, the ACR would receive Gold Certification for their recording of pediatric brain tumours based on case ascertainment higher than 95%.

When assessing case ascertainment of all pediatric brain tumour cases captured by either the ACR or the physician databases from 2004 to 2011, the ACR captured 309 of the 317 cases

(97%) while the physician databases captured 205 of the 317 cases (65%). The higher case ascertainment demonstrated by the ACR was expected as physicians from across the province are mandated to report all cancer cases to the ACR (Government of Alberta, 2015) and the ACR has an entire department of staff dedicated to ensure the collection and proper coding of all cancer cases in Alberta.

When performing case-by-case comparisons of data from the ACR with data from the physician databases, 'age of diagnosis', 'sex', and 'year of diagnosis' showed less than 10% disagreement between data sources. 'Method of diagnosis', 'chemotherapy received', and 'radiotherapy received' showed between 10% to 20% disagreement between data sources. Case-by-case comparisons could not be made for topography and morphology codes as the physician database did not use the same coding system as the ACR.

When reviewing the case breakdown of the physician databases and the cases captured only in the ACR, a few key findings arose:

- A disproportionately larger percentage of patients aged 15 to 17 years old were missed in the pediatric physician databases, possibly due to these patients opting for (or being referred to) non-pediatric physicians to avoid the potentially difficult transition in care once they turn 18 years of age;
- Some cases were missed in the Edmonton physician database during 2004 and 2005 due to their physician database being in its infancy stage;

- The Edmonton physician database missed a disproportionate number of cases which were diagnosed by imaging;
- The lack of a clear brain tumour definition is a major concern and the differences in opinion around what constitutes a brain tumour have led to some discrepancies between the ACR and the physician databases; and
- Patients only captured in the ACR were less likely to have been recorded as having received chemotherapy (21%) compared to physician databases (37%). Similarly, patients only captured in the ACR were less likely to have been recoded as having received radiotherapy (24%) compared to those in the physician databases (38%).

The results of this study show the ACR should be considered a reliable database for physicians, researchers, and operational planners when pediatric brain tumour data are required, however caution should be exercised when using certain information. The findings should also allow the ACR to assess their own coding practices and will hopefully encourage similar studies to be performed in other cancers that are at higher risk of being under-reported.

This study has already had an immediate impact, improving the data quality of the ACR by generating an investigation into the eight cases that were captured in the physician databases yet were missing in the ACR. In seven of the cases, the ACR staff was able to locate the required radiology and pathology reports and register the cases in the ACR. They are continuing to search for information on the remaining case. In addition, the ACR staff is investigating potential variations in topography coding practices between Edmonton and Calgary.

Preface

This thesis is an original work by Christopher Marc Normandeau. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Health Research Ethics Board – Health Panel, Project Name "Comparing Brain Tumour Physician Databases with the Alberta Cancer Registry", No. 47424, September 26, 2014. Research ethics approval was also received through the Conjoint Health Research Ethics Board at the University of Calgary, No. REB15-0028, February 20, 2015.

Acknowledgments

I would like to thank my co-supervisors Dr. Faith Davis (University of Alberta) and Dr. Juanita Hatcher (University of Alberta) for all their assistance and guidance through the writing of my thesis. I would like to thank Dr. Don Voaklander (University of Alberta) and Amanda Shaw (Public Health Agency of Canada) for serving on my Supervisory Committee.

I would also like to thank Dr. Vivek Mehta (University of Alberta) and Dr. Douglas Strother (University of Calgary) for serving as co-principal investigators on this study and allowing me the opportunity to compare their physician databases with the Alberta Cancer Registry. I would like to thank Stacey Hall (Alberta Health Services) and Jeremy Levine (University of Calgary) for compiling, reviewing, and providing the required physician data, along with Janine Walsh (Alberta Health Services) who performed the data linkage of the physician database with the Alberta Cancer Registry.

Finally, I would like to thank my wife Daria for all her encouragement and support throughout the writing of my thesis.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

ACR: Alberta Cancer Registry

AHS: Alberta Health Services

C-MORE: Cancer Measurement Outcomes Research and Evaluation

CBTRUS: Central Brain Tumor Registry of the United States

CCR: Canadian Cancer Registry

CNS: Central Nervous System

I:M: Incidence-to-Mortality Ratios

ICD-O-3: International Classification of Diseases for Oncology, 3rd Edition

NAACCR: North American Association of Central Cancer Registries

NOS: Not Otherwise Specified

ULI: Unique Lifetime Identifier

%DCO: Percentage of Cancers Registered by Death Certificate Only

Chapter 1 – Introduction

1.1 Thesis Statement

This thesis will evaluate case ascertainment of primary brain tumours cases present in physician databases captured by the Alberta Cancer Registry (ACR), specific to the pediatric population. The overall pediatric brain tumour case ascertainment of the ACR and the pediatric physician databases will also be compared. Demographic, diagnostic, and treatment information from the physician databases and the ACR will also be reviewed to assess data quality including comparability and validity.

1.2 Literature Review – Recording Brain Tumours in Cancer Registries

Primary malignant brain tumours are among the most disabling and lethal types of cancer. Although they constitute only about 2% of all cancers, brain tumours are associated with severe disability and a high risk of death (Mao, 1991). In Alberta, 203 patients were diagnosed with brain cancer during 2011. Of the 203 cases, children under the age of 17 years old accounted for 21 cases (10%) (Alberta Health Services (AHS), 2014).

The most common childhood cancer types diagnosed in Alberta from 2008 to 2012 were leukemias (27%), followed by central nervous system (CNS) tumours (23%), lymphomas (10%), neuroblastomas (7%), and soft tissue tumours (6%) (AHS, 2015a). A study performed in the United States of America shows approximately 90% of CNS tumours in children develop in the brain (Gurney, 1992). Since 1992, childhood cancer incidence rates in Alberta have increased while mortality rates have remained stable (AHS, 2015a). The increase in incidence agrees with an American study performed by Patel et al. (2013), which showed an increase in pediatric brain tumours from 1973 to 2008. Potential causes for this increase were thought to include environmental carcinogens, but more research is needed to confirm the factors contributing to the rise in incidence over the years (Patel, 2013).

In terms of reportable brain tumour cases, in addition to all malignant cancer cases, the Canadian Council of Cancer Registries recommends the following tumours should be reported to the Canadian Cancer Registry (CCR) (Government of Canada, 2015):

- Primary, benign tumours of the meninges, brain, spinal cord, cranial nerves and other parts of the CNS (including behaviour codes of 0); and
- Primary, benign tumours of the pituitary gland, craniopharyngeal duct and pineal gland (including behaviour codes of 0, for 2007 and later).

It is important to note that benign brain tumours (behaviour codes of 0) are included as reportable brain tumours. Typically cancer registries do not report benign tumours, therefore the reporting of benign tumours is unique to those of the CNS.

There are many studies that highlight the issues of under-reporting of benign brain tumours in cancer registries (Teppo, 1994; Davis, 1999; Pobereskin, 2001). The CCR contains cancer information from each cancer registry across Canada. While the reporting of malignant tumours is thought to be complete, the reporting of benign tumours is estimated at only 33% of the actual number of cases expected within the country (Shaw, 2014). In a study performed in the United States, Davis et al. (1999) suggests that the exclusion of reporting benign brain tumours in a cancer registry causes all primary brain tumours to be underreported by approximately 40%. A twenty-two year population-based study performed by Rosychuk et al. (2011) assessed the situation in Alberta and showed that 568 children were diagnosed with CNS tumours, of which nearly 82% of the cases were malignant.

These studies highlight the need to gain a better understanding of the case ascertainment of the ACR, as benign brain tumours may be under-reported. In Canada, data on benign brain tumours are not collected by all regional cancer registries which leads to a recognized underestimation of the burden of brain tumours for Canadians (Davis, 2015). The Canadian House of Commons passed Bill M235 in February 2007 (Parliament of Canada, 2015), to create national guidelines for the surveillance of all malignant and benign brain tumours. Since 2007, Alberta aims to collect all benign brain tumours.

1.3 Literature Review – Cancer Registry Case Ascertainment

Cancer registries across Canada have been useful at the regional level for understanding the burden of disease, evaluating trends in disease occurrence, and providing an infrastructure for clinical, epidemiologic and health services research (Davis, 2015). All cancer registries across Canada are members of the CCR and the North American Association of Central Cancer Registries (NAACCR) (Davis, 2015).

NAACCR is a professional organization that develops and promotes uniform data standards for cancer registration, provides education and training, certifies population-based registries, aggregates and publishes data from central cancer registries, and promotes the use of cancer surveillance data and systems for cancer control and epidemiologic research, public health programs and patient care, to reduce the burden of cancer in North America (NAACCR, 2015a). All central cancer registries in the United States and Canada are members, including the ACR. A primary role of this organization is to certify cancer registry data quality and through its evaluation criteria listed below, they set standards by which performance of the registries can be measured.

NAACCR estimates completeness by expressing the observed number of cancer cases as a percentage of the expected number for a given population (Hofferkamp, 2008). Expected age-standardized cancer incidence rate for the sex, region, and year of interest are calculated based on national cancer incidence data and United States cancer mortality data. The observed cancer incidence rate is then expressed as a percentage of this expected incidence rate to estimate the completeness of case ascertainment (Hofferkamp, 2008).

Various other methods exist to estimate cancer registry completeness. One method is to investigate the percentage of cancer cases registered by death certificate only (%DCO). This is a simple way to estimate completeness as a high %DCO suggests incomplete case ascertainment due to failure to capture cases while patients are alive (Zakaria, 2015). Another simple method is to calculate age-standardized incidence-to-mortality ratios (I:M), whereas a ratio below 1.00 indicates under-reporting as there are more cancer deaths than cases recorded (Zakaria, 2015).

However, to assess cancer registry completeness for the purpose of this study, NAACCR's methodology will be used. To receive Gold Certification, a Cancer Registry needs to meet all of the following criteria (NAACR, 2015b):

- Overall case ascertainment has achieved 95% or higher completeness
- A death certificate is the only source for identification of fewer than 3% of reported cancer cases
- Fewer than 0.1% duplicate case reports are in the file
- All data variables used to create incidence statistics by cancer type, sex, race, age, and county are 100% error-free
- Less than 2% of the case reports in the file are missing meaningful information on age, sex, and county
- Less than 3% of the cases in the file are missing meaningful information on race (United States only)
- The file is submitted to NAACCR for evaluation within twenty-three months of the close of the diagnosis year under review

To receive Silver Certification, a Cancer Registry needs to meet all of the following criteria (NAACR, 2015b):

- Overall case ascertainment has achieved 90% or higher completeness;
- A death certificate is the only source for identification of fewer than 5% of reported cancer cases;
- Fewer than 0.2% duplicate case reports are in the file;
- All data variables used to create incidence statistics by cancer type, sex, race, age, and county are 97% error-free;
- Less than 3% of the case reports in the file are missing meaningful information on age, sex, and county; and
- The file is submitted to NAACCR for evaluation within twenty-three months of the close of the diagnosis year under review.

NAACCR Certification for all the provinces and territories awarded in 2012 to 2014 is summarized in the Table 1 (NAACCR, 2015c):

Table 1: NAACCR Certified Canadian Registries List

	Gold Standard (95% Case Ascertainment)	Silver Standard (90% Case Ascertainment)	No Certification
2014	**Alberta** Manitoba New Brunswick Newfoundland and Labrador Northwest Territories Prince Edward Island Saskatchewan Yukon	British Columbia Nova Scotia	Ontario Nunavut Quebec
2013	**Alberta** Manitoba Saskatchewan	New Brunswick Newfoundland and Labrador Nova Scotia Prince Edward Island	British Columbia Northwest Territory Nunavut Ontario Quebec Yukon
2012	**Alberta** Manitoba Saskatchewan Northwest Territories	Newfoundland and Labrador Nova Scotia	British Columbia New Brunswick Nunavut Ontario Prince Edward Island Quebec Yukon

Alberta is one of the few provinces or territories that received Gold Certification in each of the past three years. Further to this, the ACR has received Gold Certification for 16 of the last 17 years (NAACCR, 2015c). This speaks to the high quality of the ACR, as case ascertainment is consistently above 95%.

It is important to note that the certification received is due to achieving overall case ascertainment above 95% and this does not necessarily mean that each tumour-specific site demonstrates case ascertainment above 95%. Through dialogue with ACR staff and brain tumour physicians, there is a feeling that under-reporting of brain tumours in the ACR may be a problem, and case ascertainment is likely less than 95%. No studies have been performed in Alberta to investigate this issue.

