



## Current State of the Neurotrauma Registry Implementation in Africa (NEUTRIA STUDY) and Challenges

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■ **BACKGROUND:** Traumatic brain injury (TBI) data in Africa remain limited, underscoring the need for a robust neurotrauma registry. This study evaluates the availability, implementation, and challenges of the Neurotrauma Registry in Africa (NEUTRIA) and provides recommendations for developing a continent-wide TBI registry.

■ **METHODS:** An e-survey was distributed via Google Forms to neurosurgeons and neurosurgical trainees across Africa from November 1 to December 10, 2024. From the 54 African countries, 81.5% (n = 44) responded. Ninety-seven responses were recorded for 91 (93.8%) inclusion from 39 (72.2%) African countries. Statistical analysis was performed using JAMOVI 3.2.0.

■ **RESULTS:** Neurosurgical centers were unevenly distributed, with 47.3% of respondents reporting 3–5 centers across 21 countries. Most centers (75.8%) served public and private systems, while 22.0% were exclusively public. Paper-based registries for TBI and traumatic spinal cord injury were used in 79.1% of centers, while 46.2% employed electronic systems, with Excel being the most common platform. Seven countries (Tanzania, Mozambique, Egypt, Rwanda, Cameroon, Zambia, and Uganda) had national registries, each with variable patient volumes. Key challenges included administrative burdens, material and staffing shortages, time constraints, and limited awareness about the registry's importance. Financial support from governments and nongovernment organizations was

### Key words

- Africa
- Challenges
- Neurotrauma registry
- Implementation

### Abbreviations and Acronyms

**AFAN:** Association of Future African Neurosurgeons  
**CAANS:** Continental Association of African Neurosurgical Societies  
**GEO-TBI:** Global Epidemiology and Outcomes following Traumatic Brain Injury  
**GNOS:** Global Neurotrauma Outcomes Study  
**LMICs:** Low and middle-income countries  
**MDI:** Minimum Dataset for Injury  
**NEUTRIA:** Neurotrauma Registry in Africa  
**NTRs:** Neurotrauma registries  
**SAFNA:** Sub-Saharan African Future Neurosurgeons Association  
**TBI:** Traumatic brain injury  
**TSCI:** Traumatic spinal cord injury  
**WHO:** World Health Organization  
**Young CAANS:** Young African Neurosurgeons Forum

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## crucial for implementing national registries and improving data collection and neurotrauma care across the continent.

■ **CONCLUSIONS:** This study highlights the uneven distribution of neurotrauma care and African registries. Although progress is evident, significant barriers hinder widespread implementation. Expanding financial support and addressing systemic challenges is critical for advancing data collection and improving neurotrauma care continent-wide.

## INTRODUCTION

Neurotrauma, encompassing injuries to the brain and spinal cord, is a leading cause of death and disability among trauma patients.<sup>1</sup> Globally, motor vehicle accidents (road traffic accidents), falls, and interpersonal violence are the primary contributors, resulting in approximately 4 million deaths annually.<sup>2,3</sup> To address the burden and outcomes of neurotrauma effectively, registries have emerged as essential public health tools. These registries help to: 1) assess trends in neurotrauma, 2) determine the prevalence and incidence over time, 3) evaluate the effectiveness of interventions, and 4) identify gaps in care, providing a foundation for developing standardized and context-adapted approaches to neurotrauma care.<sup>4</sup> Neurotrauma registries (NTRs) have been established in several countries worldwide and have proven to be invaluable in improving neurotrauma care. However, there is a significant disparity in developing NTRs between high-income countries and low- and middle-income countries (LMICs). Despite the higher burden of neurotrauma in LMICs, the majority lack a functional NTR or trauma system.<sup>5</sup> A review by Barthélémy et al. (2022) found that only 16 LMICs had a NTR, with just 3 in Africa: Cameroon, Egypt, and Rwanda.<sup>6</sup>

Developing a NTR is crucial, particularly in Africa, to facilitate data collection for scientific research, inform legislation treatment coordination, and ultimately improve clinical outcomes.<sup>1</sup> Furthermore, the large pool of neurotrauma patients in Africa must be studied to develop effective local protocols and understand the unique characteristics of African patients.<sup>3</sup> However, the establishment of such a registry is hindered by challenges, including a limited workforce, insufficient awareness among healthcare workers, inadequate technological infrastructure, and lack of funding. The Global Neurotrauma Outcomes Study (GNOS), initiated by the National Institute for Health and Care Research Global Health Research Group on Neurotrauma, established the Global Epidemiology and Outcomes following Traumatic Brain Injury (GEO-TBI) registry.<sup>7</sup> Still, African participation was limited to Ethiopia, Tanzania, and Zambia.<sup>8</sup>

Recognizing the outdated and fragmented nature of existing data on NTRs in Africa, this study aims to evaluate the availability, implementation, and challenges of NTRs across the continent. It also seeks to provide actionable recommendations for a continent-wide approach to establishing NTRs.

