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Creation of a Retinoblastoma Registry in a Resource-Limited Country in Sub-Saharan Africa

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ABSTRACT

Background: Retinoblastoma (RB) is the most common ocular tumor in young children, originating from the developing retina, with the burden remaining higher in regions of low socio-demographic index. A registry of RB is essential for creating effective referral networks for evaluating treatment patterns and contributing to the global pool of knowledge.

Aim: To develop an RB registry for Ghana and assess its feasibility and acceptability.

Methods: An online REDCap (Research Electronic Data Capture) database was created as a registry of children diagnosed with RB in Ghana. Data completeness across core variables was analyzed and presented as a percentage. Technical, operational feasibility, and acceptability of the registry were assessed. Qualitative in-depth interviews were conducted with 2 users from each center to assess acceptability. At each treatment center, a registry lead was trained to enter data into the REDCap database.

Results: Data were entered, aggregated, and stored in the REDCap database. Data captured included: socio-demographic and clinical information, clinical staging and systemic evaluations, histopathological risk assessment and staging, and final treatment outcomes. With reliable hardware performance, safe software features, and steady network connectivity backed by offline caching, the registry proved technically and operationally feasible. The average data entry time was 15 min, and the data quality was over 70%. Acceptability was emphasized in user interviews by themes of completeness and data quality, timeliness and workflow integration, and correctness and clinical relevance.

Conclusions: The registry demonstrated strong technical and operational feasibility, with efficient workflows and reliable infrastructure. High data quality and user-validated acceptability underscore its integration into routine clinical practice.

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1 | Introduction

Retinoblastoma (RB) is a rare malignant tumor and the most common primary ocular malignancy in children, originating from the developing retina, with the burden remaining higher in regions of low socio-demographic index, demonstrating socioeconomic disparities [1, 2]. Epidemiological studies have revealed that the incidence differs regionally, with global incidence estimated at 1 in 15,000 to 20,000 live births [3, 4]. Due to its rarity, RB cases are often misdiagnosed or diagnosed late until the advanced stage, resulting in high rates of loss of sight and death in most developing countries [5, 6].

Children living in developed countries are said to have more than a 90% chance of surviving, far higher than those in developing countries, where RB survival ranges from 10% to 30% [7, 8]. Late diagnosis and presentation, lack of access to specialized care, and poor adherence to recommended therapy have been mentioned as reasons for this survival disparity [4, 9].

Because RB is rare, it is sometimes difficult to pool sufficient data for analysis. Data collection from multiple centers in a registry of diseases is useful for the study of rare diseases [10]. The development of a well-established disease registry could facilitate the continuous supply of data to aid in the evaluation of interventions and treatments in patient populations compared to data derived from a single institution.

In Ghana and most low- and middle-income countries, data on RB usually come from single institutions, resulting in little or no knowledge about the broader picture of national incidence and survival outcomes [11–13]. To obtain more representative data, a population-based hospital registry could serve as a first step in developing a national registry for RB in Ghana.

Unlike Ghana, countries such as India, the UK, Japan, and Canada have well-established registries for childhood cancers, including RB, which have supported better management of the condition and contributed to the global pool of knowledge in RB research [14–18].

The creation of an RB registry is therefore key to assessing clinical outcomes of patients at different RB treatment centers and identifying geographical areas needing special attention in the allocation of scarce resources for managing RB.

In this manuscript, we report the development of an online database for registering children with RB receiving care at treatment centers in Ghana. The main objective was to develop an RB Registry for Ghana and assess its feasibility and acceptability.

2 | Methods

2.1 | Study Overview

In 2019, with the support of ORBIS International, an online registry of RB cases in Ghana was initiated, which sought to design a national RB register in partnership with the School of Public Health, University of Ghana, through an institutional agreement with Vanderbilt University for the use of the REDCap database.

An RB-specific database was created using REDCap to facilitate the online collection of epidemiological and clinical data of children with RB retrospectively from 2014 to 2019 and prospectively from 2020 and beyond at five treatment centers in Ghana, including the Korle Bu Teaching Hospital (KBTH), Komfo Anokye Teaching Hospital (KATH), Cape Coast Teaching Hospital (CCTH), Tamale Teaching Hospital (TTH), and Sunyani Regional Hospital (SRH). The study data were collected and managed using REDCap electronic data capture tools hosted at the School of Public Health, University of Ghana. REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing (1) an intuitive interface for validated data capture; (2) audit trails for tracking data manipulation and export procedures; (3) automated export procedures for seamless data downloads to common statistical packages; and (4) procedures for data integration and interoperability with external sources [19–21].

