

A review of ophthalmic registries in Africa – The shortage and importance

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ABSTRACT

BACKGROUND: Clinical registries systematically collect standardized information for pre-defined purposes on patients with a particular condition of interest. The characteristics and quantity of ophthalmic registries in Africa are unclear.

This study aimed to quantify ophthalmic clinical registries in African countries from published literature, and to supply an overview of the features and study outcomes of these registries.

METHODS: A systematic search of the EMBASE, PubMed, and Web of Science databases was conducted to find ophthalmology clinical registries in Africa without time and language limitations. Relevant data elements about registry characteristics, nature, methodology, and outcomes were extracted for each individual registry identified.

RESULTS: Six clinical eye registries were found with no substantial growth over time. The most common condition captured is ocular tumors (n=3), of which two were retinoblastoma-specific registries. Five of them were focused on retinal diseases and one on blindness and low vision. None addressed cataracts and glaucoma. A third of the registries originated outside Africa, and one was multinational. Only three African countries produced a registry data set, with South Africa having the majority of the registries (n=3), followed by Egypt (n=2), and Ghana (n=1). Ophthalmic registries in Africa are used to study the epidemiologic features of ocular diseases, treatment outcomes, and genetic analysis.

CONCLUSIONS: The potential for clinical eye registries has not been adequately harnessed in Africa, as only a few ophthalmic registries exist. Findings from this study may help inform the planning and implementation of future ophthalmic registries and suggest focus areas that have not received due attention.

Keywords: Registries, Africa, Vision, ocular, Eye Diseases, Improvement, quality

INTRODUCTION

A registry is an organized system for collecting, analyzing, and reporting health data from a group of individuals defined by either a particular

disease, condition, or exposure to an event or a substance. Registries serve one or more predetermined scientific, clinical, or policy purposes [1]. Alternative keywords used in this type of literature are outcome registries, patient

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registries, clinical registries, clinical data registries, and disease registries to emphasize the focus on health information [1-4].

Clinical registries have existed since 1856 when what is thought to be the world's first national patient registry, the National Leprosy Registry, was established in Norway [5]. In the last 50 years, large population-based, health administrative-based, and clinical registries have come to the forefront in industrialized nations. The United Kingdom currently has about 55 clinical audit and registry programs. The United States has more than 80 clinical registries. Sweden has over 100 registries, covering a broad range of health conditions and procedures across all age ranges [6-8]. The increasing number and size of clinical registries in the developed nations illustrate the value of registries as a vital resource for clinical practice evaluation, health research, and overall health care improvement.

Though conditions such as cancer and cardiovascular diseases have traditionally led the way in registry development, the discipline of ophthalmology has also exemplified the need for registries. In the last few decades, registries have been utilized to study the epidemiologic features of rare ophthalmic diseases and diverse conditions from blindness to ocular trauma, to monitor visual outcomes of procedures, such as corneal transplantation or cataract surgeries, and to monitor and describing adverse events and their associated risk factors [9].

The characteristics and quantity of ophthalmic registries in Africa are unclear. Thus, this review was conducted to systematically map the research done in this area, as well as to identify any existing gaps in knowledge. Specifically, this review aims to examine ophthalmology clinical registries in Africa

from published literature and supply an overview of their features and study outcomes. Our analysis could be used by clinicians, researchers, and policymakers to maximize the potential of existing clinical registries and plan for future registries that will examine the eye health needs of the African population.

METHODS

Our protocol, available on request from the corresponding author, was drafted in advance. The methodology followed the PRISMA-ScR guidelines [10]. The literature search was carried out in two parts in June 2020. The first part of the literature search sought to identify ophthalmology registries in Africa without date or language restrictions. EMBASE, PubMed, and Web of Science were the databases explored for this literature search. These are three of the largest databases containing biological sciences and medicine literature. Furthermore, PubMed also indexes other databases such as the African Journal Online (AJOL) that concentrate on literature produced in the region. Table 1 shows the search strategy utilized with Boolean operators for the PubMed database.