## METHODS

### Study Design and Participants

This multinational, cross-sectional survey was conducted across Africa. The target participants were neurosurgeons and neurosurgical trainees, identified through neurosurgical societies and interest groups, including the Association of Future African Neurosurgeons (AFAN), the Young African Neurosurgeons Forum of the Continental Association of African Neurosurgical Societies (Young CAANS), and the sub-Saharan African Future Neurosurgeons Association (SAFNA).

### Survey Distribution

An electronic questionnaire was designed using Google Forms and distributed from November 1 to December 10, 2024. The survey was shared through social media platforms (Telegram and WhatsApp) to maximize reach and engagement. Weekly reminders were sent to participants to enhance response rates. Two weeks after the initial launch, personalized reminders were sent to 478 neurosurgeons and trainees from neurosurgical interest groups (AFAN = Association of Future African Neurosurgeons and SAFNA = sub-Saharan African Future Neurosurgeons Association), with subsequent follow-ups every 3 days for 2 additional weeks. Unfortunately, many did not fill out the form because they were either medical students or not working at a neurotrauma center, as the questionnaire demands. A QR code linked to the survey was also displayed during the pre-congress courses (>150 participants) of the fifth Continental Association of African Neurosurgical Societies (CAANS) Congress in Kinshasa, Democratic Republic of Congo (November 23–25, 2024).

### Survey Instrument

The survey comprised 22–30 open- and closed-ended questions covering respondent demographics, the availability and types of NTRs, their coverage, and challenges in implementing them (**Supplementary: Questionnaire**). Respondents provided institution-specific data on NTRs and estimated information on their current employment settings.

### Data Collection and Analysis

Data on NTR types—paper-based, electronic, and national—were collected from respondents and organized by country distribution. The responses were prospectively compiled and tabulated in Microsoft Excel for further analysis. Out of 97 responses from 44 participating countries (81.5%, considering the 54 African countries), 91 (93.8%) responses were included (**Table 1**). Statistical analysis was performed using JAMOVI 3.2.

## RESULTS

### Center Distribution and Facilities for Neurotrauma Patient Care

From the 54 African countries, 81.5% (n = 44) responded, and **Table 1** shows the 6 responses excluded with the reasons. A total of 91 responses (93.8%) from 39 (72.2%) African countries were analyzed, with all respondents reporting involvement in neurotrauma patient management.

**Table 1.** The Distribution of Responses and Reasons for Inclusion and Exclusion in the Study

Responses from	Excluded Responses and Reasons	Included Responses and Reasons
2 countries	4 responses from non-African countries	-
1 country	1 incomplete response	-
1 country	1 response from anesthesiologist	-
39 countries	-	91 responses from neurosurgery departments in African countries
44 countries	6 responses excluded	91 responses included

The distribution of neurosurgical centers varied widely (Table 2). The majority of respondents (47.3%, n = 43) reported the presence of 3–5 centers in 21 countries. Nine countries had more than 5 centers (38.5%, n = 35), while 7.7% (n = 7) of respondents indicated a single center in 3 countries, and 4 countries were reported to have approximately 2 centers (6.6%, n = 6).

In terms of facility types, 75.8% (n = 69) of centers operated within both public and private healthcare systems across 31

countries. Public-only facilities accounted for 22.0% (n = 20), located in Benin, Cabo Verde, Liberia, and Gabon. Exclusively private care was reported in Guinea-Bissau and Equatorial Guinea (2.2%, n = 2) (Table 2).

#### Paper-Based Hospital Neurotrauma Registry:

The availability and usage of paper-based hospital registries for TBI and traumatic spinal cord injury (TSCI), based on the 7 components of the World Health Organization (WHO) Minimum Dataset for Injury (MDI), were reported in 72 centers (79.1%) across 37 countries (Table 2). In 76.9% (n = 70) of these centers, TBI and TSCI were documented in separate registries, while 2.2% (n = 2) of centers used a combined registry for both conditions. A smaller proportion of respondents, 17.6% (n = 16), confirmed having a paper-based registry, while 3.3% (n = 3) were uncertain of their availability.