A review of literature in North America did not find any similar studies, which highlights a significant gap of knowledge around this topic. European literature pertaining to this topic was reviewed and relevant studies are summarized in the Table 2 (Kaatsch, 2001; Larsen, 2009; Teppo, 2004; Woehrer, 2012; Klint, 2009; Pobereskin, 2001; Counsell, 1997):

Table 2: Review of Literature Pertaining to Cancer Registry Case Ascertainment

Country	Journal Article	Year	Authors	Aim of the Study	Findings
Germany	Population-Based Epidemiologic Data on Brain Tumours in German Children	2001	Kaatsch et al.	To assess the completeness of the German Childhood Cancer Registry.	The level of completeness of patient registration is 95%, but it is somewhat lower for patients with brain tumors. For children with central nervous system tumors, the ascertainment of newly diagnosed patients needs further improvements.
Norway	Data Quality at the Cancer Registry of Norway: An Overview of Comparability, Completeness, Validity, and Timeliness	2009	Larsen et al.	To provide a comprehensive evaluation of the quality of data collected at the Cancer Registry of Norway.	While overall completeness of all cancer sites in the Cancer Registry of Norway was estimated at 99%, tumours of the central nervous system (c70-c72) showed the worst estimation of completeness of all cancer sites with only 94% appearing in the cancer registry.
Finland	Data Quality and Quality Control of a Population-Based Cancer Registry	1994	Teppo et al.	To provide a comprehensive evaluation of the quality of data collected at the Finnish Cancer Registry.	While overall completeness of all solid tumour sites in the Finnish Cancer Registry was 92%, there was an estimated under-reporting of 11% for tumours of the central nervous system.
Austria	Brain Tumor Epidemiology in Austria and the Austrian Brain Tumour Registry	2013	Woehrer et al.	Provide an epidemiological review of brain tumors in Austria.	Cancer registration is only mandatory for malignant brain tumors. No epidemiological data on benign and intermediate neoplasms are available.
Sweden	Cancer Reporting Can Be Improved	2009	Klint et al.	To review the reliability of the Swedish Cancer Registry.	While the reporting of breast cancer and urological cancers showed no problems, under-reporting of up to 10% to 20% was found in the reporting of brain tumors, leukemia, and lymphoma.
United Kingdom (Devon and Cornwall)	The Completeness of Brain Tumour Registration in Devon and Cornwall	2001	Pobereskin et al.	To determine ascertainment rates for primary brain tumours and examine factors influencing those rates when comparing a clinical database with official figures from the Regional Cancer Intelligence Unit.	Under-reporting of brain tumours is a problem as only 52% of 1480 potential cases appeared in the registry. Only two-thirds of patients operated on were registered and less than one-third who were not operated appeared in the registry.
Scotland	Limitations of Using a Cancer Registry to Identify Incident Primary Intracranial Tumours	1997	Counsell et al.	To compare the completeness and accuracy of registration of primary intracranial tumours in the Scottish Cancer Registry with a detailed incidence study performed over a two year period.	Of 228 patients with any primary intracranial tumour in the incidence study, 124 (54%) were identified as intracranial tumours in the cancer registry. The cancer registry therefore significantly underestimated the incidence of all primary intracranial tumours, and of malignant intracranial tumours.

Although literature in this area is limited, the existing studies show that under-reporting of brain tumours is consistently observed when a comprehensive evaluation of a cancer registry is performed. As seen in Table 2, the studies performed in Germany, Norway, Finland, Sweden, the United Kingdom, and Scotland, found under-reporting of brain tumours ranging from 6% to 48%. Counsell et al. (1997) found that common predictors of registration in a cancer registry included patients who received an operation, were 60 years or older, and had a tumour requiring radiotherapy.

Woehrer et al. (2013) highlighted the need to collect data on benign and intermediate brain tumours, as they were not consistently being collected. And while it was focused on haematological malignancies, not brain tumours, a study in Thames (Phekoo, 2002) highlights the disagreement that can be found when comparing physician databases to a cancer registry. This study assessed case ascertainment and diagnostic accuracy of physician databases compared to the Thames Cancer Registry and showed the cancer registry was missing 30% of cancer cases.

This literature supports the concerns expressed by local brain tumour physicians and ACR staff and highlights the need to further evaluate this issue in Alberta.

1.4 Why Is More Work in This Area Necessary?

Brain tumour physicians, health care professionals, and researchers across Alberta (and elsewhere in Canada) need to understand the quality of data in cancer registries so they can evaluate if the data are valid and reliable for research studies and operational planning. Incomplete or inaccurate brain tumour data have a direct effect on the ability of a province to accurately assign health care dollars by region, create centres of excellence for treatment, create efficiencies and plan for the greatest needs. The more that is known about the incidence of all types of brain tumours, will allow for the enormous treatment cost to be planned for, targeted and reduced (Brain Tumour Foundation of Canada, 2015). In addition, cancer registries need to understand the completeness of brain tumour case ascertainment to evaluate their performance and make process improvements, as required.

Through discussions with brain tumour physicians within Alberta, the ACR department, and other cancer registries across Canada, the perception is that brain tumour cases are relatively more difficult to code in a cancer registry than most other types of cancer. While the reporting of all tumours is mandatory in Alberta (Government of Alberta, 2015), it is thought that some brain tumours that are radiologically diagnosed and/or non-malignant tumours may not be captured. Even when the cases are captured, the demographic, diagnostic, and treatment information may not always be completely accurate. There is very little evidence in the literature looking at the completeness and validation of data within cancer registries, and as such, it is not known to what degree this may be a problem in Alberta. As such, pediatric brain tumour physicians are collecting brain tumour information in their own databases so they may have timely and accurate information on all variables that are relevant to them.

Much work was performed on the descriptive epidemiology of brain tumours in the United States of America and suggests that improving the accuracy and standardization of descriptive data will increase the likelihood that rates consistently reflect disease occurrence. Hypotheses based on accurate variations in rates will be more fruitful in directing efforts toward identifying causes of these tumours (Davis, 1999). Furthermore, diagnostic consistency and a high-quality cancer registry data are essential for assessing trends in incidence as well as the impact of current and emerging treatment and diagnostic procedures on patterns of occurrence, recurrence, and survival rates (Castillo, 2004).

To explore this issue further, a definition of what constitutes a brain tumours needs to be established. The International Classification of Diseases for Oncology, 3rd Edition (ICD-O-3) is used by cancer registries to classify brain tumours. ICD-O-3 is a coding system used principally in cancer registries for coding the site (topography) and the histology (morphology) of neoplasms, usually obtained from a pathology report (World Health Organization, 2015). For the purposes of this study, brain cancer was defined using topography codes C70 through C72, C75.1 through C75.3, and C30.0 (with morphology codes 9522 and 9523). This brain tumour definition is from the Central Brain Tumor Registry of the United States (CBTRUS) and it was chosen as it is the most all-inclusive method when compared to using simply the ICD-O-3 brain

cancer topography (C71) or the Public Health Agency of Canada definition (C70 through C72) (Normandeau, 2013).

1.5 Study Objectives and Hypotheses

This study has three main objectives:

Objective #1: Evaluate case ascertainment of brain tumour cases present in physician databases captured by the ACR, specific to the pediatric population.

- **Hypothesis #1:** Based off discussions with subject matter experts and a review of the literature, despite the ACR receiving Gold Certification from NAACCR for the past number of years, our hypothesis is that the ACR will capture 85% to 90% of the pediatric brain tumour cases that the physician databases recorded.

Objective #2: Determine and compare overall pediatric brain tumour case ascertainment of the ACR and the pediatric physician databases.

- **Hypothesis #2:** Based off the review of literature and discussions with subject matter experts, our hypothesis is that overall pediatric brain tumour case ascertainment of the ACR will be around 85%-90%. We expect overall pediatric brain tumour case ascertainment of the physician databases to be lower compared to that of the ACR as physicians from across the province are mandated to report all cancer cases to the ACR (Government of Alberta, 2015) and the ACR has an entire department of staff dedicated to ensure the collection and proper coding of all cancer cases in Alberta. (Government of Alberta, 2015).

Objective #3: Compare the demographic, diagnostic, and treatment information captured in the physician database with the information captured in the ACR to assess data quality and evaluate whether there are systematic differences between the databases. Provincial variances in coding

practices may exist as cancer cases are coded in either Edmonton or Calgary, depending on where the patient received their care.

- **Hypothesis #3:** Our hypothesis is that there will be agreement between the physician databases and the ACR on key demographic information (name, date of birth, sex) and no significant differences will be found in coding practices between Edmonton and Calgary in the ACR. Some disagreement is expected to occur between the physician databases and the ACR regarding diagnostic variables (year of diagnosis, method of diagnosis, topography code, morphology code) and treatment variables (chemotherapy and radiotherapy received) as this information is collected at different points in time.

Chapter 2 – Methodology

2.1 Study Population

The study population included all brain tumour patients diagnosed in Alberta between the ages of 0 through 17 years of age, during the time period of 2004 to 2011. As previously mentioned, topography codes C70 through C72, C75.1 through C75.3, and C30.0 (with morphology codes 9522 and 9523) were used to define brain tumour cases. Patients must have been residents of Alberta at the time of diagnosis and only primary cancer diagnoses were considered for the purposes of this research study, as the ACR does not capture cancer recurrence and metastases in a consistent and comprehensive manner.

The pediatric brain tumour population was chosen as we had engaged pediatric brain tumour physicians Dr. Vivek Mehta, Edmonton, Alberta, and Dr. Douglas Strother, Calgary, Alberta, that were interested in investigating this issue and willing to share their physician databases for the purpose of this study.

At the onset of this study, it was thought all pediatric brain tumour patients would go to either the Stollery Children's Hospital in Edmonton, Alberta, or the Alberta Children's Hospital in Calgary, Alberta due to the specialized nature of care for this patient population. The age range of 0 to 17 years was chosen as both these sites only provide care for patients 17 years and under (AHS, 2015b; Coppes, 1999). As the pediatric brain tumour physician databases should capture all cases seen at the Stollery Children's Hospital and the Alberta Children's Hospital, the assumption was made that their physician databases would capture all pediatric brain tumour cases in Alberta.

The starting time frame of 2004 was chosen as that was the first year both Dr. Mehta's and Dr. Strother's physician databases consistently began capturing brain tumours. A closing year of 2011 was chosen as the ACR had only reviewed available data up until the end of that year.

2.2 Data Sources and Variables

Three main databases were used for this research study; the pediatric physician brain tumour database in Edmonton, the pediatric physician brain tumour database in Calgary, and the ACR.

The Edmonton database provided data for 122 pediatric brain tumour patients diagnosed between 2004 to 2011, including patient name, patient identification, date of birth, sex, date of diagnosis, method of diagnosis, tumour name, whether the patient had chemotherapy, date of chemotherapy, whether the patient had radiation, and date of radiation.

The Calgary database provided data for 99 pediatric brain tumour patients diagnosed between 2004 to 2011, including patient name, patient identification, date of birth, sex, date of diagnosis, method of diagnosis, tumour name, whether the patient had chemotherapy, date of chemotherapy, whether the patient had radiation, and date of radiation.

The ACR is a population-based registry established in 1942 that records and maintains data on all new cancer cases and cancer deaths occurring in the province. The ACR is operated by AHS and is mandated by the Regional Health Authorities Act of Alberta (Government of Alberta, 2015). The Registry records information about a patient's type of cancer, as well as personal information such as name, date of birth, sex, provincial health care number, and postal code. The ACR is notified of new cancer cases by doctors and laboratories throughout the province (AHS, 2014).

2.3 Gathering Data and Performing Quality Assurance

An ethics application was submitted through the University of Alberta to the 'Health Research Ethics Board Health Panel' and approval was received on September 26, 2014, to gain access to the physician databases, link the brain tumour cases with the ACR, and perform chart reviews as required. As data in Calgary are also being used, an additional ethics application was submitted to the Conjoint Health Research Ethics Board of the University of Calgary and approval was received February 20, 2015.

A data request form was filled out, requesting the data linkage of the pediatric physician databases to the ACR. This form, along with the ethics approvals, was sent to Cancer Measurement Outcomes Research and Evaluation (C-MORE). C-MORE is a department within CancerControl Alberta, AHS that oversees data requests for ACR data. Approval was received and the linked data were provided on March 23, 2015.

C-MORE reviews, approves and coordinates all data requests requesting information from the ACR. They have a team of experienced cancer surveillance analysts with a strong understanding of the ACR data. Through their internal data request processes, an Analyst is assigned to perform the data linkage. Once complete, a second Analyst performs a quality assurance assessment to ensure accuracy of the data. The Director, Surveillance & Reporting, then completes a final review and approves the data release to the requestor. This multi-stage quality assurance process helps ensure accurate and appropriate data are provided to the requestor.

All cases from the Edmonton and Calgary physician databases were linked to data from the ACR using the patient's Unique Lifetime Identifier (ULI) number. For those with matching ULI numbers, their last names and dates of birth were compared to determine if the match was appropriate. When either the last name or date of birth did not match, the C-MORE Analyst performed a visual assessment of the patient's records to determine if the match was appropriate. Once the linked data were received from C-MORE, the entire patient list was reviewed to ensure all patients fell within the defined population of this study.

Of the 122 patients originally in the Edmonton physician database, two patients were removed as they fell outside the study window (one was diagnosed in 2003, and one was diagnosed in 2013), and six patients were removed as they were in the physician database due to a recurrence during the 2004 to 2011 timeframe (not due to an initial diagnosis). This brought the number of patients in the Edmonton physician database to 114 cases.

Of the 99 patients originally in the Calgary physician database, one patient record was removed as they were accidentally entered twice and another patient was removed as they were 20 years

old at the time of diagnosis according to both the physician database and the ACR. This brought the number of patients in the Calgary physician database to 97 cases.

Further quality assurance tests were performed to ensure there were no mistakes made during the linkage or when sorting the databases. Each patient in the linked database was systematically reviewed to ensure the patient information provided in the physician database did not change during the data linkage and no errors were found.

The patient linkages with the ACR were also verified to ensure proper matches were made. For the Edmonton physician database, 105 of the 114 patients had a perfect match, meaning their patient identification, name, and date of birth all matched. Two cases had a match on patient identification and name, but not on date of birth, while four cases matched on patient identification and date of birth, but not on name. These cases were reviewed and deemed to be appropriate matches as the month and day of their birthday was reversed when their data were entered into the physician database or there was a small alteration in the spelling of their name. This left three cases in the Edmonton physician database that were unable to be matched with the ACR.

