# The Existence, Functionality, and Utilization of Liver Cancer Registries in Sub-Saharan Africa: A Scoping Review

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**A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine in the field of Vaccinology**

**Johannesburg, 25 September 2025**

**Declaration**

I, **Bandile Myeni**, declare that this research project is my own unaided work. It is being submitted for the Master of Science in Medicine in the field of Vaccinology in the Department of Pathology at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.

_____ _____

(Signature of candidate)

25 September 2025

**Dedication**

I would like to dedicate this research to my family because of their unwavering love, the sacrifices they have made, and the unwavering support they have provided every step of the way throughout my academic path.

**Presentations arising from this research project**

The preliminary findings of this research were presented during the joint annual meeting of the Network for Oncology Research in Africa/Research and Excellence in Africa Capacity to Control Cancer (NORA/REACCT-CAN) and African Cancer Registry Network (AFCRN) , which took place at Hotel Sky in Cape Town, South Africa, from October 19 to October 23, 2024.

**Abstract**

Background: In Sub-Saharan Africa (SSA), liver cancer is the 5th most diagnosed and 4th most deadly cancer, with 46,000 cases and a 93% mortality rate. Preventable risk factors, including chronic Hepatitis B virus infection is the primary cause of hepatocellular carcinoma (HCC), which is the most frequent type of liver cancer. The administration of the Hepatitis B virus (HBV) birth dose vaccination is essential for preventing perinatal transmission of the virus and preventing chronic Hepatitis B infection. The WHO has established a target of obtaining 90% coverage for both the hepatitis B birth dose vaccine and the conventional three-dose baby vaccination series to eliminate hepatitis B. HCC is a highly fatal disease globally with the burden compounded in SSA by low HBV vaccination rates, late diagnosis, and limited access to care. Strengthening cancer registries is vital for clearly defining liver cancer burden, and for prioritising interventions and providing measurable targets to track effectiveness of strategies on disease burden reduction.

Objective: Define the existence, functionality, and utilisation of liver cancer registries in SSA and describe the adherence to existing hepatitis B vaccine recommendations in SSA.
Design: This scoping review adhered to the updated 2020 framework described in the Joanna Briggs Institute Manual for Evidence Synthesis (JBIMES) for the composition of scoping reviews.
Data sources: Employing the inclusion criteria, PubMed, Google Scholar, Google searches, African Cancer Registry Network (AFCRN) , International Agency for Research on Cancer (IARC), World Health Organisation (WHO), Health Ministry websites, and grey literature. Information was requested via a questionnaire to every cancer registry in the SSA found during the search.
Results: Two hundred and six of 2733 studies were included. Three cancer registries participated in the questionnaire, which further consolidated findings for the 3 cancer registries. The data suggest that 77 cancer registries in 37 Sub-Saharan African countries report liver cancer. Thirteen SSA countries lacked liver cancer registry data. Of the 77 cancer registries, 56 are population-based, 18 are hospital-based, and 3 are pathology-based. South Africa is the sole nation with a policy regulating the National Cancer Registry for cancer registration, whereas other countries lack such a framework. Healthcare facilities house most cancer registries. Due to understaffing and financial constraints, the majority of registries employ a director or registrar. All SSA nations have included Hepatitis B immunisation in their Expanded Programme on Immunisation in different schedules, with 16 having included birth doses. One nation has achieved the WHO birth dose coverage goal of ≥90%, while 13 nations have attained the third dosage target coverage of ≥90%.

Conclusions: African cancer registries face access, financing, obsolete data, and few monitoring tools, making cancer surveillance difficult. SSA and East Asia account for approximately 80% of hepatocellular carcinoma cases, making birth-dose hepatitis B vaccine, immunisation, and liver cancer screening essential. Taiwan's experience shows that immunisation and aflatoxin management may dramatically decrease HCC, emphasising the necessity for continental stakeholder cooperation.

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**Acronyms**

| | |
|---|---|
| AFCRN | African Cancer Registry Network |
| ALT | Alanine aminotransferase |
| CHB | Chronic hepatitis B |
| CHC | Chronic hepatitis C |
| CI5 | Cancer Incidence In 5 Continents |
| COVID-19 | Coronavirus disease 2019 |
| DNA | Deoxyribonucleic Acid |
| DoH | Department of Health |
| EPI | Expanded Programme on Immunisation |
| EQUATOR | Enhancing the QUAlity and Transparency Of health Research |
| GHIS | Gambia Hepatitis Intervention Study |
| GICR | Global Initiative for Cancer Registry Development |
| GLOBOCAN | Global Cancer Observatory |
| HBCR/s | Hospital Based Cancer Registry/Registries |
| HBsAg | Hepatitis B surface antigen |
| HBV | Hepatitis B virus |
| HCC | Hepatocellular carcinoma |
| HCV | Hepatitis C virus |
| HDI | Human Development Index |
| HIV | Human Immunodeficiency Virus |
| IACR | International Association of Cancer Registries |
| IARC | International Agency for Research on Cancer |
| ICD-10 | 10th revision of the International Classification of Diseases |
| ICD-O | International Classification of Diseases for Oncology |
| INCTR | International Network for Cancer Treatment and Research |
| JBIMES | Joanna Briggs Institute Manual for Evidence Synthesis |
| MoH | Ministry of Health |
| NAFLD | Non-Fatty Liver Disease |
| NASH | Non-alcoholic Liver Disease |
| NCR | National Cancer Registry |
| NDPR | Nigeria Data Protection Regulation |

| | |
|---|---|
| NORA | Network for Oncology Research in Africa |
| PBCR/s | Population Based Cancer Registry/Registries |
| PIVKA-II | Protein Induced by vitamin K absence or antagonist-II |
| POPIA | Protection of Personal Information Act |
| PRISMA | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| PRISMA-ScR | Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews |
| REACCT-CAN | Africa Research and Excellence in Africa Capacity to Control Cancer |
| SSA | Sub-Saharan Africa |
| T2DM | Type 2 Diabetes Mellitus |
| TNM | Tumour, Node, Metastasis |
| UICC | Union for International Cancer Control |
| WHO | World Health Organization |
| WUENIC | WHO/UNICEF Estimates of National Immunisation Coverage |

# 1. Introduction

## 1.1. Distribution of cancer globally

Cancer is the second leading cause of death in non-communicable diseases and responsible for approximately 9 million deaths with an incidence rate reaching 19 million cases worldwide in 2022 (1, 2). Within the spectrum of more than 200 cancer types, liver cancer holds a significant position, currently standing as the sixth most diagnosed cancer globally with 866 136 cases, while ranking third in cancer mortality rates with 758 725 cases in 2022 (2, 3). Regions that are highly affected are the northern and western parts of Africa and the eastern and south-eastern parts of Asia (3).

Alarmingly, liver cancer mortality rates have shown a trend of continuous rise in recent years compared to the 2008 global cancer report, where liver cancer accounted for 696 000 deaths, representing a 9% increase in 14 years (2-4). The incidence and mortality rates of liver cancer are considerably higher in males than in females (3). Males are more likely to develop hepatocellular carcinoma due to greater exposure to risk factors, while females have better prognoses due to hormonal protection and tendencies for earlier healthcare access, including higher adherence to HCC surveillance programs that detect and reduce mortality (5, 6). This trend elaborates on the urgent need for heightened awareness, prevention, and treatment strategies to address the growing burden of liver cancer on a global scale. Liver cancer encompasses two main categories: primary and secondary liver cancers. Primary liver cancers include hepatocellular carcinoma (HCC) and cholangiocarcinoma, which originate within the liver and gallbladder. HCC is the predominant form of the disease, accounting for approximately 75% of reported liver cancer cases(7). Cholangiocarcinoma, though less prevalent, constitutes roughly 10% of liver cancer diagnoses and arises from the bile ducts within the liver (7). Secondary liver cancer arises from metastases originating from other primary cancer sites, such as the gastrointestinal tract (colon, pancreas and stomach), lungs and breasts. While not originating within the liver itself, secondary liver cancers pose significant challenges due to their aggressive nature and limited treatment options. Beyond the primary categories, liver cancer encompasses various rare subtypes, collectively constituting the remaining 15% of cases(7). These include hepatoblastoma, hepatic angiosarcoma, hepatic adenoma, and fibrolamellar carcinoma, among others. Although less

common, these rare subtypes present unique diagnostic and therapeutic challenges and underscore the heterogeneity within the spectrum of liver cancer (8).

1.2. Distribution of Liver Cancer in Sub-Saharan Africa

The African continent consists of Northern Africa and Sub-Saharan Africa (SSA), which have evolved linguistically, religiously, and culturally. SSA has around 49 countries (9), which are low-income countries and lower middle-income countries and are predominantly represented by African (Black) people, while Northern Africa shares linguistic, religious, and cultural similarities with Middle Eastern countries, which are also low-income countries and lower middle-income countries.

The majority of cancer cases occur in nations with the middle to lowest human development index more often than in nations with a higher index, as defined by the United Nations Development Programme (3, 10). In 2022, 41 825 cases of liver cancer were estimated to have occurred in SSA, which placed liver cancer as 5th in incidence among cancers reported in SSA; 39 523 liver cancer deaths were estimated to have occurred in SSA, ranking it 4$^{th}$ in cancer mortality in SSA (11); the 95% "mortality to incidence ratio" is without parallel for liver cancer globally and when comparing mortality to incidence ratios for other cancers(12). Liver cancer was the second most frequently reported cancer in males in SSA(11). One critical factor contributing to the challenge of understanding the actual burden of liver cancer in SSA is the underdiagnosis of the disease, often due to late-stage presentation and limited access to healthcare services.

1.3. Aetiology and diagnosis of Liver Carcinoma in Sub-Saharan Africa

Hepatitis B virus (HBV) plays an important role in the cause of hepatocellular carcinoma (HCC) SSA (13). Perinatal or early childhood transmission of the virus, in the absence of vaccination or antiviral treatment, frequently results in chronic hepatitis B (CHB). CHB is characterised by persistent hepatic inflammation with detectable hepatitis B surface antigen (HBsAg), elevated HBV-DNA (HBV-Deoxyribonucleic Acid), and increased alanine aminotransferase (ALT) levels. Hepatocarcinogenesis occurs both indirectly, through chronic liver inflammation and cirrhosis, and directly, through HBV DNA integration into the host genome, which induces genomic instability.

Hepatitis C virus (HCV) infection is also implicated in HCC development in SSA, although to a lesser extent compared to HBV; the estimated prevalence of chronic hepatitis C (CHC) in the region ranges from 2.1% to 3.3%, with variation across countries (14).

Aflatoxins, a toxin and carcinogen generated by Aspergillus flavus, are a prevalent cause of HCC in West African nations, particularly through the consumption of aflatoxin-contaminated foods (15). Aflatoxins, particularly aflatoxin B1, are potent mycotoxins produced by Aspergillus flavus and Aspergillus parasiticus, which commonly contaminate staple foods such as maize and groundnuts in SSA. Chronic dietary exposure to aflatoxins is a well-established cause of HCC, largely due to their ability to form DNA adducts and induce specific mutations in the p53 tumour suppressor gene, most notably at codon 249.

Importantly, aflatoxin exposure has a synergistic relationship with chronic HBV infection, which dramatically amplifies the risk of HCC. This co-exposure explains the particularly high burden of liver cancer in West African nations.

Chronic alcohol consumption is another established cause of HCC(14). Long-term alcohol intake promotes the development of alcoholic liver disease and progression to cirrhosis, a key predisposing condition for liver cancer. Alcohol metabolism generates acetaldehyde and reactive oxygen species, both of which damage DNA and impair repair mechanisms. Additionally, chronic alcohol use worsens hepatic inflammation and fibrosis, creating a microenvironment conducive to malignant transformation of hepatocytes.

Metabolic and lifestyle factors such as obesity, type 2 diabetes mellitus (T2DM), and cigarette smoking are increasingly recognised as significant contributors to HCC in SSA, reflecting ongoing epidemiological transition with urbanisation(14). Obesity and diabetes drive the development of non-alcoholic fatty liver disease (NAFLD) and its progressive form, non-alcoholic steatohepatitis (NASH), which can advance to fibrosis, cirrhosis, and ultimately HCC. Smoking compounds these risks by exposing the liver to tobacco-derived carcinogens, including nitrosamines and polycyclic aromatic hydrocarbons, which directly damage hepatocyte DNA and promote carcinogenesis.

Other contributing factors include cirrhosis from any underlying cause, which remains a strong predictor of HCC development. Additionally, genetic and metabolic disorders such as hereditary haemochromatosis and Wilson's disease are rare but recognised risk factors(14). Though less frequently encountered in SSA, they highlight the multifactorial nature of HCC aetiology, where both infectious and non-infectious pathways converge to drive malignant transformation in the liver.

In the assessment of suspected HCC, initially, abdominal ultrasound and serum AFP levels are done (16). Subsequent imaging, like CT or MRI is required for lesions measuring ≥10 mm or any size with AFP levels ≥ 20 ng/mL following initial diagnosis (17) . A liver biopsy is done when imaging is inconclusive or lesions raise suspicion in a non-cirrhotic individual(17) . Following HCC confirmation, additional studies are performed for staging purposes. Diagnosis often occurs in the late stages of the disease, as most patients are asymptomatic during the early phases and only seek medical attention when they experience jaundice and ascites, which occur during advanced liver cancer, and is nearly always fatal in sub-Saharan Africa. These diagnostic barriers also mean that many cases are never formally confirmed or recorded, leading to substantial under-reporting in cancer registries and limiting the reliability of population-level HCC data.

1.4. Hepatitis B virus vaccination

Globally, the prevalence of CHB among children under five has significantly decreased from 4.7% to 1.3% following the introduction of the HBV birth dose vaccination (18). In Sub-Saharan Africa, CHB affects approximately 60 million individuals, with higher incidence rates observed in western and central Africa (13). Human Immunodeficiency Virus (HIV) infection, highly prevalent in SSA, increases the risk of HCC among patients with CHB (19). The World Health Organization recommends HBsAg testing for the general population, especially since many CHB infections occur during perinatal or early childhood transmission. Integrating HBsAg serological testing into antenatal screening and timely administration of the hepatitis B vaccine within 24 hours of birth, followed by additional doses as per WHO guidelines, can prevent a significant number of infections. The first licensed HBV vaccine, developed in the early 1980s in the United States and France, used purified HBsAg from the plasma of asymptomatic carriers; it was later on replaced by recombinant deoxyribonucleic acid (DNA) vaccines because of the global concern of the rising HIV epidemic in the mid 1980s since the virus was transmitted via blood(20). Since 1992, the WHO has recommended that all countries include the HBV vaccine in their national Expanded Programme on Immunisation (21). The WHO/UNICEF Estimates of National Immunisation Coverage (WUENIC) data sheds light on immunisation trends in the region. Only 18% of newborns in the region receive their initial vaccine dose, significantly lower than the global average of 45%;and the third dose coverage of 72% compares favorable to the global average of 85% (22, 23). However, HBV vaccination coverage dropped during the COVID-19 pandemic,

with HepB3 coverage in Africa decreasing from 73% to 66% and 58% under 10% and 20% interruptions and birth-dose coverage falling from 17% to 15% and 14%(24).These figures underscore the mixed progress in vaccination efforts across Africa, emphasising the need to enhance coverage, particularly for newborns. Despite challenges, the HBV vaccine has been effective in reducing CHB infections in African children; African adolescents aged 15–17 years have low hepatitis B vaccine seroprotection rates (~32%) (25). Yet, increasing the uptake of the crucial third dose remains a hurdle, since the objective of eradicating hepatitis B has not been achieved, although it is trending positively. This dose is vital for enduring immunity, which is projected to last around 20 years or possibly a lifetime, according to the WHO.

### 1.5. Global strategy to eliminate viral hepatitis

The WHO has implemented a comprehensive strategy aimed at eliminating viral hepatitis by 2030 (26). This comprehensive strategy integrates country-specific initiatives into primary healthcare systems with supportive data. Hepatitis B birth dose vaccination and maternal screening to minimise vertical transmission and with additional doses of hepatitis B vaccine for children within at-risk categories are key strategies. High-risk individuals for hepatitis B infection include those with incomplete vaccination or waning immunity, sexually active individuals, those with high-risk medical exposures, children born to HBV-infected mothers, and those engaging in behaviours involving shared or unsterile sharp instruments. Early detection of hepatitis viral infections requires increased knowledge of HBV and HCV testing status, access to timely antiviral treatment, and robust disease control and response surveillance systems. Given that HBV is one of many aetiologies of HCC, regular HCC screenings equal access to care, and major investments in healthcare worker training, research, and preventative and treatment techniques are also stressed. To succeed, nations and sectors must work together on these measures, which form the foundation of the global strategy to eliminate viral hepatitis.

### 1.6. Cancer registries

Cancer registries are a specific type of continuous and systematic disease surveillance, either active or passive surveillance, meant to collect, store, manage and analyse information about cancer within a well-defined population or geographic area over a defined period of time. There are many types of cancer registries, but the population-based cancer registry is the gold

standard in cancer registration, as it is able to provide an unbiased profile of the burden of cancer in clearly defined population distinguished by identifiable demographic and pertinent characteristics over a specified timeframe, employing systematic collection of incidence data from various sources(27).

A population-based cancer registry (PBCR) systematically collects and records all new cancer cases occurring in a defined population, usually within a specific geographic area. It gathers demographic information, cancer type, stage, and sometimes treatment and outcomes from hospitals, laboratories, and death certificates. Data are coded using standardised systems, validated for accuracy, and analysed to calculate incidence, prevalence, mortality, and trends. A population-based cancer registry facilitates strategic planning by identifying cancer kinds and locations, guiding interventions, resource allocation, and policies, and assisting in prioritising the use of limited resources to mitigate the cancer burden. Moreover, if interventions are required, a population-based cancer registry assists in identifying focal areas, determining which aetiologies should be addressed for elimination, and specifying essential behavioural alterations. It underscores the need of establishing screening programs and other methods for early detection, guaranteeing that treatments are both strategic and effective in alleviating the cancer burden.

A hospital-based cancer registry collects detailed information on cancer patients diagnosed and/or treated within a specific hospital. This, hospital-based cancer registries rely on cases that are treated at a specific facility, and can analyse the performance of that particular facility when it comes to patient care, education of healthcare workers, and the administration of that specific facility (26). Unlike population-based registries, a hospital-based registry typical  is not able to cover an entire population but focuses on patient care and hospital management. Hospital-based cancer registries record demographic data, tumour type, stage, treatment, and outcomes, helping hospitals monitor caseload, evaluate treatment outcomes, and support clinical research. Hospital-based cancer registries focus on improving patient care and education among healthcare workers and capturing information and research.

A pathology-based cancer registry collects information on all cancer diagnoses confirmed by pathology laboratories within a defined area or network. It focuses on histologically or cytologically verified cases, recording patient demographics, tumour type, site, and microscopic characteristics. Pathology-based cancer registries are valuable for monitoring cancer incidence, identifying trends, and supporting research, especially in settings where

hospital- or population-based data may be incomplete. However, they may underestimate the total cancer burden, as cases diagnosed clinically or treated without pathology confirmation are not captured. A pathology-based cancer registry passively collects data from laboratories on histologically diagnosed cancers. Pathology-based registries are highly specific, providing accurate liver cancer diagnoses through tissue analysis; however, their sensitivity may be constrained if biopsies are not conducted or cases are missed. Conversely, population-based registries exhibit superior sensitivity by including a broader spectrum of cases; however, their specificity may be diminished owing to dependence on clinical or imaging data (i.e. may often have missing pathology data), which may sometimes lead to misclassification. Both methods may be improved by using them together to assess liver cancer incidence, especially in resource-constrained areas.

In Sub-Saharan Africa, cancer registration efforts started around the 1950s to collect more structured data on cancer cases. However, these initiatives faced obstacles such as economic instability and political interference, leading to the decline of many registries over time(28). Some of these political instabilities may be patronage appointments of inexperienced personnel, diversion of cash to politically driven programs, and concealment or manipulation of facts that may reflect poorly on leadership may be typical. When local government leaders change, registry policies may be ignored if they contradict with political goals. These interferences impair registries' autonomy, sustainability, and trustworthiness, reducing health data accuracy. Even with some initial successes, lack of resources and sustained support hindered the continuity of data collection, making it difficult to track cancer trends effectively. In the 1980s, there was a renewed push to revive and strengthen cancer registries across the SSA region. This resurgence was fuelled by a growing recognition of the importance of tracking cancer patterns for public health planning and intervention. Despite the challenges, this period marked a turning point, signalling a shared commitment to confront the rising burden of cancer in SSA and improve health outcomes for its populations. By the end of 2021, there were 35 population-based cancer registries based in 25 different countries in SSA, which are members of the AFRCN(11). However, this coverage is restricted, as Global Cancer Observatory (GLOBOCAN) 2020 depends on estimates for a significant portion of SSA because of the absence of operational population-based cancer registries or limitations impacting their functionality. Volume 12 of Cancer Incidence in Five Continents includes just eight nations from SSA, where 12 population-based cancer registries with high-quality data are situated and published. Some of the cancer registries in Africa

might have been excluded from the publication of GLOBOCAN due to inadequate quality, incomplete information, and uneven coverage, which arise from issues such as limited financing, a shortage of skilled workers, fragile health infrastructure, and an urban bias in data collecting.

1.7. Cancer Networks

Considering cancer rates rising across Sub-Saharan Africa (11), it is critical to accurately assess the extent of the issue to target the regions that require the greatest attention. This emphasises how important it is to set up well designed, functioning cancer registries sustained over time to provide longitudinal data. Originally conceived in 2009 as a project within the International Network for Cancer Treatment and Research (INCTR) Cancer Registry Programme, the African Cancer Registry Network (AFRCN) was established in 2012(29). The main goals of AFRCN are to strengthen the healthcare system, increase research opportunities, and improve long-term cancer surveillance in Sub-Saharan Africa by providing technical support to address concerns that have been discovered and expertly assessing current challenges(29). The International Agency for Research on Cancer (IARC) and AFRCN collaborated after AFRCN was founded to build a regional hub for cancer registration in the SSA region. The role of the regional hub in SSA includes several critical responsibilities. First and foremost, it entails providing technical and scientific assistance to countries within its jurisdiction. This support could range from delivering experience in data collection approaches to advising on best practices in cancer registration. Second, the regional hub is responsible for providing personalised training sessions on population-based cancer registration and the optimal use of acquired data. These training initiatives aim to provide local experts with the skills and knowledge to improve cancer monitoring efforts in their locations. The regional hub additionally serves an important role in lobbying for the importance of cancer registration in the region, promoting support for the cause, and encouraging the formation of cancer registry associations and networks. Furthermore, as the coordinator of international research initiatives, the hub encourages stakeholder collaboration, monitors project implementation, and ensures that research findings are disseminated to increase our understanding of cancer epidemiology and inform evidence-based therapies. The AFRCN's operations are supervised by the WHO, the International Association of Cancer Registries (IACR), the International Agency for Research on Cancer (IARC), and the Union for International Cancer Control (UICC). In 2022, the IARC-Global Initiative for Cancer Registry Development (GICR), with support from the Bloomberg Philanthropies Data for

Health Initiative, designated existing cancer registries in Côte d'Ivoire, Kenya, and South Africa as Centres of Expertise to enhance cancer registration, improving collaboration and strengthening multiple cancer registries in SSA(30).