Regarding staffing, the registries were predominantly managed by “senior registered nurse + residents” in 48.7% (n = 38) of cases, followed by “medical secretary + residents + staff” in 20.5% (n = 16), “residents” alone in 17.9% (n = 14), and “residents + staff” in 12.8% (n = 10) of cases.

The patient volume recorded in the registries varied, with 43.2% (n = 32) of centers documenting between 500 and 1500 patients, 41.9% (n = 31) handling fewer than 500 patients, 10.8% (n = 8) reporting between 1500 and 3000 patients, and only 4.1% (n = 3) documenting over 3000 patients (Figure 1).

**Table 2.** Summary of Major Study Findings Description

Category	Description	Number (Percentages)	Countries
Number of neurosurgical departments	More than 5 centers	35 (38.5%)	Nigeria, Tanzania, Morocco, Democratic Republic of Congo, Ethiopia, Burkina Faso, Mali, Egypt, Zimbabwe
	3–5 centers	43 (47.3%)	Niger, Ghana, Somalia, Senegal, Togo, Mozambique, Rwanda, Cameroon, Botswana, Namibia, Zambia, Malawi, Angola, Kenya, Chad, Algeria, Tunisia, Congo, Guinea, Ivory Coast, Uganda
	2 centers	6 (6.6%)	Benin, Djibouti, Gabon, Equatorial Guinea
	1 center	7 (7.7%)	Cape Verde, Liberia, Guinea-Bissau
Facilities distribution	Private and public facilities	69 (75.8%)	Nigeria, Tanzania, Morocco, Democratic Republic of Congo, Ethiopia, Burkina Faso, Mali, Egypt, Djibouti, Zimbabwe, Niger, Ghana, Somalia, Senegal, Togo, Mozambique, Rwanda, Cameroon, Botswana, Namibia, Zambia, Malawi, Angola, Kenya, Chad, Algeria, Tunisia, Congo, Guinea, Ivory Coast, Uganda
	Public facilities only	20 (22.0%)	Benin, Cabo Verde, Liberia, and Gabon
	Private facilities only	2 (2.2%)	Guinea-Bissau and Equatorial Guinea
Paper-based neurotrauma registries	Available and used in centers (WHO-MDI)	72 (79.1%)	Côte d'Ivoire, Zambia, Cabo Verde, Nigeria, Tanzania, Morocco, Democratic Republic of Congo, Ethiopia, Burkina-Faso, Benin, Togo, Mali, Egypt, Zimbabwe, Somalia, Niger, Ghana, Mozambique, Rwanda, Cameroon, Botswana, Namibia, Malawi, Angola, Kenya, Djibouti, Chad, Congo, Guinea, Equatorial Guinea, Guinea-Bissau, Algeria, Tunisia, Uganda, Liberia, Gabon
Electronic-based neurotrauma	WHO Minimum Dataset for Injury (MDI)	42 (46.2%)	Nigeria, Tanzania, Morocco, Democratic Republic of Congo, Ethiopia, Mali, Egypt, Zimbabwe, Niger, Cabo Verde, Ghana, Mozambique, Rwanda, Cameroon, Botswana, Namibia, Malawi, Angola, Kenya, Algeria, Tunisia, Uganda, Equatorial Guinea, Liberia

**Electronic Hospital-Based Neurotrauma Registry.** Electronic hospital-based registries for TBI and TSCI, aligned with the 7 components of the WHO MDI, were reported in 42 centers (46.2%) across 24 countries (Table 2). 47.3% (n = 43) of the respondents indicated their centers lacked a NTR, while 6.6% (n = 6) were unsure. TBI and TSCI were documented in separate systems in the centers using electronic registries.