2.2 | Registry Sites

The Eye Center and the Pediatric Oncology Unit at the KBTH are the main sources of data for RB cases at the KBTH. The Eye Center at the KBTH is one of the largest clinics in Ghana and Sub-Saharan Africa and serves a large number of patients with diverse eye diseases from Ghana and some West African countries. The facility is endowed with a sub-specialty clinic for RB and serves as a training center for undergraduate and postgraduate training in Ophthalmology. The Pediatric Oncology Unit is responsible for the care of childhood-related cancer conditions at the KBTH. About 20–30 new cases of retinoblastoma are diagnosed annually at the KBTH (the Eye Center and Pediatric Oncology Unit combined).

The Eye Center at the Komfo Anokye Teaching Hospital (KATH) in the Ashanti Region of Ghana is the second largest eye hospital in Ghana, receiving referred cases from the northern half of the country. The eye clinic runs a pediatric ophthalmology clinic where about 20 new cases of retinoblastoma are recorded annually.

Cape Coast Teaching Hospital (CCTH) is located in the Central Region of Ghana. The Eye Unit at the CCTH is a referral facility that takes care of various ocular complications, including retinoblastoma. The facility records about 12 new cases of RB annually.

The Tamale Teaching Hospital (TTH) is one of the teaching hospitals in Ghana, providing a comprehensive range of specialist healthcare services across the whole of the Northern Sector of Ghana. About 15 new cases of RB are recorded annually at the TTH.

The Sunyani Regional Hospital (SRH) is the main referral health facility in the Bono Region of Ghana, serving the whole region of the Brong Ahafo (Bono, Bono East, and Ahafo) and

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some parts of the Northern regions of Ghana. About 5 new cases of RB are recorded annually at the Eye Department of the hospital.

2.3 | Development of the RB Registry

The development of the registry began with the definition of its objective to collect data on incidence, demographic characteristics, treatment outcomes, and access, staging, and facilitate research and collaboration. The next was the engagement of stakeholders such as ophthalmologists, ophthalmic nurses, pediatric oncologists, and nurses, the Ministry of Health, teaching and regional hospitals, non-governmental and international organizations. The infrastructure and resources included a paper-based data collection system and tablets or phones with offline capabilities. Ophthalmologists and ophthalmic nurses were trained on data entry and management. Ethical considerations were very important, as patient consent and compliance with local data privacy laws were adhered to. Data elements included patient demographics such as age, gender, geographic location, clinical data (laterality of cancer), stage at diagnosis, methods of treatment (chemotherapy, enucleation, radiotherapy, etc.), and follow-up (survival status, metastasis, loss to follow-up reasons).

2.4 | Inclusion/Exclusion Criteria

Included in this registry were children aged 0–15 years with a confirmed diagnosis of retinoblastoma from 1st January 2014 to 31st December 2019 for the retrospective register and those aged 0–15 years after 1st January 2020 for the prospective register. Cases were excluded from the registry where the chart showed evidence that confirmed that the patient did not have retinoblastoma (e.g., histology inconsistent with retinoblastoma). For the prospective arm, any data initially entered into the database with a presumed diagnosis of RB, which was later not confirmed on clinical re-evaluation or, in enucleated specimens, on histopathology, was corrected or removed by the registry leads at the respective treatment centers.

2.5 | Ethics Statement

The management of the registry adhered to the ethical principles of the Declaration of Helsinki for human subjects in medical research, with ethical clearance from the Korle Bu Teaching Hospital and the Ghana Health Service, with protocol identification numbers: KBTH-IRB/000135/2019 and GHS-ERC002/02/20, respectively.

Since the retrospective aspect of the register utilized secondary data from medical charts of confirmed RB cases, we requested a waiver of consent, as it was quite difficult to make contact with all patient families. However, those who came for follow-up visits were invited to participate. Such participants were informed about the purpose of the registry, the confidential issues about their data protection, including potential risks and benefits from the registry. Written informed consent and assent forms were signed, with a copy of the signed consent form given to the participant while another copy was kept by the principal investigator (PI) in a secure cabinet. Codes were created as special identity numbers known only to the principal investigator to promote confidentiality. Participation in the registry was voluntary. Participants were told they may choose to withdraw from the registry at any time. Data obtained before the withdrawal in this case may be included, except in an event where consent to participate was suspended.

