



Editorial

Establishing the National Brain Tumor Registry of Libya (NBTRL): A Comprehensive Approach to Enhance Patient Care

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Brain tumors, both benign and malignant, represent a significant and complex health challenge due to their impact on the central nervous system. In Libya, the absence of a centralized database has hindered the ability to accurately track the incidence, outcomes, and trends of brain tumors, leading to gaps in effective management, treatment, and research. This research proposal outlines the establishment of a National Brain Tumor Registry in Libya, aimed at systematically collecting, managing, and analyzing data on brain tumor cases across the country. This initiative is intended to enhance patient care, facilitate research, and inform public health policies.

The primary objective of the National Brain Tumor Registry of Libya (NBTRL) is to establish a comprehensive national registry that will systematically collect and manage data on brain tumor cases from major hospitals and specialized oncology centers across Libya. This registry is designed to enhance patient care by providing insights into treatment outcomes based on data-driven analysis. Additionally, it aims to facilitate both national and international research collaborations by offering a robust dataset on brain tumor epidemiology and clinical characteristics. Furthermore, the registry seeks to inform public health policies and guide resource allocation for brain tumor treatment and research.

The establishment of a brain tumor registry in Libya is essential for several reasons. It will provide critical epidemiological data necessary to understand the incidence and distribution of brain tumors within the country. This registry will enable healthcare providers to monitor patient outcomes, identify best practices, and ultimately improve the quality of care. By consolidating data from multiple centers, the registry will also serve as a valuable resource for researchers aiming to uncover new insights into the biology and treatment of brain tumors. Moreover, the registry will position Libya as a contributor to the global body of knowledge on brain tumors, thereby fostering international collaborations and participation in multicenter studies.

The methodology for establishing the NBTRL will be executed in three phases. The initial setup and pilot phase will involve establishing a central registry office, developing the Web-based Health Information Portal (WHIP) integrated with an online office suite for data entry and management, and piloting the registry in selected hospitals, including Tripoli University Hospital and Benghazi Medical Center. The expansion phase will involve extending the registry to additional hospitals, such as Misrata Cancer Center and Sabha Medical Center, and launching a public-facing website with real-time data updates, dynamic maps, and interactive dashboards. The final phase will include the full implementation of the registry across all identified hospitals in Libya, along with regular evaluations and refinements of protocols based on feedback and data analysis.

Data collection for the NBTRL will involve the comprehensive collection of patient information, including demographics, medical history, and treatment details, detailed surgical records, and histopathological and molecular data of brain tumors, including tumor type, grade, and genetic markers. To ensure data quality and integrity, standardized data entry formats will be employed, accompanied by validation checks and regular training sessions for hospital staff.

The NBTRL will adhere to strict ethical guidelines to ensure patient confidentiality and compliance with legal standards. A standardized consent form will be developed for patient permission for data collection and use, and robust cybersecurity measures, including encryption, multi-factor authentication, and regular security audits, will be implemented to protect sensitive data. The expected outcomes of the NBTRL include improved patient care

through data-driven decision-making, facilitation of both national and international research collaborations leading to new insights into brain tumor treatment and biology, and informed public health strategies and policies based on reliable epidemiological data.

The establishment of the National Brain Tumor Registry of Libya (NBTRL) represents a transformative step forward in the healthcare landscape of Libya. This initiative holds the promise of significantly enhancing patient care, advancing research, and informing public health strategies. By systematically collecting, managing, and analyzing data on brain tumor cases, the NBTRL will provide invaluable insights into the epidemiology, treatment outcomes, and clinical characteristics of brain tumors in Libya. These insights will not only improve the quality of care provided to patients but also position Libya as a key contributor to the global understanding of brain tumors.

The benefits of the NBTRL extend across multiple dimensions. For healthcare providers, the registry will serve as a critical tool for monitoring patient outcomes, identifying best practices, and improving clinical decision-making. In addition, for researchers, the aggregated data will offer a robust foundation for studies aimed at uncovering new insights into brain tumor biology and treatment. Moreover, for public health officials, the registry will provide the data necessary to inform policies and resource allocation, ultimately leading to better healthcare planning and delivery across the country [1-2].

While the potential benefits of the NBTRL are significant, the project also faces several challenges and limitations that must be carefully managed to ensure its success. One of the primary challenges in establishing the NBTRL is ensuring consistent and accurate data collection across various hospitals and healthcare centers in Libya. The current variability in medical record-keeping practices across different facilities poses a significant obstacle to creating a standardized and reliable dataset. Inconsistent data entry and reporting could lead to incomplete or inaccurate information, undermining the registry's overall effectiveness. Addressing this challenge will require the development and enforcement of uniform data collection protocols, along with continuous training and support for healthcare personnel involved in data entry.

The NBTRL is heavily dependent on a centralized web-based Health Information Portal (WHIP) and an integrated online office suite for data management. However, the technological infrastructure in some regions of Libya may not be sufficiently developed to support these tools effectively. In rural or conflict-affected areas, hospitals may experience unreliable internet connectivity, inadequate hardware, and limited technical support, which could hinder their participation in the registry. To overcome these challenges, significant investment in technological infrastructure and ongoing technical support will be necessary. The success of the NBTRL also relies on the availability and expertise of trained personnel to accurately enter and manage data. However, there is considerable variation in the skill levels and availability of trained staff across Libyan healthcare facilities. Ensuring that all personnel involved in the registry are adequately trained will be crucial to maintaining high standards of data quality. This will require the implementation of comprehensive training programs, which may be resource-intensive and necessitate ongoing support to ensure that staff remain proficient in their roles.

Obtaining informed consent from patients is an essential ethical requirement for the NBTRL. However, the process of securing consent may be complicated by cultural differences, varying levels of patient literacy, and concerns about privacy. Some patients may be hesitant to consent to data collection due to fears about potential misuse of their information or breaches of confidentiality. To address these concerns, it is important to develop culturally sensitive and clear consent processes that ensure patients fully understand and agree to the use of their data.

The long-term sustainability of the NBTRL is another critical consideration. The registry's operations, including technological maintenance, training, and data management, will require consistent and reliable funding. Fluctuations in funding availability, particularly in the context of Libya's political and economic instability, could jeopardize the sustainability of the registry. Ensuring long-term funding will likely require securing commitments from both governmental and non-governmental organizations, as well as exploring partnerships with international research institutions. Effective coordination among the various hospitals and healthcare centers (Inter-Hospital Coordination) involved in the NBTRL is essential for its success. However, differences in management structures, operational protocols, and institutional priorities across these facilities may complicate coordination efforts. These variations could lead to delays in data submission or inconsistencies in the quality of data provided. Establishing a central coordinating body to oversee the registry's implementation and

ensure alignment among participating hospitals will be crucial, though it may present challenges in execution.

The ongoing political instability and social unrest in certain regions of Libya present additional challenges to the uniform implementation of the NBTRL. In conflict-affected areas, healthcare facilities may experience disruptions in service delivery, making consistent data collection and reporting difficult. Ensuring that the registry remains operational and accessible in these regions will require the development of adaptive strategies and contingency plans, such as phased implementation or the use of mobile data collection units.

The National Brain Tumor Registry of Libya has the potential to significantly improve patient care, advance research, and inform public health strategies in the country. By addressing the challenges and limitations outlined above, the NBTRL can achieve its full potential and become a cornerstone of Libya's healthcare system. Through careful planning, strategic investments, and sustained commitment from all stakeholders, the registry can provide invaluable insights that will drive advancements in the treatment and management of brain tumors both nationally and internationally.

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