The article suggestions given via the "related articles" algorithm were used to identify other potentially suitable articles. For this and the subsequent part of the literature search, the references within each article were also reviewed to further scout for relevant studies identifying registries.

The initial literature search identified a total of 1,736 articles whose abstracts and titles were exported into the EndNote X9 software (Clarivate

Table 1: Full Search Strategy of One Database

Database	Full search strategy
PubMed	((registry OR register) AND (Africa OR Algeria OR Angola OR Benin OR Botswana OR "Burkina Faso" OR Burundi OR "Cabo Verde" OR Cameroon OR "Central African Republic" OR Chad OR Comoros OR Congo OR "Cote d'Ivoire" OR Djibouti OR Egypt OR Eritrea OR Eswatini OR Swaziland OR Ethiopia OR Gabon OR Gambia OR Ghana OR Guinea OR Kenya OR Lesotho OR Liberia OR Libya OR Madagascar OR Malawi OR Mali OR Mauritania OR Mauritius OR Morocco OR Mozambique OR Namibia OR Niger OR Nigeria OR Rwanda OR "Sao Tome and Principe" OR Senegal OR Seychelles OR "Sierra Leone" OR Somalia OR Sudan OR Tanzania OR Togo OR Tunisia OR Uganda OR Zambia OR Zimbabwe) AND (Eye OR vision OR cornea OR cataract OR glaucoma OR retina OR blind))

Analytics, Pennsylvania), a reference managing tool. This program automatically removed Duplicates, leaving behind 1,386 unique abstracts of articles. The authors reviewed these abstracts and excluded 1,341, while 45 articles were forwarded for full-text review.

The authors assessed the full-text articles one by one for inclusion based on the predetermined eligibility criteria. Articles were included in the study only if published on clinical registries collecting data from an African country on ocular diseases or conditions, ocular manifestations of systemic illness, or exposure to a particular eye health service, such as cataract surgery or corneal transplantation. Articles with inaccessible full texts were excluded. Published works from administrative databases were equally excluded. The literature review process is shown in Figure 1. At the end of the first part of the literature review, a compilation of eye registries in Africa was created.

The second part of the literature review was aimed at identifying all the research studies published

in each registry and available on PUBMED, Web of Science, EMBASE, Hinari, Scopus, or Google Scholar. Thus, the name of each registry was entered as a search term into these databases. For example, the South African National Ocular Tumour Registry was employed as a search term to identify all published research studies that are linked with this registry. The reviewers extracted data elements about the registry characteristics, nature, and methodology from the information in the published articles. The results and conclusions of each study were summed up, and the nature of their research outcomes was identified. All the extracted data were entered into a data charting form. Discrepancies at any point in the search or selection process were resolved by the consensus of the reviewers.

RESULTS

Six distinct ophthalmic registries in Africa were identified from the literature search. Table 2 and Table 3 describes the six clinical eye registries, including the name, contact information, country

