

Establishment of the National Brain Tumor Registry of China

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Brain tumors encompass a complex group of intracranial neoplasms that mostly affect young adults and children, with a high incidence rate and poor prognosis.¹ Brain tumor registries have been instituted in several developed countries to support multicenter collaborative studies across the world.² In 2002, the National Central Cancer Registry of China was established to focus on the epidemiologic distribution and characteristics of various cancers, including brain tumors.³ However, the National Central Cancer Registry of China does not collect detailed patient-level data (eg, diagnosis and treatment), which are critical for conducting multicenter clinical studies.

To provide high-quality data for multicenter research and to break the barriers in database sharing between different hospitals from diverse regions in China,⁴ the National Brain Tumor Registry of China (NBTRC) was established by the China National Clinical Research Center for Neurologic Diseases in January 2018 with the support of the Chinese government.

The NBTRC consists of 54 national or regional neurosurgery centers and is chaired by Professor Liwei Zhang, president of the Chinese Neurosurgeons Association and vice president of the Beijing Tiantan Hospital.⁵ The NBTRC is administered by its scientific and executive committees. The scientific committee provides design and guidance for the construction and operation of the platform and assesses the scientific rationale and feasibility of research protocols. The executive committee is responsible for technical support and daily management.

Rigorous quality control of the platform is maintained by the executive committee on the basis of seven quantifiable indicators of each center's incoming data:

without interruption, similar monthly volumes, diagnostic accuracy, timeliness, completeness, percent of reported cases, and follow-up rate. Rather than monopolizing the database at the leadership level, the NBTRC provides data to participating centers in a manner commensurate with the quantity and quality of data they report to the platform.

The NBTRC is highly feasible, with unique attributes. First, because neuro-oncologic surgeon availability is concentrated in urban areas,⁴ patients with brain tumors must seek medical care within a small subset of all the hospitals. The NBTRC collects data solely from such hospitals, which ensures the quality of the platform. Second, the data sharing among participating centers inspires enthusiasm, promotes cooperation, and makes full use of data, thereby making clinical research more efficient. Third, the NBTRC provides customized follow-up schedules, including data entry templates at prespecified time intervals on the basis of the diagnosis and location of tumor, which significantly improves the quality and convenience of follow-up. Fourth, participating hospitals can upload data to the NBTRC in multiple ways, including the Web site and offline software (both requiring manual entry) and remote physical servers that automatically abstract data into the platform. This flexibility increases the convenience and inclusiveness of the NBTRC.

We welcome more hospitals to join us in this meaningful endeavor. We are exploring brain tumor data collection, management, and application patterns. We believe that the NBTRC can serve as a reference for registries of other complex diseases. The detailed protocol of the platform is forthcoming.

Author affiliations and support information (if applicable) appear at the end of this article.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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