For the Calgary physician database, 77 of the 97 patients had a perfect match, meaning their patient identification, name, and date of birth all matched. Four cases had a match on patient identification and name, but not on date of birth, while five cases matched on patient identification and date of birth, but not on name. Similar to Edmonton, these cases were reviewed and, deemed to be appropriate matches as the month and day of their birthday was reversed when their dates of birth were entered into the physician database or there was a small alteration in the spelling of their name. This left eleven cases in the Calgary physician database that were unable to be matched with the ACR.

Further to this, as part of the data request, C-MORE provided 112 brain tumour patients diagnosed from 2004 to 2011, between the ages of 0 to 17 that do not appear in either physician database yet appeared in the ACR. These pediatric brain tumour cases will be used to assess the completeness of the physician databases and patterns in the data will be used to assist in

determining what may be causing the pediatric physician databases to miss pediatric brain tumour cases.

2.4 Analyzing the Data

2.4.1 Case Ascertainment

Analysis began by assessing the case ascertainment of primary brain tumour cases present in physician databases captured by the ACR. A frequency table was created to summarize the number and percentage of cases that linked from the physician databases to the ACR, broken down by Edmonton (114 cases) and Calgary (97 cases) physician databases. Overall case ascertainment was also measured (211 cases). 95% confidence intervals were calculated and NAACCR certification criteria were used to objectively assess the case ascertainment of the ACR.

A chart review was performed on all cases present in the physician database that were unable to be linked to the ACR to investigate the reasons for the unsuccessful linkages. Alberta Netcare was used to perform the chart review and ACR staff provided assistance throughout this process to ensure the findings were accurate and comprehensive. Depending on the reason the case was not captured in the ACR, the decision was made on a case-by-case basis to either include or remove the pediatric brain tumour case from the study. Once the ineligible ACR cases were removed from the study, case ascertainment was re-evaluated.

After assessing case ascertainment of the ACR, the reverse process was performed to assess how many pediatric brain tumours the ACR captured from 2004 to 2011 that the physician databases did not. A frequency table was created to summarize the number and percentage of cases that appeared only in the ACR, broken down by where the patients received their care. Patients with charts at either the University of Alberta Hospital or Cross Cancer Institute were considered to have received their care in Edmonton, Alberta, while patients with charts at the Alberta Children's Hospital or Tom Baker Cancer Centre were considered to have received their care in Calgary, Alberta. Going forward, these cases that were only captured in the ACR will be

considered another data source (labelled 'ACR Only') and will be compared with the Edmonton and Calgary physician databases when reviewing the demographic, diagnostic, and treatment information.

Finally, overall case ascertainment of all known pediatric brain tumours was assessed and summarized for the ACR and physician pediatric brain tumour databases. Table 3 helps depict the findings:

Table 3: Summary of Brain Tumours in Alberta

		Physician	
	Recorded?	Yes	No
ACR	Yes	**A**	**B**
	No	**C**	**D**

The ideal scenario is when both the physician database and the ACR capture the brain tumour case (Scenario A). When the ACR captures a case that the physician database is missing (Scenario B) or the physician database captures a case that the ACR is missing (Scenario C), it is not ideal but the case is still being captured somewhere.

This study was unable to pick up the cases when the ACR and the physician database both missed a case as those cases are unknown (Scenario D). While the number of cases that are missed by both databases are thought to be very small, the omission of these cases from the study will artificially inflate overall case ascertainment as the total brain tumour study population will be smaller than reality. To investigate this issue further, this study attempted to estimate the expected number of pediatric brain tumour cases so that overall case ascertainment could be assessed.

In a Canadian study, Shaw et al. (2014) estimated the number of non-malignant CNS tumours missing from the CCR by comparing the expected number of CNS tumours and observed number of CNS tumours. CBTRUS CNS tumour rates from the United States were applied to the Canadian population to estimate the expected number of CNS tumours for each province. This

study found the overall national capture of non-malignant CNS tumours is estimated at 33%, with the highest capture rates occurring in Manitoba (73%) and Alberta (46%).

Similar methodology was used to estimate the total number of expected pediatric brain tumour cases (A + B + C + D) in this study. The total number of expected pediatric brain tumours was estimated by applying the CBTRUS incidence rate of pediatric and adolescent primary malignant and non-malignant brain and CNS tumours in the United States (CBTRUS, 2015b) to the Alberta population. Each year from 2004 to 2011, the CBTRUS pediatric incidence rate was applied to the Alberta population aged 0 to 14, while the CBTRUS pediatric and adolescent incidence rate was applied to the Alberta population aged 15 to 17. Population data was obtained from the annual Alberta Cancer Registry Reports (AHS, 2015c).

Overall case ascertainment of the ACR and physician databases could then be estimated by comparing the observed cases in either the ACR (A + B) or the physician databases (A + C) to the total number of expected pediatric brain tumour cases. While the case ascertainment will only be an estimated, it will still provide an estimation factoring in potential cases that may be missed by both the ACR and the physician databases.

2.4.2 Demographic Information

When linking cases from the physician database to the ACR, the expectation was that key demographic variables from both databases would match. Age at time of diagnosis and sex were the demographic variables chosen for review as they were key variables used when describing brain tumours statistics in Alberta. Frequency tables outlining case-by-case agreement were used to summarize agreement between the databases. A chart review was performed on cases showing disagreement to investigate the reason and determine the source of truth. Alberta Netcare was used to review these cases and the ACR staff provided assistance to ensure the findings were accurate and comprehensive.

Further to this, a case breakdown of the Edmonton physician database, the Calgary physician database, and the cases captured only by the ACR were reviewed to identify differences in

patient populations. A more detailed review of the cases captured only in the ACR was also performed, breaking the data down into where the patients received care, to assess whether demographic variables were systematically causing cases to be missed in the Edmonton or Calgary physician databases. Chi-square tests were performed on any suspected differences to test the statistical significance of the difference.

2.4.3 Diagnostic Information

Diagnostic information is one of the primary reasons physician databases and cancer registries exist, as it is important to have an understanding of how many cancers are being diagnosed each year, what are the primary methods of diagnosing cancer, and what types of cancer are being diagnosed. As such, year of diagnosis, method of diagnosis, morphology code, and topography code were the diagnostic variables chosen for review. For patients appearing only in the ACR, the location at time of diagnosis were also reviewed. Frequency tables outlining case-by-case agreement were used to summarize agreement between the databases for year of diagnosis and method of diagnosis. When relevant, a chart review was performed when there was a significant disagreement to determine the source of truth. Alberta Netcare was used to review these cases and the ACR staff provided assistance to ensure the findings were accurate and comprehensive.

As the physician databases did not use ICD-O-3 coding when recording morphology and topography codes, case-by-case comparisons could not be performed. The morphology codes of all brain tumour cases were classified into histology groupings based off the 2012 CBTRUS Histology Grouping Scheme (CBTRUS, 2015a) to help alleviate some concerns of basing conclusions off of small numbers. A detailed breakdown of morphology codes for each histology grouping can be found in the Appendix.

Further to this, a case breakdown of the Edmonton physician database, the Calgary physician database, and the cases captured only by the ACR were reviewed to identify differences in patient populations. The pattern of diagnostic methods among those cases only identified in the ACR, was also investigated to determine how they compared to the patterns observed in the

Edmonton and Calgary databases. Chi-square tests were performed on any suspected differences to test the statistical significance of the difference.

2.4.4 Treatment Information

Treatment information provides valuable information to researchers, physicians, and planners as this information helps evaluate which treatment methods are improving health outcomes and supports long-term planning of what resources will be required in the future. As such, the treatment variables chosen for review are whether the patient received chemotherapy and/or whether the patient received radiotherapy. Frequency tables outlining case-by-case agreement were used to summarize agreement between the databases for both these variables. A chart review was performed when there was disagreement to determine the source of truth. Alberta Netcare was used to review these cases and the ACR staff provided assistance to ensure the findings were accurate and comprehensive.

Further to this, frequency tables were created to review and identify differences in documentation of treatment received between the Edmonton physician database, the Calgary physician database, and the cases captured only by the ACR. A more detailed review of the cases captured only in the ACR was also performed, identifying where the patients received care, and to assess whether those receiving a certain type of treatment were less likely to be captured in the Edmonton or Calgary physician databases than those not receiving the treatment. Chi-square tests were performed on any suspected differences to test the statistical significance of the difference.

2.5 Reviewing the Findings

Once the data were analyzed and the initial findings were summarized, meetings were scheduled with Dr. Mehta, Dr. Strother, and staff from the ACR, to discuss and review the findings. Their expertise was used to help explain inconsistencies in the data, validate hypotheses, and potentially explain some of the findings.

2.6 Data Limitations and Assumptions

As previously referenced in Section 2.1, a key assumption made at the onset of this study was that the physician databases in Edmonton and Calgary captured all pediatric brain tumour cases in Alberta. It is assumed that any pediatric patient with a brain tumour would travel to Edmonton or Calgary and be logged in the physician databases.

Furthermore, there are some limitations to the ACR data that should be highlighted. The 'Initial Treatment' variable supplied by the ACR only lists the initial treatment plan for the patient. This means, for example, that even if the initial treatment plan for the patient is to receive radiation, yet the patient ends up having surgery after treatment, the 'Initial Treatment' variable will still only list radiation.

Another limitation is that the ACR will occasionally use a more generic date of treatment if the exact date of treatment is unknown. For example, if a patient receives radiation on February 10, 2014, yet the ACR does not receive the exact date of treatment, they will input February 1, 2014, as the treatment date if they only know the month but not the day, or they will input January 1, 2014, if they only know the year of treatment but not the month or day.

Chapter 3 – Results and Discussion

3.1 Case Ascertainment

3.1.1 Initial Case Ascertainment of the Alberta Cancer Registry

Table 4: Initial Case Ascertainment of Pediatric Brain Tumours Cases Present in Physician Databases Captured by the Alberta Cancer Registry

	EDM		CGY		Overall	
	EDM #	**EDM %**	**CGY #**	**CGY %**	**OVR #**	**OVR %**
Link	111	97%	86	89%	197	93%
No Link	3	3%	11	11%	14	7%
Total	**114**	**100%**	**97**	**100%**	**211**	**100%**

When assessing the case ascertainment of pediatric brain tumours cases present in physician databases captured by the ACR, Table 4 shows that 111 of the 114 cases from the Edmonton physician database were properly linked to the ACR, showing a case ascertainment rate of 97%, with a 95% confidence interval of 94% to 100%. From the Calgary physician database, 86 of the 97 cases were properly linked to the ACR, showing a case ascertainment rate of 89%, with a 95% confidence interval of 82% to 95%. Overall, 197 of the 211 cases in the physician databases were captured in the ACR, with a 95% confidence interval of 90% to 97%.

Using NAACCR certification criteria, the ACR would receive Silver Certification as their case ascertainment falls between 90% and 95%. Case ascertainment is better in Edmonton (97%) compared to Calgary (89%). Overall, the ACR performed better than the initial hypothesis that 10% to 15% of the pediatric brain tumour cases would be missed.

3.1.2 Case Ascertainment of Alberta Cancer Registry after Chart Reviews

Chart reviews of the unmatched cases were performed to see why there was no link. Upon review, the unlinked cases could be summarized into five main groups:

- **Diagnosed via imaging and no contact with the cancer centres (5 cases in Calgary)**: These patients were diagnosed via imaging and were being clinically followed. These

patients did not have any contact with the cancer centres and the only way the ACR would have been aware of the diagnosis is if the physician sent in radiology reports. As per discussions with the ACR staff, the onus is on the physician to send in radiology reports as they are mandated by Regional Health Authorities Act of Alberta (Government of Alberta, 2015).

- **Brain tumour confirmed via imaging yet uncertain diagnosis (1 case in Edmonton, 2 cases in Calgary):** These patients were diagnosed via imaging but the official brain tumour diagnosis is unclear. There was no biopsy performed, no treatment planned and these patients were being clinically followed to see if the tumour worsened. As per discussions with the ACR, these cases would not be captured by the ACR until a diagnosis was made from the radiology reports or a biopsy was performed.

- **Out of province cases (3 cases in Calgary):** These patients lived in another province and never registered at an Alberta cancer centre for treatment. As per discussions with the ACR staff, unless the patient received treatment at a cancer centre in Alberta, these cases would not be recorded in the ACR and would instead be coded in their home province cancer registry.

- **Non-reportable brain tumours (2 cases in Edmonton):** These patients were diagnosed with benign tumours that were non-reportable to the ACR – mature epignathus teratoma (9080/0) and nasopharyngeal angiofibroma (9160/0) tumours. Upon review of these cases, Dr. Mehta and ACR staff agreed that these cases were non-reportable and they should not have been recorded in the ACR.

- **Brain metastases (1 case in Calgary):** One patient was diagnosed with pleural pulmonary blastoma (lung cancer) that, according to the ACR, metastasized to the brain. Metastases and recurrences fall outside the scope of our study as the ACR does not consistently capture these occurrences.

Based upon these findings, it was decided that the brain tumours diagnosed via imaging that either had no contact with a cancer centre (5 cases) or had an uncertain diagnosis (3 cases) would remain in our study population. Even though the ACR did not have the necessary information to properly record these cases, a brain tumour was diagnosed based off the radiology reports and therefore, when assessing case ascertainment, it should be expected the case would be recorded in the cancer registry.