1.8. Monitoring HCC: HBV Vaccination and registry studies in SSA

The Gambia Hepatitis Intervention Study (GHIS) sought to demonstrate the prevention of adult liver cancer through child HBV immunisation; endorsed by the National Cancer Registry of The Gambia, a population-based registry founded in 1986 as part of the GHIS. Notwithstanding the initiation of newborn HBV immunisation in 1990, an examination of two decades of cancer registry data (1990–2009) revealed no substantial reduction in liver cancer incidence throughout that time frame(31). The data were inadequate to identify the impact of HBV immunisation on hepatocellular cancer rates in The Gambia(31). Long latency periods for HCC formation made it difficult to determine whether HBV vaccination, which began in the late 1980s, caused an HCC decline in The Gambia. Moreover, other co-factors such as aflatoxin exposure also contributed to HCC, complicating the attribution of alterations exclusively to vaccination.

The Kampala Cancer Registry, established in 1954, has continuously recorded a significant incidence of hepatocellular carcinoma (HCC), mostly due to chronic hepatitis B virus (HBV) infection. While universal HBV vaccination was introduce in Uganda in the early 2000s, its influence on liver cancer trends remains unclear, partially owing to the protracted latency period of CHB leading to HCC(32). South Africa included the HBV vaccine into its Expanded Programme on Immunisation (EPI) in 1995. Research has shown a reduction in HBV prevalence in youngsters, implying a potential decrease in HBV-related hepatocellular carcinoma in future generations(33).

Data from The Gambia, Uganda, and South Africa underscores the advancements and constraints of using HBV vaccine and cancer registries to track hepatocellular carcinoma (HCC) in sub-Saharan Africa. Although immunisation programmes have markedly decreased HBV prevalence in children; however, registry data has not been examined to determine if there has been a decline in HCC due to the lengthy latency period of HCC. Given that studies have shown a decline in chronic hepatitis B infection, this suggests that further study is required to thoroughly analyse the data. Nonetheless, these registries are essential for monitoring disease trends, assessing the long-term effects of vaccination, and informing public health initiatives to mitigate the incidence of liver cancer in the area.

## 1.9. Research in Taiwan

Over the past few decades, there has been a notable decline in both the incidence and mortality rates of liver cancer in countries with historically higher risk profiles, largely attributed to the widespread implementation of the HBV vaccination. Taiwan is a pioneer in demonstrating the profound impact of HBV vaccination on liver cancer rates, particularly through its comprehensive vaccination programmes initiated in the 1980s.

In July 1984, Taiwan embarked on a significant public health endeavour by introducing the HBV vaccine(34). Initially targeting newborns born to Hepatitis B surface antigen (HBsAg) - positive mothers, the vaccination programme expanded in 1986 to encompass all infants, thus ensuring broad coverage within the population(34). This proactive approach played a crucial role in curbing HBV transmission and subsequently reducing the incidence of liver cancer across age groups. In Taiwan, HBV vaccination coverage rose to over 90% by 1986, leading to a drop in childhood HBsAg carrier rates from ~10% to under 1% within two decades, with corresponding declines in new HBV infections and childhood liver cancer.

Taiwan's commitment to combating liver cancer extended beyond vaccination efforts. Between 1995 and 2003, the integration of abdominal ultrasonography screening into the national healthcare system further bolstered early detection and intervention strategies. This proactive screening approach allowed for the identification of liver abnormalities at earlier stages, enabling timely medical interventions and reducing the burden of advanced liver cancer cases. In the early 2000s, alpha-fetoprotein and protein induced by vitamin K absence or antagonist-II (PIVKA-II) tests have been performed for HCC surveillance every six months or every three months for high-risk patients (35). High-risk patients include those with chronic HBV infection (especially with high viral load, family history of HCC, or cirrhosis), cirrhosis of any cause (HBV, HCV, alcohol, NAFLD/NASH), chronic HCV with advanced fibrosis or cirrhosis**,** and patients with advanced genetic/metabolic liver diseases such as hemochromatosis or Wilson’s disease.

Building upon these initiatives, Taiwan implemented a comprehensive national viral hepatitis surveillance programme from 2004 to 2016. This programme aimed to enhance disease monitoring, improve access to diagnostic services, and strengthen public health interventions. By systematically monitoring viral hepatitis cases and implementing targeted interventions, Taiwan demonstrated its commitment to reducing liver cancer incidence and mortality rates.

The collective impact of these multifaceted approaches has been profound. Not only has the incidence of liver cancer, both in childhood and adulthood, significantly decreased due to widespread HBV vaccination, but mortality rates have also substantially declined thanks to enhanced screening and early detection efforts. Taiwan's success serves as a compelling testament to the effectiveness of proactive public health measures in combating liver cancer and improving population health outcomes.

1.10. Why was the study of liver cancer registries in Sub-Saharan Africa, looking at their existence, functionality, and utilisation undertaken?

In response to the elevated prevalence of liver cancer in SSA, where it ranks among the foremost causes of cancer-related mortality, a review of liver cancer registries in the region was conducted to examine these registries, as limited information is available regarding them. Functional registries are crucial instruments for disease surveillance, facilitating early detection, trend monitoring, and outcome tracking. This information is essential for informing public health policy, optimising resource allocation, and assessing interventions, such as hepatitis B vaccination programmes, which aim to decrease liver cancer incidence by mitigating one of its primary risk factors.

The study aims to discover operational deficiencies in liver cancer registries, including inadequate financing, insufficient staffing, poor data quality, and limited infrastructure, by examining their existence, functionality, and utilisation. Mitigating these issues can improve health systems' ability to gather, evaluate, and utilise cancer data efficiently. This research ultimately aids regional and worldwide initiatives to alleviate the burden of liver cancer and enhance health outcomes in SSA.

## 2. Rational for the scoping review

Conducting a scoping review on liver cancer registries in SSA is crucial, especially in light of the region's unique healthcare challenges and the pivotal role of cancer registries in understanding disease patterns. Given the significant disparities in healthcare access and socio-economic factors, effective public health interventions demand a nuanced understanding of local epidemiology. This review assesses the status of liver cancer registries, bridging knowledge gaps and empowering policymakers and healthcare professionals to devise evidence-based strategies for liver disease prevention and management. Moreover, it aligns with global health initiatives and fosters collaborative efforts within the SSA region.

## 3. Objectives

### Primary Objective

1) Define the Existence, Functionality, and Utilisation of Liver Cancer Registries in SSA using IARC, IACR and WHO guidelines for cancer registration(36) (Appendix 8: Summarised key criteria for a functional Cancer Registry).

### Secondary Objectives

1) Describe the guidelines for Hepatitis B vaccine recommendations in SSA.
2) Identify and scrutinise existing databases of liver cancer registries in SSA, specifically focusing on hepatocellular carcinoma data.
3) Describe the breadth of information collected by current cancer registry databases in SSA, looking at different types of registries, including patient demographics, emphasising characteristics of liver cancer, stage of liver cancer, therapy, and prognosis of liver cancer.
4) Describe who is responsible for overseeing cancer registries throughout SSA, including if they fall under the jurisdiction of the Ministry of Health, the geographical location of the registry and where they are based/managed, the personnel involved in the collection of the data and entry, and if the data reordered is longitudinal. Additionally, enquire about the existence of a tumour register that captures histological findings at diagnosis.
5) Describe the practical utility of cancer registries in SSA, emphasising whether reports or published material derived from these databases are easily accessible.

## 4. Review question

What is the scope of existing liver cancer registries, and what are the gaps and challenges affecting the functionality, availability, and utilisation since establishing and implementing the liver cancer registries across Sub-Saharan Africa?

## 5. Keywords

“Cancer registr*”, “Liver cancer”, “Carcinoma, Hepatocellular”, “Hepatitis B Vaccines”, “health planning guidelines”, “Immunisation program” “Sub–Saharan Africa”.

## 6. Eligibility Criteria:

6.1. Participants

This scoping review does not involve human subjects or participants but rather an analysis of the existing literature on data relevant to liver cancer registries in SSA.

6.2. Concept

The principal concept under the search is the delineation of the existence, operational efficacy, and utilisation of liver cancer registries in SSA. This study employs a scoping review methodology, incorporating an extensive literature analysis that encompasses both published and unpublished sources. The focus is exclusively on liver cancer registries within the SSA region, analysing their presence, functionality, and application.

6.3. Context

The research includes a range of sources such as scoping reviews, systematic reviews, primary research studies, case studies, meta-analyses, grey literature, and reports, all of which scrutinise the existence, functionality, and utilisation of liver cancer registries in SSA. The geographic emphasis is explicitly on SSA. The selected journals and articles for analysis are derived from peer-reviewed journals, conference proceedings, reputable research databases, and unpublished materials such as clinical guidelines, government reports, health-related policies, academic databases, conference proceedings, and institutional repositories from SSA. These sources were accessed via web searches to minimise publication bias and ensure comprehensive coverage for the scoping review. Stakeholders, including heads of cancer registries and authors affiliated with these registries, were contacted via email using a standardised questionnaire to get perspectives on the registries in their respective countries. Literature published in English, as well as other languages, provided they have an English translation, were considered if it met the eligibility criteria. Studies from as early as 1980 were included to account for the resurgence of cancer registries in Africa (37). Any studies or reports not focusing on liver cancer, liver cancer registries, or hepatitis within SSA were excluded to maintain relevance to the study objectives.

## 7. Type of sources

The type of sources that were eligible encompasses materials published in peer-reviewed journals, unpublished literature, conference proceedings, and reputable research databases.

There were no restrictions on study type, with both qualitative and quantitative research being eligible for inclusion. Grey literature and unpublished materials were accessed via a web search, including clinical guidelines, government reports, health-related policies, academic databases, conference proceedings, and institutional repositories from SSA. Furthermore, AFCRN was contacted to offer assistance and to contact their members to share their most recent cancer registry report, and SSA registries were invited to participate by responding to a questionnaire emailed to them. This approach aimed to mitigate publication bias and ensure a comprehensive scope for the scoping review.

## 8. Methodology

### 8.1. Design

This scoping review followed the latest 2020 updated framework delineated in the Joanna Briggs Institute Manual for Evidence Synthesis (JBIMES) for conducting a search project for a scoping review(38). The scoping review process involved the following: identifying relevant studies based on eligibility and inclusion criteria, selecting studies, extracting data using the provided tables (Appendix 6: Data extraction/ Data charting tables), analysing the evidence, and presenting results according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR) guidelines(39).

### 8.2. Inclusion and exclusion criteria

#### 8.2.1. Inclusion criteria:

A. Quantitative and qualitative published and unpublished data sources concerning liver cancer registries, liver cancer, and hepatitis B vaccines.

B. All research articles and reports related to the SSA region.

C. All types of liver cancer registries.

D. Sources written in English or any other language with an English-translated version.

E. Studies and resources from 1980 onwards.

#### 8.2.2. Exclusion criteria:

A. Studies conducted outside the SSA region are not relevant to the SSA.

B. Sources focusing only on registries unrelated or not inclusive of liver diseases or conditions.

C. Sources that lack sufficient data to inform the study's objectives will be excluded.

D. Sources dating back before 1980.

8.3. Search strategy

A meticulously devised search strategy was created between May and September 2024, which is detailed in 18.2. This search strategy utilised specific keywords and phrases, including "Cancer Registries," "Liver cancer," "Hepatitis B vaccine," "Sub-Saharan Africa," and "healthcare guidelines," in conjunction with Boolean operators "AND" and "OR." These terms facilitated a controlled vocabulary essential for the search process, which was manually tailored to core databases, including Medline (PubMed and Ovid) and Google Scholar, and keywords were mainly used for subject-specific databases. The preliminary search was done on core databases, including Medline (PubMed and Ovid) and Google Scholar. A systematic advanced search approach on Google Scholar was employed to reduce the amount of papers where titles were primarily screened because over a thousand mostly irrelevant papers were displayed for each country. The literature search included not only core resources but also subject-specific databases, such as the AFCRN website, numerous regional cancer registry websites, governmental and health ministry agency websites, and international organisations like the WHO and the IARC websites.

8.4. Data collection

Due to the outdated reports on their website, the AFRCN was approached to facilitate communication with their members for the dissemination of their findings. Field experts on cancer registries in SSA were consulted via email using a questionnaire (Appendix 3: Questionnaire form), accompanied by an information sheet, a consent form, and ethics approval for study participation. In order to verify any missing articles or data, a final Google search was conducted.

8.5. Study/source of evidence selection

Upon completion of the advanced search technique, the identified source citations were aggregated and input into a citation management system. EndNote (version 21), provided by Clarivate Analytics, Pennsylvania, United States, was used for this purpose. By following this systematic methodology (identification, screening, eligibility, and inclusion), redundancy was methodically eradicated. Subsequent to the preliminary search phase, titles and abstracts were meticulously evaluated to confirm adherence to the established inclusion criteria. REDcap

version 13.10.6 - © 2023 Vanderbilt University was used to administer the questionnaire created by Vanderbilt University, which was sent to stakeholders to authenticate the information present on their Department of Health or Ministry of Health websites about unpublished data.

8.6. Data charting / Data extraction

To address the study objectives, a Microsoft Excel data extraction spreadsheet (Appendix 6: Data extraction/ Data charting tables) was made to extract information from publications, cancer registries, and Hepatitis B vaccination guidelines in SSA. Consistency and accuracy were ensured by holding monthly meetings with the reviewer from June to October 2024 to compare data extraction tables and information extracted to see if they could answer the objectives. The data extraction tool underwent iterative modifications during the process. Data was exported to Microsoft Excel from the REDcap Questionnaire (Appendix 3: Questionnaire form).

8.7. Data Analysis and Presentation

The analysis and presentation of the scoping review findings involved systematically organising and synthesising data to address the research questions, focusing on the existence, functionality, and utilisation of liver cancer registries in SSA. The data were categorised and analysed based on common characteristics, identifying trends, patterns, and gaps through descriptive statistics analysis. The process for synthesising and categorising data relating to the study objectives using an inductive approach was collaborative and iterative. Meetings were held with the scoping reviewer on 4 occasions between August and October 2024 in blended online/in-person meetings to examine each of the justifications of included articles and liver cancer registries to discuss initial thoughts and to discuss and compare findings that would lead to distinct categories. The scoping reviewer was selected due to the similarity of our research topics and the use of the same methodology and our affiliation with the same faculty. The PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews) checklist was utilised (Appendix 7: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist) to assess and emphasise the need to adhere to predetermined reporting criteria, which helps to support the validity and reliability of the findings produced. The checklist was created by a panel of 24 experts and 2 research leaders in accordance with

the guidelines established by the EQUATOR (Enhancing the QUAlity and Transparency Of health Research) Network(39). The findings were presented through narrative synthesis, supported by tables and figures that provided an overview of the included studies, as well as visual maps illustrating conceptual relationships and the distribution of liver cancer registry studies.

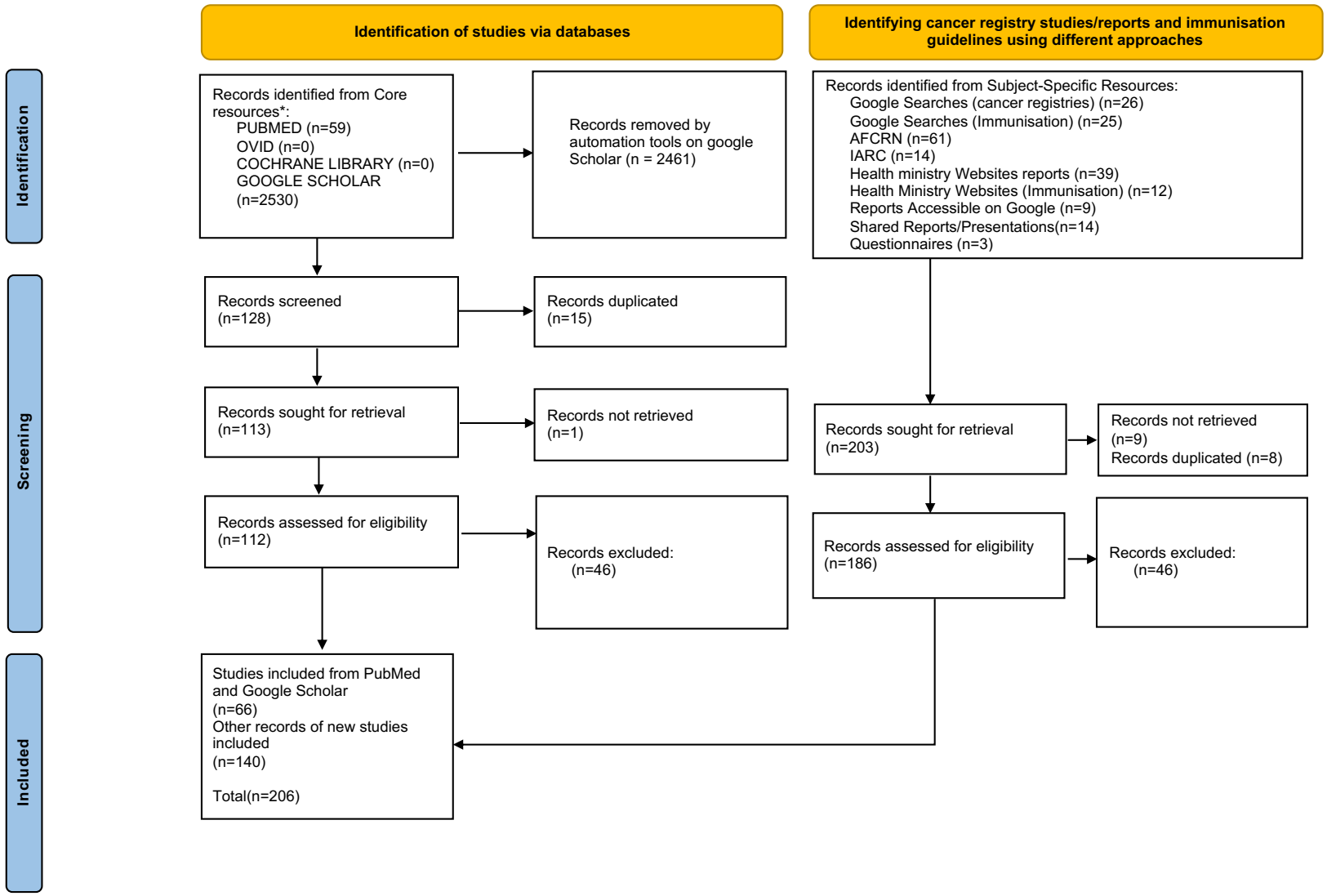
## 9. Ethical considerations

The scoping review relied on resources that were both publicly available and unpublished, as well as questionnaires that were answered by contacting stakeholders from a variety of countries in SSA. A protocol application to the Postgraduate Committee of Health Sciences at the University of the Witwatersrand and Human Research Ethics Committee at the University of the Witwatersrand. On February 19, 2024; a clearance certificate was issued after an application was submitted to the Human Research Ethics Committee at the University of the Witwatersrand (HERC reference number: H24/01/25, Appendix 4: Ethics clearance certificate).

## 10. Results

During the search, 2733 articles and resources were located. For the purpose of this scoping review, a total of 206 studies were incorporated. The PRISMA flowchart (Figure 1), which is a visual representation of the screening and selection process, provides a detailed summary of the search results that were obtained during this scoping review. These sources served as the basis for the extraction of pertinent data, which was then methodically organised into tables in Microsoft Excel for the purpose of analysis (Appendix 6: Data extraction/ Data charting tables). The PRISMA-ScR framework served as a guide for the review process, which ensured that the methodology was rigorous and that there was transparency.

Figure 1: PRISMA flow chart



## 10.1. Characteristics of included articles

Google Scholar discovered a greater number of publications than PubMed because to its broader indexing of sources, which include thesis, conference proceedings, preprints, and grey literature, alongside peer-reviewed journals. Conversely, PubMed is more discerning and mostly comprises biomedical journals that adhere to certain indexing criteria, often excluding regional or less widely disseminated papers. Significantly, about fifty per cent of the articles used in this study were sourced from grey literature, highlighting the need for extensive database coverage when investigating liver cancer registries in Sub-Saharan Africa.

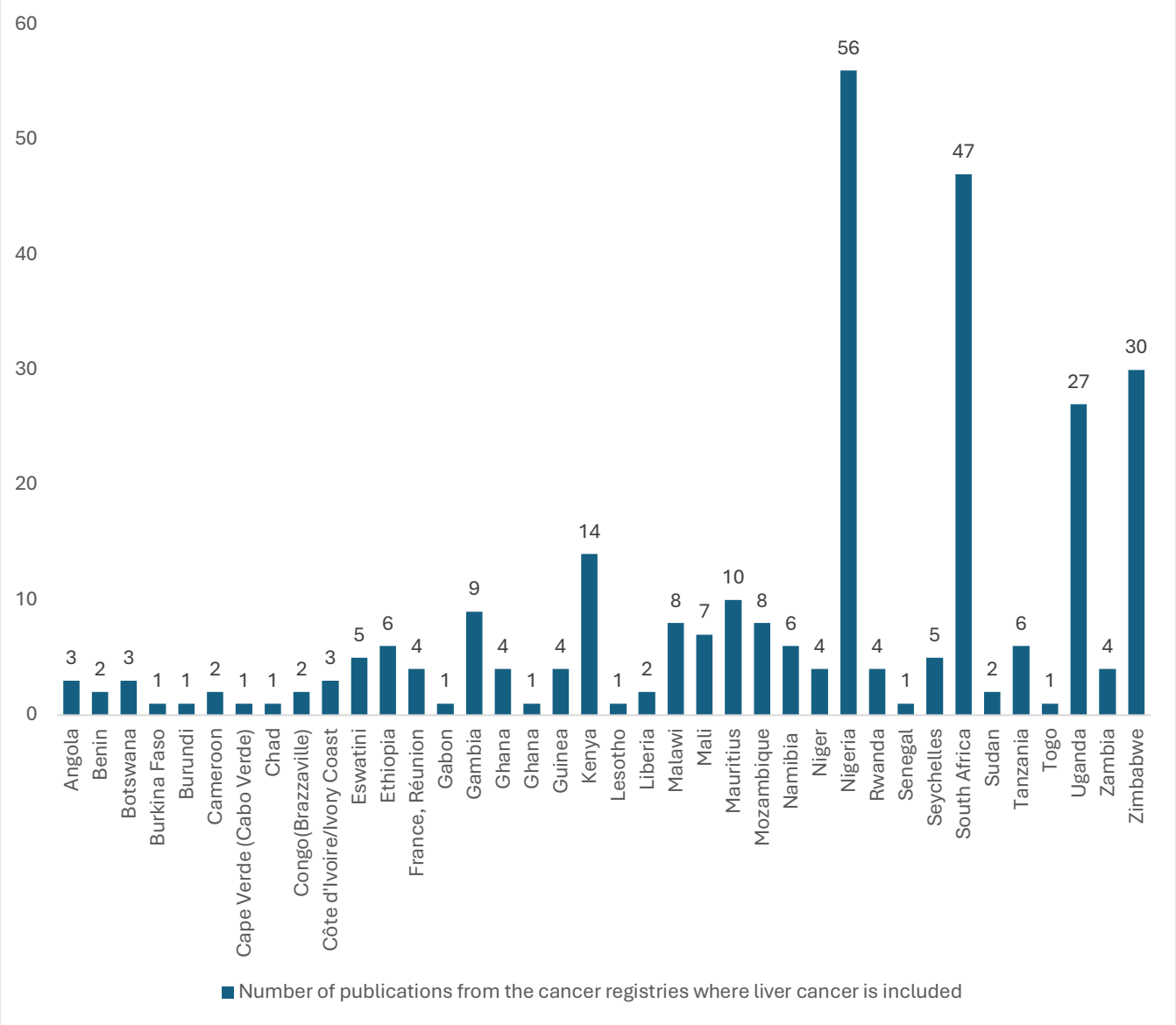
An overview of the features of the studies and articles that were included in the scoping review is presented in **Error! Reference source not found.**. The majority of these studies were registry studies, which are retrospective analyses of data obtained from registries, e.g., cancer registries, for the objective of this scoping review. Figure *2* delineates the publications from cancer registries in countries throughout SSA that document liver cancer. Additionally, specific cancer registries that contributed data for the GLOBOCAN 2022 projections but lacked publications were excluded from Figure *2*, as their data were utilised to generate estimates. However, since these estimates satisfied the inclusion criteria for the scoping review, they were incorporated into this study. vaccination and questionnaire data were omitted from the Figure *2* as well. This structured technique, a scoping review, facilitated a thorough synthesis of the literature and cancer registry data, enabling an extensive investigation of liver cancer registries.