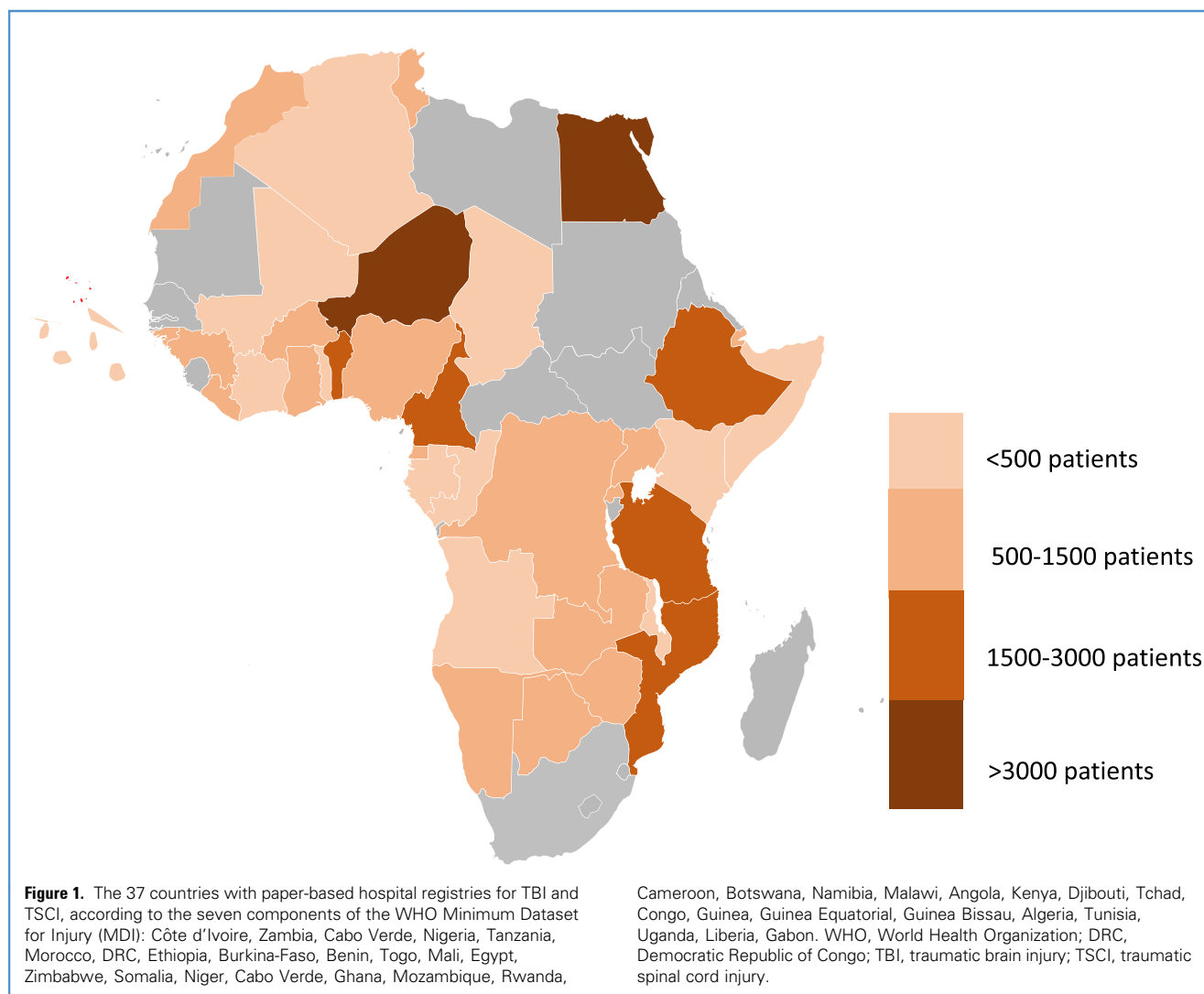
The staffing for these registries was most commonly comprised of “medical secretary + residents + staff” in 47.6% (n = 20) of centers, followed by “resident + staff” in 45.2% (n = 19), and “senior registered nurse + residents” in 7.1% (n = 3).