It was decided that the cases where patients were living out of province (3 cases), cases with non-reportable brain tumours (2 cases), or cases with a brain metastasis (1 case) would be removed from this study as they do not belong in the ACR.

As such, the initial case ascertainment table was revised and Table 5 shows the case ascertainment of the ACR after chart reviews with the revised patient population.

Table 5: Case Ascertainment of Pediatric Brain Tumours Cases Present in Physician Databases Captured by the Alberta Cancer Registry after Chart Reviews

	EDM		CGY		Overall	
	EDM #	**EDM %**	**CGY #**	**CGY %**	**OVR #**	**OVR %**
Link	111	99%	86	92%	197	96%
No Link	1	1%	7	8%	8	4%
Total	**112**	**100%**	**93**	**100%**	**205**	**100%**

Overall, 197 of the 205 cases in the physician databases were captured in the ACR, with a 95% confidence interval of 93% to 99%. Using NAACCR certification criteria, the ACR would receive Gold Certification as their case ascertainment is above 95%. Case ascertainment was better in Edmonton (99%, 95% confidence interval of 97% to 100%) compared to Calgary (92%, 95% confidence interval of 87% to 98%) but the overall severity of under-reporting was less than our initial hypothesis (10% to 15%).

These results were in-line with the under-reporting of 6% observed in Norway (Larsen, 2009). Of all the published literature, the Cancer Registry of Norway captured the highest percentage of brain tumour cases and performed much better than the under-reporting observed in the United Kingdom (48%) and Scotland (46%) (Pobereskin, 2001 and Counsell, 1997).

These results showed the ACR captured the majority of pediatric brain tumour cases in Alberta and researchers and physicians should not be hesitant to use ACR data. While the case ascertainment in Edmonton and Calgary are encouraging, a further review of the brain tumour coding practices should be performed to see if any differences exist between Calgary and Edmonton that may increase their case ascertainment. This review will be summarized further in this study.

3.1.3 Alberta Cancer Registry – Cases Not Captured in Physician Databases

After linking the physician databases with the ACR, brain tumour cases appearing in ACR that do not appear in the physicians databases were also reviewed in an attempt to understand why they were not captured in the physician databases.

A total of 112 cases were found in the ACR that did not appear in either physician database. Compared to the case ascertainment of the ACR that did not capture 8 known pediatric brain tumour cases, the physician databases missed significantly more brain tumour cases.

To further investigate this issue, the site location of the patient's charts were used to indicate whether the patient missing from the physician database received their care in either the Edmonton area (University of Alberta Hospital, Cross Cancer Institute) or the Calgary area (Alberta Children's Hospital, Tom Baker Cancer Centre). Table 6 summarizes the location where the 112 brain tumours patients captured only by the ACR received care:

Table 6: Chart Location of Pediatric Brain Tumour Patients Missing from Physician Databases

Location	Count	Percentage
Calgary	39	35%
Edmonton	73	65%
Total	**112**	**100%**

Table 6 shows that 73 of the 112 cases (65%) the ACR captured, that were missing from the physician databases, received their care in Edmonton. As noted previously in Table 5, 112 of 205

cases (55%) of the brain tumours were diagnosed in Edmonton. All else being equal, it would be expected that a similar geographic distribution would exist in the cases that were only recorded in the ACR. As this is not the case, this suggests that the Edmonton physician database is missing a disproportionately larger number of cases compared to the Calgary physician database.

Going forward, when applicable, these 112 cases appearing only in the ACR will be compared to the patient population from the Edmonton and Calgary physician databases.

3.1.4 Overall Case Ascertainment of All Known Pediatric Brain Tumours

Overall case ascertainment of all known pediatric brain tumours was assessed for the ACR and physician pediatric brain tumour databases and summarized in Table 7:

Table 7: Summary of Brain Tumours in Alberta

		Physician		
	Recorded?	**Yes**	**No**	**Total**
ACR	**Yes**	197	112	**309**
	No	8	?	**8**
	Total	**205**	**112**	**317**

Overall, 317 pediatric brain tumour cases were captured by either the ACR or the physician databases from 2004 to 2011. The ACR captured 309 of the 317 cases (97%) while the physician databases captured 205 of the 317 (65%). This demonstrates that the ACR was able to capture many more cases than the physician databases. The higher case ascertainment demonstrated by the ACR was expected as physicians from across the province are mandated to report all cancer cases to the ACR (Government of Alberta, 2015) and the ACR has an entire department of staff dedicated to ensure the collection and proper coding of all cancer cases in Alberta. This suggests that the processes by which physicians record patients in their databases should be examined.

Again, it should be noted that the number of cases that were missed by both the ACR and the physician databases is unknown. While this number is not expected to be high, the omission of

these cases will artificially inflate overall pediatric brain tumour case ascertainment for both the ACR and the physician databases.

3.1.5 Overall Case Ascertainment Using Expected Number of Pediatric Brain Tumours

As described in Section 2.4.1, the CBTRUS incidence rate of malignant and non-malignant pediatric brain tumours (CBTRUS, 2015b) was applied to the Alberta population to estimate the total number of expected pediatric brain tumour cases from 2004 to 2011. From these calculations, the Table 8 was obtained:

Table 8: Expected Number of Pediatric Brain Tumour Cases, 2004-2011

Year	Population Aged 0-14	Rate (per 100,000)	Population Aged 15-17	Rate (per 100,000)	Total Population Aged 0-17	Expected Brain Tumours
2004	625,487	5.30	140,366	5.42	765,853	**41**
2005	633,084	5.30	142,071	5.42	775,155	**41**
2006	641,597	5.30	143,435	5.42	785,032	**42**
2007	657,480	5.30	146,047	5.42	803,527	**43**
2008	669,601	5.30	147,535	5.42	817,136	**43**
2009	688,161	5.30	148,249	5.42	836,410	**45**
2010	703,700	5.30	147,720	5.42	851,420	**45**
2011	719,415	5.30	148,213	5.42	867,628	**46**
					Total	**346**

Based off CBTRUS pediatric brain tumour rates, 346 brain tumour cases were expected during the 2004 to 2011 study timeframe. Based off the 317 cases observed by the ACR and the physician databases, an estimated 29 cases were not captured by either database. The ACR captured 309 of the 346 expected cases (89%) while the physician databases captured 205 of the 346 expected cases (59%). This was in line with the initial hypotheses, as the ACR is under-reporting pediatric brain tumours by approximately 11% while the physician databases are capturing even less cases.

It should be noted that while the CBTURS United States pediatric brain tumour rates allow the cases that were missed by both the ACR and physician databases to be factored into the case

ascertainment calculation, these rates may not be the best estimation of the actual reality in Alberta. The actual pediatric brain tumour rates in Alberta may be higher or lower and any difference compared to the estimated rates being used by this methodology will have a direct effect on the case ascertainment of the ACR and physician databases.

3.2 Demographic Information – Age at Time of Diagnosis

3.2.1 Assessing Agreement between Physician Databases and the Alberta Cancer Registry

As previously discussed in the methodology, date of birth was reviewed when performing the data linkage from the physician database to the ACR. There was disagreement between the physician database and the ACR in only 6 of the 205 cases (3%). A further review was performed on these six cases and a data entry error was found to be the cause of the discrepancy, with the physician database reversing the month and date of birth. While this was a relatively minor data entry error, an error like this can still potentially affect the patient's age at time of diagnosis.

Furthermore, the patient's recorded date of birth is not the only variable that has an effect on the patient's age at time of diagnosis. The recorded date of diagnosis in the physician database also has an effect on the age at time of diagnosis so both these variables must be looked at in tandem, to properly assess agreement between the physician databases and the ACR. Table 9 summarizes this case-by-case comparison below:

Table 9: Age at Time of Diagnosis, Case-by-Case Comparison of Physician Databases with Alberta Cancer Registry Data

Age	EDM		CGY		Overall	
Perfect Match	99	88%	83	89%	182	89%
Disagreement	12	11%	3	3%	15	7%
No Link	1	1%	7	8%	8	4%
Total	**112**	**100%**	**93**	**100%**	**205**	**100%**

In Edmonton, of the 12 cases showing disagreement, there were only two cases where a disagreement on date of birth led to a disagreement on age at time of diagnosis. The remaining

ten cases were due to disagreement between the date of diagnosis coded in the physician database compared to the ACR. A chart review was performed on these cases and for the majority of cases, the disagreement was either due to a small disagreement on the date of diagnosis that led to a different age at time of diagnosis, or a small data entry error recording either a day, month, or year incorrectly in the physician database. There was one instance where the physician database recorded a date of diagnosis when they began actively following a patient with a suspicion of a brain tumour but their official brain tumour diagnosis did not occur until a few years later.

In Calgary, of the 3 cases showing disagreement, there was only one case where a disagreement on date of birth led to a disagreement on age at time of diagnosis. The other two cases were due to disagreement between the date of diagnosis coded in the physician database compared to the ACR. A chart review was performed on these cases, confirming a data entry error in the physician database on the date of birth for one of the patients. For the other two cases, the physician database recorded a date of diagnosis when they began actively following a patient with a suspicion of a brain tumour but their official brain tumour diagnosis did not occur until a few years later.

Overall, only 15 of 205 cases (7%) did not show perfect agreement. There was the expectation of some disagreement between the physician databases and the ACR due to small differences in the recorded date of diagnosis: physicians may not always be aware of prior imaging or biopsy results or may be aware but may not have the exact dates of the tests; there is a higher risk for data entry errors due to the manual data entry processes; and there may be some subjectivity involved when determining a date of diagnosis when the patient is having multiple appointments and tests over a period of time. The chart reviews confirmed these suspicions as 12 of the 15 cases were due to differences in date of diagnosis, as opposed to differences in date of birth.

There was better case-by-case agreement between the Calgary physician database and the ACR (3% disagreement), compared to the Edmonton physician database and the ACR agreement (11% disagreement).

3.2.2 Comparing Case Breakdown between Data Sources

For the results below, the ACR was used as the data source to summarize the patient's age at time of diagnosis to review overall patterns across physician databases and cases captured only in the ACR. This data source was chosen as opposed to the physician database as previously noted, as the age at time of diagnosis was quite similar between data sources (7% disagreement) and the chart reviews confirmed the data entered in the ACR. Due to the small numbers, patients were broken down into three-year age groups.

Table 10: Comparison of Age at Time of Diagnosis Distribution of Pediatric Brain Tumour Patients by Patient Population

	EDM		CGY		ACR Only		Total	
Age	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**	**Total #**	**Total %**
< 3 years	23	21%	21	23%	12	11%	**56**	**18%**
3-5 years	29	26%	13	14%	19	17%	**61**	**19%**
6-8 years	15	13%	20	22%	16	14%	**51**	**16%**
9-11 years	14	13%	13	14%	8	7%	**35**	**11%**
12-14 years	13	12%	8	9%	28	25%	**49**	**15%**
15-17 years	17	15%	11	12%	29	26%	**57**	**18%**
No Link	1	1%	7	8%	0	0%	**8**	**3%**
Total	**112**	**100%**	**93**	**100%**	**112**	**100%**	**317**	**100%**

Overall, as seen in Table 10, the age at time of diagnosis appears to be relatively similar between Edmonton and Calgary. Due to the small sample size, there were some differences but nothing appeared to be systematically different between the two groups.

Of interest, when comparing cases captured in the physician databases to the cases captured only in the ACR, a higher percentage of the cases captured only in the ACR were diagnosed at a later age. 51% of cases captured only in the ACR were aged 12 to 17 years old at the time of diagnosis, compared to 27% in Edmonton and 21% in Calgary. To assess whether the differences in cases captured only by the ACR and the physician databases were statistically significant, a chi-square test was performed to compare the number of pediatric brain tumour cases diagnosed in patients 12 to 17 years of age compared to patients less than 12 years of age. A chi-square

statistic of 21.45 was found with a p-value of 0.000004, meaning there was a significant difference at the $p < 0.05$ level.

Part of this may be explained as some of these patients could have opted for (or be referred to) non-pediatric physicians to avoid the potentially difficult transition in care. Once pediatric patients turn 18 years of age, they no longer qualify to receive care in the Stollery Children's Hospital or the Alberta Children's Hospital. In follow-up discussions with Dr. Mehta, he agreed that this hypothesis made sense as they often try to avoid an unnecessary and foreseeable transition of care when possible.

Further supporting this hypothesis, only 11% of all cases captured only in the ACR were aged 0 to 2 years old at the time of diagnosis, compared to 21% of cases in the Edmonton physician database and 23% of cases in the Calgary physician database. This shows that the pediatric physician databases are more likely to capture younger patients, compared to older ones.

3.3 Demographic Information – Sex

3.3.1 Assessing Agreement between Physician Databases and the Alberta Cancer Registry

Sex is a demographic variable commonly used by physicians, researchers, and health care professionals when analysing brain tumour data. There is also the expectation that almost perfect agreement will exist between the physician databases and the ACR. A case-by-case comparison was performed and the results are summarized in Table 11:

Table 11: Sex, Case-by-Case Comparison of Physician Databases with Alberta Cancer Registry Data

Sex	EDM		CGY		Overall	
Perfect Match	111	99%	85	91%	196	96%
Disagreement	0	0%	1	1%	1	0%
No Link	1	1%	7	8%	8	4%
Total	**112**	**100%**	**93**	**100%**	**205**	**100%**

As expected, Table 11 shows there was almost perfect agreement between the physician databases and the ACR when comparing the sex recorded for each patient. There was disagreement in only one of the linked cases (1%). A chart review was performed on this patient and the sex recorded in the ACR was confirmed. This possibly means a data entry error was made when the patient was recorded in the Calgary physician database.