Table 1: Study/article characteristics

| **Overall study/article characteristics** | **n/206 (%)** |
|---|---|
| Type of evidence source | |
| Primary research article | 95(46.1) |
| Formal scientific literature | 7(3.4) |
| Grey literature and *other studies and sources | 104(50.5) |

*These included articles on hepatitis B vaccination from which the vaccination guidelines could be derived, although the research article was not pertinent to the objective and social media government sites with vaccination guidelines.

Figure 2: Publications from the Cancer registries where liver cancer is included in Sub-Saharan Africa. created using Microsoft Excel




Note: Total n = 166. Some publications covered more than one country; therefore, the sum of country-specific publications exceeds 166. This total excludes the 3 questionnaires and the immunisation data.

10.2. Existence, functionality, and utilisation of liver cancer registries

In terms of existence, 77 cancer registries spread across 37 Sub-Saharan African countries collect data on liver cancer (Figure 3 & Figure 4). Thirteen Sub-Saharan African nations lacked cancer registry data pertaining to liver cancer among their respective populations. Of the seventy-seven cancer registries that recorded liver cancer, 3 were pathology-based (3.9%), 56 were population-based (72.7%), and 18 were hospital-based (23.2%).

The data collection process employed by population-based cancer registries generally involves active surveillance, either independently or alongside passive surveillance. In contrast, hospital-based and pathology-based cancer registries utilise passive surveillance; however, eight of the registries did not provide any information about their data collection methods. The majority of cancer registry data sources include pathology laboratories, hospitals, and clinics in both the public and private sectors. Death registries are utilised by only a limited number of cancer registries due to that they typically have inadequate information. These cancer registries are given names that correspond to the geographical area or country that they cover or the hospital that serves as their primary location. In 2024, 37 out of the 77 cancer registries that collect data on liver cancer are members of the AFCRN (Figure 5). Sierra Leone's registry is the 38th member; however, no information about its registry is available online (Figure 5). The 38 members comprise one pathology-based cancer registry and 37 population-based cancer registries. Approximately seventy-one percent of these PBCR data were utilised in the most recent national estimates for 2022 that were published by GLOBOCAN, and 19.6% of the PBCR data that were collected between 2013 and 2017 were used in the Volume 12 report on the Cancer Incidence In 5 Continents (CI5). Approximately 14% of the reports from the cancer registry are readily available to the general public. A standardised form for data collection was either available on the websites or attached to the reports of 19.5% of the registries, all of which are population-based registries. These standardised forms adhere to IARC guidelines and delineate a minimum dataset for cancer registries, encompassing essential variables (e.g., personal information, cancer location, morphology), recommended variables (e.g., last contact, disease stage, treatment), and optional variables (e.g., risk factors, socioeconomic status). Unique identifiers, like identification numbers, under personal information and data-matching procedures are employed to accurately reconcile data and reduce duplication, so ensuring data integrity while preserving patient anonymity. A coding component is included in the standardised forms, where coding standards utilise systems such as International Classification of Diseases for Oncology (ICD-O) and Tumour, Node, Metastasis (TNM) Summary Staging, where it integrates the most reliable diagnostic criteria (e.g., histology, imaging), and complies with international regulations for recording several cancers in a single patient. Only South Africa has a policy governing cancer registration that applies to four cancer registries. The data gathered from these forms are entered into CanReg5, a cancer registry database designed by IARC, where tumour data are standardised using international classification systems, including the ICD-O. Cancer

registry data are gathered, maintained, and analysed in accordance with established protocols recommended by organisations such as IARC and AFCRN, with the objective of producing reports that enhance comprehension of cancer trends and outcomes; however, the degree of data verification and validation may differ among registries. During this procedure, rigorous compliance with privacy standards is should be upheld, assuring respect to data protection legislation, ethical principles, and the anonymisation of sensitive patient data to safeguard individual identities and ensure confidentiality according to AFCRN and IARC. In SSA, cancer registries adhere to varying data protection frameworks to ensure patient confidentiality. Patient confidentiality is regulated by diverse frameworks among nations in SSA. South Africa implements the Protection of Personal Information Act (POPIA), whereas Kenya's Data Protection Act, Nigeria's Data Protection Regulation (NDPR), and Uganda's Data Protection and Privacy Act govern health data privacy. Section 10.6 goes into further detail about the staffing of these registries, which are more commonly understaffed due to the limited amount of funding from the 48.1% of registries that mentioned their funding. The funding for cancer registries in SSA is sourced from diverse entities, including national governments, international agencies, universities, and non-governmental organisations like vital strategies, pink cancer foundation and cancer associations across the region. Key contributors include a mix of government institutions, international organisations, research institutions, and private foundations. For instance, registries are financed by their respective Ministries of Health, often through national cancer control programs. In addition, international agencies like the IARC, the WHO, and the AFCRN provide financial and technical support. Academic and research institutions/councils, including universities and hospitals, also contribute funding, while private foundations, such as the Bristol-Myers Squibb Foundation and the Calouste Gulbenkian Foundation, offer additional support. Some registries receive direct government funding for infrastructure and staffing. Many registries also receive support through grants, and donations from prominent individuals or local organisations. However, several registries lack stable funding and rely on sporadic contributions or out-of-pocket expenses. In SSA, training for cancer registries is primarily provided by the AFCRN, the IARC, and the WHO. Additionally, cancer registry funders provide additional training support. Around 22.1% of cancer registries in SSA reported significant disruptions throughout the years owing to political instability, financial constraints, and conflicting public health goals. For example, Angola's registry halted operations in 1991, while Liberia's registry was impeded by civil turmoil and the collapse of healthcare facilities in the 1980s(40, 41). In Côte d'Ivoire, activities were suspended for a decade (2000–2010) due to political instability,

while Rwanda's registry encountered challenges after the 1994 genocide(42, 43). Between 2002 and 2009, South Africa witnessed a reduction in cancer registry operations because of low prioritisation of chronic diseases, whereas Uganda's registry was discontinued during the 1971 coup but was reinstated in 1989(41, 44). Comparable difficulties arose in Zimbabwe, where the Bulawayo registry was terminated in 1977 and subsequently reinstated in 2011(45).

Figure 3: Liver Cancer Registries in Sub-Saharan Africa between 1980-2024. created using © MapChart.net. Retrieved from https://www.mapchart.net/

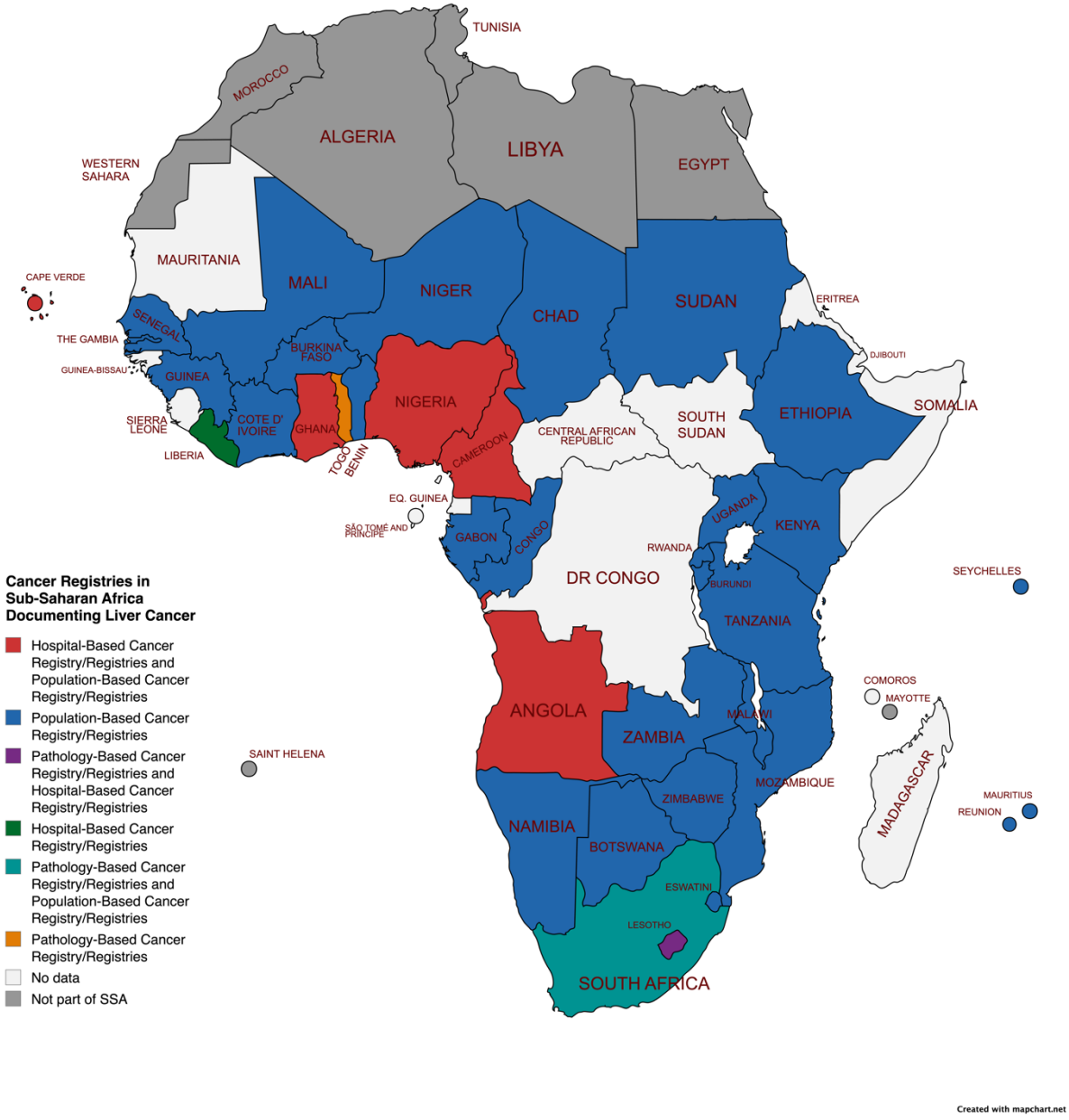


Figure 4: Liver Cancer Registries in Sub-Saharan Africa between 1980-2024

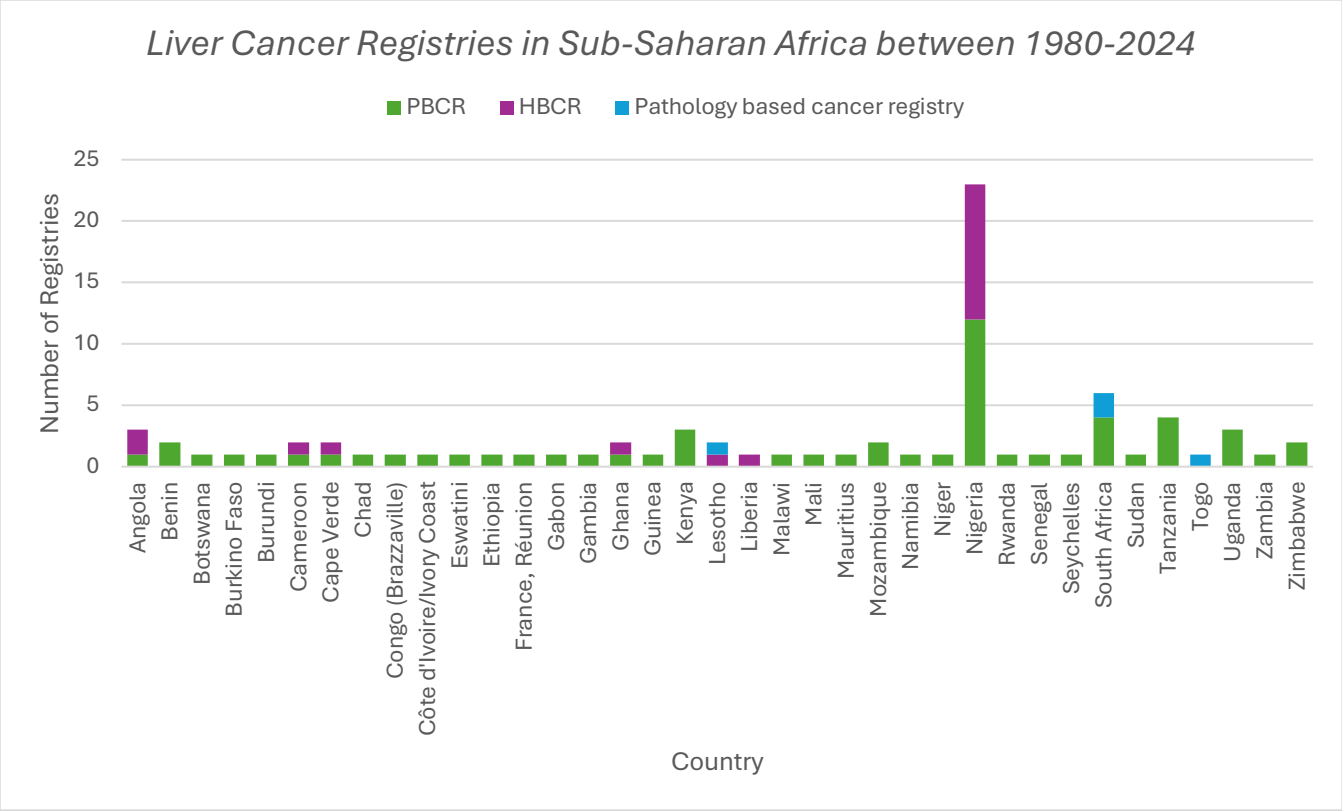


Figure 5: Liver Cancer Registries in Sub-Saharan Africa that are members of AFCRN in 2024. created using © MapChart.net. Retrieved from https://www.mapchart.net/

Seven cancer registries located in 6 countries have websites where their literature and reports are distributed. Two of these cancer registry websites (Cote D'Ivoire and France Réunion) could not be further examined because they were not in English. Research involving the use of cancer registry data and the distribution of cancer reports is consistent in some SSA countries. Approximately eighteen percent of cancer registries indicated the utilisation of data collected by

the cancer registry in their cancer registry reports, whereas data from other cancer registries was employed in research publications, contingent upon the research conducted. Cancer registries track cancer incidence, mortality, and trends, allowing the cancer registries to monitor prevalent cancers and assess health burdens. Fifteen cancer registries (19.5%) indicated the utilisation of the data they collected, albeit with rather ambiguous specifics.

Information on cancer control plans and policies is scant, especially concerning the utilisation of registry data, with only ambiguous references offered. Cancer registry data is an essential resource for guiding public health policy and enhancing healthcare interventions, but with ambiguous references. Nevertheless, although it was cited in 19.5% of cancer registries, it was not properly elucidated or linked in their papers. In SSA, registry data has informed HBV vaccination initiatives. There is scant discussion of cancer control programs and procedures, particularly concerning the utilisation of registry data, which is only referenced ambiguously. HIV-related cancers continue to pose a substantial health challenge in sub-Saharan Africa, with cancer registry data being essential for identifying common tumours and guiding screening protocols. Despite the expansion of antiretroviral therapy, the incidence of HIV-associated malignancies, including AIDS-defining cancers like Kaposi sarcoma and non-AIDS-defining cancers such as cervical cancer, remains elevated in the region(46). Registry data in the SSA aids research and education, bolstering both global and local cancer prevention strategies, specifically the vaccination against Hepatitis B virus and Human papillomavirus, as they are associated with hepatocellular carcinoma and cervical cancer, respectively.

10.3. Hepatitis B Vaccination Recommendations in Sub-Saharan Africa

The extensive implementation of the hepatitis B vaccination under the Expanded Programme on Immunisation (EPI) throughout 49 of 50 sub-Saharan African (SSA) nations signifies a significant achievement in regional efforts to address HBV infection (Figure 6). Nonetheless, discrepancies persist: vaccination statistics were unavailable for Réunion. Botswana and Zimbabwe led the way in 1994, with Botswana taking further initiative as the first to incorporate the birth dose into its EPI in 1998. Despite these advancements, the adoption of the HBV birth dose across the region has been slow, with only 16 countries including it in their national EPI schedules over three decades (Figure 7).

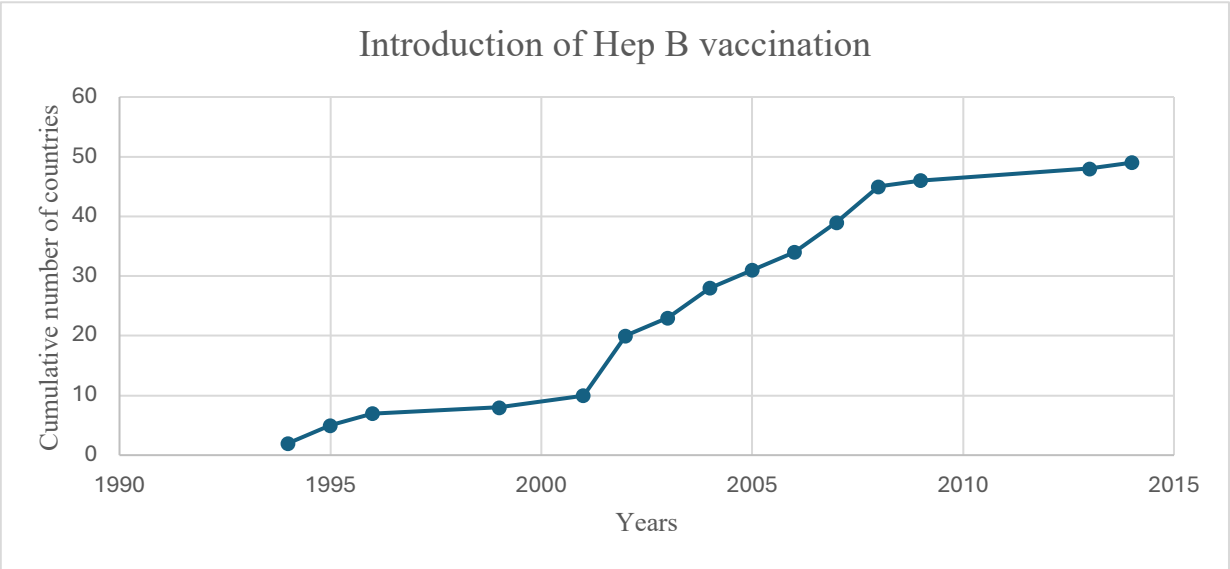



*Figure 6: Trends of Hepatitis B introduction in Sub-Saharan Africa over 3 decades (1990-2024)*

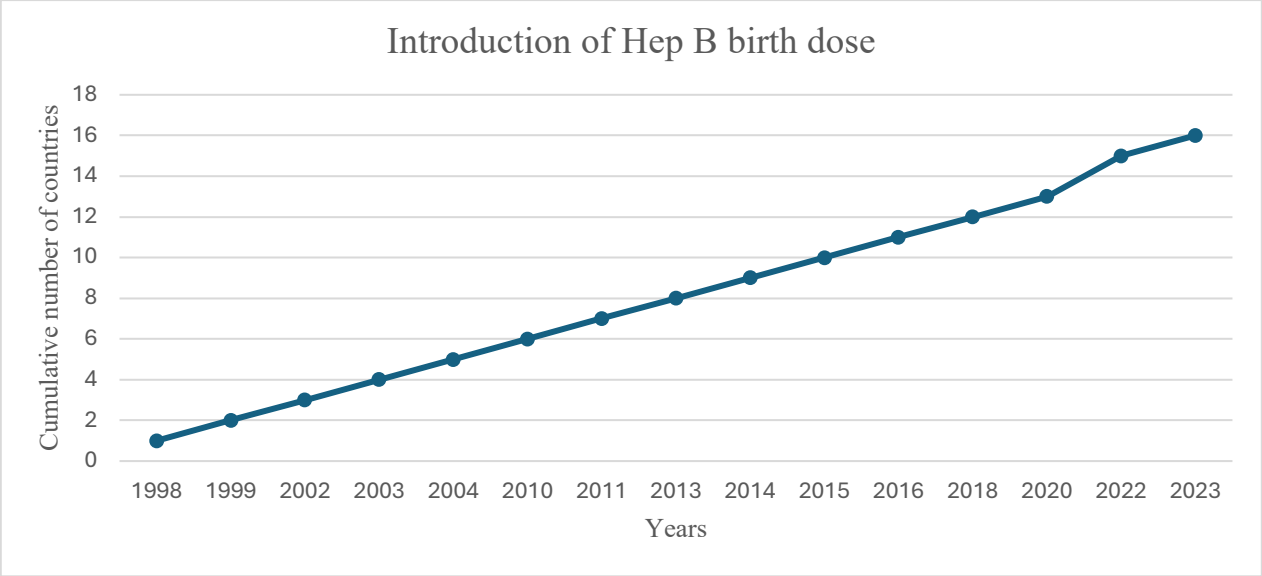



*Figure 7: Trends of Hepatitis B birth dose introduction in Sub-Saharan Africa over 3 decades (1990-2024)*

The administration of the first dose of the hepatitis B vaccine varied across sub-Saharan African countries. The majority (65%) of countries administered the first dose at six weeks, followed by 31% at birth, 2% at two months, and 2% at eight weeks (Figure 8). For the third dose, most countries (84%) provided it at 14 weeks, with smaller proportions administering it at four months (6%), 16 weeks (4%), six months (4%), and five months (2%) (Figure 9). In 31% of SSA countries, the HBV birth dose is incorporated into their EPI, with Cape Verde being the sole nation achieving the WHO recommendation of ≥ 90% coverage necessary for the elimination of viral hepatitis. In SSA countries, third-dose vaccinations are in use; however, only 15 nations, or

31% of SSA countries, have achieved the WHO-recommended coverage of 90% or higher for the third dose of viral hepatitis treatment. While these immunisation programmes have effectively reduced childhood HBV infections, the limited implementation of the birth dose leaves a critical gap in preventing perinatal transmission, which requires administration of the vaccine within 24 hours of birth.