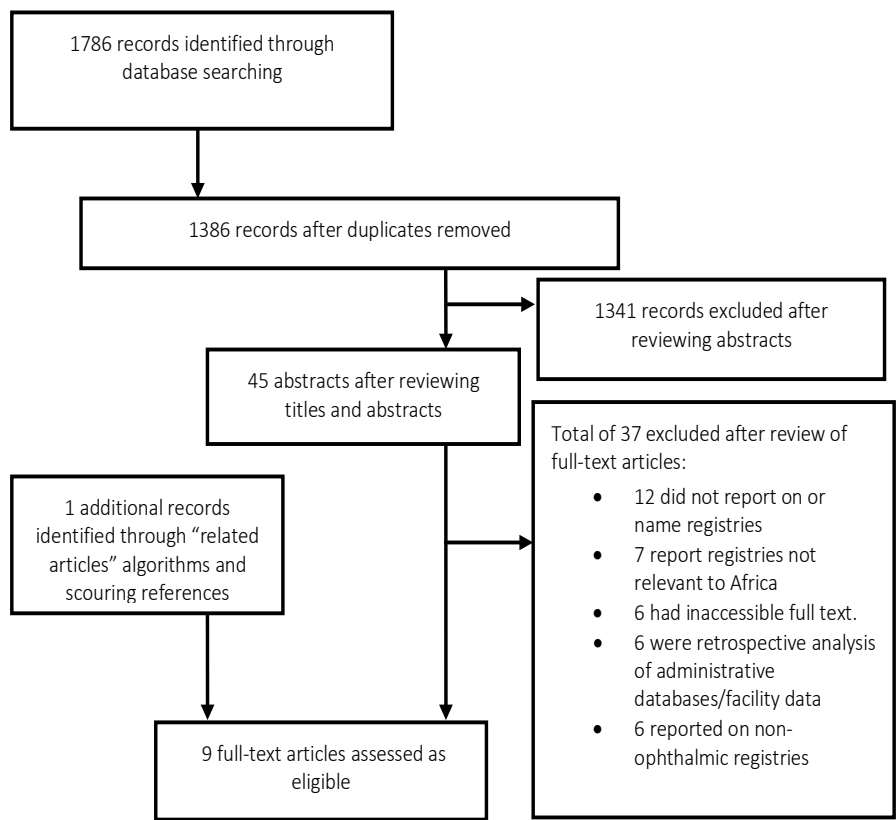


Figure 1: Outline and summary of article selection process

Table 2: Characteristics of clinical eye registries cited in the literature

No	Name	African region involved/ country of origin	Disease condition	Initiation year	Characteristics
Retina/retinoblastoma					
1	South Africa diabetic retinopathy register	South Africa/ South Africa	Diabetic retinopathy	-	National Voluntary Web-based
2	Retinoblastoma hospital-based registry	Children's Cancer Hospital, Egypt/ Egypt	Retinoblastoma	2007	Single-centre Web-based
3	DNA banking center register for Retinal Degenerative Disorders	South Africa/ South Africa	Retinal Degenerative Disorders	1990	National
4	American Joint Committee on Cancer Ophthalmic Oncology Task Force Retinoblastoma Registry	Ghana/ Canada	Retinoblastoma	2001	Multinational Web-based
Blindness/Low vision					
5	Blindness register demonstration project	Egypt/ United States	Blind/low vision	1965	Regional Voluntary
Miscellaneous					
6	South Africa national ocular tumor registry	South Africa/ South Africa	Ocular tumor	1960s	National

of origin, type, year of initiation, coverage, characteristics, data elements collected, and registry outcomes in ophthalmic research.

Classification of registries

The registries found were sorted by the ophthalmic disorder reported, and this classification is presented in Table 4. The most common condition recorded is ocular tumors (n=3), of which two registries were specific to retinoblastoma. Five of them focused on retinal diseases, one on blindness, and one on low vision.

Origin and growth of registries

One-third of the registries in this study originated outside Africa, specifically from North America. Three out of the 54 countries of Africa produced

at least one registry (Table 2). South Africa had the majority of the registries (three out of six, 50%), followed by Egypt (two, 33%) and Ghana (one, 17%). Of the five registries with known initiation dates, three began within the last 50 years, with the others starting in the 1960s.

Structure and coverage

Data on the structure and coverage of registries was acquired from the descriptions of registries in research publications (Table 2). Of the six registries, three were described as national, whereas one was regional, and another was based in a single center. The only multinational registry, the American Joint Committee on Cancer Ophthalmic Oncology Task Force Retinoblastoma Registry, was created by the American Joint Committee on Cancer to evaluate