2.6 | Registry Implementation

Key persons involved in the management of RB at centres were brought together in a stakeholders' meeting. The PI, including some of the authors, traveled to treatment centers to train registry leads and local teams on data collection and entry into the registry. Data were collected and entered by trained ophthalmologists and ophthalmic nurses. The retrospective data collection started from 2014 to 2019, as data for the previous years were not available. The prospective data entry was done by trained ophthalmologists and ophthalmic nurses as soon as a patient was confirmed as having RB. Thus, patients' charts were reviewed to identify cases with a confirmed diagnosis of retinoblastoma. Patients were de-identified, assigned a participant ID, and a code-breaking log was maintained in accordance with ethical policies. Cross-referred cases were identified to avoid duplicate counting of patients. A corresponding paper questionnaire was also used as a backup to allow for data capture in case of unforeseen difficulties with the REDCap app, which was usually entered later into the REDCap database.

As a standard operating procedure for all sites, data were usually collected during clinical consultations, which allowed the inclusion of children who had been treated as well as those who would begin follow-up. At each center, sub-specialists in RB management were designated as registry leads to oversee the management of the database. These registry leads were involved in the decision on the type of data to be included in the REDCap database during the stakeholders' meeting. Registry leads were given access to log in and out of the registry using a username and a password to enter data in each field. The registry was piloted over a period of six months, and the outcome of the pilot was reported.

2.7 | Data Management and Quality Assurance

In addition to REDCap's built-in validation checks, a secondary quality assurance process has been put in place. The data manager will conduct weekly audits of entries, flag inconsistencies, and coordinate corrections with registry leads from all sites. All modifications will be documented in REDCap's audit trail. Quarterly data quality reports will be reviewed by the registry steering committee to ensure accuracy and completeness.

All data entered into REDCap are encrypted during transmission and stored on secure institutional servers. Access is restricted through role-based permissions, with audit trails documenting all activity. Direct identifiers such as patient names are collected only for clinical linkage and follow-up but are excluded from analytic datasets. These safeguards ensure patient safety and compliance with ethical and regulatory standards.

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2.8 | Follow-Up Procedures

Patients will be followed prospectively throughout childhood and adolescence, with intensive monitoring during the first five years post-diagnosis. Survivors, especially those with hereditary RB, will remain in lifelong follow-up to document recurrence, secondary tumors, treatment sequelae, and survivorship outcomes. This approach aligns with international standards for RB management and ensures comprehensive long-term data capture [14].

2.9 | Outcome Measures

The outcome measures were the feasibility and acceptability of the registry, which were evaluated by assessing how complete the data captured was and the interviews with the registry leads on the overall experience with the registry. Acceptability was also assessed through semi-structured interviews with registry leads, asking questions about their overall experience with the registry, their preferences/suggestions for important data fields to collect, and their perception of the acceptability of the registry to the patients' families. Interviews were recorded, transcribed verbatim, and analyzed thematically to aid in further refinement of the database.

3 | Results

3.1 | Core Features and Functional Architecture of the RB Registry

The RB registry was created and implemented throughout the treatment centers with success. To handle varying connectivity across sites, the registry was constructed utilizing a safe, cloud-based architecture that also had offline capabilities. Three clinical staff members received training, which made the registry operationally ready.

Upon logging into the registry, a user interface showing the project home and design would present with a project status and record status dashboard (view data collection status of all records, add/edit records, create new records, or edit/view existing ones).

The resultant RB REDCap database registry included several variables categorized under the following sections, namely: socio-demographic data and history, clinical staging and systemic evaluation, histopathological high-risk characteristics, treatment course and investigations, and treatment outcomes (Figure 1).

Under clinical staging and systemic evaluation, the following variables were recorded: visual acuity assessment, number of tumors present, location of tumor, presence and types of vitreous or subretinal seeds/fluids from tumor, the clinical stage at presentation, presence of glaucoma, hyphema, IIRC (International Intraocular Retinoblastoma Classification), TNM (Tumor Nodes Metastasis), Reese—Ellsworth, and clinical tumor classifications, presence of lymph node, and metastasis. Investigations done (ultrasound, CT scan, MRI, bone marrow analysis, Cerebrospinal Fluid (CSF) Analysis, and others) were also recorded (Figure 2).

For histopathological high-risk characteristics assessment, data on evidence of primary tumor, optic nerve invasion, choroidal invasion/iris/ciliary body invasion, scleral invasion, extraocular extension, primary tumor (pT), pathology TNM stage (where applicable), regional lymph nodes (pN), and distant metastasis (pM) were recorded (Figure 3).