Figure 8: Age of the 1st dose of the hepatitis B vaccine in Sub-Saharan African countries

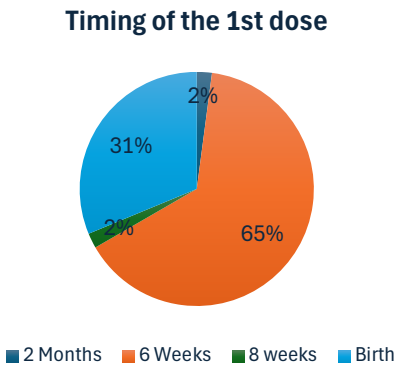
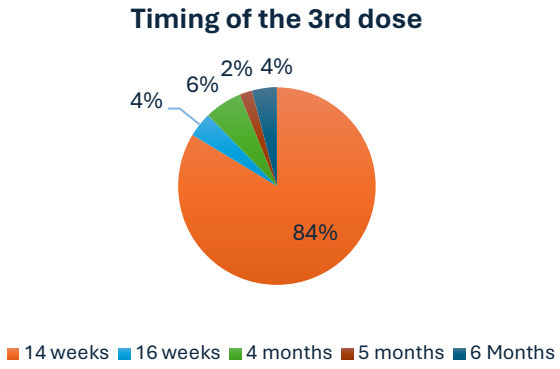



Figure 9: Age of the 3rd dose of the hepatitis B vaccine in Sub-Saharan African countries




The guidelines on the WHO website and those of health ministries or other resources in 12 different countries reveal some discrepancies regarding the administration of the hepatitis birth dosage and the absence of adult vaccination recommendations from either source.

10.4. Analysis of Existing Liver Cancer Databases in Sub-Saharan Africa with a Focus on Hepatocellular Carcinoma Data

The cases of HCC are reported separately in only 24.7% of the liver cancer registries. Childhood HCC is very rare, with only 1 to 7 cases reported over various time periods in a specific area covered by the cancer registry, where childhood cancer is defined as children 14 years of age and younger. Some regions, however, report higher overall HCC incidence when not simply looking at the childhood cancer data. For example, Malawi reported 97 cases in a study done at Tiyanjane Clinic (at Queen Elizabeth Central Hospital, Blantyre) and Mzuzu Central Hospital palliative care clinics between 2010 and 2015, while Mali reported 634 cases nationally between 1987 and 2015. The studies that reported HCC reported the cases in absolute numbers. Further

analyses would be necessary with data requests from these registries, though, as many data points are still vague, exposing information gaps across time periods and geographical locations.

10.5. Scope of Data Collected by Cancer Registry Databases in Sub-Saharan Africa

Twenty percent of liver cancer registries had standardised forms used for data collection, which were located. These standardised forms encompass patient information and demographics, tumour data, clinical staging and treatment details, source information, follow-up data, additional diseases, risk factor profiles, information about the data collector, office coding, and prior cancer history. While the 80.6% of the registries the forms were not located from their data and analysis it is clear that patient information and demographics is being collected while other details as per those that have forms cannot be concluded that they are not collected. Some cancer registries do not stage for all cancer but stage for cervical and breast cancers only. The Rwanda cancer registry is the sole source that documented the staging of liver cancer, reporting 33 cases between 2014 and 2018 (15 cases at stage 1 and 18 cases at stage 4). Other registries aggregate the staging of all cancers, complicating the analysis of liver cancer staging independently; thus, information from these registries is essential for deriving further conclusions about liver cancer staging. Further analysis and data requests from these registries are essential to determine the prognosis and treatment of liver cancer, as their reports currently lack information.

10.6. Oversight and Management of Cancer Registries in Sub-Saharan Africa

Forty-six percent of registries have directors or department heads managing them, whereas in 54.6% of registries, the responsible overseer is ambiguous. Among the registries, 61% do not explicitly indicate whether the director or head is affiliated with the Ministry of Health's / Department of Health (MoH/DoH) 35.1% confirm such affiliation, and 1.3% deny it. Sixty-six percent of registries are located in hospitals, predominantly those associated with universities or the largest facilities where cancer patients are most frequently referred. In addition, 13% of the registries only list the city name as part of their designation, not mentioning their precise location within the city. Furthermore, national institutes house 9.1% of the registries, whereas cancer associations house 1.3%. Finally, 9.1% of the registries did not include any information about their locations. Forty-four percent of cancer registries did not specify or have information on the staff working in the registry, whereas 55.8% of cancer registries shared information about their staff (**Error! Reference source not found.**). Staffing patterns vary greatly amongst registries, according to the results of the liver cancer registry's staff data. These variances are a reflection of the resources, duties, and capacities of each registry. Approximately ninety seven percent of

cancer registries did not specify whether the data they collect is longitudinal, while 2.6% indicated that the data are not longitudinal, and 1.3% reported collecting longitudinal data. Aproximately eight percent of cancer registries lacked sufficient information regarding the existence of a tumour registry, whereas 79.2% of cancer registries have tumour registries that capture histological findings.

Table 2: Simplified Summary of Staff Composition in Liver Cancer Registries

| Staff Role/Position | Description/Notes | Prevalence Across Registries |
|---|---|---|
| **Medical Directors/Pathologists** | Typically serve as registry directors or supervisors. | Common in several registries |
| **Cancer Registrars** | Full-time or part-time registrars involved in data collection and registry maintenance. | Present in many registries, some have multiple registrars |
| **Data Managers/Clerks** | Handle data collection, entry, and analysis. Often includes clerks, data abstractors, and managers. | Common in several registries |
| **Public Health Specialists** | Contribute to data analysis, health education, and promotion activities. | Less common |
| **Volunteers and Medical Students** | Provide support for data collection, entry, or registry activities. | Occasionally involved |
| **Epidemiologists** | Focus on data interpretation and cancer trends analysis. | Reported in some registries, often combined with other roles like cancer registrars |
| **Specialised Registry Staff** | Includes roles like registry managers, surveillance officers, quality assurance managers. | Limited to few cancer registries |

| | | |
|---|---|---|
| **Part-Time Staff** | Staff working on a temporary or part-time basis (e.g., registrars, data collectors). | Reported in several registries |
| **Support Staff (e.g., Nurses, Clerks)** | Includes nurses, clerks, and others aiding in data entry or patient care | Reported a few registries |

10.7. Practical Utility of Cancer Registries in Sub-Saharan Africa: Accessibility of Reports and Published Materials

Seven of the cancer registries had websites where they posted their reports and made them easily accessible to the public, but two of them were in French and could not be investigated further. Among these websites, the South Africa National Cancer Registry maintained the most current and consistent record of annual report publications. Only 11 out of the 77 cancer registries that report liver cancer have easily accessible and publicly available reports. Data from 67 of the 77 registries reporting on liver cancer are available online through sources such as IARC publications, the AFCRN website and publications (which are not frequently updated), as well as various research journals and online platforms.

## 11. Discussion

This scoping review aimed to identify cancer registries documenting liver cancer from the 1980s to 2024 across 50 countries in Sub-Saharan Africa while also analysing their functionality and utilisation. A total of 203 articles and three questionnaires were included in this review. Seventy seven cancer registries that record liver cancer were identified in 37 (of 50; 74%) of the countries in SSA. Of the 77 cancer registries, 56 were population-based cancer registries (PBCRs), widely regarded as the gold standard for cancer registration. PBCRs compile comprehensive data from various sources, including death registries, hospitals, pathology labs, and hospices, to provide statistics on cancer occurrence and a framework for assessing its public health impact. Unlike hospital-based, pathology-based, or specialised registries, which primarily serve clinical or institutional purposes, PBCRs offer community-wide insights essential for understanding cancer epidemiology and informing control strategies. Some of these 56 PBCRs began as Hospital-based cancer registries (HBCRs), or pathology-based cancer registries.

Functionality is a key criterion for membership in the AFCRN, requiring registries to undergo a consultant assessment visit and receive recommendations from two current members.

Population-based registries must cover at least 50% of their target population and maintain a minimum coverage of 70% over three years to retain membership. Functional registries participate in collaborative research projects, contribute to the AFCRN Database, update their web pages, and attend annual meetings to foster networking and knowledge-sharing. While AFCRN membership provides valuable opportunities for capacity-building and alignment with global standards, financial sustainability remains a major challenge for some of these registries. Many registries rely on short-term grants and partial government funding, which threatens their ability to meet operational and membership requirements, as evidenced by the forfeiture of membership by The Gambia, Niger, and Malawi. Despite these hurdles, registries that meet these standards greatly enhance their functionality and contribute significantly to cancer control efforts in the region.

The functionality of cancer registries is essential for their incorporation in publications like Cancer Incidence in Five Continents, AFCRN, and GLOBOCAN. A functional registry ensures systematic and comprehensive data collection, meeting high-quality standards set by the IARC, the WHO, GICR and the IACR for low and middle-income settings (47) which is applicable for a setting like SSA. High-quality cancer registry data includes completeness (The standard for cancer registry completeness is currently set at 50-70% for lower-middle-income countries, but it should improve to above 70% over the coming years as healthcare systems and data collection infrastructure strengthens), validity, comparability of data, and timeliness (48, 49). PBCRs covering well-defined populations and utilising internationally recognised classification systems such as 10th revision of the International Classification of Diseases (ICD-10) and ICD-O are prioritised in these publications. Functional registries also provide detailed demographic and tumour data (size, morphology, and behaviour) and follow ethical and regulatory standards. Engagement in regional networks such as the African Cancer Registry Network (AFCRN) and ongoing data sharing significantly bolster the sustainability of cancer registries in sub-Saharan Africa (SSA), thereby improving their capacity to provide accurate global cancer burden estimations. The AFCRN offers technical support, training, standardisation, and a collaborative research platform, essential in resource-constrained environments. Similar regional organisations are present in other low- and middle-income countries, including the Asian Cancer Registry Network in Asia and the Red de Institutos y Programas Nacionales de Cáncer (RINC) in Latin America. These entities perform analogous roles in enhancing capacity, standardising data, and promoting research collaborations. These networks facilitate registries in adhering to the high-quality standards established by IARC/WHO and IACR, while also promoting regional

coordination of cancer surveillance, thereby reducing fragmentation. In contrast, registries in SSA that have not integrated their data into AFCRN-led initiatives or international publications present challenges in assessing their functionality or verifying compliance with international benchmarks, underscoring the uneven progress across the region.

Insufficient funding significantly impedes the operation of liver cancer registries, especially in resource-constrained areas such as SSA. Registries necessitate significant financial investment for infrastructure, qualified personnel, data management systems, and ongoing upkeep. In the absence of continuous financing, numerous registries function with insufficient personnel and irregular data collection methodologies. Moreover, inadequate resources hinder training programmes and restrict outreach efforts, resulting in underreporting and incomplete statistics. This budget limitation diminishes the registries' ability to furnish dependable data for liver cancer surveillance, preventative initiatives, and legislation, hence perpetuating deficiencies in healthcare planning and intervention.

In SSA the lack of comprehensive strategies to direct cancer registration results in a substantial deficiency in cancer monitoring and control initiatives. In the absence of explicit procedures, data collecting often becomes fragmented, since reporting sources may hesitate to provide patient information owing to apprehensions over data protection requirements and possible legal consequences. This leads to inadequate case documentation and restricts cancer registries' capacity to effectively guide public health initiatives. The absence of standardised frameworks or obligatory reporting further limits the production of dependable cancer data, hindering the surveillance of disease trends, resource distribution, and the execution of targeted treatments. Enhancing policies is crucial to optimise the efficacy of cancer registries and eventually improve cancer outcomes across the area.

Liver cancer registries need reliable demographic data from a current census to determine the exact burden of liver cancer, but political instability, logistical issues, and financial limits have prevented some SSA countries from conducting population censuses. Many of these nations are implementing more current censuses with cooperation from international organisations like the United Nations Economic Commission for Africa to improve demographic data collection and health systems(50).

The absence of unique identifying methods and electronic medical records hinders cancer registration by rendering patient tracing across healthcare facilities imprecise, resulting in fragmented and untrustworthy data. This leads to misidentification, duplicate information, and difficulties in correctly evaluating the cancer burden or strategising therapies. Without consistent

identification, monitoring cancer outcomes and evaluating health policies becomes difficult. Many Sub-Saharan African countries are working with international organisations to develop or improve national ID systems, aiming to enhance data accuracy, governance, and the effectiveness of health systems, including cancer registries(51).

Only 18.2% of cancer registry reports utilised registry data directly, indicating a significant underutilisation of registries for standard public health reporting. This suggests that some cases may be missed, particularly where there are no legal frameworks mandating healthcare workers to report. However, the situation becomes more complex in countries where such laws exist, as it then requires an analysis of how the legislation is framed, the extent of enforcement, and whether it effectively translates into complete and reliable cancer registration. Data from established cancer registries in SSA are often employed in research publications, offering significant insights relevant to the project's scope and objectives. This indicates that these registries are crucial for public health interventions, yet it highlights an ongoing gap in converting registry findings into effective health policy and programmatic actions. The inclusion of registries in international publications, such as Cancer Incidence in Five Continents (CI5), is contingent upon meeting stringent standards. This underscores the necessity for ongoing enhancement of data quality and completeness among existing registries. Cancer registries are essential for evaluating the cancer burden in various regions and populations, tracking trends, and identifying gaps in healthcare services and resources. Their data are essential for research in cancer epidemiology and aetiology, and they bolster national immunisation initiatives, including hepatitis B vaccination and screening programmes. Data from AFCRN-affiliated registries have been crucial in illustrating the significant burden of cervical cancer, thus establishing a foundation for the introduction of HPV vaccines. Additionally, registry data on liver cancer has highlighted the necessity to enhance hepatitis B vaccination efforts. These activities facilitate the development of cancer centres and regionally specialised care systems. The reliability of registry data is essential for governments, healthcare providers, and researchers, as it supports evidence-based strategies for cancer prevention, treatment, and management. Nevertheless, enhancements are required to effectively bridge the feedback loop between data collection and the application of insights in public health interventions and clinical practice, thereby ensuring that registries fulfil their potential in bolstering cancer control in Sub-Saharan Africa.

HBV is a significant public health challenge in Sub-Saharan Africa, with high prevalence rates and a strong association with hepatocellular carcinoma(52). The World Health Organization's strategy for 2022–2030 seeks to eradicate viral hepatitis by 2030, incorporating tailored

initiatives into primary healthcare frameworks. Essential measures encompass the hepatitis B birth dose vaccine, maternal screening to avert vertical transmission, expanded immunisation programs, early HBV and HCV testing, prompt antiviral treatment, and enhanced surveillance. Regular screening for hepatocellular carcinoma (HCC), equitable access to healthcare, and investments in the training of healthcare workers, research, and preventive strategies are emphasised. Despite the implementation of hepatitis B vaccination across all SSA countries, disparities persist in the introduction and coverage of the birth dose. Although HCV prevalence is low in Sub-Saharan Africa, transmission predominantly occurs among individuals who use drugs. This situation requires the implementation of targeted harm-reduction strategies, including needle and syringe programmes, opioid substitution therapy, and outreach testing and treatment services. Eliminating viral hepatitis and reducing the incidence of HCC requires coordinated efforts across nations and sectors to implement interventions, emphasising both universal measures and strategies targeting high-risk populations. The incorporation of the hepatitis B virus (HBV) birth dosage into standard immunisation campaigns is restricted in sub-Saharan Africa (SSA), with just 31% of nations implementing this essential measure. Cape Verde (Cabo Verde) is the only nation to meet the World Health Organisation (WHO) objective of ≥90% coverage, deemed critical for the eradication of viral hepatitis. Although the majority of SSA nations provide the third dose of the HBV vaccination, coverage is still inadequate. Merely 15 countries, representing 31% of Sub-Saharan African nations, have attained the WHO-recommended criterion of 90% or above for the third dosage. These results emphasise ongoing deficiencies in vaccination coverage, highlighting the need for enhanced efforts to increase both the birth dose and the entire vaccine series to achieve global eradication objectives.

Analysing SSA's liver cancer registries identifies important knowledge gaps that prevent a thorough understanding and effective treatment of HCC. It is necessary to apply for additional analysis to the registries in order to further analyse their data on HCC, as 75.3% of them do not differentiate HCC incidences from other liver cancers.

Only 17 PBCRs that record liver cancer, established in 2004 or earlier, and countries that initiated Hepatitis B vaccination in their expanded immunisation programmes in 2004 or prior, qualify for an evaluation of the Hepatitis B vaccine's impact on reducing HCC incidence. Due to the lengthy incubation period that occurs between HBV infection and the onset of hepatocellular carcinoma, it is typically necessary to investigate the impact of HBV vaccination on the incidence of liver cancer over a period of twenty to forty years. The Gambia Hepatitis Intervention Study used the Gambia National Cancer Registry to assess the long-term effects of

HBV vaccination on the incidence of HCC(53). The registry's data showed a decrease in chronic HBV infection among vaccinated groups, indicating a preventive effect against HCC, underscoring the importance of HBV vaccination for HCC prevention in Africa(53). It is crucial to acknowledge that no nation in Sub-Saharan Africa is now qualified to evaluate the birth dose vaccine and its role in reducing HCC, which is essential for mitigating chronic Hepatitis B infections. Continuous strengthening of population-based cancer registries will be essential, both to assess the role of vaccination and to monitor progress toward HCC elimination.

Management and oversight of cancer registries present another layer of complexity. Over half of the registries lack clear leadership affiliations, with 61% not indicating connections to the Ministry of Health's/Department of Health. This ambiguity in governance can hinder coordinated efforts in data collection, analysis, and utilisation for public health interventions. The variability in staffing roles and the low prevalence of specialised registry staff, such as epidemiologists and public health specialists, limit the registries' capacity to perform in-depth analyses and contribute to informed policy-making.

Despite these challenges, the accessibility of cancer registry reports remains relatively limited, with only 11 out of 77 registries providing publicly available and easily accessible data. The South Africa National Cancer Registry stands out for its consistent and current reporting, serving as a model for other registries in the region. Enhancing the accessibility and transparency of cancer registry data is crucial for fostering research collaborations, informing public health strategies, and ultimately improving cancer outcomes in SSA.

## 12. Limitations

Determining whether certain cancer registries are still operational in 2024 is challenging due to inconsistent data collection and locating information for registries established between 1980 and 2024. Language barriers and limited funding for translation services also posed limitations, as registries in languages other than English lacking available translations were excluded from the study. Additionally, the infrequent updating of cancer registry information on health ministry or AFCRN websites, coupled with some registries only providing their names, further complicates the analysis. Hard copy cancer registry reports, often distributed at conferences, are not easily accessible, and obtaining registry data typically requires formal requests, with responses being delayed or hindered by changes in contact details or leadership. Furthermore, research articles on cancer registries tend to focus more on cancer incidence, risk factors, and outcomes rather than

on detailed information about registry operations. In contrast, cancer reports, which include essential details on registry staffing, funding, methodologies, cancer rates, and demographics, are often difficult to obtain. The absence of immunisation data for France Réunion limits the comprehensiveness of the analysis regarding HBV vaccination trends SSA. The discrepancy between WHO guidelines and national immunisation protocols across multiple countries introduces variability, complicating the assessment of HBV vaccine implementation. Without uniform guidelines, it is difficult to pinpoint the reasons behind differences in vaccination coverage, which may be due to policy or logistical factors. Moreover, the lack of adult vaccination recommendations restricts the scope of HBV prevention strategies, potentially underestimating the impact of vaccination programmes. The ambiguous management structures and limited staffing information in many cancer registries reveal weaknesses in data governance and operational capacity, potentially affecting the accuracy and timeliness of reporting. This further diminishes the utility of cancer registries in informing public health interventions. The restricted accessibility of cancer registry reports, with only a small fraction being publicly available, hampers the ability of researchers and policymakers to effectively engage with and utilise registry data. These challenges highlight the need for improved data dissemination, better registry management, and more comprehensive HBV vaccination strategies to enhance public health efforts. Addressing these limitations will require standardised data collection, improved oversight, and enhanced accessibility of both vaccination and registry data to support initiatives aimed at controlling HBV infection and reducing liver cancer incidence in SSA.

## 13. Recommendations

Efforts to enhance the accessibility of cancer registry reports are essential, as currently majority of these cancer registry reports are not available to the public. The AFCRN website also needs to be updated regularly, as some cancer registries barely have information about their registry, except their name. This limited access hampers the ability of individuals and communities to understand cancer trends and prevention strategies effectively.

To address functionality issues, it is vital to secure stable and sustainable funding for cancer registries, moving away from the reliance on sporadic contributions. Establishing partnerships with international organisations, private foundations, and local governments can provide the necessary financial support to ensure the longevity and effectiveness of these registries.

Moreover, it is essential to leverage cancer registry data more effectively in public health policy and cancer control initiatives, explicitly delineating where and how they intersect. This includes

making clearer references and applications in research publications, which can guide interventions and improve health outcomes.

Encouraging the use of cancer registry data in research and educational initiatives is also important, particularly in relation to Hepatitis B virus vaccination and developing screening programs for hepatocellular carcinoma. The Ministry of Health/Department of Health should ensure that vaccination schedules and recommendations are readily available on their websites and updated as necessary to facilitate comprehension and comparison with WHO/UNICEF immunisation guidelines. The implementation of the hepatitis B birth dose vaccine within 24 hours of birth across all SSA countries is an urgent priority to prevent perinatal transmission of the virus. Increasing awareness and training among healthcare providers about the importance of administering this birth dose is essential for its success. Additionally, clarifying the management structure of cancer registries by ensuring that each registry has designated directors or heads affiliated with the Ministry of Health will improve oversight and accountability.

Transparency regarding the staffing and operational details of cancer registries is also necessary to enhance accountability and resource allocation. Increasing the number of cancer registries that publish their reports online and ensuring these reports are easily accessible to the public will further promote awareness.

## 14. Conclusion

Accessing cancer registries in Africa is difficult due to the scarcity of online data and the obsolescence of information on essential platforms like the AFCRN and health ministry websites. Furthermore, acquiring physical copies of reports is frequently challenging. Cancer surveillance in many nations is impeded by inefficiencies such as discrepancies in population census in some SSA countries, limited funding in cancer registries, limited healthcare access, and the absence of unique identification mechanisms. Enhanced efforts are required for the implementation of the hepatitis B birth dose and increasing coverage of the hepatitis B vaccine to eradicate viral hepatitis by 2030. Currently, there are no liver cancer screening programmes in Sub-Saharan Africa, underscoring the urgent need for such initiatives to produce accurate liver cancer statistics, as over 80% of hepatocellular carcinoma cases are estimated to occur in Sub-Saharan Africa and East Asia. Implementing these initiatives would enable the assessment of hepatitis B vaccination efficacy as it is one of the most common risk factors of HCC in SSA, as Taiwan demonstrated how the vaccine reduced HCC cases and other interventions like decreasing aflatoxins through improved agricultural practices, biocontrol with atoxigenic strains,

proper drying and storage, food processing methods like nixtamalization, education for farmers, and strict regulatory enforcement. Improved collaboration with various stakeholders is essential for addressing the issues encountered by cancer registries and promoting cancer and hepatitis surveillance throughout the continent.

