UNIVERSITY OF ALBERTA
SCHOOL OF PUBLIC HEALTH

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What can we learn about rare cancers: An example from Brain Tumors

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Rare Cancers

- Receive less scientific attention and fiscal support than common tumours.
- Scarcely documented in the medical and public health literature.
- Understanding basic descriptive epidemiology has been impeded
- Can be highly fatal: limited evidence to guide clinical deliberations.

An example from brain tumours

- Background
  - Rationale (CBTRUS)
- Current Status in Canadian registries
- Ongoing work to harmonize and report brain tumour data
- Implications for other rare cancers

Historical Perspective (US): Cancer Reporting Criteria

	Clinical	Registry
Malignant	Yes	Yes
Nonmalignant	Yes	No

*SEER and NAACCR

Rationale: Reporting Brain Tumors

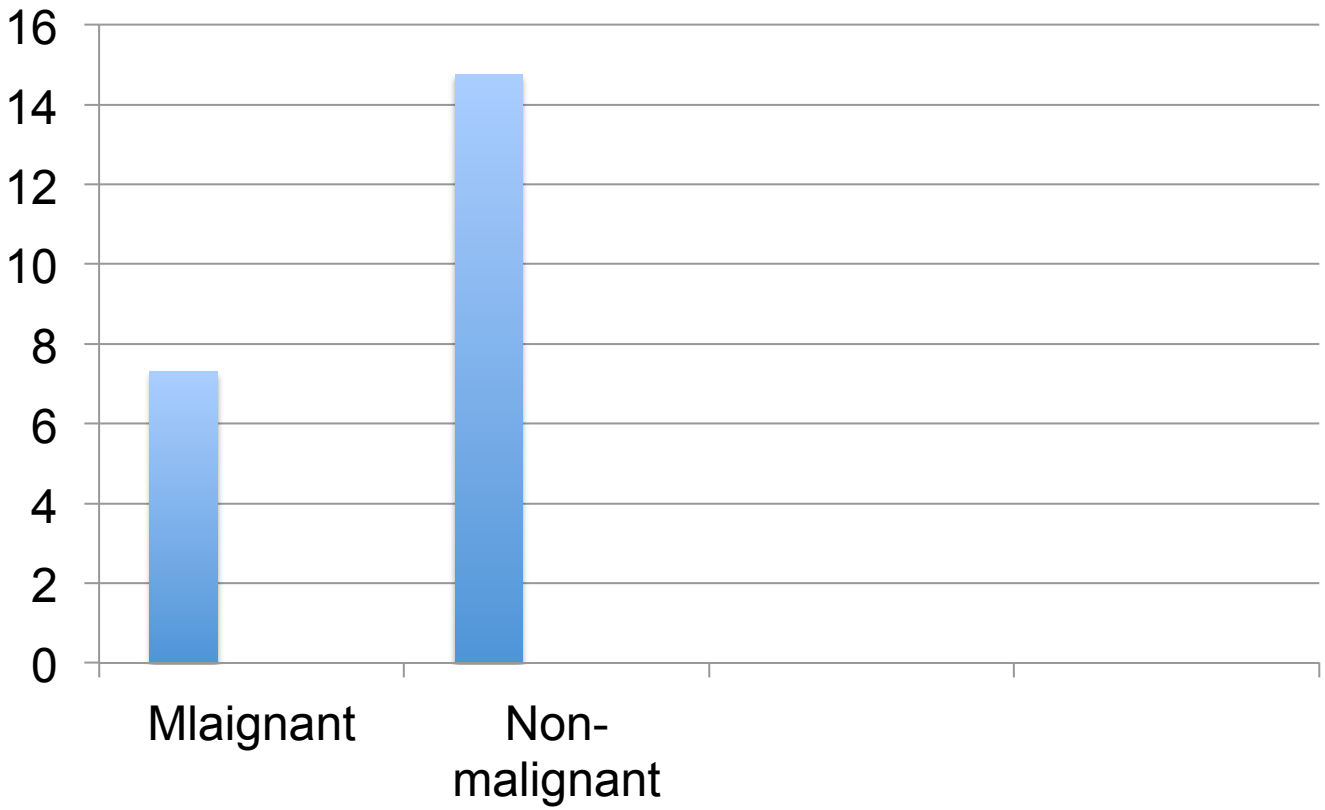
- Malignant and nonmalignant tumors may be devastating
- Prognosis dependent on histology, location then behavior
- Unique patterns by tumor type
- Differing etiology by tumor type Schoenberg, 1970s
- Progression: low to high grade gliomas