3.3.2 Comparing Case Breakdown between Data Sources

The ACR and physician data sources are almost identical in regard to the patient's sex, so it will not make a big difference which data source was used to summarize the data. Regardless, the ACR was chosen as the data source as they did not have any observed data entry errors when recording sex.

Table 12 summarizes the sex breakdown of pediatric brain tumour patients by patient population:

Table 12: Comparison of Sex Distribution of Pediatric Brain Tumour Patients by Patient Population

	EDM		CGY		ACR Only		Total	
Sex	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**	**Total #**	**Total %**
F	43	38%	40	43%	44	39%	**127**	**40%**
M	68	61%	46	49%	68	61%	**182**	**57%**
No Link	1	1%	7	8%	0	0%	**8**	**3%**
Total	**112**	**100%**	**93**	**100%**	**112**	**100%**	**317**	**100%**

As can be seen in Table 12, some modest differences exist between the patient populations but no systematic differences in the pattern of proportions appear to be of concern between the two groups. Males were more likely than females to be diagnosed with a brain tumour but these results were expected and they are consistent with the findings in the literature (McKinney, 2004).

3.4 Diagnostic Information – Year of Diagnosis

3.4.1 Assessing Agreement between Physician Databases and the Alberta Cancer Registry

Year of diagnosis is a diagnostic variable commonly used by physicians, researchers, and health care professionals when comparing brain tumour data by year. It is especially important as it helps identify trends in incidence rates and it is an important calculation in five-year survival rate calculations. Some disagreement is expected between the physician databases and the ACR as the ACR does not capture the date the physician may first learn about the tumour, instead defaulting to the date the brain tumour was clinically diagnosed.

A case-by-case comparison was performed and the results are summarized in Table 13:

Table 13: Year of Diagnosis, Case-by-Case Comparison of Physician Databases with Alberta Cancer Registry Data

Year of Diagnosis	EDM		CGY		Overall	
Perfect Match	98	88%	83	89%	181	88%
Disagreement	13	12%	3	3%	16	8%
No Link	1	1%	7	8%	8	4%
Total	**112**	**100%**	**93**	**100%**	**205**	**100%**

Overall, 16 of 205 cases (8%) did not show perfect agreement. There was better case-by-case agreement between the Calgary physician database and the ACR (3% disagreement), compared to the Edmonton physician database and the ACR agreement (12% disagreement).

However, in five cases, once linked to the ACR, the year of diagnosis fell outside our study time period of 2004 to 2011 (1 case in 2001, 1 case in 2002, 3 cases in 2003). Chart reviews were performed on these five cases to investigate the discrepancy and the following was found:

- One patient diagnosed in Edmonton in 2001 showed a year of diagnosis of 2004 in the physician database. The chart review confirmed the patient was diagnosed and received surgery in 2001 to remove the 9424/3 Pleomorphic xanthoastrocytoma tumour. In 2004, a recurrence was diagnosed and the patient was entered into the physician database. As

recurrences are not captured in the ACR, only the primary tumour was recorded in the ACR. Therefore, when the linkage was performed, the 2004 recurrence from the physician database was linked to the brain tumour diagnosed in 2001 as it was the only brain tumour diagnosis showing in the ACR. As the case in the physician database was a recurrence, this case likely should not have been included in the study.

- One patient diagnosed in Edmonton in 2002 showed a year of diagnosis of 2004 in the physician database. The chart review showed that this patient was diagnosed via imaging in 2002 yet did not go on to receive treatment until 2004. It is possible the ACR captured the brain tumour diagnosis based on the imaging reports but the physician database did not record this patient until they first had contact in 2004.

- One patient diagnosed in Edmonton in 2012 showed a year of diagnosis of 2006 in the physician database. The chart review did not show any relevant tests for brain tumours (CT scans or MRIs) until 2012. Therefore it should be safe to assume 2012 as the year of diagnosis

- The other patient diagnosed in Edmonton in 2012 showed a year of diagnosis of 2011 in the physician database. The chart review confirmed that this patient had a recurrence in 2011 but then had a new primary brain tumour diagnosed in 2012. The initial primary brain tumour was captured by the ACR but was diagnosed prior to 2004 so it fell outside the scope of this study. When the linkage was performed, the recurrence diagnosed in 2011 from the physician data was linked to the new primary brain tumour diagnosed in 2012. As this was a recurrence, this case likely should not have been included in the study.

- One patient diagnosed in Calgary in 2012 showed a year of diagnosis of 2007 in the physician database. The chart review confirmed the brain tumour was diagnosed in 2012; however, due to a high risk of developing a childhood cancer due to a DNA mismatch repair deletion, the physician began following this patient back in 2007 until they were eventually diagnosed with a brain tumour.

While the date of diagnosis for these patients fell outside the scope of the study, they were not omitted from the study as the date of diagnosis from the physician database, even if incorrect, showed that they should be included. This differs from the nine patients that were previously omitted from the study in the quality assurance phase as those patients had a date of diagnosis outside the study timeframe in both the physician and ACR databases.

3.4.2 Comparing Case Breakdown between Data Sources

Once the cases from the physician databases were linked to the ACR, the year of diagnosis as defined by the ACR was summarized in Table 14:

Table 14: Comparison of Year of Diagnosis Distribution of Pediatric Brain Tumour Patients by Patient Population

	EDM		CGY		ACR Only		Total	
Year	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**	**Total #**	**Total %**
2001	1	1%	0	0%	0	0%	**1**	**0%**
2002	1	1%	0	0%	0	0%	**1**	**0%**
2004	13	12%	7	8%	21	19%	**41**	**13%**
2005	13	12%	12	13%	18	16%	**43**	**14%**
2006	9	8%	8	9%	8	7%	**25**	**8%**
2007	8	7%	16	17%	7	6%	**31**	**10%**
2008	14	13%	15	16%	13	12%	**42**	**13%**
2009	16	14%	12	13%	14	13%	**42**	**13%**
2010	22	20%	5	5%	12	11%	**39**	**12%**
2011	12	11%	10	11%	19	17%	**41**	**13%**
2012	2	2%	1	1%	0	0%	**3**	**1%**
No Link	1	1%	7	8%	0	0%	**8**	**3%**
Total	**112**	**100%**	**93**	**100%**	**112**	**100%**	**317**	**100%**

For the most part, Edmonton saw similar patterns to Calgary. As noted, 5 of the 205 cases (2%) fell outside the 2004 to 2011 study timeframe once linked to the ACR however the date of diagnosis in the physician database was within the 2004 to 2011 time frame, allowing these patients to be included in the study.

When reviewing Table 14, 39 of the 112 cases (35%) captured only in the ACR occurred in 2004 and 2005, when the physician databases were potentially in their infancy stage. To assess whether the differences in cases captured only by the ACR and the physician databases were statistically significant, a chi-square test was performed to compare the number of pediatric brain tumour cases diagnosed in 2004 to 2005 compared to cases diagnosed in all other timeframes. A chi-square statistic of 4.58 was found with a p-value of 0.032, meaning there was a significant difference at the $p < 0.05$ level.

The missing cases from the physician databases could be due to the fact that internal processes were still being established to ensure all brain tumours were properly recorded. After discussions with Dr. Mehta, he agreed and expected more cases to be missed back in 2004 and 2005 as the Edmonton physician database was still in its early days. Dr. Strother did not think this would have been a major problem.

Table 15 was created to further investigate this issue by categorizing the cases that were only captured in the ACR by where they received their care:

Table 15: Year of Diagnosis Breakdown of Pediatric Brain Tumour Patients Captured only in the Alberta Cancer Registry by Location of Care

	EDM Care		CGY Care		Total - ACR Only	
Year	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**
2004	18	25%	3	8%	21	19%
2005	11	15%	7	18%	18	16%
2006	5	7%	3	8%	8	7%
2007	4	5%	3	8%	7	6%
2008	7	10%	6	15%	13	12%
2009	11	15%	3	8%	14	13%
2010	7	10%	5	13%	12	11%
2011	10	14%	9	23%	19	17%
Total	**73**	**100%**	**39**	**100%**	**112**	**100%**

Table 15 shows that Edmonton, in particular, was missing more brain tumour cases that the ACR captured in 2004 and 2005. 29 of the 112 cases (26%) that were only captured in the ACR received care in Edmonton during this timeframe. This seems to confirm the hypothesis that more cases were missed during that timeframe due to the Edmonton physician database still being in its infancy stage.

To further explore the cases only being captured by the ACR and to see if the physician databases showed better case ascertainment in certain years, Table 16 was created to highlight the percentage of cases missed by the physician databases each year:

Table 16: Percentage of Pediatric Brain Tumour Patients Missed by Physician Databases, by Year of Diagnosis

Year	Overall Total #	ACR Only Total #	Cases Missed (%)
2004	41	21	51%
2005	43	18	42%
2006	25	8	32%
2007	31	7	23%
2008	42	13	31%
2009	42	14	33%
2010	39	12	31%
2011	41	19	46%
Total	**317**	**112**	**35%**

Overall, 112 of 317 (35%) pediatric brain tumours were missed by the physician databases. As previously discussed, 2004 (51%) and 2005 (42%) missed more cases compared to subsequent years. There were 19 of 41 cases (46%) pediatric brain tumour cases missed in 2011, which is alarming as the physician databases were only missing around 30% of cases over the previous five years. After discussions with Dr. Mehta and Dr. Strother, there were no known issues that would have caused the increase in missed cases during 2011.

3.5 Diagnostic Information – Method of Diagnosis

3.5.1 Assessing Agreement between Physician Databases and the Alberta Cancer Registry

Method of diagnosis is an important diagnostic variable used to help describe how brain tumours are being diagnosed. Histology and radiology are the most common methods of diagnosis for brain tumours. Some disagreement is expected between the physician databases and the ACR as there are differing ways on how to code the method of diagnosis. A database can either record how the diagnosis was primarily established or it can record the most definitive form of diagnosis of the cancer using a hierarchal table, where pathology is considered more definitive than imaging. The ACR records the method of diagnosis using both methods but for the purpose of this study, the primary method of diagnosis was used when linking the physician data to the ACR, as that is how physician databases code their method of diagnosis.

A case-by-case comparison was performed and the results are summarized in Table 17:

Table 17: Method of Diagnosis, Case-by-Case Comparison of Physician Databases with Alberta Cancer Registry Data

Method of Diagnosis	EDM		CGY		Overall	
Perfect Match	98	88%	64	69%	162	79%
Disagreement	12	11%	22	24%	34	17%
No Link	1	1%	7	8%	8	4%
Total	**111**	**99%**	**93**	**100%**	**204**	**100%**

Overall, 34 of 205 cases (17%) did not show perfect agreement. There was better case-by-case agreement between the Edmonton physician database and the ACR (11% disagreement), compared to the Calgary physician database and the ACR (24% disagreement).

Of the 34 cases showing disagreement, 2 cases in Edmonton and 6 cases in Calgary were due to the ACR coding the method of diagnosis as ‘cytology’, while the physician databases coded the cases as histologically confirmed. The physician databases coded all cases as either histologically or radiologically confirmed so there was likely no chance for agreement on these cases.

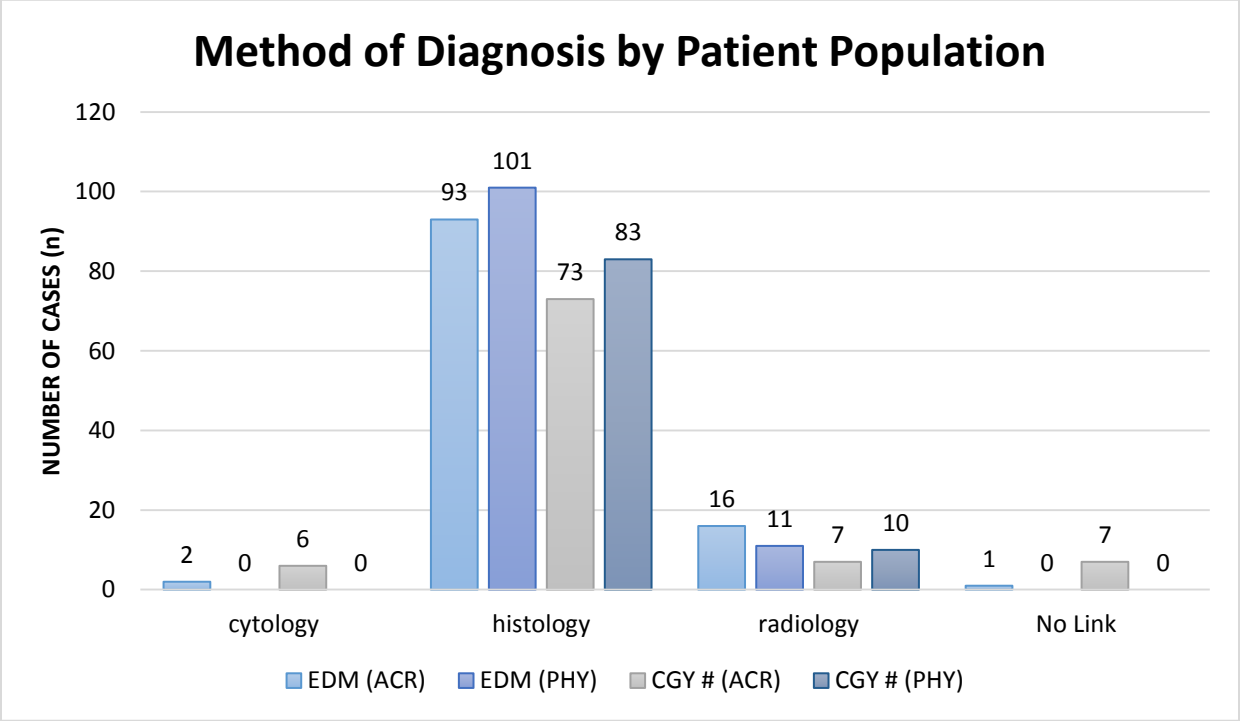
As previously discussed, there was the expectation of some disagreement between the physician databases and the ACR due to the various approaches that can be taken when coding a method of diagnosis. While the ACR has specific guidelines in place regarding how the method of

diagnosis is chosen, the physicians may use a bit more of a subjective approach in terms of how they record the method of diagnosis.