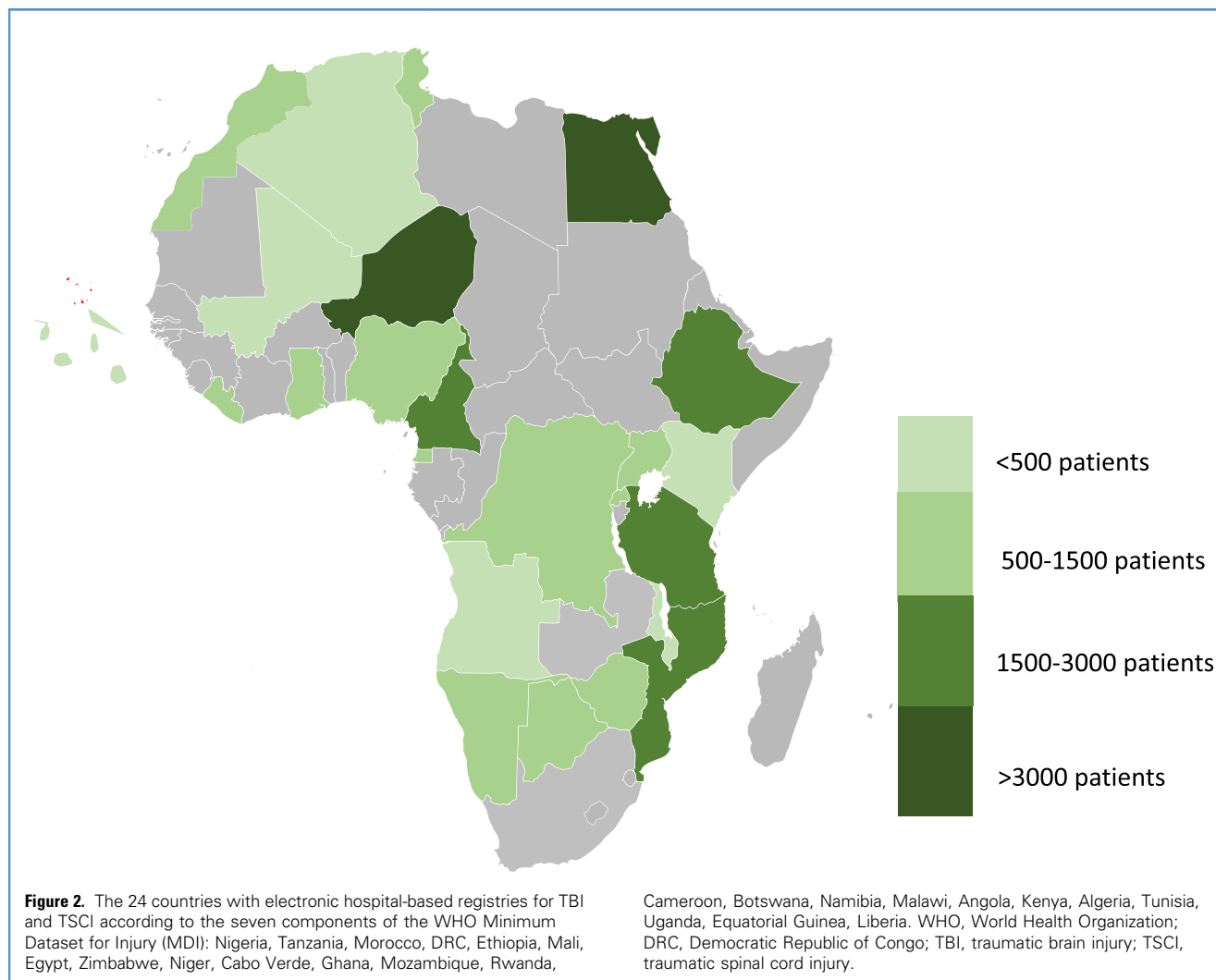
Patient volumes varied, with 38.1% (n = 16) of centers documenting fewer than 500 patients annually and another 38.1% (n = 16) recording between 500 and 1500 patients. Larger volumes were reported in 14.3% (n = 6) of centers (1500–3000 patients) and 9.5% (n = 4) of centers (more than 3000 patients) (Figure 2).

Excel was the most commonly used software (76.2%, n = 32), followed by RedCap (14.3%, n = 6), Word (4.8%, n = 2),

Electronic Medical Records systems (2.4%, n = 1), and the Lightwave Health Information Management System (2.4%, n = 1).

**National Neurotrauma Registry.** National NTRs were reported in 7 countries: Tanzania, Mozambique, Egypt, Rwanda, Cameroon, Zambia, and Uganda, accounting for 15.9% (n = 14) of respondents. The registry is managed by a team consisting of medical secretaries, residents, and staff. The annual size of the registry varies, with the majority (35.7%, n = 5) recording between 1500 and 3000 patients, followed by 28.6% (n = 4) reporting between 500 and 1500 patients, 21.4% (n = 3) with over 3000 patients, and 14.3% (n = 2) recording fewer than 500 patients (Figure 3). One respondent from Nigeria reported their national registry is ongoing, and 12 respondents from 5 countries (Ghana, Democratic Republic of Congo, Morocco, Angola, and Ethiopia) have reported their national registry “may be” ongoing. Moreover, the survey was set to allow only those reporting that “yes” they do have a national registry to continue





and give details about the challenges and their national registry characteristics.