## 15. Source of funding

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## 16. Conflicts of interest

There is no conflict of interest in this project.

## 17. References


1. Wang H, Naghavi M, Allen C, Barber RM, Bhutta ZA, Carter A, et al. Global, regional, and national life expectancy, all-cause mortality, and cause-specific mortality for 249 causes of death, 1980–2015: a systematic analysis for the Global Burden of Disease Study 2015. The Lancet. 2016;388(10053):1459-544.
2. Ferlay J EM, Lam F, Laversanne M, Colombet M, Mery L, Piñeros M, Znaor A, Soerjomataram I, Bray F Global Cancer Observatory: Cancer Today 2024 [Available from: https://gco.iarc.who.int/today.]
3. Bray F, Laversanne M, Sung H, Ferlay J, Siegel RL, Soerjomataram I, et al. Global cancer statistics 2022: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. CA Cancer J Clin. 2024.
4. Ferlay J, Shin HR, Bray F, Forman D, Mathers C, Parkin DM. Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. Int J Cancer. 2010;127(12):2893-917.
5. Liou WL, Tan TJ, Chen K, Goh GB, Chang JP, Tan CK. Gender survival differences in hepatocellular carcinoma: Is it all due to adherence to surveillance? A study of 1716 patients over three decades. JGH Open. 2023;7(5):377-86.
6. Tran TT, Be HT, Hoang KD, Dong HD. Sex and gender disparities in hepatocellular carcinoma: insights into risk, diagnosis, and therapeutic outcomes. Clin Transl Oncol. 2025.
7. Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A, et al. Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries. CA: A Cancer Journal for Clinicians. 2021;71(3):209-49.
8. Altekruse SF, Devesa SS, Dickie LA, McGlynn KA, Kleiner DE. Histological classification of liver and intrahepatic bile duct cancers in SEER registries. J Registry Manag. 2011;38(4):201-5.
9. Administration ITa. Sub-Saharan Africa 2025 [Available from: https://www.trade.gov/sub-saharan-africa.]
10. Undp. Human Development Report 2023-24. UNDP (United Nations Development Programme) http://reporthdrundporg. 2024.
11. Bray F, Parkin DM, Gnangnon F, Tshisimogo G, Peko J-F, Adoubi I, et al. Cancer in sub-Saharan Africa in 2020: a review of current estimates of the national burden, data gaps, and future needs. The Lancet Oncology. 2022;23(6):719-28.

12. Lawa QO, Lawal I, Eigbefoh J, Aigbonoga DE, Lawal G. Cancer Care Gap: Examining Cancer Mortality-Incidence Rate Ratio in Sub-Saharan Africa. JCO Global Oncology. 2024;10(Supplement_1):35-.
13. Kew M. Hepatocellular carcinoma: epidemiology and risk factors. Journal of Hepatocellular Carcinoma. 2014:115.
14. El-Kassas M, Elbadry M. Hepatocellular Carcinoma in Africa: Challenges and Opportunities. Front Med (Lausanne). 2022;9:899420.
15. Spearman CW. The burden of chronic liver disease in west Africa: a time for action. The Lancet Global Health. 2023;11(9):e1319-e20.
16. Marrero JA, Ahn J, Rajender Reddy K. ACG clinical guideline: the diagnosis and management of focal liver lesions. Am J Gastroenterol. 2014;109(9):1328-47; quiz 48.
17. Marrero JA, Kulik LM, Sirlin CB, Zhu AX, Finn RS, Abecassis MM, et al. Diagnosis, Staging, and Management of Hepatocellular Carcinoma: 2018 Practice Guidance by the American Association for the Study of Liver Diseases. Hepatology. 2018;68(2):723-50.
18. WHO. GLOBAL HEPATITIS REPORT, 2017 World Health Organization2017 [Available from: www.who.int/hepatitis/publications/global-hepatitis-report2017/en/.]
19. Ngwa W, Addai BW, Adewole I, Ainsworth V, Alaro J, Alatise OI, et al. Cancer in sub-Saharan Africa: a Lancet Oncology Commission. The Lancet Oncology. 2022;23(6):e251-e312.
20. Romano L, Zanetti AR. Hepatitis B Vaccination: A Historical Overview with a Focus on the Italian Achievements. Viruses. 2022;14(7).
21. Organization WH. Hepatitis B vaccines: WHO position paper, July 2017–Recommendations. Vaccine. 2019;37(2):223-5.
22. Coverage WUEoNI. African Region Reported cases of vaccine-preventable diseases (VPDs) and African Region Vaccination coverage trendline WHO: WHO; 2022 [Available from: https://immunizationdata.who.int/dashboard/regions/african-region.]
23. WHO. Global Reported cases of vaccine-preventable diseases (VPDs) and Global Vaccination coverage trendline 2022 [Available from: https://immunizationdata.who.int/dashboard.]
24. Kabore HJ, Li X, Allison RD, Avagyan T, Mihigo R, Takashima Y, et al. Effects of Decreased Immunization Coverage for Hepatitis B Virus Caused by COVID-19 in World Health Organization Western Pacific and African Regions, 2020. Emerg Infect Dis. 2022;28(13):S217-s24.
25. Muwanda F, Sendagire H, Mboowa G, Kateete DP, Achan B, Mupere E, et al. A systematic review reveals that African children of 15–17 years demonstrate low hepatitis B vaccine seroprotection rates. Sci Rep. 2023;13(1).

26. WHO. Global health sector strategies on, respectively, HIV, viral hepatitis and sexually transmitted infections for the period 2022-2030: WHO; 2022 [Available from: https://www.who.int/publications/i/item/9789240053779.]

27. Freddie Bray AZ, Patricia Cueva, Anne Korir, Rajaraman Swaminathan, Andreas Ullrich, Susan A. Wang, and Donald Maxwell Parkin. Planning and Developing Population-Based Cancer Registration in Low- or Middle-Income Settings. Lyon (FR): International Agency for Research on Cancer (IARC Technical Report, No. 43.). National Library of Medicine, National center for biotechnology information2014. Available from: https://www.ncbi.nlm.nih.gov/books/NBK566966/.

28. Omonisi AE, Liu B, Parkin DM. Population-Based Cancer Registration in Sub-Saharan Africa: Its Role in Research and Cancer Control. JCO Glob Oncol. 2020;6:1721-8.

29. Network ACR. About AFCRN: AFCRN; 2025 [Available from: https://afcrn.org/index.php/about-us.]

30. Das M. New collaborating centres in sub-Saharan Africa to improve cancer data access. Lancet Oncol. 2023;24(2):128.

31. Bah E, Carrieri MP, Hainaut P, Bah Y, Nyan O, Taal M. 20-Years of Population-Based Cancer Registration in Hepatitis B and Liver Cancer Prevention in The Gambia, West Africa. PLoS One. 2013;8(9):e75775.

32. Wabinga HR, Nambooze S, Amulen PM, Okello C, Mbus L, Parkin DM. Trends in the incidence of cancer in Kampala, Uganda 1991-2010. Int J Cancer. 2014;135(2):432-9.

33. Moonsamy S, Suchard M, Pillay P, Prabdial-Sing N. Prevalence and incidence rates of laboratory-confirmed hepatitis B infection in South Africa, 2015 to 2019. BMC Public Health. 2022;22(1).

34. Liao S-H, Chen C-L, Hsu C-Y, Chien K-L, Kao J-H, Chen P-J, et al. Long-term effectiveness of population-wide multifaceted interventions for hepatocellular carcinoma in Taiwan. Journal of Hepatology. 2021;75(1):132-41.

35. Su TH, Wu CH, Liu TH, Ho CM, Liu CJ. Clinical practice guidelines and real-life practice in hepatocellular carcinoma: A Taiwan perspective. Clin Mol Hepatol. 2023;29(2):230-41.

36. Boyle P, Parkin DM. Cancer registration: principles and methods. Statistical methods for registries. IARC Sci Publ. 1991(95):126-58.

37. Cancer in Africa: epidemiology and prevention. 2003. Report No.: 0300-5038 (Print)

0300-5038 Contract No.: 153.

38. Peters MDJ, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, et al. Updated methodological guidance for the conduct of scoping reviews. JBI Evid Synth. 2020;18(10):2119-26.
39. Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. Ann Intern Med. 2018;169(7):467-73.
40. Armando A, Bozzetti MC, de Medeiros Zelmanowicz A, Miguel F. The epidemiology of cancer in Angola-results from the cancer registry of the national oncology centre of Luanda, Angola. Ecancermedicalscience. 2015;9:510.
41. D.M. Parkin AJ, F. Bray, A.R. Korir, B. Kamaté, E. Singh, W.Y. Joko, M. Sengayi-Muchengeti, B. Liu and J. Ferlay. Cancer in Africa: epidemiology and prevention. 2003. Report No.: 0300-5038 (Print)

0300-5038 Contract No.: 153.
42. Parkin DM JA, Bray F, Korir AR, Kamaté B, SIngh E, Joko WY, Sengayi-Muchengeti M, Liu B, Ferlay J. Cancer in Sub-Saharan Africa. 2019.
43. Newton R, Ngilimana PJ, Grulich A, Beral V, Sindikubwabo B, Nganyira A, et al. Cancer in Rwanda. Int J Cancer. 1996;66(1):75-81.
44. (NCR-SA) TSANCR. South Africa National Cancer Registry (NCR-SA) AFCRN2024 [Available from: https://www.afcrn.org/membership/members/87-ncrsa.]
45. Parkin DM, Chingonzoh T, Vuma S, Liu B, Chokunonga E, Ndlovu N, et al. Changes in the Incidence of Cancer in Bulawayo, Zimbabwe over a 50-Year Period. Cancer Epidemiol Biomarkers Prev. 2021;30(5):867-73.
46. Chinula L, Moses A, Gopal S. HIV-associated malignancies in sub-Saharan Africa: progress, challenges, and opportunities. Curr Opin HIV AIDS. 2017;12(1):89-95.
47. Bray F, Znaor A, Cueva P, Korir A, Swaminathan R, Ullrich A, et al. Planning and developing population-based cancer registration in low-or middle-income settings. 2021.
48. Bray F, Parkin DM. Evaluation of data quality in the cancer registry: principles and methods. Part I: comparability, validity and timeliness. Eur J Cancer. 2009;45(5):747-55.
49. Parkin DM, Bray F. Evaluation of data quality in the cancer registry: principles and methods Part II. Completeness. Eur J Cancer. 2009;45(5):756-64.
50. (ECA) UNECfA. Status of the 2020 round of population and housing censuses in Africa 2020 [Available from: https://www.uneca.org/sites/default/files/ACS/Statcom-VII/2020_round_of_censuses.pdf.]
51. Bank W. The state of identification systems in Africa. ID4D Country Profiles Report. 2020.

52. Kedar Mukthinuthalapati VVP, Sewram V, Ndlovu N, Kimani S, Abdelaziz AO, Chiao EY, et al. Hepatocellular Carcinoma in Sub-Saharan Africa. JCO Glob Oncol. 2021;7:756-66.
53. Viviani S, Carrieri P, Bah E, Hall AJ, Kirk GD, Mendy M, et al. 20 years into the Gambia Hepatitis Intervention Study: assessment of initial hypotheses and prospects for evaluation of protective effectiveness against liver cancer. Cancer Epidemiol Biomarkers Prev. 2008;17(11):3216-23.
54. UGANDA TRO. UGANDA GUIDELINES FOR PREVENTION, TESTING, CARE AND TREATMENT OF HEPATITIS B AND C VIRUS INFECTION. In: HEALTH MO, editor. 2019.
55. International Agency for Research on Cancer WHO. GLOBOCAN 2022 registries list 2024 [Available from: https://gco.iarc.who.int/media/globocan/material/GLOBOCAN2022_registries_list.pdf.]

## 18. Appendices

### 18.1. Appendix 1: References of included articles

PubMed


1. Echimane AK, Ahnoux AA, Adoubi I, et al. Cancer incidence in Abidjan, Ivory Coast: first results from the cancer registry, 1995-1997. *Cancer*. 2000;89(3):653-663. doi:10.1002/1097-0142(20000801)89:3<653::aid-cncr22>3.0.co;2-z
2. Peers F, Bosch X, Kaldor J, Linsell A, Pluijmen M. Aflatoxin exposure, hepatitis B virus infection and liver cancer in Swaziland. *Int J Cancer*. 1987;39(5):545-553. doi:10.1002/ijc.2910390502
3. Sighoko, Dominique et al. “Increase in female liver cancer in the Gambia, West Africa: evidence from 19 years of population-based cancer registration (1988-2006).” *PloS one* vol. 6,4 e18415. 7 Apr. 2011, doi:10.1371/journal.pone.0018415
4. Bah, E et al. “Cancer in the Gambia: 1988-97.” *British journal of cancer* vol. 84,9 (2001): 1207-14. doi:10.1054/bjoc.2001.1730
5. Bah, E et al. “The first 2 years of the Gambian National Cancer Registry.” *British journal of cancer* vol. 62,4 (1990): 647-50. doi:10.1038/bjc.1990.347
6. Bah, Ebrima et al. “20-years of population-based cancer registration in hepatitis B and liver cancer prevention in the Gambia, West Africa.” *PloS one* vol. 8,9 e75775. 30 Sep. 2013, doi:10.1371/journal.pone.0075775
7. Koulibaly, M et al. “Cancer incidence in Conakry, Guinea: first results from the Cancer Registry 1992-1995.” *International journal of cancer* vol. 70,1 (1997): 39-45. doi:10.1002/(sici)1097-0215(19970106)70:1<39::aid-ijc6>3.0.co;2-7
8. Sobo, A O. “Cancer in Liberia: a review of cases registered from the Liberia Cancer Registry 1973-1977.” *Cancer* vol. 49,9 (1982): 1945-51. doi:10.1002/1097-0142(19820501)49:9<1945::aid-cncr2820490933>3.0.co;2-g
9. Amadou, Amina et al. “Decrease in liver cancer incidence rates in Bamako, Mali over 28 years of population-based cancer registration (1987-2015).” *World journal of hepatology* vol. 14,9 (2022): 1767-1777. doi:10.4254/wjh.v14.i9.1767
10. Bayo, S et al. “Cancer in Mali, 1987-1988.” *International journal of cancer* vol. 45,4 (1990): 679-84. doi:10.1002/ijc.2910450418
11. Carrilho, Carla et al. “Cancer incidence in Mozambique in 2015-2016: data from the Maputo Central Hospital Cancer Registry.” *European journal of cancer prevention : the official journal of the European Cancer Prevention Organisation (ECP)* vol. 28,4 (2019): 373-376. doi:10.1097/CEJ.0000000000000457
12. Lorenzoni, Cesaltina et al. “Trends in cancer incidence in Maputo, Mozambique, 1991-2008.” *PloS one* vol. 10,6 e0130469. 25 Jun. 2015, doi:10.1371/journal.pone.0130469
13. Awodele, Olufunsho et al. “Cancer distribution pattern in south-western Nigeria.” *Tanzania journal of health research* vol. 13,2 (2011): 125-31. doi:10.4314/thrb.v13i2.55226

14. Silas, Olugbenga Akindele et al. “Predictors of Mortality From a Population-Based Cancer Registry Data in Jos, Nigeria: A Resource-Limited Setting.” *Frontiers in medicine* vol. 7 227. 4 Jun. 2020, doi:10.3389/fmed.2020.00227
15. Silas, Olugbenga Akindele et al. “Changing patterns in trend of top 10 cancers in the Jos University Teaching Hospital's (JUTH) cancer registry (1996-2018), Jos, north-central Nigeria.” *Journal of medicine in the tropics* vol. 21,2 (2019): 81-86.
16. Echejoh, G O et al. “Hepatocellular carcinoma in Jos, Nigeria.” *Nigerian journal of medicine : journal of the National Association of Resident Doctors of Nigeria* vol. 17,2 (2008): 210-3. doi:10.4314/njm.v17i2.37386
17. Hagenimana, Marc et al. “Stage at diagnosis and survival among adult patients with cancer in Rwanda: A population-based study.” *International journal of cancer* vol. 155,6 (2024): 988-995. doi:10.1002/ijc.34969
18. Newton, R et al. “Cancer in Rwanda.” *International journal of cancer* vol. 66,1 (1996): 75-81. doi:10.1002/(SICI)1097-0215(19960328)66:1<75::AID-IJC14>3.0.CO;2-A
19. Moore, S W et al. “Malignant liver tumors in South African children: a national audit.” *World journal of surgery* vol. 32,7 (2008): 1389-95. doi:10.1007/s00268-008-9526-8
20. Moore, Samuel W et al. “Hepatocellular carcinoma and liver tumors in South African children: a case for increased prevalence.” *Cancer* vol. 101,3 (2004): 642-9. doi:10.1002/cncr.20398
21. Stefan C, Bray F, Ferlay J, Liu B, Maxwell Parkin D. Cancer of childhood in sub-Saharan Africa. *Ecancermedicalscience*. 2017;11:755. Published 2017 Jul 28. doi:10.3332/ecancer.2017.755
22. Mutyaba, Innocent et al. “A Population-Level Evaluation of the Effect of Antiretroviral Therapy on Cancer Incidence in Kyadondo County, Uganda, 1999-2008.” *Journal of acquired immune deficiency syndromes (1999)* vol. 69,4 (2015): 481-6. doi:10.1097/QAI.0000000000000620
23. Ocama, P et al. “Trends in the incidence of primary liver cancer in Central Uganda, 1960-1980 and 1991-2005.” *British journal of cancer* vol. 100,5 (2009): 799-802. doi:10.1038/sj.bjc.6604893
24. Bukirwa, Phiona et al. “Trends in the incidence of cancer in Kampala, Uganda, 1991 to 2015.” *International journal of cancer* vol. 148,9 (2021): 2129-2138. doi:10.1002/ijc.33373
25. Chokunonga, E et al. “Aids and cancer in Africa: the evolving epidemic in Zimbabwe.” *AIDS (London, England)* vol. 13,18 (1999): 2583-8. doi:10.1097/00002030-199912240-00012
26. Bassett, M T et al. “Zimbabwe National Cancer Registry: summary data 1986-1989. National Cancer Registry Advisory Committee.” *The Central African journal of medicine* vol. 38,3 (1992): 91-4.
27. Chokunonga, Eric et al. “Black-white differences in cancer risk in Harare, Zimbabwe, during 1991-2010.” *International journal of cancer* vol. 138,6 (2016): 1416-21. doi:10.1002/ijc.29883

Google Scholar


1. Armando A, Bozzetti MC, de Medeiros Zelmanowicz A, Miguel F. The epidemiology of cancer in Angola—results from the cancer registry of the national oncology centre of Luanda, Angola. ecancermedicalscience. 2015;9.
2. Miguel F, Bento MJ, De Lacerda GF, Weiderpass E, Santos LL. A hospital-based cancer registry in Luanda, Angola: the Instituto Angolano de Controlo do Cancer (IACC) Cancer registry. Infectious agents and cancer. 2019 Dec;14:1-9.
3. Egue M, Gnangnon FH, Akele-Akpo MT, Parkin DM. Cancer incidence in Cotonou (Benin), 2014–2016: First results from the cancer Registry of Cotonou. Cancer epidemiology. 2019 Apr 1;59:46-50.
4. Dryden-Peterson S, Medhin H, Kebabonye-Pusoentsi M, Seage III GR, Suneja G, Kayembe MK, Mmalane M, Rebbeck T, Rider JR, Essex M, Lockman S. Cancer incidence following expansion of HIV treatment in Botswana. PloS one. 2015 Aug 12;10(8):e0135602.
5. Afungchwi GM, Kruger M, Wharin PD, Bardin R, Kouya FN, Hesseling PB. The evolution of a hospital-based cancer registry in Northwest Cameroon from 2004 to 2015. Journal of Tropical Pediatrics. 2021 Jun 1;67(3):fmaa038.
6. Silva ET, Spencer HB, Costa V, Gonçalves AF, Castro C, Bento MJ, Barbosa C, Santos LL. Cancer in Santiago Island, Cape Verde: data from the Hospital Agostinho Neto Cancer Registry (2017–2018). ecancermedicalscience. 2019;13.
7. Fadlelmola FM. Cancer registries and cancer genomics research in east Africa: challenges and lessons learned. IntClinPathol J. 2016; 2 (4): 67-76 [Internet].
8. Shimakawa Y, Bah E, Wild CP, Hall AJ. Evaluation of data quality at the Gambia national cancer registry. International Journal of Cancer. 2013 Feb 1;132(3):658-65.
9. Kamita M, Waweru H, Githinji M, Kibiro E, Makokha F. Establishing a Cancer Registry and Baseline Incidence Data for Nyandarua County, Kenya: A Step Towards Targeted Cancer Control Programs. Kenya: A Step Towards Targeted Cancer Control Programs.
10. Msyamboza KP, Dzamalala C, Mdokwe C, Kamiza S, Lemerani M, Dzowela T, Kathyola D. Burden of cancer in Malawi; common types, incidence and trends: national population-based cancer registry. BMC research notes. 2012 Dec;5:1-8.
11. Lorenzoni CF, Ferro J, Carrilho C, Colombet M, Parkin DM. Cancer in Mozambique: results from two population-based cancer registries. International Journal of Cancer. 2020 Sep 15;147(6):1629-37.
12. Jedy-Agba E, Curado MP, Ogunbiyi O, Oga E, Fabowale T, Igbinoba F, Osubor G, Otu T, Kumai H, Koechlin A, Osinubi P. Cancer incidence in Nigeria: a report from population-based cancer registries. Cancer epidemiology. 2012 Oct 1;36(5):e271-8.
13. Omonisi A, Komolafe A, Adefehinti O, Olasode B, Lawal O, Durosinmi M, Odesanmi W. Cancer in Ife-Ijesha, Southwestern Nigeria: An Account of a 20-year Cancer Registration from Ife-Ijesha Cancer Registry. International Journal of Internal Medicine. 2020;9(1):11-9.
14. Mohammed AZ, Edino ST, Ochicha O, Gwarzo AK, Samaila AA. Cancer in Nigeria: a 10-year analysis of the Kano cancer registry. Nigerian Journal of Medicine. 2008 Sep 16;17(3):280-4.