Consensus and Legislation

- Definition
  - "all histologies of primary neoplasms found (regardless of behavior) and reported in the brain or CNS with ICDO site codes (C70.0-C72.9 and C75.1-C75.3) and available within the most recent coding and classification schemes, ICDO-3 and WHO 2000"
- Legislation passed for reporting of all brain tumours in 2002

➢ Definition implemented through cancer surveillance legislation 2002

Primary brain tumours:
CBTRUS 2015



Canada: Private Member Bill: M-235

- That, in the opinion of the House, the Minister of Health should continue to work collaboratively with Statistics Canada, the provincial and territorial cancer registries and key stakeholders towards the ultimate goal of creating uniform national standards and guidelines for the surveillance of all malignant and benign brain tumours, including data collection, analysis and reporting" (passed 02/14/2007)

PHAC report (2009)

- Identified barriers to BBTs reporting
  - 4/13 CRs did not report (QU, ON, NWT, Yukon)
  - No provincial legislation MB, NB, PEI
- When collected – not reported to SC for CCR

- 1/3 of benign brain tumours expected are collected at the provincial level (Shaw unpub)
- The numbers of gliomas reportes are similar to those expected based on US rates (Shaw unpub)

Where are we at?

- Over half of brain tumor cases missed but:
- Moving forward with BC/AB ascertainment of nonmalignant data from 2010 forward
- Creating multidisciplinary synergies within and across provinces to make high quality data/multidisciplinary research feasible
- Goal: sustainability and innovation

Does it matter?

- Health services cannot
  - adequately plan for and efficiently fund healthcare for brain tumor patients if do not know they exist.
  - measure whether they are meeting their targets.
- Scientific research into brain tumours is hampered.

Comments on rare cancers

- What is rare? (Greenlee 2010)
  - <15 cases/100,000/yr (40k US cases)
  - 60 of 71 cancer types rare
  - account for 25% of all cancer
  - Disproportionately affect younger, nonwhite, hispanic ethnicities

CCS 2015

- Common:
  - Lung, breast, colorectal, prostate, bladder, non-hodgkins lymphoma, body of uterus
  - Accounts for 63% of all new estimated cases in 2015.
- Rare (<15/100,000):
  - Remaining 18 categories: 37% of all cancers
  - Expect 6300 cases per year

Categories of rare tumours CCS 2015

- 10-15/100,000/yr
  - Melanoma, thyroid, kidney, leukemia
- <10/100,000/yr
  - Pancreas, oral, stomach, brain/cns, ovary, multiple myeloma, esophagus, liver, cervix, larynx, testis, hodgkins lymphoma

Patterns over time (CCS 1986-2015)

- Increasing in males and female
  - Liver (Labine 2015), larynx
- Increasing in females
  - Melanoma, bladder
- Increasing in males
  - Stomach, thyroid

Opportunity to be innovative

- Population based registries of high quality
- Population/administrative databases provide opportunities for linkages (ie – SEER/ medicare files, cohort studies)
- new technology/strategies may help reduce the delays in case identification that limit registry use by clinicians and researchers
- Teams of stakeholders for each rare cancer may help drive forward progress on these tumours – each will have unique issues.

- Thank you to the Canadian Brain Tumor Foundation for their vision and
- To brain tumor patients and their families for support of the current registry initiative
- To the many collaborators making this work possible.

Study of rare cancers (ORD 2009) Recommendations

- Biospecimens
- Centers of excellence
- Funding
- Comprehensive Knowledge database
- Animal models
- New detection, prevention methods
- Role for advocacy groups

A comprehensive approach

- Aim 1: BBT from 2010 forward AB, BC
- Aim 2: Compile comprehensive surveillance report (2010-2015)
  - Qu, On, MB, AB, BC
  - Reflect 90% of all primary BTs in Canada
- Aim 3: Enhance research support (accessibility, RCA? Linkages?)
- Aim 4: Recommendations for new molecular markers/classifications