**Challenges Implementing the National Registry.** Challenges included administrative burdens (42.9%,  $n = 6$ ), material and staffing limitations (50.0%,  $n = 7$ ), and time constraints due to high patient volumes (64.3%,  $n = 9$ ). Limited awareness of registry importance was universally noted. Support for New Technology and Informatics was received by 85.7% ( $n = 12$ ) of respondents. Funding sources for registry implementation were evenly split between governments (50.0%,  $n = 7$ ) and nongovernment organizations (50.0%,  $n = 7$ ).

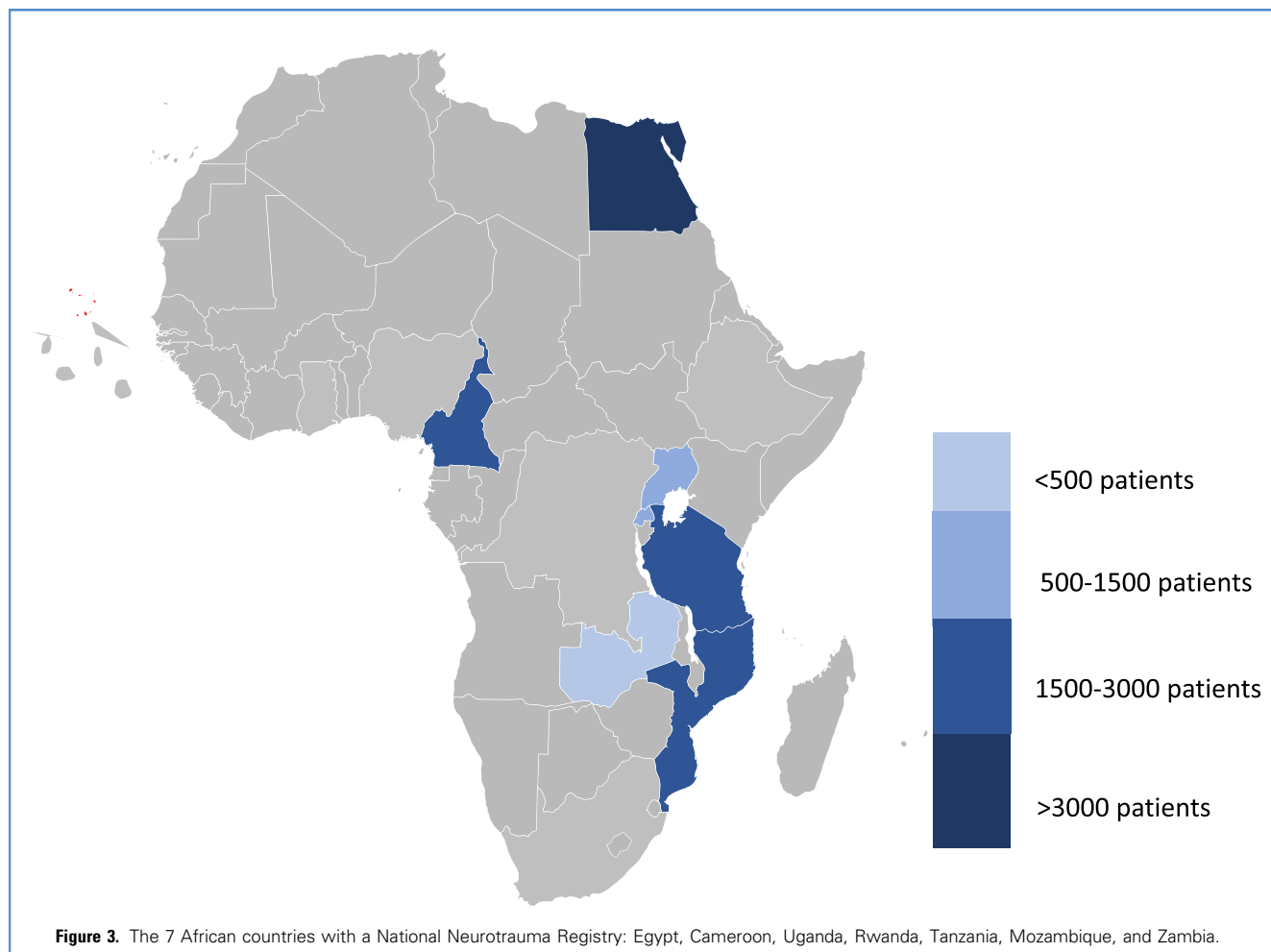
## DISCUSSION

### Key Findings

This study reveals significant disparities in the distribution of neurosurgical centers across Africa, with most countries hosting

3–5 centers while others have only 1 or 2. Notably, 75.8% of centers provide neurotrauma care through public and private healthcare systems. Paper-based NTRs (79.1%) are more prevalent than electronic systems (46.2%), with staffing primarily composed of senior registered nurses, residents, and medical staff. Seven African countries have established national NTRs, but patient volumes and operational structures vary widely. Key barriers to implementing national registries include administrative burdens, material and staffing limitations, and time constraints.