15. Yusuf I, Atanda AT, Umar AB, Imam MI, Mohammed AZ, Ochicha O, Haruna MS. Cancer in Kano, Northwestern Nigeria: A 10-year update of the Kano cancer registry. Annals of Tropical Pathology. 2017 Jul 1;8(2):87-93.
16. Mandong BM, Manasseh AN, Ayuba DM, Olugbenga SA, Emmanuel I, Kwaghe BV, Mandong JB. Burden of cancer in plateau state, central nigeria: a 27-year report from a tertiary hospital-based cancer registry. J Adv Med Medi Res. 2018:1-.
17. Christopher OC, Osagbemiro BB, Akani NA. Cancer incidence in the Niger delta region of Nigeria; a population based review of Port Harcourt cancer registry. The Nigerian Health Journal. 2019;19(2):85-95.
18. Ukah CO, Nwofor AM. Cancer incidence in south-east Nigeria: a report from Nnewi cancer registry. Orient Journal of Medicine. 2017 Apr 10;29(1-2):48-55.
19. Afolayan A. Cancer in the North-Western region of Nigeria: an update analysis of Zaria cancer registry data. Western Nigeria Journal of Medical Sciences. 2008;1(01 May/June).
20. Stefan DC, Kruger M, Stones DK, Wainwright RD, Davidson A, Poole J, Hadley GP, Forman D, Colombet M, Foucher SE. Childhood cancer incidence in South Africa, 1987-2007. South African Medical Journal. 2015 Nov 1;105(11):939-47.
21. Saeed IE, Weng HY, Mohamed KH, Mohammed SI. Cancer incidence in Khartoum, Sudan: first results from the Cancer Registry, 2009–2010. Cancer medicine. 2014 Aug;3(4):1075-84.
22. Darre T, Kpatcha TM, Bagny A, Maneh N, Gnandi-Piou F, Tchangai B, Daré S, Adani-Ifé S, Walla A, Amégbor K, Napo-Koura G. Descriptive Epidemiology of Cancers in Togo from 2009 to 2016. Asian Pacific Journal of Cancer Prevention: APJCP. 2017;18(12):3407.
23. Gondos A, Brenner H, Wabinga H, Parkin DM. Cancer survival in kampala, Uganda. British journal of cancer. 2005 May;92(9):1808-12.
24. Wabinga HR, Nambooze S, Amulen PM, Okello C, Mbus L, Parkin DM. Trends in the incidence of cancer in Kampala, Uganda 1991–2010. International journal of cancer. 2014 Jul 15;135(2):432-9.
25. Parkin DM, Nambooze S, Wabwire-Mangen F, Wabinga HR. Changing cancer incidence in Kampala, Uganda, 1991–2006. International journal of cancer. 2010 Mar 1;126(5):1187-95.
26. Mbulaiteye SM, Katabira ET, Wabinga H, Parkin DM, Virgo P, Ochai R, Workneh M, Coutinho A, Engels EA. Spectrum of cancers among HIV-infected persons in Africa: the Uganda AIDS-Cancer Registry Match Study. International Journal of Cancer. 2006 Feb 15;118(4):985-90.
27. Wabinga HR, Parkin DM, Wabwire-Mangen F, Nambooze S. Trends in cancer incidence in Kyadondo County, Uganda, 1960–1997. British journal of cancer. 2000 Apr;82(9):1585-92.
28. Wabinga HR, Mugerwa JW, Parkin DM, Wabwire-Mangen F. Cancer in Kampala, Uganda, in 1989–91: changes in incidence in the era of AIDS. International Journal of Cancer. 1993 Apr 22;54(1):26-36.
29. Kakande I, Ekwaro L, Obote WW, Nassali G, Kakande RI, Kabuye S. The pattern of cancer in Kampala, Uganda. East and Central African Journal of Surgery. 2001;6(1).
30. Okongo F, Ogwang DM, Liu B, Maxwell Parkin D. Cancer incidence in Northern Uganda (2013–2016). International Journal of Cancer. 2019 Jun 15;144(12):2985-91.

31. Kalubula M, Shen H, Makasa M, Liu L. Epidemiology of cancers in Zambia: a significant variation in cancer incidence and prevalence across the nation. Malawi Medical Journal. 2021 Sep 27;33(3):186-95.
32. Zyaambo C, Nzala SH, Babaniyi O, Songolo P, Funkhouser E, Siziya S. Distribution of cancers in Zambia: Evidence from the Zambia national cancer registry (1990–2009). J Public Health Epidemiol. 2013 Feb;5(2):95-100.
33. Chokunonga E, Borok MZ, Chirenje ZM, Nyabakau AM, Parkin DM. Cancer survival in Harare, Zimbabwe, 1993Г1997.
34. Bassett MT, Chokunonga E, Mauchaza B, Levy L, Ferlay J, Parkin DM. Cancer in the African population of Harare, Zimbabwe, 1990–1992. International journal of cancer. 1995 Sep 27;63(1):29-36.
35. Chokunonga E, Levy LM, Bassett MT, Mauchaza BG, Thomas DB, Parkin DM. Cancer incidence in the African population of Harare, Zimbabwe: second results from the cancer registry 1993–1995. International journal of cancer. 2000 Jan 1;85(1):54-9.
36. Chokunonga E, Borok MZ, Chirenje ZM, Nyakabau AM, Parkin DM. Trends in the incidence of cancer in the black population of Harare, Zimbabwe 1991–2010. International journal of cancer. 2013 Aug 1;133(3):721-9.
37. Parkin DM, Chingonzoh T, Vuma S, Liu B, Chokunonga E, Ndlovu N, Borok M. Changes in the incidence of cancer in Bulawayo, Zimbabwe over a 50-year period. Cancer Epidemiology, Biomarkers & Prevention. 2021 May 1;30(5):867-73.
38. Bassett MT, Levy L, Chokunonga E, Mauchaza B, Ferlay J, Parkin DM. Cancer in the European population of Harare, Zimbabwe, 1990–1992. International journal of cancer. 1995 Sep 27;63(1):24-8.

AFCRN

1. Stoeter O, Seraphin TP, Chitsike I, Chokunonga E, Kambugu JB, Wabinga H, Parkin DM, Kantelhardt EJ. Trends in childhood cancer incidence in sub-Saharan Africa: Results from 25 years of cancer registration in Harare (Zimbabwe) and Kyadondo (54). International Journal of Cancer. 2021 May 4.
2. Pat MK, Manraj M, Fauzee J, Sewsurn S, Parkin DM, Manraj S. Trends in cancer incidence in the Republic of Mauritius, 1991–2015. Cancer epidemiology. 2019 Dec 1;63:101616.
3. Pilleron S, Soerjomataram I, Charvat H, Chokunonga E, Somdyala NIM, Wabinga H, Korir A, Bray F, Jemal A, Parkin DM. Cancer incidence in older adults in selected regions of sub-Saharan Africa, 2008-2012. Int J Cancer. 2018 Sep 21. doi:10.1002/ijc.31880.
4. Ekanem IO, Parkin DM. Five year cancer incidence in Calabar, Nigeria (2009-2013). Cancer Epidemiol. 2016 Jun;42:167-72.
5. Korir A, Okerosi N, Ronoh V, Mutuma G, Parkin M. Incidence of cancer in Nairobi, Kenya (2004-2008). Int J Cancer. 2015 Nov 1;137(9):2053-9.
6. Somdyala NI, Parkin DM, Sithole N, Bradshaw D. Trends in cancer incidence in rural Eastern Cape Province; South Africa, 1998-2012. Int J Cancer. 2015 Mar1;136(5):E470-4
7. Korir AR, Kamaté B, Singh E, Joko WY. Cancer in Sub-Saharan Africa. 2019;[Volume III]:[302]. ISBN: 978-2-8399-2787-1 (PDF)
8. Timotewos, Genebo et al. “First data from a population based cancer registry in Ethiopia.” *Cancer epidemiology* vol. 53 (2018): 93-98. doi:10.1016/j.canep.2018.01.008

9. Laryea, D.O., Awuah, B., Amoako, Y.A. *et al.* Cancer incidence in Ghana, 2012: evidence from a population-based cancer registry. *BMC Cancer* 14, 362 (2014). https://doi.org/10.1186/1471-2407-14-362
10. Laryea DO, Awittor FK, Sonia C, Boadu KO Three Years of Population-Based Cancer Registration in Kumasi: Providing Evidence for Population-Based Cancer Surveillance in Ghana Online J Public Health Inform 2016;8(1):e61848
11. Tenge, C. N., et al. "Burden and pattern of cancer in Western Kenya." *East African medical journal* 86.1 (2009).
12. Burhoo, P., et al. "Cancer Incidence in the Republic of Mauritius-5 Years Review 1997 to 2001." *Internet Journal of Medical Update* (2006).
13. Carreira, Helena et al. "Spectrum of pediatric cancers in Mozambique: an analysis of hospital and population-based data." *Pediatric hematology and oncology* vol. 31,6 (2014): 498-508. doi:10.3109/08880018.2014.909547
14. Lucas, E. *Cancer survival in Africa, asia, the caribbean and central America*. Eds. Rengaswamy Sankaranarayanan, and Ramasamyiyer Swaminathan. Vol. 162. Lyon: International Agency for Research on Cancer, 2011.
15. Kampala Cancer Registry. *Kampala Cancer Registry Report, 2010-2012*. Kampala, Uganda: Kampala Cancer Registry; September 2017. Compiled by: Wabinga HR, Parkin DM, Nambooze S, Amulen PM, Kwagonza L.
16. Seychelles National Cancer Registry. *Seychelles National Cancer Registry Report for 2009-2011*. Ministry of Health, Seychelles Hospital; January 2014. Compiled by: Parkin DM, Finesse A.
17. Parkin DM, Ferlay J, Jemal A, Borok M, Manraj SS, N'da GG, Ogunbiyi FJ, Liu B, Bray F, editors. *Cancer in Sub-Saharan Africa*. IARC Scientific Publication No. 167. Lyon, France: International Agency for Research on Cancer; 2018. ISBN-13: 978-92-832-2220-0, 978-92-832-2221-7.
18. E. Chokunonga, M.Z. Borok, Z.M. Chirenje, A.M, Nyakabau and R. Makunike-Mutasa. Cancer Incidence in Harare: Triennial Report 2010-2012. (2013)

IARC

1. Parkin DM, Whelan SL, Ferlay J, Teppo L, Thomas DB, editors. *Cancer Incidence in Five Continents, Volume VIII.* IARC Scientific Publication No. 155. Lyon, France: International Agency for Research on Cancer; 2002.
2. Curado MP, Edwards B, Shin HR, Storm H, Ferlay J, Heanue M, et al., editors. *Cancer Incidence in Five Continents, Volume IX.* IARC Scientific Publication No. 160. Lyon, France: International Agency for Research on Cancer; 2007.
3. Forman D, Bray F, Brewster DH, Gombe Mbalawa C, Kohler B, Piñeros M, et al., editors. *Cancer Incidence in Five Continents, Volume X.* IARC Scientific Publication No. 164. Lyon, France: International Agency for Research on Cancer; 2014.
4. Bray F, Colombet M, Mery L, Piñeros M, Znaor A, Zanetti R, et al., editors. *Cancer Incidence in Five Continents, Volume XI.* IARC Scientific Publication No. 166. Lyon, France: International Agency for Research on Cancer; 2017.
5. Parkin DM, Ferlay J, Hamdi-Cherif M, Sitas F, Thomas JO, Wabinga H, et al., editors. *Cancer in Africa: Epidemiology and Prevention.* IARC Scientific Publication No. 153. Lyon, France: International Agency for Research on Cancer; 2003.

Google search

1. Belay, Amanuel et al. “Incidence and pattern of childhood cancer in Addis Ababa, Ethiopia (2012-2017).” *BMC cancer* vol. 23,1 1261. 21 Dec. 2023, doi:10.1186/s12885-023-11765-7
2. Memirie, Solomon Tessema et al. “Estimates of Cancer Incidence in Ethiopia in 2015 Using Population-Based Registry Data.” *Journal of global oncology* vol. 4 (2018): 1-11. doi:10.1200/JGO.17.00175
3. Calys-Tagoe, Benedict N L et al. “Profile of cancer patients' seen at Korle Bu teaching hospital in Ghana (a cancer registry review).” *BMC research notes* vol. 7 577. 27 Aug. 2014, doi:10.1186/1756-0500-7-577
4. O'Brien, Kieran S et al. “Establishing effective registration systems in resource-limited settings: cancer registration in Kumasi, Ghana.” *Journal of registry management* vol. 40,2 (2013): 70-7.
5. Kobia, F., Gitaka, J., Makokha, F., Kamita, M., Kibera, J., Mwenda, C., Mucee, G. and Kilingo, B., 2019. The state of cancer in Meru, Kenya: a retrospective study. *AAS Open Research*, *2*, p.167.
6. Banda, L T et al. “Cancer incidence in Blantyre, Malawi 1994-1998.” *Tropical medicine & international health : TM & IH* vol. 6,4 (2001): 296-304. doi:10.1046/j.1365-3156.2001.00707.x
7. Mukhula, Victoria, et al. "Characterising cancer burden and quality of care at two palliative care clinics in Malawi." *Malawi Medical Journal* 29.2 (2017): 130-135.
8. Chasimpha, Steady JD, et al. "Three-year cancer incidence in Blantyre, Malawi (2008–2010)." *International journal of cancer* 141.4 (2017): 694-700.
9. Koon Sun Pat, Marvin et al. “Trends in cancer incidence in the Republic of Mauritius, 1991-2015.” *Cancer epidemiology* vol. 63 (2019): 101616. doi:10.1016/j.canep.2019.101616
10. Oko-oboh, Agbonvihele Gregrey, et al. "Utilizing Local Government Area in the Estimation of Cancer Incidence in Edo-Benin, Nigeria."/ Oko-oboh, G.A., Auvinen, A., Obaseki, D.E. *et al.* Improving cancer incidence evaluation through local government area matching: a study of the Edo-Benin cancer registry in Nigeria. *BMC Public Health* **24**, 514 (2024). https://doi.org/10.1186/s12889-024-17972-6
11. Nwafor, C. C., and N. N. Nwafor. "The pattern and distribution of cancers in Akwa Ibom State, Nigeria." *Nigerian Journal of Clinical Practice* 21.5 (2018): 603-608.
12. Ojo, J. O., et al. "Analyses and distribution of various types of cancers recorded in Ife-Ijesha cancer registry in the five year period 2010-2014." *Ife Journal of Science* 18.4 (2016): 1005-1017.
13. Obiorah, Christopher Chinedu, and Emeka Ray-Offor. "Epidemiology of gastrointestinal malignancies in Nigeria: Port Harcourt cancer registry study." *Oncology Journal of India* 4.1 (2020): 1-7.
14. Afolayan, E. A. O., and A. Rafindadi. "Zaria cancer registry (1992-1994)." *Sahel Medical Journal* 5.1 (2002): 34-38.
15. Odutola, Michael Kolawole, et al. "Cancers attributable to alcohol consumption in Nigeria: 2012–2014." *Frontiers in oncology* 7 (2017): 183.
16. Anifowoshe, Abass T., et al. "Incidence of common and rare cancers in Ilorin, Nigeria." *Notulae Scientia Biologicae* 10.4 (2018): 453-459.

17. Olson, Adam C., et al. "Cancer incidence and treatment utilization patterns at a regional cancer center in Tanzania from 2008-2016: initial report of 2,772 cases." *Cancer Epidemiology* 67 (2020): 101772.
18. Cancer in Nigeria 2009-2016. Editors: Adeola Akintola, Michael Odutola, Temitope Olayinka, Akinwale Akinjiola, Uchechukwu E. Nwokwu, and Clement Adebamowo. Nigeria: Nigerian National System of Cancer Registries; 2021. ISBN-13: 978-978-979-992-3, ISBN-13: 978-978-979-993-0. Available from: https://www.ncbi.nlm.nih.gov/books/NBK581073/. Accessed 10 July 2024.
19. Improving Data Collection and Use of Data for NCCP Implementation - PowerPoint presentation of cancer registry functions experience. Presenter: Dr. Maurice Mulenga. Presentation date: 10 December 2020. Available from:https://www.iccp-portal.org/system/files/resources/Cancer%20Registry%20functions.%20Malawi%20Experience.pdf. Accessed 25 June 2024.
20. Cancer Registry Case Studies. Available from: https://ecsahc.org/wp-content/uploads/2021/07/Cancer-registry-case-studies.pdf. Accessed 25 June 2024
21. Chesumbai, Gladys & Buziba, Nathan & Patel, Kirtika. (2024). THE ELDORET CANCER REGISTRY TECHNICAL REPORT NO. 1. 10.13140/RG.2.2.34620.21125. Available: https://www.researchgate.net/publication/378140396_THE_ELDORET_CANCER_REGISTRY_TECHNICAL_REPORT_NO_1 Accessed: 20 June 2024
22. Cancer Incidence Report Nairobi 2000 – 2002. Available from: https://healthresearchwebafrica.org.za/?action=download&file=CancerIncidenceReportKEMRI.pdf. Accessed 25 June 2024.
23. Ministry of Health, Seychelles Hospital, January 2014. Compiled by: Dr. Maxwell, Donald Parkin (AFRN Consultant & Epidemiologist), Ms. Anne Finesse (Registrar). *Seychelles National Cancer Registry Report for 2009-2011*. Available from: https://afcrn.org/images/M_images/attachments/96/SNCR%20Triennial%20Report%202009-2011.pdf. Accessed 28 June 2024..
24. Report on Cases of Cancers in Swaziland (2014-2015), March 23, 2016. Available from: https://afcrn.org/images/M_images/attachments/146/Swaziland%20situational%20analysiss%20of%20cancers%20incidence%202014-2015.pdf. Accessed 26 June 2024.
25. Chokunonga E, Borok MZ, Chirenje ZM, Nyakabau AM, editors. Zimbabwe National Cancer Registry 2006 Annual Report. Harare: Zimbabwe National Cancer Registry; April 2010. Available from: https://cancertrust.files.wordpress.com/2011/10/zimbabwe-cancer-registry-2006-annual-report.pdf. Accessed 28 June 2024.
26. Chokunonga E, Borok MZ, Chirenje ZM, Makunike-Mutasa R, Ndlovu N, Nyakabau AM, editors. Pattern of Cancer in Zimbabwe: Cancer Registration and Surveillance for Cancer Control. Zimbabwe National Cancer Registry 2015 Annual Report. Harare: Zimbabwe National Cancer Registry; August 2017. Available from: https://www.globalgiving.org/pfil/40777/projdoc.pdf. Accessed 28 June 2024.
27. Republic of Rwanda. National Guidelines for the Prevention and Management of Viral Hepatitis B and C in the Republic of Rwanda. Available from: https://www.rbc.gov.rw/IMG/pdf/national_guidelines_for_the_prevention_and_management_of_viral_hepatitis_b_and_c_-_final_signed.pdf . Accessed 2 July 2024.

28. Federal Ministry of Health, Nigeria. National Guidelines for the Prevention, Care and Treatment of Viral Hepatitis B & C in Nigeria. Available from: https://www.hepb.org/assets/Uploads/Nigeria-Hepatitis-Guidelines-TX-guidelines.pdf Accessed 4 July 2024.
29. Ghana Health Service. National Guidelines for Prevention, Care and Treatment for Viral Hepatitis. Available from: https://www.hepb.org/assets/Uploads/Ghana-Hepatitis-Tx-Guidelines-Final-1-30.12.pdf . Accessed 5 July 2024.
30. Ministry of Health, Eritrea. Draft 1 Expanded Programme on Immunization Comprehensive Multi-Year Plan (2012-2016). Available from: https://extranet.who.int/countryplanningcycles/sites/default/files/planning_cycle_repository/eritrea/eritrea_cmyp_doc.pdf . Accessed 6 July 2024.
31. Ministry of Health, Djibouti. National Program of Immunisation Comprehensive Plan (CMYP) 2011-2015. Available from: https://www.gavi.org/sites/default/files/document/comprehensive-multi-year-plan-for-2011-2015pdf.pdf . Accessed 6 July 2024.
32. Cooper S, et al. Vaccination coverage in rural Burkina Faso under the effects of COVID-19: evidence from a panel study in eight districts. BMC Health Services Research. 2023;23(1):1016. Accessed 7 July 2024.
33. Aregawi HG, et al. Determinants of defaulting from completion of child immunization in Laelay Adiabo District, Tigray Region, Northern Ethiopia: a case-control study. PloS one. 2017;12(9):e0185533. Accessed 8 July 2024.
34. Dlamini TN, et al. Prevalence and factors associated with incomplete immunization among children aged 12 to 35 months in Eswatini: analysis of the Eswatini multiple indicator cluster survey. Pan African Medical Journal. 2023;45(1). Accessed 8 July 2024.
35. Baah J, et al. Evaluation of social mobilization component of the second year of life (2YL) project on immunization coverage in Adaklu district, Ghana. International Journal of Health Services Research and Policy. 2022;7(1):1-14. Accessed 9 July 2024.
36. Camara BS, et al. Influence of the 2014–2015 Ebola outbreak on the vaccination of children in a rural district of Guinea. Public Health Action. 2017;7(2):161-167. Accessed 10 July 2024.
37. Fisker AB, et al. Health effects of utilising hospital contacts to provide measles vaccination to children 9–59 months—a randomised controlled trial in Guinea-Bissau. Trials. 2022;23(1):349. Available from: https://trialsjournal.biomedcentral.com/articles/10.1186/s13063-022-06276-4. Accessed 10 July 2024.
38. ObiOha–ThOpE a maTObO, EmeKa E. The role of state and non-state actors in the sustenance of the Expanded Program on Immunization in Lesotho, Southern Africa. Available from: https://www.researchgate.net. Accessed 11 July 2024.
39. Mali Zero-Dose Landscape 2023. Available from: https://zdlh.gavi.org/country-profiles/mali. Accessed 12 July 2024.
40. Powelson J, et al. Determinants of immunisation dropout among children under the age of 2 in Zambézia province, Mozambique: a community-based participatory research study using Photovoice. BMJ Open. 2022;12(3):e057245. Available from: https://bmjopen.bmj.com/content/12/3/e057245. Accessed 13 July 2024.
41. Baby Immunization Schedule - Namibia. Available from: https://welwitschiahospital.com/news/baby-immunization-schedule-namibia. Accessed 14 July 2024.
42. Sow A, et al. Impact of COVID-19 on routine immunization: A cross-sectional study in Senegal. 2021. Available from: https://www.researchgate.net. Accessed 15 July 2024.