For the treatment section the following variables were obtained: name of health facility where treatment was performed, the type(s) of treatment planned vs. received (enucleation, laser, cryotherapy, periocular chemotherapy, systemic chemotherapy, intraarterial chemotherapy, intravitreal chemotherapy, plaque brachytherapy, stereotactic radiotherapy, external beam radiotherapy, stem cell transplant, palliative treatment, and others), and date of last follow-up (Figure 4).

Patient outcome variables collected included status at last follow up (alive/dead), evidence of abandoned treatment (failure to start/complete treatment) or lost to follow up (the failure to start/complete therapy), presence of metastasis, date of detection of metastasis, interval between enucleation and metastasis (months), site of metastasis (orbit, brain, chest, bones, lymph nodes, others), duration of follow-up (time of diagnosis or first treatment to last follow-up) in months, date of last follow-up, and disease status at last follow-up (no active disease, active intraocular disease, metastatic) (Figure 5).

Data collected could be analyzed and visualized by using appropriate charts and tables. Data could also be exported from the registry in various formats, including Microsoft Excel, SAS, Stata, R, or SPSS for analysis.

The database could allow each treatment center to see information on patients registered at their own center. However, de-identified data on all patients registered in the database could be obtained on reasonable request from the managers of the registry. Other applications on the database included: a calendar, data exports, reports, a statistics-generating function, email logging, a field comment log, a file repository, and user rights.

3.2 | Patient Enrollment and Data Capture

All five treatment centers contributed data to the registry. A total of 299 patient records were reviewed, of which 234 children—representing 289 affected eyes—met the inclusion criteria for retinoblastoma and were enrolled in the registry. The majority of cases (152/234; 65.0%) were between 1 and 4 years of age, and most presented with unilateral disease (179/234; 76.5%). Comprehensive demographic characteristics of the enrolled patients have been reported in a separate publication [22].

Data completeness across core variables exceeded 70%, with an average of 15 min required to complete each patient entry. The registry supported real-time data entry and retrieval and enabled seamless export of datasets to external statistical software for analysis.

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DEMOGRAPHIC DATA & HISTORY

Record ID	_____
CENTER OR FACILITY CODE	_____
Object	
Name of Patient	_____
Patient / Subject ID./Code / Pseudonym	_____
Region	◯ Greater Accra ◯ Brong Ahafo ◯ Ashanti ◯ Eastern ◯ Volta ◯ Central ◯ Western ◯ Northern ◯ Upper East ◯ Upper West
Facilities in Greater Accra	◯ Emmanuel Eye Centre, ◯ 37 Military Hospital ◯ Greater Accra Regional Hospital (Ridge) ◯ Korle Bu Teaching Hospital ◯ Lekma Hospital ◯ Tema General Hospital ◯ Tema Christian Eye Centre ◯ The Trust Hospital ◯ Interstar Eye Centre ◯ Crystal Eye Clinic ◯ Dziram Eye Clinic, ◯ St. Thomas Eye Hospital ◯ Bright Opticals Centre Ltd ◯ Pentecost Hospital ◯ Agarwal's Eye Hospital ◯ Save the Nations Sight Clinic ◯ Cocoa Clinic ◯ Other
Facilities in Greater Accra - Other specify	_____
Facilities in Brong Ahafo	◯ Regional Hospital ◯ Holy Family Hospital ◯ Other
Facilities in Brong Ahafo - Other specify	_____

04/05/2023 2:00pm projectredcap.org REDCap

FIGURE 1 | Demographic data and history.

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CLINICAL STAGING & SYSTEMIC EVALUATION

Visual Acuity	☐ Right ☐ Left
Right	◯ 6/6 ◯ 6/9 ◯ 6/12 ◯ 6/18 ◯ 6/24 ◯ 6/36 ◯ 6/60 ◯ 3/60 ◯ HM ◯ PL ◯ NPL ◯ FFL
Left	◯ 6/6 ◯ 6/9 ◯ 6/12 ◯ 6/18 ◯ 6/24 ◯ 6/36 ◯ 6/60 ◯ 3/60 ◯ HM ◯ PL ◯ NPL ◯ FFL
No. of Tumors - RIGHT	_____
No. of Tumors - LEFT	_____
Max tumour size(mm): - RIGHT	_____
Max tumour size(mm): - LEFT	_____
Distance from fovea (mm): - RIGHT	_____
Distance from fovea (mm): - LEFT	_____
Distance from optic nerve (mm): - RIGHT	_____
Distance from optic nerve (mm): - LEFT	_____
Location of Tumors (in zones 1, 2, 3) - RIGHT	_____

FIGURE 2 | Clinical staging and systemic evaluation.