These findings are consistent with the GNOS by Clark et al.<sup>7</sup> in 2022, highlighting the limited availability of neurotrauma centers in LMICs, especially in sub-Saharan Africa. Similarly, a recent review found that reliance on paper-based systems persists in African countries,<sup>6</sup> underscoring the slow transition to electronic registries. While this study highlights progress, such as the establishment of national registries in 7 African countries, data management continues to be largely fragmented and dependent on paper-



based systems. From the same scoping review (published in 2022), Barthelemy et al.<sup>6</sup> confirmed the national registries reported by our respondent: They found 20 studies that reported over 10 national registries in LMICs, including the national registry of Cameroon, Rwanda, and Egypt. Other countries (Tanzania, Mozambique, Zambia, and Uganda) may not have made their national NTR information available in the literature 3 years ago when these authors carried out this scoping review. Therefore, our results added value to the existing literature by filling the gap of the underreported existing national registries.

### Neurotrauma Registry Implementation

The importance of NTRs for improving the quality of care and informing policy decisions is widely demonstrated in the existing literature. Pati et al.<sup>9</sup> concluded in a study published in 2019 that the NTR has become an essential tool for improving the quality of care. NTRs are distributed globally, with North America having the highest number (4 registries), followed by Europe and Asia, each with 2 registries.<sup>1</sup> The GEO-TBI registry, established by 156 professionals from 53 countries, aims to standardize TBI

management and outcome tracking across high-, middle-, and low-income nations.<sup>1,8</sup> Expanding initiatives like GEO-TBI in Africa could provide standardized frameworks for data collection, enhance case tracking, and support policy development to improve outcomes.<sup>8,10</sup> The success of such efforts often relies on local champions, institutional administrative support, and the motivation driven by the potential to enhance care and guide research.<sup>4</sup> Regional collaborations, such as the shared registry initiatives in Latin American and Caribbean nations, further demonstrate the importance of partnerships and local engagement in building robust NTRs.<sup>11</sup> Therefore, collaborative efforts at local, regional, and interregional levels are essential to establish robust NTRs, spanning from individual neurotrauma centers to national and regional networks.<sup>12</sup>

### Challenges in Implementation

Standardizing data collection to facilitate international comparisons and enhance data utility remains a significant challenge, as many LMIC registries fail to align with the WHO's MDI.<sup>1,5,13</sup> In our study, only 42 centers (46.2%) across 24 countries had electronic

hospital-based registries that adhered to the 7 components of the WHO MDI, potentially due to inadequate network or energy infrastructure in LMICs, particularly in Africa. However, involvement from 7 stakeholders supported by third-party technological systems significantly mitigated these challenges.<sup>14</sup>

Barriers to implementing NTRs in LMICs include incomplete clinical data, resource limitations, insufficient IT support, ethical approval challenges, and a lack of trained personnel and infrastructure for effective data management.<sup>6,13,15,16</sup> Limited financial resources and infrastructure are well-known challenges when implementing a NTR in resource-limited settings.<sup>17-20</sup> For example, a NTR implementation in Bhutan required step-by-step planning and a phased approach to overcome these challenges.<sup>21</sup> To summarize all the challenges, Lazem et al.<sup>15</sup> categorized the limitations of the registry implementation into 7 categories, namely management, data management, stakeholder cooperation, technology, ethics/privacy/data security, patient involvement, and disease-related factors. Participants in our study emphasized the importance of governmental involvement in addressing the global burden of neurotrauma. Collaborations with neurosurgery and neurointensive care unit specialists can play a pivotal role in developing evidence-based policies and preventative protocols, as highlighted by Thango et al.<sup>5</sup> in 2023. Our study also highlights some other challenges in implementing national NTRs, as extensively discussed by Asfaw et al.<sup>22</sup> These include the need for training, Information and Communication Technology expertise, reliable internet access, funding for database subscriptions, and dedicated staff. This explains why while the GEO-TBI registry employs the Orion MedTech Database,<sup>8</sup> most African electronic-based registries rely on REDCap.<sup>23,24</sup>