3.5.2 Comparing Case Breakdown between Data Sources

The method of diagnosis, using the physician database as the source, was compared and summarized in Figure 1. Note that 8 cases (1 in Edmonton and 7 in Calgary) were captured in the physician databases but could not be linked to the ACR:

Figure 1: Method of Diagnosis by Patient Population



As can be seen from Figure 1, all brain tumour cases were primarily diagnosed via histology in Edmonton (83%) and Calgary (78%). Aside from the cases not linked to the ACR (8 cases), the primary reason for the disagreement was due to the physician databases not recording cytology as a method of diagnosis (8 cases).

Table 18 investigates the breakdown of cases captured only by the ACR, to see if any trends can be noticed:

Table 18: Method of Diagnosis of Pediatric Brain Tumour Patients Captured only in the Alberta Cancer Registry by Location of Care

	EDM Care		CGY Care		Total - ACR Only	
Method	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**
Cytology	0	0%	1	3%	1	1%
Histology	32	44%	30	77%	62	55%
Laboratory	1	1%	0	0%	1	1%
Radiology	40	55%	8	21%	48	43%
Total	**73**	**100%**	**39**	**100%**	**112**	**100%**

For patients receiving care in Calgary that were only captured in the ACR, the method of diagnosis showed very similar attributes to the patients in the Calgary physician database. 77% of these cases were histologically confirmed, whereas 78% of cases from the Calgary physician database were histologically confirmed.

This is not the case for patients receiving care in Edmonton that were only captured in the ACR. Only 44% of these patients were histologically confirmed, whereas 82% of cases from the Edmonton physician database were histologically confirmed. This suggests that the Edmonton database is missing a large portion of cases which are radiologically confirmed. This finding was surprising to Dr. Mehta as he expected more surgical cases to be missing from his physician database as he is more involved with the radiation cases. Further investigation is required to see why this is happening.

3.6 Diagnostic Information – Topography Code

3.6.1 Assessing Agreement between Physician Databases and the Alberta Cancer Registry

The topography code indicates the site of origin of a neoplasm; in other words, where the tumour arose (National Cancer Institute, 2015a). When collecting data from the physician databases, this variable was requested in order to compare coding from the physician databases to the ACR. As both the Edmonton and Calgary databases do not record brain tumours using the ICD-O-3 coding system, ‘CNS’ was listed as the topography for every case in the physician databases. This level

of detail is less than what is required to perform meaningful comparisons, so as such, case-by-case agreement comparing the physician database to the ACR could not be measured.

3.6.2 Comparing Case Breakdown between Data Sources

Table 19 summarizes the topography of the pediatric brain tumours, once linked, according to the ACR:

Table 19: Comparison of Topography Distribution of Pediatric Brain Tumour Patients by Patient Population

	EDM		CGY		ACR Only	
Topography	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**
C30.0 Nasal cavity	0	0%	0	0%	1	1%
C41.2 Vertebral column	1	1%	0	0%	0	0%
C70.0 Cerebral meninges	3	3%	0	0%	3	3%
C70.1 Spinal meninges	1	1%	0	0%	1	1%
C71.0 Cerebrum	7	6%	10	11%	6	5%
C71.1 Frontal lobe	3	3%	4	4%	4	4%
C71.2 Temporal lobe	8	7%	4	4%	17	15%
C71.3 Parietal lobe	1	1%	5	5%	3	3%
C71.4 Occipital lobe	5	4%	1	1%	1	1%
C71.5 Ventricle NOS	5	4%	5	5%	5	4%
C71.6 Cerebellum, NOS	11	10%	30	32%	12	11%
C71.7 Brain stem	18	16%	17	18%	17	15%
C71.8 Overlapping lesion of brain	2	2%	1	1%	4	4%
C71.9 Brain NOS	24	21%	2	2%	8	7%
C72.0 Spinal cord	3	3%	1	1%	8	7%
C72.3 Optic nerve	4	4%	1	1%	4	4%
C72.4 Acoustic nerve	0	0%	0	0%	3	3%
C72.5 Cranial nerve, NOS	0	0%	0	0%	1	1%
C72.9 Nervous system NOS	0	0%	0	0%	7	6%
C75.1 Pituitary gland	2	2%	0	0%	6	5%
C75.2 Craniopharyngeal duct	4	4%	2	2%	0	0%
C75.3 Pineal gland	8	7%	3	3%	1	1%
C80.9 Unknown primary site	1	1%	0	0%	0	0%
No Link	1	1%	7	8%	0	0%
Total	**112**	**100%**	**93**	**100%**	**112**	**100%**

Due to the small numbers in this table, there are few conclusions of significance that can be made. However, of note from Table 19, 24 of 112 cases of brain tumours (21%) diagnosed in Edmonton are coded as C71.9 Brain Not Otherwise Specified (NOS). Compared to only 2 of 97 cases of brain tumours (2%) diagnosed in Calgary, it appears that Edmonton uses the Brain NOS code more frequently. Moreover, 30 of 97 brain tumour cases (31%) diagnosed in Calgary are coded as C71.6 Cerebellum, NOS compared to only 11 of 112 brain tumour cases (10%) diagnosed in Edmonton. From this, it appears that Edmonton has a tendency to use the C71.9 Brain NOS code while Calgary codes a large majority of these cases to C71.6 Cerebellum, NOS. This seems to point to a training or process issue. Upon discussion with ACR staff, they did agree that a variance in process existed and further investigation would be required to see if this was a coder training error or if the biopsy reports are not as clear in Edmonton.

A relatively larger number of C71.2 Temporal lobe brain tumours captured only in the ACR (17 cases) compared to the physician databases (12 cases) was also observed. Of the 17 cases, 10 cases (59%) were neuronal and mixed neuronal-glial tumours, which could point to an issue where these types of brain tumours are not seen by the pediatric brain tumour physicians. To assess whether the differences in cases captured only by the ACR and the physician databases were statistically significant, a chi-square test was performed to compare the number of pediatric brain tumour cases diagnosed as C71.2 Temporal lobe compared to all other topography codes. A chi-square statistic of 6.93 was found with a p-value of 0.008, meaning there was a significant difference at the $p < 0.05$ level.

Upon review of Table 19, Dr. Mehta (Edmonton) noted that while they may occasionally record some spinal cord and other CNS cases in their brain tumour database, they likely do not capture all these cases. He highlighted C70.1 Spinal meninges, C72.0 Spinal cord, C72.3 Optic nerve, C72.4 Acoustic nerve, C72.5 Cranial nerve, NOS, and C72.9 Nervous system, NOS, C75.1 Pituitary gland, C75.2 Craniopharyngeal duct, and C75.3 Pineal gland as brain tumour topography codes that would not consistently be captured in the Edmonton physician database. This could explain up to 30 of the 112 brain tumour cases (27%) that the ACR captures that the physician databases did not.

It is worth further investigating on the cases that were only captured in the ACR to see if certain topography codes are more or less likely to be missed by the physician databases:

Table 20: Topography Breakdown of Pediatric Brain Tumour Patients Captured only in the Alberta Cancer Registry by Location of Care

	EDM Care		CGY Care		Total - ACR Only	
Topography	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**
C30.0 Nasal cavity	0	0%	1	3%	**1**	**1%**
C70.0 Cerebral meninges	1	1%	2	5%	**3**	**3%**
C70.1 Spinal meninges	0	0%	1	3%	**1**	**1%**
C71.0 Cerebrum	3	4%	3	8%	**6**	**5%**
C71.1 Frontal lobe	4	5%	0	0%	**4**	**4%**
C71.2 Temporal lobe	10	14%	7	18%	**17**	**15%**
C71.3 Parietal lobe	1	1%	2	5%	**3**	**3%**
C71.4 Occipital lobe	0	0%	1	3%	**1**	**1%**
C71.5 Ventricle NOS	2	3%	3	8%	**5**	**4%**
C71.6 Cerebellum, NOS	7	10%	5	13%	**12**	**11%**
C71.7 Brain stem	14	19%	3	8%	**17**	**15%**
C71.8 Overlapping lesion of brain	1	1%	3	8%	**4**	**4%**
C71.9 Brain NOS	7	10%	1	3%	**8**	**7%**
C72.0 Spinal cord	4	5%	4	10%	**8**	**7%**
C72.3 Optic nerve	3	4%	1	3%	**4**	**4%**
C72.4 Acoustic nerve	3	4%	0	0%	**3**	**3%**
C72.5 Cranial nerve, NOS	1	1%	0	0%	**1**	**1%**
C72.9 Nervous system NOS	7	10%	0	0%	**7**	**6%**
C75.1 Pituitary gland	4	5%	2	5%	**6**	**5%**
C75.3 Pineal gland	1	1%	0	0%	**1**	**1%**
Total	**73**	**100%**	**39**	**100%**	**112**	**100%**

Table 20 highlights that 14 of the C71.7 Brain stem cases are occurring in Edmonton while only 3 cases occurred in Calgary. Furthermore, the Edmonton physician database was the only database that missed patients diagnosed with C71.1 Frontal lobe (4 cases), C72.4 Acoustic nerve (3 cases), C72.5 Cranial nerve, NOS (1 case), C72.9 Nervous system NOS (7 cases) and C75.3 Pineal gland (1 case). In discussions with Dr. Mehta, he mentioned that a major issue is the lack of a clear brain tumour definition. As the definition of a brain tumour is unclear, it is very likely these cases are not being captured in the Edmonton physician databases simply due to the fact

that the physicians in Edmonton are not considering them brain tumours while the physicians in Calgary are.

These variances between brain tumour definitions are important to resolve as accurate classification is important in guiding appropriate treatment decisions, but is also relevant in understanding the patterns of disease and the etiology (or causes) of disease and in assessing progress in the diagnosis and outcomes of treatment of tumours at the population level (Davis, 2015).

3.7 Diagnostic Information – Morphology Code

3.7.1 Assessing Agreement between Physician Databases and the Alberta Cancer Registry

The morphology code records the type of cell that has become neoplastic and its biologic activity; in other words, it records the kind of tumour that has developed and how it behaves (National Cancer Institute, 2015b). As the physician databases did not use the ICD-O-3 coding system, meaningful case-by-case comparisons were not possible to assess comparability.

3.7.2 Comparing Case Breakdown between Data Sources

The morphology codes of all brain tumour cases were classified into histological groupings based off the *2012 CBTRUS Histology Grouping Scheme* (CBTRUS, 2015a) to help alleviate some concerns of basing conclusions off of small numbers. A detailed breakdown of morphology codes for each histology grouping can be found in the Appendix.

Table 21 summarizes the histological groupings of brain tumours, once linked, according to the ACR:

Table 21: Comparison of Histology Grouping Distribution of Pediatric Brain Tumour Patients by Patient Population

	EDM		CGY		ACR Only		Total	
Morphology	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**	**ACR #**	**ACR %**
Anaplastic astrocytoma	1	1%	3	3%	1	1%	**5**	**2%**
Anaplastic oligodendroglioma	0	0%	0	0%	1	1%	**1**	**0%**
Choroid plexus tumours	1	1%	2	2%	1	1%	**4**	**1%**
Craniopharyngioma	7	6%	2	2%	1	1%	**10**	**3%**
Diffuse astrocytoma	2	2%	1	1%	5	4%	**8**	**3%**
Embryonal tumours	21	19%	17	18%	10	9%	**48**	**15%**
Ependymal tumours	13	12%	11	12%	5	4%	**29**	**9%**
Germ cell tumours, cysts and heterotopias	6	5%	3	3%	1	1%	**10**	**3%**
Glioblastoma	1	1%	10	11%	2	2%	**13**	**4%**
Glioma malignant, NOS	9	8%	7	8%	23	21%	**39**	**12%**
Hemangioma	0	0%	0	0%	1	1%	**1**	**0%**
Meningioma	4	4%	0	0%	3	3%	**7**	**2%**
Mesenchymal tumours	1	1%	0	0%	1	1%	**2**	**1%**
Neoplasm, unspecified	2	2%	0	0%	2	2%	**4**	**1%**
Nerve sheath tumours	0	0%	0	0%	11	10%	**11**	**3%**
Neuronal and mixed neuronal-glial tumours	6	5%	3	3%	14	13%	**23**	**7%**
Oligodendroglioma	0	0%	1	1%	0	0%	**1**	**0%**
Other hemopoietic neoplasm	0	0%	0	0%	1	1%	**1**	**0%**
Other neoplasms related to the meninges	2	2%	1	1%	3	3%	**6**	**2%**
Pilocytic astrocytoma	30	27%	25	27%	21	19%	**76**	**24%**
Tumours of the pituitary	1	1%	0	0%	5	4%	**6**	**2%**
Unique astrocytoma variants	2	2%	0	0%	0	0%	**2**	**1%**
Not Linked	1	1%	7	8%	0	0%	**8**	**3%**
Total	**110**	**100%**	**93**	**100%**	**112**	**100%**	**315**	**100%**

Overall, ‘pilocytic astrocytoma’ tumours are the most common histological grouping of brain tumours (24%), followed by ‘embryonal tumours’ (15%), and ‘glioma malignant, NOS’ tumours (12%). The histological grouping breakdown of brain tumours is fairly consistent across Edmonton and Calgary.