43. Hodges MH, et al. Integrating vitamin A supplementation at 6 months into the Expanded Program of Immunization in Sierra Leone. Maternal and Child Health Journal. 2015;19:1985-1992. Available from: https://link.springer.com/article/10.1007/s10995-015-1709-x. Accessed 16 July 2024.
44. Somalia National Immunisation Policy. September 2014. Available from: https://www.slideshare.net/slideshow/national-immunisation-policy-somalia/67214416#11. Accessed 17 July 2024.
45. Immunisation Practice in Southern Sudan 2011. Available from: https://coregroup.org/wp-content/uploads/2018/02/Immunization-in-Practice-in-South-Sudan.pdf. Accessed 18 July 2024.
46. Tanzania Vaccination Schedule. Available from: https://tz.goodinternet.org/en/sections/facts-for-life/vaccine-information-centre/tanzanias-vaccination-schedule/#:~:text=When%20should%20I%20vaccinate%20my,doses%20of%20the%20HPV%20vaccine. Accessed 19 July 2024.
47. Mangbassim NT, et al. Prevalence and factors associated with "zero-dose" in children 12 to 23 months in Togo. Cent Afr J Public Health. 2023;9:12. Available from: https://www.ncbi.nlm.nih.gov. Accessed 19 July 2024.
48. Uganda Immunization Schedule. Presentation slides, 9 August 2022. Available from: https://www.slideshare.net/slideshow/edited-immunization-scheduleppptx/256968923#4. Accessed 16 July 2024.
49. Zambia Immunisation Schedule. 2022. Available from: https://www.slideshare.net/slideshow/immunization-schedule-in-zambiapdf/254167210. Accessed 16 July 2024.
50. Zimbabwe Immunisation information. Available from: https://gsch.co.zw/index.php/immunisation/. Accessed 15 July 2024.
51. Open Parly ZW. Zimbabwe Immunisation Information. Available from: https://twitter.com/OpenParlyZw/status/1577632976124497921. Accessed 15 July 2024.

Health ministry/ websites

1. Ekurhuleni Population-Based Cancer Registry. *Annual Report 2022*. National Cancer Registry, South Africa. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 20 July 2024.
2. Ekurhuleni Population-Based Cancer Registry. *Annual Report 2021*. National Cancer Registry, South Africa. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 20 July 2024.
3. Ekurhuleni Population-Based Cancer Registry. *Annual Report 2020*. National Cancer Registry, South Africa. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 20 July 2024.
4. Ekurhuleni Population-Based Cancer Registry. *Annual Report 2018*. National Cancer Registry, South Africa. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 20 July 2024.
5. Ekurhuleni Population-Based Cancer Registry. *Annual Report 2017*. National Cancer Registry, South Africa. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 20 July 2024.

6. Childhood Cancer Registry. *Childhood Cancer Registry Report 2020*. National Cancer Registry, South Africa. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
7. Childhood Cancer Registry. *Childhood Cancer Registry Report 2019*. National Cancer Registry, South Africa. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
8. Childhood Cancer Registry. *Childhood Cancer Registry Report 2018*. National Cancer Registry, South Africa. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
9. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2022)*. National Health Laboratory Service (NHLS), 2022. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
10. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2021)*. National Health Laboratory Service (NHLS), 2021. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
11. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2020)*. National Health Laboratory Service (NHLS), 2020. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
12. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2019)*. National Health Laboratory Service (NHLS), 2019. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
13. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2018)*. National Health Laboratory Service (NHLS), 2018. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
14. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2017)*. National Health Laboratory Service (NHLS), 2017. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
15. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2016)*. National Health Laboratory Service (NHLS), 2016. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
16. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2015)*. National Health Laboratory Service (NHLS), 2015. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
17. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2014)*. National Health Laboratory Service (NHLS), 2014. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
18. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2013)*. National Health Laboratory Service (NHLS), 2013. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
19. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2012)*. National Health Laboratory Service (NHLS), 2012. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
20. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2011)*. National Health Laboratory Service (NHLS), 2011. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
21. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2010)*. National Health Laboratory Service (NHLS), 2010. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.

22. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2009)*. National Health Laboratory Service (NHLS), 2009. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
23. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2008)*. National Health Laboratory Service (NHLS), 2008. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
24. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2007)*. National Health Laboratory Service (NHLS), 2007. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
25. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2006)*. National Health Laboratory Service (NHLS), 2006. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
26. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2005)*. National Health Laboratory Service (NHLS), 2005. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
27. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2004)*. National Health Laboratory Service (NHLS), 2004. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
28. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2003)*. National Health Laboratory Service (NHLS), 2003. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
29. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2002)*. National Health Laboratory Service (NHLS), 2002. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
30. South African National Cancer Registry (44). *Pathology-based Cancer Incidence Report (2001)*. National Health Laboratory Service (NHLS), 2001. Available from: https://www.nicd.ac.za/centres/national-cancer-registry/. Accessed 21 July 2024.
31. Cancer Incidence in Selected Municipalities of the Eastern Cape Province 2013-2017. Eastern Cape Cancer Registry. Available from: https://www.samrc.ac.za/research-reports/eastern-cape-cancer-register. Accessed 23 July 2024.
32. Eastern Cape Province Cancer Registry 2003–2007. Eastern Cape Cancer Registry. Available from: https://www.samrc.ac.za/research-reports/eastern-cape-cancer-register. Accessed 23 July 2024.
33. Cancer Incidence in Selected Municipalities of the Eastern Cape Province 1998-2002 Summary Report. Eastern Cape Cancer Registry. Available from: https://www.samrc.ac.za/research-reports/eastern-cape-cancer-register. Accessed 23 July 2024.
34. Cancer Incidence in Selected Municipalities of the Eastern Cape Province, 1998-2002. Eastern Cape Cancer Registry. Available from: https://www.samrc.ac.za/research-reports/eastern-cape-cancer-register. Accessed 23 July 2024.
35. Cancer in the Republic of Mauritius: Incidence and Mortality Study for 2018. , Report of the National Cancer Registry, December 2019. Available from: https://health.govmu.org/health/?page_id=5707. Accessed 23 July 2024.
36. Cancer in the Republic of Mauritius: Incidence and Mortality Study for 2022, Report of the National Cancer Registry, January 2024. Available from: https://health.govmu.org/health/?page_id=5707. Accessed 23 July 2024.
37. Namibia National Cancer Registry (NNCR**).** Cancer Incidences in Namibia 2010 - 2014. Data collected and entered by Dr Annelle Zietsman, Sr Johanna Pontac, Sr Sophy Lawrence, Ms

Lizette Horn, Mrs Lizelle van Schalkwyk, and reviewed by Dr Maxwell Parken. Published February 2017. Available from: https://www.can.org.na/. Accessed 25 June 2024.
38. Namibian Cancer Registry. Cancer in Namibia 2006-2009. Data collected and entered by Dr. Annelle Zietsman, Mrs. B. Gariseb, Mrs. N. Rautenbach, Mrs. J. Pontac, Mrs. T. Rooi, and Mrs. L. Taapopi. Data cleaning, collation, and analysis by Mr. Henri Carrara, Dr. Lara Stein, and Prof. Freddy Sitas. Published March 2011. Available from: https://www.can.org.na/. Accessed 25 June 2024.
39. Korir, A., Okerosi, N., Osii, R., Kisiangani, I., Rono, V., Emai, S., Kiptanui, E., Gakunga, R., Gathere, S., & Manduku, V. Cancer Incidence Report (2009-2013); Nairobi Cancer Registry. February 2018. Available from: https://www.kemri.go.ke/cancer-registry/. Accessed 28 June 2024.
40. National Guidelines for the Management of Viral Hepatitis (December 2019). South Africa. Available from: https://knowledgehub.health.gov.za/elibrary/national-guidelines-management-viral-hepatitis. Accessed 19 May 2024
41. Uganda Guidelines for Prevention, Testing, Care, and Treatment of Hepatitis B and C Virus Infection (November 2019). Uganda Ministry of Health. Available from: https://library.health.go.ug/communicable-disease/hepatitis-b/uganda-guidelines-prevention-testing-care-and-treatment-hepatitis Accessed 11 May 2024.
42. Ministry of Health, Malawi. Guidelines for the Prevention and Management of Hepatitis B and C in Malawi. 1st Edition, June 2023. Available from: https://dms.hiv.health.gov.mw/link/bayakraf. Accessed Accessed 13 July 2024.
43. PEV Cameroon Immunization Calendar. Available from: https://pevcameroon.cm/ressources/calendrier-de-vaccinations. Accessed 13 July 2024.
44. Immunization Schedule - Ministry of Health, Botswana. Available from: https://www.facebook.com/photo.php?fbid=871140031708956&id=100064389025470&set=a.294720102684288. Accessed Accessed 13 July 2024.
45. Côte d'Ivoire Government Immunization Schedule**.** Available from: https://www.facebook.com/photo.php?fbid=912272354277770&id=100064850401703&set=a.475150091323334. Accessed 12 July 2024.
46. Kenya National Immunization Policy Guidelines 2023**.** Available from: http://guidelines.health.go.ke:8000/media/Kenya_National_Immunization_Policy_Guidelines_Version_signed.pdf. Accessed 9 July 2024.
47. National Primary Health Care Development Agency Twitter Page 2023. Available from: https://twitter.com/NphcdaNG/status/1627577180182962176. Accessed 25 October 2024.
48. Republic of Rwanda Ministry of Health and Rwanda Biomedical Centre Vaccine Calendar**.** Available from: https://rbc.gov.rw/fileadmin/user_upload/annoucement/Vaccine%20calendar.pdf. Accessed 25 October 2024.
49. South Africa Vaccine Hesitancy Webinar Overview of EPI May 2024**.** Available from: https://knowledgehub.health.gov.za/system/files/2024-05/VACCINE%20HESITANCY%20WEBINAR_OVERVIEW%20OF%20EPI_MAY_2024_FINAL.pdf. Accessed 25 October 2024.
50. Somalia Expanded Program on Immunization National Immunization Policy 2019**.** Available from: https://moh.pl.so/wp-content/uploads/2022/08/EPI-policy-new-draft-1.pdf. Accessed 25 October 2024.
51. Uganda National Expanded Program on Immunization Guidelines**.** Available from: https://www.health.go.ug/wp-content/uploads/2019/11/UNEPI-Immunization-guidelines.pdf. Accessed 25 October 2024.

Shared reports and presentations


1. Eswatini National Cancer Registry Report (2016-2022). Eswatini National Cancer Registry. Available from: Shared data. Accessed 25 October 2024.
2. Lesotho Cancer Registry 2022 Annual Report. Lesotho Cancer Registry. Available from: Shared data. Accessed 25 October 2024.
3. Report for 2013–2017, The Ibadan Cancer Registry. Ibadan Cancer Registry. Available from: Shared data. Accessed 25 October 2024.
4. Zimbabwe National Cancer Registry 2019 Annual Report. Zimbabwe National Cancer Registry. Available from: Shared data. Accessed 25 October 2024.
5. Zimbabwe Cancer Registry Report (2018). Zimbabwe National Cancer Registry. Available from: Shared data at NCR-SA. Accessed 25 October 2024.
6. Kampala Cancer Registry Report, Uganda (2013-2017). Kampala Cancer Registry. Available from: Shared data. Accessed 25 October 2024.
7. Haggar FA. The Ndjamena Cancer Registry: The establishment of the first population-based cancer registry in Chad. Available from: Shared data. Accessed 25 October 2024.
8. Update on Mauritius National Cancer Registry. Dr Marvin Koon, MNCR Coordinator. AFCRN meeting, 2024. PowerPoint presentation. Available from: Shared data. Accessed 25 October 2024.
9. Seychelles Cancer Registry Annual Report for 2023. Seychelles Cancer Registry. Available from: Shared data. Accessed 25 October 2024.
10. Mbeya Cancer Registry Report (2019-2023). Gyimbi EM, MLSc, MBCR Cancer Registrar. AFCRN meeting, 2024. PowerPoint presentation. Available from: Shared data. Accessed 25 October 2024.
11. Kilimanjaro Cancer Registry Report 2019-2023. Alloyce JP, BSc, MSc (PM, M&E). NORA/REACT-CAN & AFCRN Joint Annual Meeting, 2024. PowerPoint presentation. Available from: Shared data. Accessed 25 October 2024.
12. KZN PBCR. Mbeje N, CIDERU Cancer Registrar. AFCRN meeting, 2024. PowerPoint presentation (NCR-pathology data: liver cancer is included). Available from: Shared data. Accessed 25 October 2024.
13. Namibia National Cancer Registry. Tjiriange T. AFCRN meeting, 2024. PowerPoint presentation. Available from: Shared data. Accessed 25 October 2024.

18.2. Appendix 2: Search strategy

Keywords

Concept: “Liver Neoplasms” OR “Carcinoma, Hepatocellular” OR “Liver cancer”OR “Hepatocellular carcinoma” OR “Hepatoma” "Registries" OR “Cancer registr*” OR “Disease registr*” OR “Hepatitis B”, “Guidelines”, “Vaccination/Immunisation”

Context: “Africa South of the Sahara” OR “Sub-Saharan Africa” OR “Angola” OR “Cameroon” OR “Central African Republic” OR “Chad” OR “Republic of the Congo” OR “Democratic Republic of the Congo” OR “Equatorial Guinea” OR “Gabon” OR “São Tomé and Príncipe” OR “Burundi” OR “Comoros” OR “Djibouti” OR “Eritrea” OR “Ethiopia” OR “Kenya” OR “Madagascar” OR “Malawi” OR “Mauritius” OR “Mozambique” OR “Rwanda” OR “Seychelles” OR “Somalia” OR “South Sudan” OR “Tanzania” OR “Uganda” OR “Zambia” OR “Zimbabwe” OR “Botswana” OR “Eswatini” OR “Swaziland” OR “Lesotho” OR “Namibia” OR “South Africa” OR “Benin” OR “Burkina Faso” OR “Cape Verde” OR “Côte d'Ivoire” OR “Ivory Coast” OR “Gambia” OR “Ghana” OR “Guinea” OR “Guinea-Bissau” OR “Liberia” OR “Mali” OR “Mauritania” OR “Niger” OR “Nigeria” OR “Senegal” OR “Sierra Leone” OR “Togo” OR “Central Africa” OR “East Africa” OR “Southern Africa” OR “West Africa” OR "French Reunion "

**PubMed, Ovid Medline, and Cochrane Library search and results**

| | |
|---|---|
| Content 1 | "Liver Neoplasms" OR "Carcinoma, Hepatocellular" OR "Liver cancer"OR "Hepatocellular carcinoma" OR "Hepatoma"<br>**PubMed: 240510, Cochrane library:0, Ovid Medline: 1** |
| Content 2 | "Registries" OR “Cancer registr*” OR “Disease registr*”<br>**PubMed: 135620, Cochrane Library: 5072, Ovid Medline: 0** |
| Context | "Africa South of the Sahara"OR "Sub-Saharan Africa" OR "Angola" OR "Cameroon" OR "Central African Republic" OR "Chad" OR "Republic of the Congo" OR "Democratic Republic of the Congo" OR "Equatorial Guinea" OR "Gabon" OR "São Tomé and Príncipe" OR "Burundi" OR "Comoros" OR "Djibouti" OR "Eritrea" OR "Ethiopia" OR "Kenya" OR "Madagascar" OR "Malawi" OR "Mauritius" OR "Mozambique" OR "Rwanda" OR "Seychelles" OR "Somalia" OR "South Sudan" OR "Tanzania" OR "Uganda" OR "Zambia" OR "Zimbabwe" OR "Botswana" OR "Eswatini" OR "Swaziland" OR "Lesotho" OR |

| | |
|---|---|
| | "Namibia" OR "South Africa" OR "Benin" OR "Burkina Faso" OR "Cape Verde" OR "Côte d'Ivoire" OR "Ivory Coast" OR "Gambia" OR "Ghana" OR "Guinea" OR "Guinea-Bissau" OR "Liberia" OR "Mali" OR "Mauritania" OR "Niger" OR "Nigeria" OR "Senegal" OR "Sierra Leone" OR "Togo" OR "Central Africa" OR "East Africa" OR "Southern Africa" OR "West Africa" OR "French Reunion "<br>**PubMed: 454620, Cochrane library: 0, Ovid Medline: 114** |
| Combination | Concept1 AND Concept 2 AND Context :filter year: 1980-2024<br>**PubMed: 59 articles in total; 27 included, Cochrane library: 0, Ovid Medline: 0** |

**Google Scholar search**

| | |
|---|---|
| Content 1 | "Liver Neoplasms" OR "Carcinoma, Hepatocellular" OR "Liver cancer" OR "Hepatocellular carcinoma" OR "Hepatoma"<br>**2 010 000 articles** |
| Content 2 | "Cancer registry" OR "Cancer registries"<br>**18 300 articles** |
| Context | "Sub-Saharan Africa," OR "Angola" OR "Cameroon" OR "Central African Republic" OR "Chad" OR "Republic of the Congo" OR "Democratic Republic of the Congo" OR "Equatorial Guinea" OR "Gabon" OR "São Tomé and Príncipe" OR "Burundi" OR "Comoros" OR "Djibouti" OR "Eritrea" OR "Ethiopia" OR "Kenya" OR "Madagascar" OR "Malawi" OR "Mauritius" OR "Mozambique" OR "Rwanda" OR "Seychelles" OR "Somalia" OR "South Sudan" OR "Tanzania" OR "Uganda" OR "Zambia" OR "Zimbabwe" OR "Botswana" OR "Eswatini" OR "Swaziland" OR "Lesotho" OR "Namibia" OR "South Africa" OR "Benin" OR "Burkina Faso" OR "Cape Verde" OR "Côte d'Ivoire" OR "Ivory Coast" OR "Gambia" OR "Ghana" OR "Guinea" OR "Guinea-Bissau" OR "Liberia" OR "Mali" OR "Mauritania" OR "Niger" OR "Nigeria" OR "Senegal" OR "Sierra Leone" OR "Togo" OR "Central Africa" OR "East Africa" OR "Southern Africa" OR "West Africa" OR "French Reunion "<br>**2 680 000 articles** |

| | |
|---|---|
| Combination | ("Liver cancer" OR "Hepatocellular carcinoma" ) AND ("Cancer registry" OR "Cancer registries" ) AND ("Sub-Saharan Africa" OR "Angola" OR "Cameroon" OR "Central African Republic" OR "Chad" OR "Republic of the Congo" OR "Democratic Republic of the Congo" OR "Equatorial Guinea" OR "Gabon" OR "São Tomé and Príncipe" OR "Burundi" OR "Comoros" OR "Djibouti" OR "Eritrea" OR "Ethiopia" OR "Kenya" OR "Madagascar" OR "Malawi" OR "Mauritius" OR "Mozambique" OR "Rwanda" OR "Seychelles" OR "Somalia" OR "South Sudan" OR "Sudan" OR "Tanzania" OR "Uganda" OR "Zambia" OR "Zimbabwe" OR "Botswana" OR "Eswatini" OR "Swaziland" OR "Lesotho" OR "Namibia" OR "South Africa" OR "Benin" OR "Burkina Faso" OR "Cape Verde" OR "Côte d'Ivoire" OR "Ivory Coast" OR "Gambia" OR "Ghana" OR "Guinea" OR "Guinea-Bissau" OR "Liberia" OR "Mali" OR "Mauritania" OR "Niger" OR "Nigeria" OR "Senegal" OR "Sierra Leone" OR "Togo" OR "Central Africa" OR "East Africa" OR "Southern Africa" OR "West Africa" OR "French Reunion " ) filter year: 1980-2024<br>**2530 articles in total: Using built in google scholar advanced search on title and anywhere in the article by screening per country only 69 articles where located. 38 studies included** |

**Google search and results**

"Context", "Liver cancer", "Hepatocellular carcinoma", "Cancer registry", "Cancer registries"

27 articles in total, 17 included. 9 cancer registry reports included. 25 Vaccination guidelines included.

**AFCRN Website**

**https://afcrn.org/**

57 Articles in total, 18 publications included.

**IARC Website**

14 publications, 5 publications included.

**Cancer Today (55) and AFCRN Websites:**

1. **https://gco.iarc.who.int/today/en/data-sources-methods**
2. **https://afcrn.org/membership/membership-list**

**Health Ministry Websites**

39 reports included, and 12 Vaccination guidelines included.

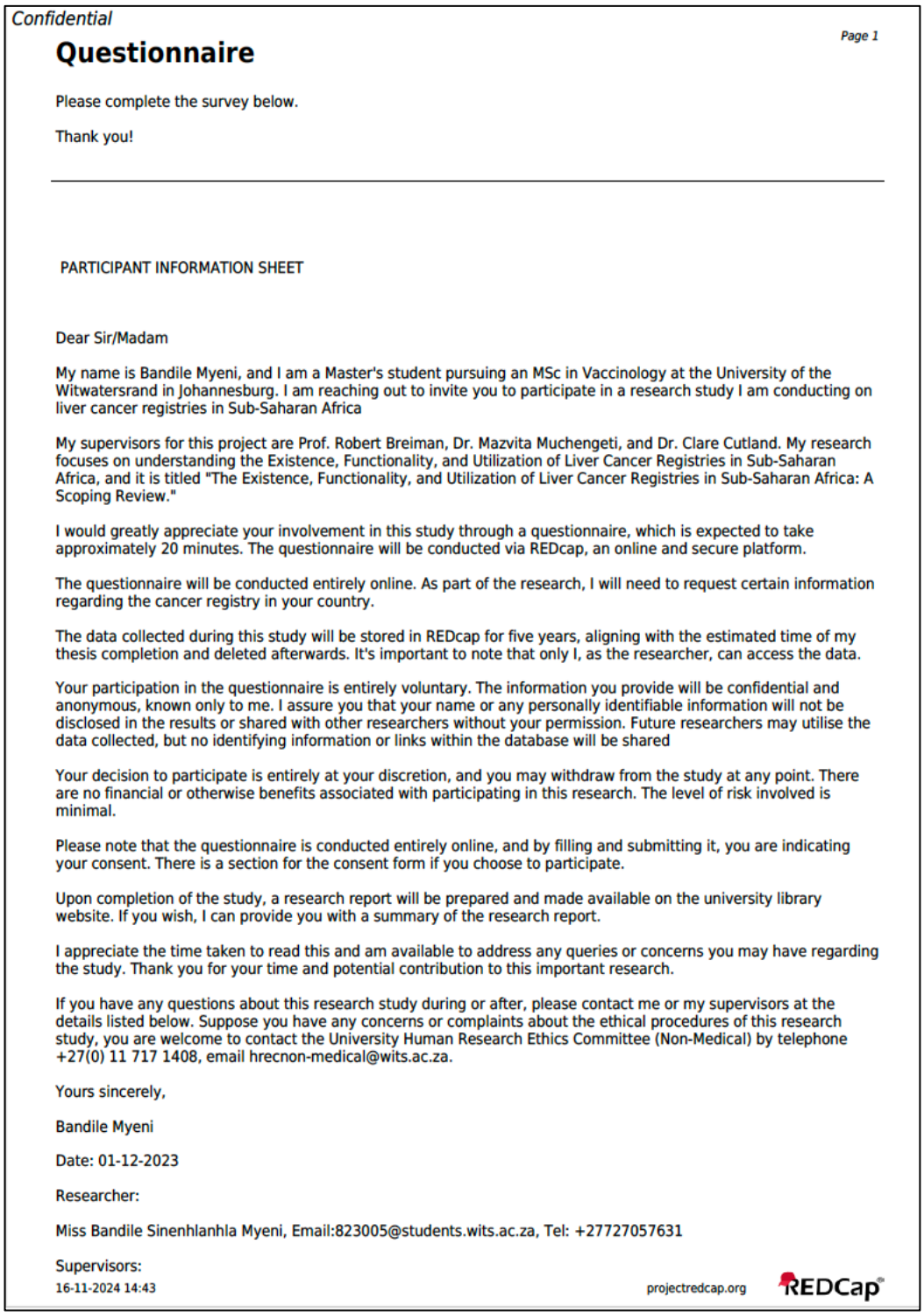
**Shared reports/Presentations**

13 reports/publications.