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HISTOPATHOLOGICAL HIGH RISK CHARACTERISTICS

Evidence of primary tumour	◯ No ◯ Yes ◯ Cannot be assessed

Optic nerve invasion

	Right	Left
None	☐	☐
Superficially invades, not past lamina cribrosa	☐	☐
Invasion past lamina cribrosa	☐	☐
Invasion past resection line	☐	☐

Choroidal invasion / Iris/ Ciliary body invasion

	Right	Left
None	◯	◯
Focal	◯	◯
Significant (< 3mm)	◯	◯
Massive (> 3mm)	◯	◯

Scleral invasion

	Right	Left
None	◯	◯
Any	◯	◯
Full thickness	◯	◯

Extra ocular extension (Right)	◯ Yes ◯ No
Extra ocular extension (Left)	◯ Yes ◯ No
Lympph node involvement	◯ Yes ◯ No
No. of Metastatic tumours	_____
Worst metatstatic site	◯ Right ◯ Left
Worst metatstatic site (Note)	_____

FIGURE 3 | Histopathological and high-risk characteristics.

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TREATMENT

Treatment Course site
○ Right
○ Left

TREATMENT COURSE NO. 1 -RIGHT

	Yes	No	Unknown	NA
Enucleation	○	○	○	○
Laser	○	○	○	○
Cryotherapy	○	○	○	○
Periocular chemotherapy	○	○	○	○
Systemic chemotherapy	○	○	○	○
Intraaterial chemotherapy	○	○	○	○
Intravitreal chemotherapy	○	○	○	○
Plaque brachytherapy	○	○	○	○
Stereostatic radiotherapy	○	○	○	○
External beam radiotherapy	○	○	○	○
Stem cell transplant	○	○	○	○
Palliative Treatment	○	○	○	○
Others	○	○	○	○

Treatment course - other specify - RIGHT _____

TREATMENT COURSE NO. 1 - LEFT

	Yes	No	Unknown	NA
Enucleation	○	○	○	○
Laser	○	○	○	○
Cryotherapy	○	○	○	○
Periocular chemotherapy	○	○	○	○
Systemic chemotherapy	○	○	○	○
Intraaterial chemotherapy	○	○	○	○
Intravitreal chemotherapy	○	○	○	○
Plaque brachytherapy	○	○	○	○
Stereostatic radiotherapy	○	○	○	○
External beam radiotherapy	○	○	○	○
Stem cell transplant	○	○	○	○
Palliative Treatment	○	○	○	○
Others	○	○	○	○

Treatment course - other specify - LEFT _____

FIGURE 4 | Treatment.

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Investigations	
Ultra sound	_____
CT Scan	_____
MRI	_____
Bone marrow analysis	_____
CSF analysis	_____
Others	_____
OUTCOME	
Metastasis	◯ Yes ◯ No
Date of detection	_____
Interval between enucleation and metastasis (months):	_____
Site of metastasis	☐ Orbit ☐ Brain ☐ Chest ☐ Bones ☐ L Nodes ☐ Other
Site of metastasis	_____
Duration of FUP (Time of Diagnosis or first treatment to last FUP) in months	_____
Date of Last FUP	_____

FIGURE 5 | Investigations and outcome.

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3.3 | Feasibility

The technical architecture (hardware, software, and network connectivity) of the registry was evaluated for stability, security, and scalability. The technical feasibility of the registry was achieved by ensuring that hardware elements, such as tablets, laptops, desktop computers, and backup hard-disc drives, performed consistently across all sites accordingly. The software framework allowed for automated backups, secured communication, and real-time data entry. All centers had fairly consistent network connectivity, which was enhanced by offline data caching.

Operational feasibility was also achieved by ensuring the registry's workflows, data collection, and management processes were efficient, followed standard operating procedures, and were aligned with existing healthcare systems. The registry's functions were smoothly integrated into routine clinical procedures. A clear governance structure and standard operating procedures were followed. Data completeness was a challenge as some of the centers did not record data in some of the fields of the registry.

3.4 | Acceptability

Two users from each participating center participated in qualitative in-depth interviews to gauge the registration system's acceptability. The users affirmed that the data collection and management processes aligned with their clinical and operational needs and emphasized that the registry ensured accurate, complete, and timely documentation while adhering to data security. The following themes were generated from the narrations of the users: accuracy and clinical relevance, timeliness and workflow integration, and completeness and data quality.