When looking at the cases that were only captured in the ACR, it is important to note that there were 11 of the 112 cases (10%) that were classified as ‘nerve sheath tumours’. It appears these

tumours are either cases the physicians do not see or the physicians do not consider these cases to be brain tumours. Through discussions with Dr. Mehta, he highlights nerve sheath tumours as a prime example to illustrate his point that there are unclear definitions of what constitutes a brain tumour. Through his experience, these tumours are generally found in the spine, would not be considered brain tumours, and therefore would not be recorded in his pediatric brain tumour database.

Of equal interest, 23 of 112 cases (21%) captured only in the ACR were 'glioma malignant, NOS'. This histology grouping accounts for a much higher percentage (21%) compared to what was observed in the physician databases (8%). This suggests that 'glioma malignant, NOS' have an increased likelihood of being missed in the physician databases.

Further investigation is required to see if the patients diagnosed with 'glioma malignant, NOS' tumours that are being missed in the physician databases are more likely receiving their care in Edmonton or Calgary.

Table 22: Morphology Breakdown of Pediatric Brain Tumour Patients Captured only in the Alberta Cancer Registry by Location of Care

	EDM Care		CGY Care		Total - ACR Only	
Morphology	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**
Anaplastic astrocytoma	0	0%	1	3%	**1**	**1%**
Anaplastic oligodendroglioma	1	1%	0	0%	**1**	**1%**
Choroid plexus tumours	0	0%	1	3%	**1**	**1%**
Craniopharyngioma	1	1%	0	0%	**1**	**1%**
Diffuse astrocytoma	5	7%	0	0%	**5**	**4%**
Embryonal tumours	5	7%	5	13%	**10**	**9%**
Ependymal tumours	3	4%	2	5%	**5**	**4%**
Germ cell tumours, cysts and heterotopias	1	1%	0	0%	**1**	**1%**
Glioblastoma	1	1%	1	3%	**2**	**2%**
Glioma malignant, NOS	19	26%	4	10%	**23**	**21%**
Hemangioma	1	1%	0	0%	**1**	**1%**
Meningioma	1	1%	2	5%	**3**	**3%**
Mesenchymal tumours	0	0%	1	3%	**1**	**1%**
Neoplasm, unspecified	2	3%	0	0%	**2**	**2%**
Nerve sheath tumours	10	14%	1	3%	**11**	**10%**
Neuronal and mixed neuronal-glial tumours	6	8%	8	21%	**14**	**13%**
Other hemopoietic neoplams	1	1%	0	0%	**1**	**1%**
Other neoplasms related to the meninges	2	3%	1	3%	**3**	**3%**
Pilocytic astrocytoma	11	15%	10	26%	**21**	**19%**
Tumours of the pituitary	3	4%	2	5%	**5**	**4%**
Total	**73**	**100%**	**39**	**100%**	**112**	**100%**

Table 22 demonstrates that 19 of the 23 cases (83%) of 9380/3 ‘glioma malignant, NOS’ that were missed in the physician databases were receiving care in Edmonton. This represents a large portion of all brain tumours being missed in the physician databases (17%) and goes back to the issue Dr. Mehta raised, of brain tumour definitions being unclear.

For the remainder of histological groupings, other than the previously discussed ‘nerve sheath tumours’, the geographical breakdown as to where the patients received care is quite similar between Edmonton and Calgary for patients that were only captured in the ACR.

3.8 Treatment Information – Chemotherapy

3.8.1 Assessing Agreement between Physician Databases and the Alberta Cancer Registry

Table 23 outlines the chemotherapy case-by-case agreement between the physician database and the ACR:

Table 23: Case-by-Case Comparison of Chemotherapy for Pediatric Brain Tumour Patients Comparing Physician Databases with Alberta Cancer Registry Data

Chemotherapy	Edmonton		Calgary		Total	
	EDM #	EDM %	CGY #	CGY %	Total #	Total %
Physician (Yes) ACR (Yes)	34	30%	30	32%	64	31%
Physician (No) ACR (No)	61	54%	50	54%	111	54%
Physician (Yes) ACR (No)	8	7%	2	2%	10	5%
Physician (No) ACR (Yes)	8	7%	4	4%	12	6%
Not Linked	1	1%	7	8%	8	4%
Total	**112**	**100%**	**93**	**100%**	**205**	**100%**

When this case-by-case assessment was performed, 95 of the 112 cases (84%) in the Edmonton showed agreement between the Edmonton physician database and the ACR data. Calgary performed similarly, with 80 of 93 cases (86%) showing agreement. Agreement was defined as both databases either showing that a patient did or did not receive chemotherapy. It should be noted that case-by-case comparison could not be performed for 1 case in Edmonton (1%) and 7 cases in Calgary (8%), which negatively affected the overall case-by-case agreement percentage. Overall, the agreement rate between the physician databases and the ACR was 85% (175/205 cases) with either 36% (74/205 cases) or 37% (76/205 cases) of the patients receiving chemotherapy, depending on whether you use the physician database or ACR as your source of data.

To further investigate the discrepancies, a chart review was performed on all cases where there was disagreement between the databases. Part of the reason for disagreement between databases is explained as the ACR only codes the initial treatment plan, as opposed to the physician databases which code the treatment(s) the patient actually receives. For example, a physician may initially decide to only provide a patient with surgery but if chemotherapy is added after the initial plan, the ACR would not capture this while the physician database would. The chart review confirmed this occurred in all 10 cases (8 cases in Edmonton, 2 cases in Calgary) where the physician database showed chemotherapy was received but the ACR did not capture this information. In the 12 cases (8 cases in Edmonton, 4 cases in Calgary) where the ACR showed chemotherapy yet the physician database did not, a chart review confirmed that the patient did receive chemotherapy in all these cases. Through discussions with Dr. Mehta and Dr. Strother, they thought it was possible some of this information could have been missed as these physician databases are maintained on the side.

3.8.2 Comparing Case Breakdown between Data Sources

To consistently compare data on whether chemotherapy was received across the physician databases and the cases that only the ACR captured, the ACR treatment data of the Edmonton and Calgary physician cases were used. Table 24 summarizes the findings:

Table 24: Comparison of Chemotherapy Distribution of Pediatric Brain Tumour Patients by Patient Population

	EDM (ACR)		CGY (ACR)		ACR Only		Total	
Chemo	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**	**Total #**	**Total %**
No	69	62%	52	56%	88	79%	**209**	**66%**
Yes	42	38%	34	37%	24	21%	**100**	**32%**
No Link	1	1%	7	8%	0	0%	**8**	**3%**
Total	**112**	**100%**	**93**	**100%**	**112**	**100%**	**317**	**100%**

Overall, 100 of 317 cases (32%) of pediatric brain tumour patients received chemotherapy as part of their initial treatment plan. Patients in Edmonton (38%) and Calgary (37%) showed very similar treatment patterns, while only 21% of the cases recorded only in the ACR received chemotherapy as part of their initial treatment plan.

To assess whether the differences in cases captured only by the ACR and the physician databases were statistically significant, a chi-square test was performed to compare the number of pediatric brain tumour cases receiving chemotherapy compared to the cases that did not receive chemotherapy. A chi-square statistic of 9.60 was found with a p-value of 0.002, meaning there was a significant difference at the $p < 0.05$ level.

The over-representation of patients not being recorded as having received chemotherapy being captured by the ACR is possibly due to these patients having fewer interactions with the health care system, thus decreasing the opportunities the physicians have to record the diagnosis. Upon discussions of this with Dr. Mehta, he expected to see an over-representation of patients not receiving chemotherapy being missed in the physician databases and he agreed with this rationale.

3.9 Treatment Information – Radiotherapy

3.9.1 Assessing Agreement between Physician Databases and the Alberta Cancer Registry

Table 25 outlines the radiotherapy case-by-case agreement between the physician database and the ACR:

Table 25: Case-by-Case Comparison of Radiotherapy for Pediatric Brain Tumour Patients Comparing Physician Databases with Alberta Cancer Registry Data

Radiotherapy	Edmonton		Calgary		Total	
	EDM #	EDM %	CGY #	CGY %	Total #	Total %
Physician (Yes) ACR (Yes)	37	33%	24	26%	61	30%
Physician (No) ACR (No)	57	51%	46	49%	103	50%
Physician (Yes) ACR (No)	15	13%	2	2%	17	8%
Physician (No) ACR (Yes)	2	2%	14	15%	16	8%
Not Linked	1	1%	7	8%	8	4%
Total	**112**	**100%**	**93**	**100%**	**205**	**100%**

When case-by-case assessment was performed, 94 of the 112 cases (84%) in Edmonton showed agreement between the data from the Edmonton physician database and the ACR data, once linked. Calgary performed similarly, although slightly worse, with 70 of 93 cases (75%) showing agreement. Again, agreement was defined as both databases either showing that a patient did or did not receive radiotherapy. It should be noted that case-by-case comparison could not be performed for 1 unlinked case in Edmonton (1%) and 7 unlinked cases in Calgary (8%), which negatively affected the overall case-by-case agreement percentage.

In Edmonton, 15 of 17 cases where there was disagreement (88%) occurred when the physician database recorded radiotherapy but the ACR showed the patient did not receive radiotherapy. A chart review was performed on these 15 patients and in every case, radiotherapy was prescribed after the initial plan. As described in the chemotherapy section, the ACR only captures the initial treatment plan so it is expected that this was not captured in the ACR. A chart review of the two cases (2%) was also performed where the ACR recorded radiotherapy yet the physician database did not. In one case, the patient received radiotherapy in a different province so the physician would not have known to update their database; while in the other case, it was confirmed the patient did receive radiotherapy so it was simply missed in the physician database.

In Calgary, a complete opposite scenario is observed. In 14 of 16 cases (88%) where there was disagreement, the ACR recorded radiotherapy whereas the physician database did not capture it. A chart review was performed on these 14 patients and in every case, it was confirmed the patient received radiotherapy. Through discussions with Dr. Strother, similar to the issue of chemotherapy going unrecorded in the physician databases, they thought it was possible some of this information could have been missed as these physician databases are maintained on the side. A chart review was also performed on the two cases (2%) in Calgary where the physician showed radiotherapy while the ACR did not record it. In both instances, it was confirmed that radiotherapy was added after the initial treatment plan was determined; therefore the ACR would not have captured it.

While there was some case-by-case disagreement between the physician database and the ACR, chart reviews were able to show that the ACR never missed any case of radiotherapy that was part of the initial treatment plan. When there was disagreement and the ACR and the physician database, it was either due to the ACR only capturing the initial treatment plan or the physician database did not record the radiotherapy.

3.9.2 Comparing Case Breakdown between Data Sources

To consistently compare data on whether radiotherapy was received across the physician databases and the cases that only the ACR captured, the ACR treatment data of the Edmonton and Calgary physician cases were used. Table 26 summarizes the findings:

Table 26: Comparison of Radiotherapy Distribution of Pediatric Brain Tumour Patients by Patient Population

	EDM (ACR)		CGY (ACR)		ACR Only		Total	
Radiation	**EDM #**	**EDM %**	**CGY #**	**CGY %**	**ACR #**	**ACR %**	**Total #**	**Total %**
No	72	64%	48	52%	85	76%	**205**	**65%**
Yes	39	35%	38	41%	27	24%	**104**	**33%**
No Link	1	1%	7	8%	0	0%	**8**	**3%**
Total	**112**	**100%**	**93**	**100%**	**112**	**100%**	**317**	**100%**

Overall, 104 of 317 cases (33%) of pediatric brain tumour patients received radiotherapy as part of their initial treatment plan. Patients in Edmonton (35%) and Calgary (41%) showed very similar treatment patterns, while only 24% of the cases recorded only in the ACR received chemotherapy as part of their initial treatment plan.

To assess whether the differences in cases captured only by the ACR and the physician databases were statistically significant, a chi-square test was performed to compare the number of pediatric brain tumour cases receiving radiotherapy compared to the cases that did not receive radiotherapy. A chi-square statistic of 7.18 was found with a p-value of 0.007, meaning there was a significant difference at the $p < 0.05$ level.

Similar to the findings with patients receiving chemotherapy, the over-representation of patients not being recorded as having received radiotherapy being captured by the ACR is likely due to these patients having fewer interactions with the health care system, thus decreasing the opportunities the physicians will have to receive the required information to record the diagnosis. Upon discussions of this with Dr. Mehta, he expected to see an over-representation of patients not receiving radiotherapy being missed in the physician databases and he agreed with this rationale.