Table 3: Characteristics of clinical eye registries cited in the literature

No	Name	Data elements				Reported findings
		Demographic information and Clinical features (e.g. diagnosis)	Examination findings (e.g. visual acuity)	Investigations (visual fields, Fundus Fluorescein Angiography etc.)	Other	
Retina/retinoblastoma						
1	South Africa diabetic retinopathy register	Yes	Yes	Yes	-	No published results
2.		Yes	Yes	Yes	Disease & management outcomes	Presentation of Retinoblastoma, and the influence of protocols and multi-disciplinary approach on care and outcomes
3.	DNA banking centre register for Retinal Degenerative Disorders	Yes	Yes	-	DNA sample	Genetic categorization of families with inherited retinal diseases.
4.	American Joint Committee on Cancer Ophthalmic Oncology Task Force	Yes	Yes	-	Disease complications, management & outcome	Value of staging in predicting metastatic risk, patient survival salvage.
Blindness/Low vision						
5.	Blindness register demonstration project	Yes	Yes	Yes	-	Epidemiology of visual impairment and blindness.
Miscellaneous						
6.	South Africa national ocular tumor registry	Yes	-	-	Pathological specimen of tumors	Racial differences and similarities in ocular tumors.

Table 4: Characteristics of clinical eye registries cited in the literature

Condition	Number of registries
Ocular tumors and Retinoblastoma	3
Diabetic retinopathy	1
Retinal degenerative disorder	1
Blindness and low vision	1

the staging system for retinoblastoma. It involved eighteen eye cancer specialty centers from 13 countries in over six continents, with one country from Africa, Ghana.

As of 2001, the DNA banking center registry for Retinal Degenerative Disorders (RDDs) in South Africa held genetic data from 1,829 individuals among 531 families with inherited RDDs. Of these individuals, 802 had RDDs, making it one of the largest registries for RDDs in the world. This was the only registry identified in Africa that maintained a repository of participant DNA from biological specimen.

Three of the six eye registries identified were hosted on web-based platforms. Two of these were the registries most recently initiated, and the third had no initiation date.

Data elements

Data elements collected by registries commonly consisted of demographic data, diagnoses, medical and ocular history, examination findings, including visual acuities, and investigation results, such as visual fields (Table 3). Other less common additional data sets captured include details on management and complications, histopathologic specimen, and DNA samples.

DISCUSSION

Research outcomes of eye registries in Africa

The value of registries in improving healthcare lies in the usefulness of the information from the analysis of the data elements and what is published as research outcomes. The research outcomes of the ophthalmic registries identified in this review can be broadly categorized as an epidemiological or descriptive analysis of a disease or condition, treatment outcomes analysis, or genetic analysis.

As in this study, registries commonly have a descriptive objective, providing valuable

information on the natural history of a disease over time, the value of various therapies utilized in different stages of a disease, and the treatment outcomes and incidences of adverse events [1]. Such registries play a particularly important role in studying rare and heterogeneous diseases, such as inherited retinal degenerative diseases and retinoblastoma [1]. For example, the Children Cancer Hospital retinoblastoma registry provided epidemiological data on the clinical presentation of an estimated 40-50% of all retinoblastoma patients receiving routine care in Egypt. It also supplied real-world evidence of the influence of protocols and multidisciplinary approach on care and outcomes.

The unharnessed potential of registries to improve healthcare quality in Africa

This review finds that the deficiency of ophthalmic registries is disproportionately acute in Africa, identifying only six registries from published literature with no substantial growth over time. For comparison, Tan et al. searched a single online database and identified 96 clinical registries from the rest of the world [9]. The mismatch is even more unsettling considering that 16% of the world population lives in Africa and Africa contributes a disproportionately large portion to the global burden of blindness and visual impairment [16].

It is possible that this study may not have identified all the clinical eye registries and their publications that do exist in Africa. On the other hand, we emphasize that a registry is only valuable if its outcomes are disseminated in platforms easily available to ophthalmic care providers and policymakers. We, therefore, argue that accessibility to registry data should be improved and that the analyses and dissemination of registry outcomes should be encouraged.