Compounding these issues, Africa faces a projected health workforce deficit of 6.1 million by 2030, with paradoxically high unemployment among health professionals, posing significant barriers to registry maintenance and data integrity.<sup>5,25-27</sup>

### Recommendations

NTRs in Africa remain scarce, fragmented, and underfunded, often relying on paper-based systems that limit their utility. To address this, governments and stakeholders must prioritize funding, adopt standardized frameworks like the WHO MDI, and promote cost-effective electronic platforms. Partnerships with international organizations and heightened policymaker awareness are critical for sustainable support and advancing public health interventions.

Effective implementation hinges on capacity building, resource allocation, and stakeholder engagement. Training personnel, transitioning to interoperable electronic systems, and integrating prehospital and rehabilitation data into registries ensure comprehensive data collection. Collaboration between institutions and regional partnerships enhances scalability, enabling evidence-based decision-making at both national and regional levels.

Challenges persist, including inadequate funding, workforce shortages, and limited stakeholder participation. Infrastructure gaps, such as unreliable internet access and outdated hospital systems, complicate the transition to electronic platforms.

Resistance from healthcare providers and policymakers, often due to low awareness, further hinders progress, while ensuring data consistency and interoperability across systems remains a critical barrier. Overcoming these issues requires coordinated efforts, including securing financial support, legislative mandates, and fostering a culture of data-driven decision-making in neurotrauma care.

Five steps are proposed to guide national registry implementation in LMICs:

- (1) Raise awareness among healthcare workers about neurotrauma incidents.
- (2) Utilize the WHO MDI to develop an adapted Excel-based registry focusing on its 7 key components.
- (3) Publish findings after 6 months of prospective data collection.
- (4) Expand the electronic registry to other departments managing TBI patients and consolidate annual data into a unified national registry.
- (5) Publish results after one year of prospective data collection to validate and strengthen the registry framework.

### Limitations

This survey highlighted the lack of focus on prehospital care for neurotrauma patients and the significant heterogeneity in data elements tracked by registries, which complicates standardization efforts. The main limitations of this study are related to electronic questionnaire-based biases. Selection bias is a concern, as the survey primarily targeted neurosurgeons and neurosurgery trainees in Africa, potentially limiting its generalizability. Moreover, the exact number of neurotrauma centers in Africa is unknown. Additionally, unclear instructions and limited interaction with participants may have affected response accuracy and depth. Finally, heterogeneity in tracked data elements complicates standardization efforts, further limiting the applicability of the findings to broader contexts.

### CONCLUSION

This study highlights the uneven distribution of neurotrauma care facilities across Africa and the predominance of paper-based registries for traumatic brain and spinal cord injuries. While progress has been made in establishing national NTRs in 7 countries, significant barriers persist, including resource limitations, administrative burdens, and inadequate infrastructure. Moreover, limited awareness of the value of NTRs further hinders their adoption and effective implementation.

Addressing these challenges requires targeted investments by governments and nongovernment organizations to improve healthcare infrastructure, provide adequate staffing, and adopt cost-effective, standardized electronic systems. Collaborative efforts involving local institutions, regional networks, and international partners are essential to build sustainable registry frameworks. Such initiatives not only enhance patient care and

data quality but also enable evidence-based policy development to reduce the burden of neurotrauma across the continent.

By prioritizing capacity building, stakeholder engagement, and resource allocation, Africa can establish robust NTR systems that integrate prehospital, clinical, and rehabilitation data. These efforts are critical for achieving equitable access to care and improving outcomes for neurotrauma patients in resource-limited settings.

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**Yao Christian Hugues Dokponou:** Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. **Abass Oluwaseyi Ajayi:** Data curation, Investigation, Methodology, Project administration, Validation, Visualization, Writing – original draft, Writing – review & editing. **Nathalie C.M. Ghoms:** Data curation, Investigation, Methodology, Validation, Visualization, Writing – original draft, Writing – review & editing. **Eghosa Morgan:** Data curation, Investigation, Methodology, Project administration, Validation, Visualization, Writing – original draft, Writing – review & editing. **Roméo Bujiriri Murhega:** Methodology, Supervision, Validation, Visualization, Writing – original draft, Writing – review &

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