3.4.1 | Accuracy and Clinical Relevance

Users described the registry's clinical usefulness and accuracy. They highlighted how the registry reduces dependency on disjointed paper records by streamlining documentation and promoting continuity of care.

> This RB registry records exactly the information most of us require for our clinical work and clinical follow-up. I no longer need to go between paper files because everything has been captured accurately and is always accessible.

One user emphasized the registry's function in standardizing clinical data across departments, stressing that accurate and consistent patient data is essential for making well-informed decisions, lowering diagnostic mistakes, and enhancing care coordination. View the following quotation:

> Before the creation of this registry, we frequently had contradictory records across departments. However, we are now able to make better decisions since the data is consistent and accurately captures almost all the information we need about the patients with RB in our settings.

3.4.2 | Timeliness and Workflow Integration

The quote below demonstrates how the registry works with current clinical procedures. Real-time data entry is thought to be effective and non-disruptive, improving documentation speed without sacrificing patient interaction.

> While the patient remains in the consulting room, I can input data. It doesn't slow us down and fits into our routine.

The registry's smooth incorporation into routine clinical tasks is explained in the response below. Data entry during patient consultations improves timeliness and lowers the backlog of documents.

> I don't have to wait until the end of the day to enter data—the registry fits right into our routine. I can complete it quickly and while consulting.

3.4.3 | Completeness and Data Quality

One user explained how integrated validation checks enhance the completeness of data. The registry's automated prompts act as quality control tools, guaranteeing that crucial data are reliably recorded.

> We no longer lack important information. The records are more comprehensive than they were previously since the technology alerts us if we miss something.

The following quotation highlights how the registry system's structured prompts improve data completeness. The system reduces omissions and enhances the accuracy of recorded information by assisting physicians in filling out necessary fields during patient visits.

> When writing notes later, I used to miss important details, but now the registry asks me to input everything, including tests, diagnoses, and referrals. Everything is there.

4 | Discussion

The RB registry was set to improve and standardize the collection of RB data in Ghana. Our RB register allows access to clinical records to identify potential patients for clinical research and trials, health service planning, and evaluation. Registries are known to provide an avenue for evaluating treatment outcomes and an opportunity for complete, updated, and more representative data required for better diagnosis, disease

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management, and reduction in blindness and death, respectively [10, 21].

In studies involving rare diseases/conditions, it is sometimes challenging to collect data at a single site [23]. However, the use of multiple centers offers researchers the opportunity to gather adequate, reliable, and well-coordinated data that could be used in answering various research questions [23].

For the first time in Ghana, systematic data collection occurred at five distinct major RB sites, which is a significant achievement in a resource-limited country such as Ghana.

Our RB registry demonstrated strong technical and operational feasibility, especially in environments with limited resources. Its architecture facilitated offline data collection, which was consistent with the development of other registries [24, 25]. Operationally, the registry improved user compliance and data entry efficiency by requiring little training and being compatible with standard clinical operations [25, 26].

Clinicians expressed a high level of acceptance, pointing to the registry's structured style and validation checks as essential components of its precision and clinical applicability. Clinical quality registries have been demonstrated to enhance care by assisting with outcome benchmarking and revealing gaps between evidence and practice [27–29]. Diagnostic, staging, and therapy factors were included in the registry to guarantee their applicability to ophthalmic decision-making [28].

Real-time data entry and automated prompts were used to improve timeliness and process integration, which decreased documentation delays and increased reporting efficiency. This is in line with the best standards for EMR integration and registration automation [26, 30].

Our registry's approximately 70% completeness across key characteristics allowed for effective policy planning and surveillance. Logic tests and multi-source verification were used to enhance the validity, completeness, and quality of the data. This was also evidenced in other studies [31–33].

Data collected from our registry included: socio-demographic data and history, clinical staging and systemic evaluation, histopathological high-risk characteristics, treatment course and investigations, and treatment outcomes. Data on socio-demographic characteristics and history of RB patients are crucial in determining the magnitude of the disease prevalence in a given population and whether these factors limit patient monitoring and prognosis. In this current registry, the socio-demographic and clinical history of patients collected may help in identifying factors that increase the risk of RB progression, delays in presentation, and hereditary-related issues in RB [34–36]. Several studies have demonstrated the significance of socio-demographic characteristics in clinical research. For instance, lower socioeconomic status has been associated with an increased incidence in some cancer cases [37–39], including retinoblastoma, where the incidence varies inversely with the level of socio-economic development, with more than 90% of children with retinoblastoma living in low and middle-income countries (LMICs) [40]. This increase in incidence may partly be attributed to the high birth rates that occur in these LMICs, such as Asia and Africa, where over 80% of these cases are found [41]. Among socio-demographic characteristics, age and sex appear to be the most important, since cancer incidence and prevalence increase with age [39].