Chapter 4 – Conclusion

4.1 Summary of Findings – Case Ascertainment

Overall, the ACR captured 197 of 205 cases (96%) recorded in the physician databases. Using the NAACCR certification criteria, the ACR would receive Gold Certification based off their case ascertainment of pediatric brain tumours. Case ascertainment was higher in Edmonton (99%) compared to Calgary (92%). Overall, the ACR performed better than our initial hypothesis as it was expected that the ACR would capture 85% to 90% of cases in the physician database.

Table 27: Summary of Brain Tumours in Alberta

		Physician		
	Recorded?	**Yes**	**No**	**Total**
ACR	**Yes**	197	112	**309**
	No	8	?	**8**
	Total	**205**	**112**	**317**

As demonstrated in Table 27, 317 pediatric brain tumour cases were captured by either the ACR or the physician databases from 2004 to 2011. The ACR captured 309 of the 317 cases (97%) while the physician databases captured 205 of the 317 (65%) of known pediatric brain tumours.

This information shows the physician databases do not capture as many pediatric brain tumour cases as the ACR. This was expected as physicians are mandated to report all cancer cases to the ACR (Government of Alberta, 2015) and the ACR has an entire department of staff dedicated to ensure the collection and consistent coding of all cancer cases in Alberta. Therefore when requiring case listings for all pediatric brain tumours, the ACR should be used as the most reliable source to ensure all cases are included.

It should be noted that overall case ascertainment of brain tumours cannot be measured due to the inability to estimate the number of pediatric brain tumour cases that neither the ACR or the physician databases captured. As such, methodology using CBTRUS pediatric brain tumour incidence rates was used to estimate the total number of expected pediatric brain tumours. An estimated 346 pediatric brain tumour cases were expected from 2004 to 2011. The ACR captured 309 of these 346 expected cases (89%) while the physician databases captured 205 of the 346 expected cases (59%). The case ascertainment demonstrated by the ACR and the physician databases were in line with the original hypothesis. Using this methodology, the ACR is estimated to be under-reporting pediatric brain tumours by approximately 11% while the physician databases are capturing even less cases.

4.2 Summary of Findings – Assessing Agreement between Physician Databases and the Alberta Cancer Registry

When performing case-by-case comparisons of data from the ACR with data from the physician databases, the following findings were observed:

- Demographic variables showed very good rates of agreement between the two data sources. 'Age at time of diagnosis' showed disagreement in only 7% of cases while 'sex' showed disagreement in 1% of cases. After performing chart reviews, the information in the ACR was confirmed and the disagreement was likely due to data entry error. There were no data entry errors found in the ACR, while 16 data entry errors were found within the physician databases.

- 'Year of diagnosis' also showed strong agreement between data sources, with only 8% of cases showing disagreement. Upon investigation, the common causes when disagreement was observed were that physicians may not always be aware of prior imaging or biopsy results, physicians may be aware of these prior diagnostic tests but may not have the accurate dates, there is a higher risk for data entry errors due to the manual data entry processes, and there may be some subjectivity involved when determining a date of

diagnosis when the patient is having multiple appointments and tests over a period of time.

- When comparing the coding of 'method of diagnosis' between the ACR and the physician databases, 17% of cases showed disagreement. There are differing ways to code 'method of diagnosis' so this likely led to some of the discrepancies. The physician databases also coded all patients diagnosed via cytology (8 of the 34 cases showing disagreement) as being histologically diagnosed, which contributed to some of the disagreement.

- Due to inconsistencies between the ACR and the physician databases in the coding of site (topography) and histology (topography), case-by-case comparisons could not be performed.

- When comparing the coding of whether a patient received chemotherapy as part of the initial treatment plan between the ACR and the physician databases, 11% of cases showed disagreement. Comparing the coding as to whether a patient received radiotherapy as part of the initial treatment plan showed similar results, with 16% of cases showing disagreement. As the ACR only captures the initial treatment plan, if information summarizing the actual treatment received by pediatric brain tumour patients is required, it is likely best to use the physician databases as the main source of information.

4.3 Summary of Findings – Comparing Case Breakdown between Data Sources

When reviewing the case breakdown of the physician databases and the cases captured only in the ACR, the following was observed:

- A disproportionately larger percentage of patients aged 12 to 17 years old were missed in the pediatric physician databases, possibly due to these patients opting for (or being

referred to) non-pediatric physicians to avoid the potentially difficult transition in care once they turn 18 years of age.

- Some cases were missed in the Edmonton physician database during 2004 and 2005 due to their physician database being in its infancy stage.

- The Edmonton physician database missed a disproportionate number of cases which were diagnosed via imaging.

- A lack of a clear brain tumour definition is a major concern and accounts for some cases not appearing in the physician databases. This is a major concern of the physicians. Some topography and morphology codes are not consistently captured in the physician databases due to the physicians not considering them brain tumours. Dr. Mehta highlighted C70.1 Spinal meninges, C72.0 Spinal cord, C72.3 Optic nerve, C72.4 Acoustic nerve, C72.5 Cranial nerve, NOS, and C72.9 Nervous system, NOS, C75.1 Pituitary gland, C75.2 Craniopharyngeal duct, and C75.3 Pineal gland as brain tumour topography codes that would not consistently be captured in the Edmonton physician database. This could explain up to 30 of the 112 brain tumour cases (27%) that the ACR captures that the physician databases did not.

- Patients only captured in the ACR were less likely to have been recorded as having received chemotherapy (21%) compared to physician databases (37%).

- Similarly, patients only captured in the ACR were less likely to have been recoded as having received radiotherapy (24%) compared to those in the physician databases (38%).

When using data from the ACR or the physician databases, these findings are very important to understand prior to using the data. These findings also help explain why the physician databases (65%) did not perform as well as the ACR (97%) when assessing overall case ascertainment and

shows how the ACR, despite some limitations, should be a trusted source for information on pediatric brain tumours.

4.4 Implications of Findings

This study has already had an immediate impact, improving the data quality of the ACR. On-going discussions with ACR staff have led to an investigation into the 8 cases that were captured in the physician databases yet were missing in the ACR. In 7 of the cases, the ACR staff was able to locate the required radiology and pathology reports and register the cases in the ACR. These cases were not registered in the ACR as the necessary information to record these cases was never sent in. No information has been found on the remaining brain tumour case but they are continuing to search for information. Furthermore, ACR staff is also investigating potential variation in coding practices between Edmonton and Calgary in how C71.9 Brain NOS and C71.6 Cerebullum brain tumours are coded.

This study has also been the first of its kind in assessing case ascertainment of brain tumours by the ACR in North America. The results and findings will be applicable to not only the ACR but to many cancer registries across Canada and elsewhere in the world. Physicians and researchers will also have a better understanding of the ACR and how it may compare to their physician databases.

The overall results of this study show that the ACR shows very strong case ascertainment of pediatric brain tumours captured by physician databases and should be considered a reliable database for pediatric brain tumour physicians and researchers when they require data for administrative or research purposes. Some caution should be exercised when using diagnostic and treatment variables though, as there is some disagreement with the data in the physician databases.

Unfortunately, the ACR is unable to provide real-time data and there is typically a two-year lag period before the data are recorded, reviewed, and ready for release. Physicians and researchers often cannot afford to wait this amount of time so they use their own resources to create their

own tumour-specific databases with relevant, real-time data. Another advantage of the physician collecting their own data is they are able to capture additional variables that are relevant to them that the ACR does not capture, such as actual treatment received, recurrences, and metastases. As evidenced in this study, the downside to this solution is that the physician databases do not use consistent coding practices for brain tumours and they only capture the patients they see.

These findings point to the need to better coordinate efforts between physicians and cancer registry staff to make the ACR more clinically relevant. If a process could be developed allowing physicians to provide the data they require in real-time to the ACR, the ACR could potentially provisionally code these data using provincially consistent standards. As the ACR goes through their formal coding practices, the coders would review the data and correct any potential discrepancies or errors the physicians had in their initial data submissions. This would allow data to be pulled from the ACR in a real-time manner, with the most recent data being provisional. Further discussion and work is required to see if this is a feasible and attainable solution but with the advancing technology we now have access to, a solution like this may be possible in the near future.

4.5 Suggested Next Steps

While overall case ascertainment of the ACR capturing pediatric brain tumours present in the physician databases was quite strong, further investigation into this issue is required. It is unclear how many cases were missed by both the ACR and the physician databases making it impossible to accurately measure overall case ascertainment of pediatric brain tumours. Methodology was used to estimate these cases but any cases that were missed by both databases would negatively affect the overall case ascertainment observed in this study. Further exploration into determining the actual number of missed cases would be beneficial.

Furthermore, this study only looked at the pediatric brain tumour population so the scope was very limited. This patient population requires very specialized care and the pediatric population often receives extra attention. As such, it is possible that while case ascertainment is strong for the pediatric brain tumour population, it may not be as good in the adult population. Also, benign

brain tumours are more common in the adult population (Rosychuk, 2011) and as the literature shows that these cases are more often missed in cancer registries, it is possible that the case ascertainment is not as good in the adult population. Also, if proportion of patients that do not have their imaging reports sent in to the ACR is higher in the adult population, this would mean that the overall case ascertainment of the ACR would be lower for this population.

To further the work in this area, a proposed next step could involve gathering adult pediatric brain tumour databases from across the province to perform a comprehensive review of ACR case ascertainment of all brain tumours. Similar studies assessing ACR case ascertainment and validation of data could also be performed in other cancers that are at higher risk of being under-reported, such as leukemia and lymphoma (Klint, 2009).

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Appendix

CBTRUS, Brain and Central Nervous System Tumor Histology Groupings (CBTRUS, 2015a)

Histology	ICDO-3[b] Histology Code
Tumors of Neuroepithelial Tissue	
Pilocytic astrocytoma	9421
Protoplasmic & fibrillary astrocytoma	9410, 9420
Anaplastic astrocytoma	9401, 9411
Unique astrocytoma variants	9383, 9384, 9424
Astrocytoma, NOS	9400
Glioblastoma	9440, 9441, 9442/3[c]
Oligodendroglioma	9450
Anaplastic oligodendroglioma	9451, 9460
Ependymoma/anaplastic ependymoma	9391, 9392, 9393
Ependymoma variants	9394
Mixed glioma	9382
Glioma malignant, NOS	9380
Choroid plexus	9390
Neuroepithelial	9381, 9423, 9430, 9444
Non-malignant and malignant neuronal/glial, neuronal and mixed	8680,8681, 8682, 8690, 8693, 9412, 9413, 9442/1[d], 9490, 9491, 9492, 9493, 9500, 9505, 9506, 9522, 9523
Pineal parenchymal	9360, 9361, 9362
Embryonal/primitive/medulloblastoma	8901, 8921, 8963, 9363, 9364, 9470, 9471, 9472,9473, 9474, 9501, 9502, 9503, 9508
Tumors of Cranial and Spinal Nerves	
Nerve sheath, non-malignant and malignant	9540, 9541, 9550, 9560, 9561, 9570, 9571
Other tumors of cranial and spinal nerves	9562
Tumors of Meninges	
Meningioma	9530, 9531, 9532, 9533, 9534, 9537, 9538, 9539
Other mesenchymal, non-malignant and malignant	8324, 8728, 8800, 8801, 8802, 8803, 8804, 8805, 8806, 8810, 8815, 8824, 8830 8831, 8835, 8836, 8850, 8851, 8852, 8853[e], 8854, 8857, 8861, 8870 , 8890, 8897, 8900, 8910, 8912[e], 8920, 8935, 8990, 9040, 9136[e], 9150, 9170, 9180, 9210, 9241, 9260, 9480, 9536
Hemangioblastoma	9161, 9535
Lymphomas and Hemopoietic Neoplasms	
Lymphoma	9590, 9591, 9596, 9650, 9651, 9652, 9653, 9654, 9655, 9659, 9661, 9662, 9663, 9664, 9665, 9667, 9670, 9671, 9673, 9675, 9680, 9684, 9687, 9690, 9691, 9695, 9698, 9699, 9701, 9702, 9705, 9714, 9719, 9727, 9728, 9729, 9731, 9733, 9734, 9740, 9741, 9750, 9755, 9756, 9757, 9758, 9760[e], 9766, 9826 , 9827, 9860, 9861, 9930, 9970
Germ Cell Tumors and Cysts	
Germ cell tumors, cysts and heterotopias	8020, 8440, 9060, 9061, 9064, 9065, 9070, 9071, 9072, 9080, 9081, 9082, 9083, 9084, 9085, 9100, 9101
Tumors of Sellar Region	
Pituitary	8022, 8040, 8140, 8146, 8190, 8202, 8240, 8246, 8260, 8270, 8271, 8272, 8280, 8281, 8290, 8300, 8310, 8320, 8323, 8333, 8334, 8341, 9582
Craniopharyngioma	9350, 9351, 9352
Local Extensions from Regional Tumors	
Chordoma/chondrosarcoma	9220, 9231, 9240, 9370, 9371, 9372, 9373
Unclassified Tumors	
Hemangioma	9120, 9121, 9122, 9123, 9125, 9130, 9131, 9133, 9140
Neoplasm, unspecified	8000, 8001, 8002, 8003, 8004, 8005, 8010, 8013, 8021
All other	8452, 8683, 8710, 8711, 8713, 8720, 8811, 8840, 8860, 8896, 8980, 9173 9580, 9751, 9752, 9753, 9754, 9823, 9826, 9837, 9866