

National brain tumour registry: a new era of research collaboration with China

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Cancer continues to be a leading cause of death globally.¹ However, there remains a significant disparity in the reported incidence of cancer in developed countries, estimated to be 295.3 cases per 100,000 people, compared with only 115.7 in developing countries.² Some of the reasons for this variation include lack of robust data collection with limited reporting systems, and insufficient data availability in the registries of these developing nations.³ Globally, there were 308,102 new cases of brain and central nervous system (CNS) cancers reported in 2020, making it the 21st most common cancer type.⁴ Consistent with its rapid economic growth, the spectrum of cancer diagnoses in China is also developing⁵; however, with it remains to be seen how Chinese CNS tumour statistics compare with the global trends over the next decade. In this issue of *The Lancet Regional Health—Western Pacific*, Xiao et al. provide the largest and most comprehensive report of patients diagnosed with brain tumours in over 50 registered institutes in China over the period of 2 years (2019–2020).⁶

The National Brain Tumour Registry of China (NBTRC) was established in 2018 to address the lack of standardised data collection at a national level. The assembled data is robust and uniform owing to the methods employed. Tumour pathology and anatomical sites were coded based on the 4th World Health Organization (WHO) classification of CNS tumours (2016) and ICD-O-3 and the Surveillance, Epidemiology, and End Results (SEER) modules at the time. Data from this first nationwide brain tumour registry can now begin to

be compared to other regions in the world. Authors were able to tease out the paediatric subgroup (0–14 years) with distinct histological and anatomical site distribution. The authors note early differences in the spectrum of diseases seen in China including less cases of meningioma and glioblastoma but more frequent diffuse and anaplastic astrocytoma compared to “Western” registries.^{7,8} This article also underscores the need for more balanced neurosurgical skills development across this vast country.

Over the last decade, data from Chinese based registries have begun to be shared globally. From 2010, registry based reports have increased from 15 to more than 250 in the available literature in 2022. While this is not a true population-based registry, the inclusion of more than 50 hospitals across China is a great start that the authors are keen to continue to expand. Global collaboration has seen the improvement in cancer outcomes for many malignancies, particularly in paediatrics, including but not limited to medulloblastoma, acute leukaemia, and others.⁹ At the heart of these collaborations is clinical trials with sharing of data and tissues with research colleagues from around the world to improve outcomes for children. As the most populous country on Earth to date, China has had little engagement in collaborative paediatric oncology projects. Through numbers alone, if the international paediatric community is better able to engage with Chinese patients and clinicians in global studies, rare conditions that take much time to accrue patients to meaningful studies could dramatically speed the time to recruitment and improve outcomes.

Recently we have seen focused international efforts to increase the speed of recruitment of patients diagnosed with uniformly lethal and rare diffuse intrinsic pontine gliomas (DIPG) or diffuse midline gliomas (DMG), and the collaborative testing of novel combination strategies through international consortia such as



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the Pacific Neuro-Oncology Consortium (PNOC) and The Collaborative Network for Neuro-oncology Clinical Trials (CONNECT). One such trial is PNOC022 (NCT05009992) slated to open in 32 centres around the world (25 open currently).^{10,11} Importantly, epidemiological data and tissue banking for correlative studies is critical in the design of this adaptive trial, and used for the determination of drug penetration, on target pharmacodynamic characteristics, immune cell profiling and molecular characterisation. While the slightly higher incidence of DMG seen in the NBTRC (5.13% vs. 4.8% in CBTRUS) can be explained on the basis of regional variation; tumour location showed marked differences. Brainstem tumours are reported to be much more common in Chinese children (20.24% NBTRC vs 12.6% CBTRUS).⁷ These data will need further exploration moving forward, which will help to identify factors associated with this increased incidence. Nevertheless, the NBTRC is a potentially powerful platform for international collaboration particularly if economic and logistic challenges around fresh sample collection and transportation can be achieved. An additional complexity that will need to be addressed, is the necessity to establish open and collaborative data sharing arrangements. But if possible, international collaboration could assist the NBTRC to provide their patients with molecular and epigenetic tissue profiling and help to refine diagnosis and prognosis, identify biomarkers of outcome and further increase the power of this initiative, thereby helping the NBTRC to play an important role in the international efforts to develop treatment strategies that improve outcomes for paediatric CNS tumour patients.

There is also a need to investigate how the geographical and ethnic factors affect brain tumour distribution and outcomes in diverse global regions. The limiting factor, however, is the lack of standard and uniform patient registries in underdeveloped countries leading to inaccurate and unreliable information. NBTRC is a significant step forward in overcoming this problem and data collected under this registry will likely provide insights into the epidemiological parameters of

brain tumour patients in China. Due to its comprehensive nature, it will also help in analysing data and increased collaboration at a global level and hopefully open the doors for more clinical trials participation of Chinese patients in international studies.

Contributors

SV, MD, and JRH each contributed to all aspects of this editorial.

Declaration of interests

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