Data on clinical staging, systemic evaluation, and histopathological high-risk characteristics of RB cases were also documented in the registry. Recording these data is important in determining which stages are the most prevalent among the children with RB and in characterizing the correct pathological staging according to acceptable standardized classifications. Such data provide information about the occurrence and clinical characteristics and signs of the advanced stage of the disease (high-risk features for metastasis), which have an impact on survival [42].

Differences in tumor biology, stage of disease at diagnosis, access to therapy, and treatment practices have been linked with survival differences among children with RB from different geographical settings [42, 43]. Differences in disease stage have also been implicated as a potential mechanism for the observed relationship between socio-economic status and cancer outcomes [44]. Therefore, data on clinical staging and histopathological high-risk characteristics in RB are essential in understanding the epidemiology and genetics of the disease.

Our registry also includes information on treatment received by the RB patients before referral and at the treatment center. This registry was created using the REDCap database, which could be accessed from any location at any time. There was no need for prior knowledge of programming languages to set up this RB database in REDCap. The RB REDCap registry provides an easy avenue to export data for users and offers daily backups, basic support, and an audit trail feature for even more security.

Ensuring data quality and consistency across sites proved challenging, requiring ongoing monitoring and feedback. Differences in site infrastructure, including hardware, software, and internet connectivity, presented challenges in implementing standardized data collection tools and protocols. Securing sustainable funding and ensuring the long-term viability of the registry remain significant challenges. Transfer of staff from either a unit in the department to another unit or another department in the participating hospitals also impacted negatively on the continuity and timeliness of data entry.

Lessons learned included the significance of establishing clearly defined goals and expected outcomes to ensure all sites are aligned and working towards the same targets. There is a need to be ready to adjust protocols and procedures as needed to accommodate site-specific challenges and variations. Another lesson learned was the need to foster regular communication and collaboration among sites to resolve challenges and ensure the success of the registry using WhatsApp messaging as well as emails. End users of the registry were trained to enhance skills and knowledge that would equip them to manage and maintain the registry.

Going forward, there is a need to secure stable funding sources to ensure the long-term viability of the registry. A need to establish a governance structure to oversee the operation of the

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registry and ensure the quality of data generated for strategic health care decision-making. This would encourage active collaboration and knowledge sharing among local and international partners to advance the management of RB and research in general. It will also be necessary to work towards linking this database to the existing electronic medical records systems found in the teaching hospitals, Lightwave Health Information Management System (LHIMS), and the district and regional hospitals, District Health Information Management Systems (DHIMS), to reduce multiple clinical data entries on patients by staff, which will result in compliance with entries into the database.

4.1 | Challenges/Limitations

Users of the registry had a few challenges, which included the complexity of the REDCap interface, which required significant training and technical expertise to set up and manage. Also, users of the registry preferred the use of the software on desktop computers to the use on tablets and phones, as the latter occasionally presented data synchronization challenges. Additionally, users of the registry preferred the use of the software on desktop computers to the use on tablets and phones, as the latter occasionally presented data synchronization challenges. Larger screens provided by desktop monitors also made it simpler to examine intricate records, numerous fields, and interfaces without having to zoom or scroll a lot. Compared to handheld devices, a solid workstation, an adjustable chair, and an appropriate screen arrangement make prolonged data entry easier and less taxing. Assessing the registry in the absence of internet connectivity was a challenge in using the online REDCap database. However, an alternative solution is to download the REDCap Mobile App to any mobile device (e.g., smartphones, tablets), which can be used for offline data collection. Although this registry captures core demographic and clinical variables, some features such as AJCC hereditary classification (TNMH), Reese-Ellsworth grades, vitreous seeding, pTNM staging, and incidence of secondary tumors are not currently included. This is a limitation of the present version. Future iterations will incorporate these variables to strengthen the comprehensiveness and clinical utility of the registry. Also, we recorded about 30% of cases with incomplete data, most frequently missing follow-up outcomes, and some clinical characteristics and pathological information. While this reflects challenges with retrospective documentation, the registry allows for retrospective completion of records through review of source documents, with all modifications logged in REDCap's audit trail. These measures aim to strengthen data completeness over time. The App can synchronize offline data back to the online REDCap database when internet connectivity is resumed. Also, data can be stored in another format and then uploaded into REDCap when the internet connection is reliable. Other limitations of the registry include collecting information from patients' medical charts, which depends on the accuracy of the outcome reported by the doctors treating the patients. Some caregivers of RB patients may also fail to remember important information from the past, which could affect the quality of the registry. Despite these potential limitations, our RB REDCap registry has demonstrated prominence in supporting RB research in Ghana and has proven to be a viable resource. Although the registry has been developed for Ghana, future plans include sharing the approach with neighboring countries and collaborating with retinoblastoma centers outside Ghana. The registry framework is adaptable and scalable, allowing replication in other resource-limited settings. Harmonization of data collection will enable regional comparisons and contribute to larger global datasets, strengthening international understanding of RB.