This review identified only one blind and low vision registry in Africa: the Blindness Register Demonstration Project in Egypt, which is no

longer operational. This low number of blindness and low-vision registry is striking for a continent that contributes to much of the world's blind population [16]. In developed nations, such registries are usually maintained at a national level, are commonplace, and require a mandatory referral from the patient's eye care provider [9]. Data from these registries are valuable for routine operational or administration purposes (e.g., tracking persons needing rehabilitation services), as well as for supplying local epidemiological data on disease patterns to inform public health planning [18, 19].

Surprisingly, no registries were identified in Africa that collected data on cataracts, glaucoma, ocular injuries, or clinical procedures and surgeries associated with these conditions. Cataracts are the major cause of blindness in Africa, with an estimated cataract surgery rate of 515 surgeries per one million people [20]. In fact, over four hundred thousand cataract surgeries were performed in sub-Saharan Africa in 2011 alone. Similarly, glaucoma is the most important cause of irreversible blindness in Africa and poses significant challenges in its epidemiology, diagnosis, and management that are unique to Africa [21]. Being of high public health relevance, these conditions should be better studied with a strong focus and commitment to filling the knowledge gaps and improving control strategies.

An important contributor to the paucity of registries in Africa could be that the resources for data collection and maintenance of patient registries may be beyond the reach of low-income countries with multiple competing healthcare and budget priorities. African regions currently devote less than 2% of their health budget to health research and thus, have poorly developed research infrastructures [17]. A registry needs funds for hardware, software, maintenance, personnel wages, security, and server. Additional considerations such as reliable electricity and internet access are equally required to effectively implement registries. Furthermore, data collection for registries is time-consuming and further exacerbates the existing human resources shortage in the health sector. Hence, without external support, the resources for operating a registry may simply be unavailable to many African countries. Illustratively, in our study, South Africa

and Egypt, collectively contributing two-thirds of Africa's ophthalmic registries, are among the top three countries with the highest Gross Domestic Product in Africa.

Nevertheless, registries are cost-effective in the long run, as they employ a single system for a larger data collection. The high cost of evaluating practice patterns and health outcomes for vast populations would not be possible if every study employed its systems and mechanisms for data collection. Furthermore, a multi-country study has demonstrated that clinical registries indeed improve health outcomes, increase the value of healthcare, and lower healthcare costs in the long run by translating data to guidelines and enabling clinicians to identify and share best clinical practices [4]. As information technology infrastructure develops, cost-efficiency may reduce [22]. Electronic medical records (EMRs) further offer the potential for patient registries to collect detailed data on a large number of patients in an efficient, less cumbersome, and relatively more cost-effective manner [23]. EMRs are not currently commonplace in African health facilities, but there could be dramatic growth in registry databases with their increasing use.

When registries show geographic variations in practice patterns and outcomes, it could be evidence of the uneven distribution of evidence-based concepts and technologies into clinical practice, a reflection of legitimate uncertainty about what is the best standard of care, or it may represent a sheer lack of prescribed guidelines [24]. Data derived from patient registries can be relied on to measure the effectiveness of practice patterns and inform the need, design, and dissemination of evidence-based guidelines and best practices [4, 25]. Such guidelines derived from African registries are needed because global generic guidelines that are not adapted for local use often fail to produce optimal clinical outcomes [26].

For healthcare providers and policymakers, local data is valuable. Frequently, it may be tricky to apply the data from robust registries obtained in dissimilar care cultures and patient contexts to a local environment. Local registries are essential and informative, whether or not they agree with similar registries from different places. In other

words, while all evidence must be taken into consideration, the local perspective from local registries need not be overlooked.

An international example that underscores the potential of loco-regional registries in influencing the development of practice guidelines is the European Registry of Quality Outcomes for Cataract and Refractive Surgery (EUREQUO). Collecting data from 523,921 cataract extractions among 18 European countries and Australia, the EUREQUO published valuable evidence-based guidelines for cataract surgery in 2012 [27]. However, phacoemulsification, a less popular cataract extraction technique in Africa, was done in 99.5% of the surgeries in the EUREQUO database. Therefore, though the guidelines derived from the EUREQUO database are valuable to developed nations, their application to the African context may be difficult.