**WHO/UNICEF**

2022 immunisation data published in 2023(https://immunizationdata.who.int/dashboard/regions/african-region/SWZ). Data on French Reunion is not available on the site

## 18.3. Appendix 3: Questionnaire form



*Confidential*

*Page 1*

# Questionnaire

Please complete the survey below.

Thank you!

---

PARTICIPANT INFORMATION SHEET

Dear Sir/Madam

My name is Bandile Myeni, and I am a Master's student pursuing an MSc in Vaccinology at the University of the Witwatersrand in Johannesburg. I am reaching out to invite you to participate in a research study I am conducting on liver cancer registries in Sub-Saharan Africa

My supervisors for this project are Prof. Robert Breiman, Dr. Mazvita Muchengeti, and Dr. Clare Cutland. My research focuses on understanding the Existence, Functionality, and Utilization of Liver Cancer Registries in Sub-Saharan Africa, and it is titled "The Existence, Functionality, and Utilization of Liver Cancer Registries in Sub-Saharan Africa: A Scoping Review."

I would greatly appreciate your involvement in this study through a questionnaire, which is expected to take approximately 20 minutes. The questionnaire will be conducted via REDcap, an online and secure platform.

The questionnaire will be conducted entirely online. As part of the research, I will need to request certain information regarding the cancer registry in your country.

The data collected during this study will be stored in REDcap for five years, aligning with the estimated time of my thesis completion and deleted afterwards. It's important to note that only I, as the researcher, can access the data.

Your participation in the questionnaire is entirely voluntary. The information you provide will be confidential and anonymous, known only to me. I assure you that your name or any personally identifiable information will not be disclosed in the results or shared with other researchers without your permission. Future researchers may utilise the data collected, but no identifying information or links within the database will be shared

Your decision to participate is entirely at your discretion, and you may withdraw from the study at any point. There are no financial or otherwise benefits associated with participating in this research. The level of risk involved is minimal.

Please note that the questionnaire is conducted entirely online, and by filling and submitting it, you are indicating your consent. There is a section for the consent form if you choose to participate.

Upon completion of the study, a research report will be prepared and made available on the university library website. If you wish, I can provide you with a summary of the research report.

I appreciate the time taken to read this and am available to address any queries or concerns you may have regarding the study. Thank you for your time and potential contribution to this important research.

If you have any questions about this research study during or after, please contact me or my supervisors at the details listed below. Suppose you have any concerns or complaints about the ethical procedures of this research study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical) by telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za.

Yours sincerely,

Bandile Myeni

Date: 01-12-2023

Researcher:

Miss Bandile Sinenhlanhla Myeni, Email:823005@students.wits.ac.za, Tel: +27727057631

Supervisors:

16-11-2024 14:43 projectredcap.org REDCap

- Prof. Robert Breiman, Email: robert.breiman@wits.ac.za
- Dr. Mazvita Muchengeti, Email: MazvitaM@nicd.ac.za
- Dr. Clare Cutland, Email: Clare.cutland@wits.ac.za

| **Consent Form** | |
|---|---|
| Cancer registry Name | _____ |
| The research study was explained to me. I understand what this study is about | ◯ Yes<br>◯ No |
| I understand that I can volunteer to take part in the study | ◯ Yes<br>◯ No |
| I agree that direct quotations from my questionnaire may be used by the researcher in their research report/ manuscript/book chapter | ◯ Yes<br>◯ No |
| I agree that my participation will remain anonymous (my name or other identifying data will not be used by the researcher in their research report/manuscript/book chapter) | ◯ Yes<br>◯ No |
| I agree that other researchers may use the information I provide in my questionnaire (depending on their own ethics clearance being obtained), but my name and any personal information will not be used or passed on | ◯ Yes<br>◯ No |
| Are you happy to proceed? | ◯ Yes<br>◯ No |
| Date | _____ |

| **Questionnaire** | |
|---|---|
| Name of Cancer Registry | _____ |
| Year Registry was established | _____ |
| Have any interruptions occurred in the cancer registries over the years since the establishment? | ◯ Yes<br>◯ No |
| If yes, please elaborate | _____ |
| Who funds/supports the Cancer registry? | _____ |
| Who is responsible for overseeing the cancer registry/registries? | _____ |

| | |
|---|---|
| Does the Director/Head of the Cancer registry fall under the jurisdiction of the Ministry of Health/Department of Health? | ◯ Yes<br>◯ No |
| If no, please elaborate on where they fall under | _____ |
| Who comprises the personnel responsible for data collection and data entry? | _____ |
| Is there a policy that guides the Cancer registry? | ◯ Yes<br>◯ No |
| If yes, please provide the specific law/policy | _____ |
| Type of cancer registry/Registries available | ☐ Population based cancer registry<br>☐ National cancer registry<br>☐ Hospital-Based Cancer Registries<br>☐ Specialized Cancer Registries<br>☐ Pediatric Cancer Registries<br>☐ Tumor Registries<br>☐ Other _____ |
| What efforts are made to ensure that the liver cancer registry reflects the diversity of the population, including various demographic groups? | _____ |
| If a tumor register exists, does it capture histological findings at diagnosis? | ◯ Yes<br>◯ No<br>◯ Not applicable |
| Data sources of the Cancer Registry | ☐ Government health care facilities<br>☐ Private health care facilities<br>☐ Laboratories, Oncology Networks and Associations<br>☐ Hospice<br>☐ Death Registration<br>☐ Other _____<br>(select all that apply) |
| What mechanisms are in place to ensure comprehensive reporting of all liver cancer cases within the healthcare system? | _____ |
| Data collection process | ☐ Passive surveillance<br>☐ Active surveillance<br>☐ Other _____<br>(select all that apply) |
| Is the data collected longitudinal? | ◯ Yes<br>◯ No |

Inclusion criteria for data collection
(select all that apply)

- ☐ All confirmed cancer cases in persons in that region
- ☐ Cancer cases diagnosed within the timeframe of 1st January to 31 December of the relevant year
- ☐ Cases classified as malignant in the morphology section of the International Classification of Diseases for Oncology (ICD-O); behaviour code-3.
- ☐ Cancers in metastatic sites (e.g., lymph nodes) registered with the primary tumour site topography
- ☐ Cases with unknown primary site, if the primary tumour site is not known.
- ☐ Other _____

| | |
|---|---|
| How quickly is data entered into the liver cancer registry after diagnosis or treatment? | _____ |
| What strategies are in place to streamline the data entry process and ensure timely updates? | _____ |
| Cancer registration form is standardised? | ◯ Yes<br>◯ No |
| If there is a form that is standardised for data collection, please upload it (If you encounter an issue when uploading the form, please email it to Bandile Myeni (Investigator) at 823005@students.wits.ac.za.) | |
| Is the captured data sent to the surveillance manager for quality assurance and quality control, involving checks for duplicates, completeness, and consistency? | ◯ Yes<br>◯ No |
| What does the surveillance manager use on CanReg or any other database for each cancer case during the quality assurance and quality control process? | ☐ physical notification forms<br>☐ electronic records<br>(select all that apply) |
| Is there ongoing training programs to enhance the skills of personnel responsible for data entry and verification | ◯ Yes<br>◯ No |
| How often are results published on the national cancer registry/Ministry of health website? | ◯ once a year<br>◯ once in two years<br>◯ other _____ |
| How many reports has the Cancer registry published since their establishment? | _____ |
| Are the published reports easily accessible to the public? | ◯ Yes<br>◯ No |
| Are there any resources that are allocated for the establishment and maintenance of the liver cancer registry? | ◯ Yes<br>◯ No |
| If yes, please specify | _____ |

Please upload the latest report of the Cancer Registry
(If you encounter an issue when uploading the form,
please email it to Bandile Myeni (Investigator) at
823005@students.wits.ac.za.)

## 18.4. Appendix 4: Ethics clearance certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Research Office

**HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)**
R14/49 Myeni

| | |
|---|---|
| **CLEARANCE CERTIFICATE** | **PROTOCOL NUMBER: H24/01/25** |
| **PROJECT TITLE** | The Existence, Functionality, and Utilization of Liver Cancer Registries in Sub-Saharan Africa: A Scoping Review |
| **INVESTIGATOR(S)** | Miss B Myeni |
| **SCHOOL/DEPARTMENT** | Pathology/ |
| **DATE CONSIDERED** | 26 Janaury 2024 |
| **DECISION OF THE COMMITTEE** | Approved<br>Risk Level: Minimal |
| **EXPIRY DATE** | 18 February 2027 |

**DATE** 19 February 2024 **CHAIRPERSON** _____
(Professor J Watermeyer)

cc: Supervisor : Prof R Breiman, Prof M Muchengeti and Dr C Cutland

---

**DECLARATION OF INVESTIGATOR(S)**

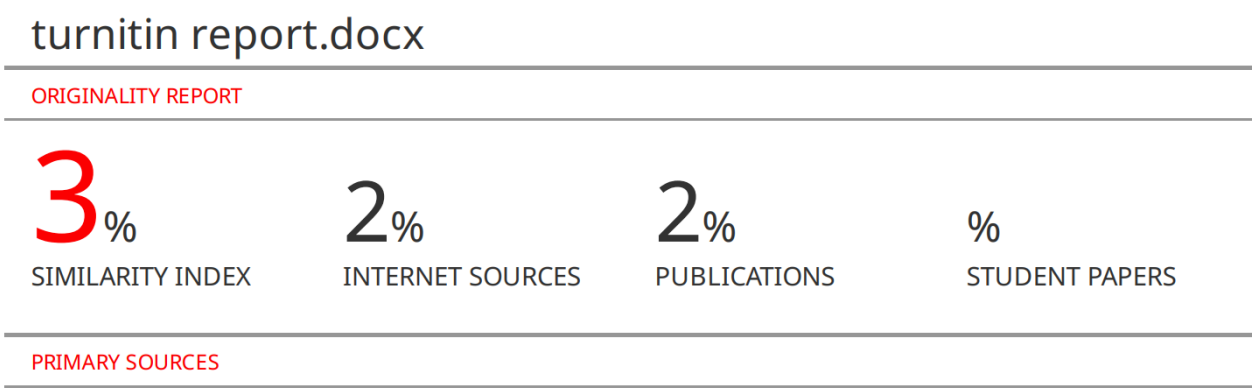
To be completed in duplicate and **A SIGNED COPY** returned to the Secretary electronically. Unreported changes to the application may invalidate the clearance given by the HREC (Non-Medical)

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved I/we undertake to submit an amendment of the protocol to the Committee. **I/we agree to completion of a regular progress report. For Minimal and Low Risk studies, this is due annually on 31 December. For Medium and High Risk studies, this is due twice annually on 30 June and 31 December.**

_____ 20 / 02 / 2024
**Signature** **Date**

**PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES**

18.5. Appendix 5: Turnitin report



turnitin report.docx

ORIGINALITY REPORT

| 3% | 2% | 2% | % |
|---|---|---|---|
| SIMILARITY INDEX | INTERNET SOURCES | PUBLICATIONS | STUDENT PAPERS |

PRIMARY SOURCES

## 18.6. Appendix 6: Data extraction/ Data charting tables

### 18.6.1. Excel table for extraction of papers

| Authorship | Primary Affiliation of First author | Publication year | Name of publication (N/A if Thesis) | Country study conducted in |
|---|---|---|---|---|
| António Armando, Mary Clarisse Bozzetti, Alice de Medeiros Zelmanowicz and Fernando Miguel | Postgraduate Program of Epidemiology, Department of Social Medicine, School of Medicine, Universidade Federal do Rio Grande do Sul (UFRGS), Rua Ramiro Barcelos, 2400, 2º andar, 90035-003 – Porto Alegre, RS, Brazil. National Oncology Centre of Luanda, Rua Amilcar Cabral, s/n, Junto Ao Hospital Pediátrico António Bernardino-Maianga, Luanda, Angola | 2015 | ecancer | Angola |

Continuation

| Title of article | Study design | Data collection | Cancer registry data extracted from/data sources of research |
|---|---|---|---|
| The epidemiology of cancer in Angola—results from the cancer registry of the national oncology centre of Luanda, Angola | Registry study | Patient Medical records of the National Oncology Centre (NOC) between 2007-2011, were a definitive diagnosis of cancer was established. Data from 2007-2010 were not used as in analysis as 50% of these medical records were not available | National Oncology Centre of Luanda(Hospital cancer registry) |

Continuation

| Participants or study populations | Primary objective/s | Ethics approval | Limitations |
|---|---|---|---|
| Patients referred to the NOC between 2007 and 2011 | Description of cancer epidemiology in Angola | Not specified | Limited coverage of the entire population. Selection bias as only people who seek medical treatment in this particular hospital were included. Incomplete data such as socioeconomic status, lifestyle factors, and long-term follow-up data may be lacking or incomplete. quality of data in hospital-based registries can vary depending on factors such as the accuracy of medical records, coding practices, and the diligence of registry staff. Inaccuracies or inconsistencies in data entry can affect the reliability of analyses and conclusions drawn from the data.Follow up limitation. Limitated resources, staff. Ethical and privacy concerns as ethical approvals were not stated on the paper |

Continuation

| Liver cancer | Overview of study outcome |
|---|---|
| Liver cancer mostly likely in the catergory of "other cancers" | There was a 35% rise in recorded cases between 2007 and 2009, followed by a 17% decline till 2011. Breast cancer predominated among women, with most patients being female, while prostate cancer was the most prevalent in men. The highest cancer incidence was in the 45-49 age group, and 77.3% of registry patients were from Luanda. Staging data was only accessible for breast and cervical cancer, while it was unavailable for other types of cancer. |

18.6.2. Liver cancer registry data Excel extraction table

| Year of publication | Name of Publication/s | Years covered | Country |
|---|---|---|---|
| 2015, 2003 | Armando, António, et al , Cancer in Africa | 2007-2011, 1987-1990 | Angola |

Continuation

| Registry Name | Type of Cancer Registry | Was the CR included in Cancer Incidence in 5 Continents volume 12 Publication? (Yes/No) | GLOBOCAN methods(2022)- Own CR used for national estimates |
|---|---|---|---|
| National Oncology Centre (NOC) of Luanda | Hospital-based Cancer Registry | No | |

continuation

| GLOBOCAN method information(2022)-Own CR used for national estimates | Is there a tumor registry that captures histological findings?(Yes/No/Not specified) | Location of Cancer Registry | Are the reports of the registry easily accessible to the public?(Yes/No) | Year registry was established |
|---|---|---|---|---|
| | Yes | National Oncology Centre (NOC) of Luanda in Angola | No | 1987 |

continuation

| Interruptions that occurred in the cancer registries over the years since establishment | Year Registry joined AFCRN | Is there a Policy/Policies that guide cancer registration?(Yes/No/Not Specified) | Where does the registry get its funding |
|---|---|---|---|
| An attempt was made to establish a National Cancer Registry in Angola in 1987. However, the registry's existence was short-lived and it was discontinued in 1991 | N/A | Not specified | Not specified |

continuation

| Person who leads the Registry (Director/Head) | Does the director of the registry fall under the jurisdiction Ministry of health/DoH? (Yes/No/Not specified) | Staff | Email | Data sources of the registry |
|---|---|---|---|---|
| Not Specified | Not specified | Not specified | Not specified | National Oncology Centre (NOC) of Luanda |

Continuation

| Data collection process | Is there a standised form for data collection? (Yes/No/No Info) | Is the data collected longitudinal (Yes/No/Not specified) | Participants/study population |
|---|---|---|---|
| Passive surveillance | No Info | Not specified | Patients diagnosed and treated at National Oncology Centre (NOC) of Luanda |

Continuation

| Is patient demographics being collected(Yes/no) | Age standardized incidence for Liver cancer | Liver cancer incidences | HCC Incidence | Stage of Liver cancer |
|---|---|---|---|---|
| Yes | Not specified | 1987-1990: 59 | Not Specified | Not Specified |

Continuation

| Therapy of Liver cancer | Prognosis of liver cancer | Publications from the registry where liver cancer is included | Utilisation/objective of the cancer registry |
|---|---|---|---|
| Not specified | Not Specified | 2 | |

18.6.3. Hepatitis Vaccination Guideline Extraction Table

| Year of publication | Name of publication | Year of introduction of Hep B Vaccine | Year of introduction of Hep B BD |
|---|---|---|---|
| 2023 | WHO immunization data report | 2006 | 2015 |

Continuation

| Country | Type of Hepatitis B vaccine | Timing of first dose administration (Birth/6 weeks) |
|---|---|---|
| Angola | Pediatric Hepatitis B vaccine and DTwP-Hib-HepB (Whole cell) vaccine | Birth |

Continuation

| Timining of 3rd dose administration | Vaccine coverage of birth dose (<=24hrs) (WUENIC) | Vaccine coverage of birth dose (<=24hrs)(Offical) | Vaccine coverage of birth dose (<=24hrs)(Admin) | Vaccine coverage of 3rd dose (WUENIC) |
|---|---|---|---|---|
| 6 months | ND | ND | ND | 42% |

Continuation

| Vaccine coverage of 3rd dose(Offical) | Vaccine coverage of 3rd doseAdmin) | Does the country have a vaccination law or other legislation that is supportive of immunization and commits the government to finance all aspects of the immunization programme at all levels? | What is the year of the vaccination law or other legislation? | Adults (at risk risk) |
|---|---|---|---|---|
| 63% | 63% | No | N/A | Not specified |

Continuation

| Adults Timing of 1st dose | Adults Timing of second dose | Adults Timing of third dose | Are the WHO and countries guidelines the same? (Yes, No, No info) | Document Name |
|---|---|---|---|---|
| Not specified | Not specified | Not specified | No Info | |

Continuation

| Guidelines on Hep B vaccination | Differences in EPI |
|---|---|
| | |

18.7. Appendix 7: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---|---|---|---|
| **TITLE** | | | |
| Title | 1 | Identify the report as a scoping review. | i |
| **ABSTRACT** | | | |
| Structured summary | 2 | Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives. | v-vi |
| **INTRODUCTION** | | | |
| Rationale | 3 | Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach. | 11 |
| Objectives | 4 | Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualise the review questions and/or objectives. | 12 |
| **METHODS** | | | |
| Protocol and registration | 5 | Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number. | 17 |
| Eligibility criteria | 6 | Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, | 13 |

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---|---|---|---|
| | | language, and publication status), and provide a rationale. | |
| Information sources* | 7 | Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed. | 13-14 |
| Search | 8 | Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated. | o-r |
| Selection of sources of evidence† | 9 | State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review. | 15-16 |
| Data charting process‡ | 10 | Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators. | 16 |
| Data items | 11 | List and define all variables for which data were sought and any assumptions and simplifications made. | l-t |
| Critical appraisal of individual sources of evidence§ | 12 | If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate). | N/A |
| Synthesis of results | 13 | Describe the methods of handling and summarizing the data that were charted. | 16-17 |

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---|---|---|---|
| **RESULTS** | | | |
| Selection of sources of evidence | 14 | Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram. | 18 |
| Characteristics of sources of evidence | 15 | For each source of evidence, present characteristics for which data were charted and provide the citations. | 19-20 |
| Critical appraisal within sources of evidence | 16 | If done, present data on critical appraisal of included sources of evidence (see item 12). | N/A |
| Results of individual sources of evidence | 17 | For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives. | l-t |
| Synthesis of results | 18 | Summarize and/or present the charting results as they relate to the review questions and objectives. | 20-31 |
| **DISCUSSION** | | | |
| Summary of evidence | 19 | Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups. | 30-35 |
| Limitations | 20 | Discuss the limitations of the scoping review process. | 36-37 |
| Conclusions | 21 | Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps. | 38-39 |
| **FUNDING** | | | |

| SECTION | ITEM | PRISMA-ScR CHECKLIST ITEM | REPORTED ON PAGE # |
|---|---|---|---|
| Funding | 22 | Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review. | 39 |

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

*From:* Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

18.8. Appendix 8: Summarised key criteria for a functional Cancer Registry

| Criteria | Description |
|---|---|
| **1. Minimum Dataset** | |
| Essential variables | Personal identification (name/unique ID), sex, date of birth, address, cancer site, morphology, behaviour |

| | |
|---|---|
| Recommended variables | Date and status of last contact, stage or extent of disease, initial treatment |
| Optional variables | Risk factors (e.g., tobacco use, alcohol consumption, infections), socioeconomic status |
| **2. Data Quality** | |
| Accuracy | Data must be correct, complete, and logically consistent |
| Completeness | All cancer cases within the registry's population must be captured |
| Timeliness | Data collection and reporting must occur without unnecessary delay |
| Data validation | Use of tools to verify and clean data for consistency and validity |
| **3. Coding Standards** | |
| Classification systems | Use ICD-O (topography, morphology, behaviour), TNM staging, and SEER Summary Staging |
| Diagnostic basis | Include most valid basis of diagnosis (histology, cytology, imaging, etc.) |
| Multiple primaries | Apply international rules for counting multiple cancers in one patient |
| **4. Infrastructure** | |
| Physical infrastructure | Secure facilities for data storage and archiving |
| Technology | Use cancer registry software (e.g., CanReg5, Surveillance, Epidemiology, and End Results Data Management System (SEER*DMS)) |
| Data linkage | Capability to link with hospital records, death registries, and screening programs |
| Trained personnel | Adequate staff trained in registry operations, coding, data analysis, and confidentiality |
| **5. Confidentiality** | |

| | |
|---|---|
| Privacy standards | Adherence to data protection laws, ethical standards, and anonymization |
| Data sharing protocols | Ensure confidentiality in shared data while supporting research |
| **6. Data Collection** | |
| Sources | Comprehensive data collection from hospitals, pathology labs, outpatient clinics, and vital statistics |
| Death certification | Inclusion of death certificate-only cases to capture unregistered cancers |
| Reporting mechanisms | Standardized forms and protocols for consistent data submission |
| **7. Analysis & Reporting** | |
| Epidemiological analysis | Trends in incidence, survival, mortality, and geographical patterns |
| Equity monitoring | Assess disparities in cancer outcomes by age, sex, ethnicity, and socioeconomic status |
| Public health impact | Evidence for cancer prevention, treatment planning, and resource allocation |
| Dissemination | Regular, public-access reports, dashboards, and publications |
| **8. International Comparability** | |
| Standardization | Follow international best practices to allow cross-registry comparisons |
| Benchmarking | Compare outcomes with global registries (e.g., CONCORD study) |
| Participation in networks | Engage in networks like the Global Initiative for Cancer Registry Development (GICR) |
| **9. Sustainability** | |
| Funding | Secure long-term funding from governments, international agencies, and partnerships |

| | |
|---|---|
| Capacity building | Continuous training for personnel and upgrading of registry infrastructure |
| Integration | Embed registry operations into national cancer control plans |
| Technology updates | Regular upgrades to software and hardware |
| **10. Evaluation and Monitoring** | |
| Performance metrics | Evaluate registry performance using indicators like completeness, accuracy, and timeliness |
| Peer review | Periodic audits by external experts to ensure registry functionality |