5 | Conclusion

An RB REDCap database registry was created as a multicenter online database for facilitating the registration of confirmed RB cases in Ghana to support the systematic planning, implementation, and evaluation of RB programs. The registry demonstrated robust technical and operational feasibility, supported by consistent hardware, secure software, and stable connectivity. Efficient workflows aligned with clinical routines, enabling timely data entry and over 70% completeness. User feedback affirmed its acceptability, highlighting strengths in data quality, workflow integration, and clinical relevance, underscoring its potential for sustainable implementation. This registry could also facilitate clinical auditing of the quality of RB services provided, the effectiveness of treatment plans and protocols, and research into causes and risk factors of RB. The registry may continue to promote better retinoblastoma research, management, and monitoring of treatment outcomes by putting sustainability first, overcoming obstacles, and putting the lessons learned into practice. Our registry can be linked to the national cancer registry when the latter is fully functional.

Author Contributions

Benjamin Abaidoo: conceptualization, methodology, formal analysis, project administration, writing – review and editing, writing – original draft, data curation. **Vera Adobea Essuman:** funding acquisition, conceptualization, investigation, writing – review and editing, writing – original draft, supervision. **Kwesi Nyan Amissah-Arthur:** writing – original draft, methodology, data curation, investigation. **Vera Mawusime Beyuo:** data curation, writing – review and editing, writing – original draft, investigation. **Doreen Amankwaa-Frempong:** investigation, data curation, writing – original draft. **Dziffa-Bella Imelda-Odille Ofori-Adjei:** conceptualization, writing – original draft, data curation. **Naa Naamuah Tagoe:** writing – original draft, data curation, investigation. **Lauretta Pinamang Owusu-Asare:** investigation, writing – original draft, data curation. **Louis Oteng-Gyimah:** data curation, investigation, writing – original draft, writing – review and editing. **Lorna Awo Renner:** conceptualization, writing – original draft, data curation, supervision. **Yaw Akye Essuman:** writing – review and editing, project administration, methodology, writing – original draft. **Gloria Gyamaa Kyeremeh:** writing – original draft, investigation, data curation. **Chris Guure:** formal analysis, software, data curation, resources, writing – original draft, investigation. **Benedicta Appiah-Thompson:** investigation, writing – original draft, data curation. **Sally Peprah:** investigation, writing – original draft, data curation. **Andrea Nimako:** data curation, writing – original draft, investigation. **Judith Simon:** investigation, writing – original draft, data curation. **James Fiifi Addy:** funding acquisition, writing – original draft. **Peter Forson Ackah:** writing – original draft, data curation, investigation. **Adolf Ollennu:** funding acquisition, writing – original draft, writing – review and editing. **Helen Dimaras:** supervision, writing – review and editing, writing – original draft, conceptualization. **Vivian Paintsil:** investigation, writing – original draft, data curation.

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Isabella Perpetual Arthur: writing – original draft, data curation, investigation. **Gilbert Batieka Bonsaana:** writing – original draft, investigation, data curation.

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Ethics Statement

The management of the registry followed the ethical principles of the Declaration of Helsinki for human subjects in medical research, with ethical clearance from the Korle Bu Teaching Hospital and the Ghana Health Service, with protocol identification numbers: KBTH-IRB/000135/2019 and GHS-ERC002/02/20, respectively.

Consent

A waiver of consent was obtained for this retrospective study, and written, informed consent was obtained from participants who presented for follow-up visits at the study sites.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The datasets analyzed during the current study are available from the corresponding author on reasonable request.

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