The standardized collection of precise data sets and the systematic follow-up of patients also allows ophthalmic registries in other parts of the world to monitor for adverse events from medications and procedures, such as endophthalmitis from cataract extraction. Additionally, it acts to create benchmarks for peer comparisons of clinical performance indicators, such as visual outcomes, indications for surgery, and use of health services [9]. Individual surgeons, hospital facilities, and local regions can compare their performances to overall averages and identify areas for improvement. This practice improves the quality of ophthalmic service delivery in regions where such a registry database is available.

Registries in contrast to administrative databases and Randomized Controlled Trials

It is important to distinguish administrative databases from ophthalmic registries, the subject of this study. Administrative databases are pre-existent managerial data sets that store information routinely collected for billing, fiscal auditing, resource allocation, and other facility-based decision-making purposes. The clinical data captured simultaneously is indirect and incidental [11]. Data retrospectively compiled from pre-existent sources, such as out-patient registers, theatre lists, billing sheets, etc., constituted administrative databases and were not the object of this review. While the usefulness of

administrative data in quality measurements and research is growing, its significant limitation in clinical research lies in the scanty clinical details it collects, thus preventing detailed analysis [12]. On the other hand, clinical registries systematically collect comprehensive and uniform clinical information in a naturalistic manner that is intentional, usually prospective, and aligned with pre-set purposes, thereby overcoming the shortfall of inadequate data elements and confounders [1, 13].

Randomized control trials are universally recognized as the gold standard for providing the strongest hierarchical level of evidence [14]. However, randomized control trials are controlled experiments often performed on populations willing to be randomized and selected under strict inclusion and exclusion criteria. The patient characteristics and clinical scenario may bear little resemblance to what is commonly observed in clinical practice. This limits the external validity of the findings. Conversely, patient registries systematically collect comprehensive data with fewer excluded patient groups and evaluate care as it is provided, making outcome results and inferences more applicable to the wide range of patients seen in routine clinical practice [1].

Registries thus offer more pragmatic, real-world information compared to randomized control trials. They are also an effective tool when filling in gaps of knowledge that cannot be supplied when randomized control trials are difficult to conduct, such as in surgery or when very long-term outcomes are desired. Randomized control trials are complex and more expensive to conduct, increasing the relevance of registries in underdeveloped nations such as Africa [15].

Registries, like observational studies, also have limitations on the quality of data and evidence they can provide; thus, inferences should be made with caution. The validity and value of registries are contingent on appropriate study design, quality data, unambiguous definitions, the use of robust statistical methods, and accurate interpretation [1].

Since the submission of data to registries by the clinician is usually voluntary and optional, concerns have been raised regarding duplication or transcription errors, omitted information, and

the influence of selection of 'best-performer' institutions or surgeons, especially when there are no independent audits from EMRs [14].

There are some limitations to this review. First, registries presented in formats such as conference abstracts, institution websites, or non-indexed journals may have been missed, as the literature search used to identify registries was limited to three abstract databases. In an attempt to reduce the effect of this limitation, we extensively hand-searched the references of identified literature for mentions of other eye registries in Africa.

Second, certain databases may collect data using observational methods akin to a clinical registry without being labeled a registry. Our literature search would not have recognized such databases.

CONCLUSION

In developed countries, clinical eye registries have constructively influenced epidemiological and clinical research, the development of evidence-based guidelines and benchmarks, clinical decision making, healthcare quality improvement, and population health management. Regrettably, the potential for clinical eye registries to be a treasure trove of invaluable data has not been harnessed in Africa, as only a few ophthalmic registries exist. This study generated information on the scope and characteristics of ophthalmic registries in Africa. This information may help inform the planning and implementation of future registries as well as suggest focus areas that have not received due attention. Researchers and sponsors have a huge obligation in this context. Advocacy groups, consortia and networks, institutions of higher education, and teaching hospitals and their partners should work together to establish and manage more registries, recognizing that implementing a registry database in African countries is a pressing priority.

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