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EKURHULENI POPULATION-BASED CANCER REGISTRY 2022 REPORT: KEY FINDINGS

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Summary

Robust, continuous cancer surveillance with quality data is essential for informing cancer prevention and control policies. Population-based cancer registries (PBCRs) systematically gather information about all cancer cases and deaths over time within a well-defined geographical area and are considered to be the gold standard for cancer surveillance worldwide. We report the 2022 key findings of the Ekurhuleni population-based cancer registry (EPBCR) in Gauteng province in South Africa. This report aims to provide essential information to inform cancer related policies locally as well as to achieve benchmark international standards for reporting of South Africa's cancer incidence rates, according to the International Agency for Cancer Research (IACR). The EPBCR uses both active and passive surveillance methods to collect data on all cancer patients diagnosed by clinical, radiological, pathology, or any other means of investigation, in keeping with international standards. Data sources include public and private healthcare facilities and laboratories, oncology networks and associations, hospital and hospice registers, patient files, and mortuary records. A total of 4 116 cancer cases was reported for the year 2022, with 1 741 cases (42.3%) occurring in males and 2 375 (57.7%) in females. Forty-three per cent of cases occurred within the White population, 55% within the Black population and 1% each in the Coloured and Asian population groups. Prostate cancer was the commonest cancer amongst men, with 426 cases (24% of total new cases) and an age standardised incidence rate (ASIR) of 27.53/100 000 population. Amongst women, the leading cancer was breast cancer, with 590 new cases (25% of total new cases) reported with an ASIR of 33.63/100 000. Thirty-three cancers were registered among children, accounting for 0.8% of all cancers registered in 2022. The National Cancer Registry (NCR) should continue to strengthen surveillance at the existing PBCR, implement additional PBCRs across the country in order to increase the accuracy of the country's cancer incidence estimations, and provide national data to the IACR.

Introduction

Cancer is a leading cause of death worldwide and remains an important public health challenge[1]. In 2022, the World Health Organization (WHO), International Agency for Research on Cancer (IARC) reported an estimated 20 million new cancer cases and about 9.7 million cancer deaths worldwide[2]. The distributions of cancer incidence and mortality vary significantly across different regions of the world. Low and middle-income countries (LMICs) are greatly affected, and it is estimated that in 2040 about two-thirds of new cancer cases will occur in LMICs[3]. The implications of increasing cancer incidence and deaths are catastrophic to individuals, families and communities, the public health system, and economies at all levels[4]. Robust continuous cancer surveillance with quality data is therefore essential to provide evidence-based planning for cancer prevention and control policies, intervention programmes, and strategies going forward[5].

Population-based cancer registries (PBCRs) systematically gather information about all cancer cases and deaths over time within a well-defined geographical area[5]. They therefore provide the best estimations of the true burden of cancer, monitor epidemiological trends, and predict future cancer burdens based on current trajectories, making them critical components for cancer prevention and control[5,6]. In 2011, the IARC, in partnership with international communities, launched the Global Initiative for Cancer Registry Development (GICR) to accelerate

PBCR coverage and quality data improvements globally[7]. Despite this initiative, there are an estimated 700 cancer registries across the world, covering only about 21% of the world's population[8]. In the African region, the PBCR coverage is estimated to be 11%[8].

The National Cancer Registry (NCR) in South Africa (SA) within the National Institute for Communicable Diseases (NICD), a division of the National Health Laboratory Service (NHLS)[9] serves as South Africa's main source of national cancer incidence data. Since 1986, the NCR has conducted pathology-based cancer surveillance, whereby data on cancer cases (diagnosed by histology, cytology, and bone marrow aspirate and trephine) are collected, analysed, and reported annually[9]. In 2011, Regulation no. 380 of the National Health Act no. 61 of 2003 was created to legally establish the NCR and to make cancer a reportable disease, with every healthcare worker obliged to report confirmed cancers to the NCR[10]. The regulation also provided a mandate for the NCR to establish and implement PBCRs across SA, the first of which was implemented in the Ekurhuleni Metropolitan Municipality, Gauteng Province. This surveillance system meets the gold standard criteria for cancer registration worldwide, as all cancers that are diagnosed clinically, radiologically, and pathologically are recorded. The Ekurhuleni population-based cancer registry (EPBCR) has yielded six years of data since its implementation in 2017. The NCR has also successfully submitted the EPBCR 2020 data to the Global Cancer Observatory (GLOBOCAN), a project under the International Agency for Research on Cancer (IARC) that provides comprehensive cancer statistics globally[2]. This is the first time that SA data will be included in the global statistics for cancer, as previous SA estimations have been modelled from neighbouring countries.

The purpose of this report is to present the key findings from the sixth cancer incidence report of the EPBCR, covering the period from January 1, 2022, to December 31, 2022. It includes comparisons of age-standardised incidence rates (ASIRs) for the most common cancers and surveillance targets across the years 2017, 2018, 2019, 2020, and 2022. This report provides valuable information to key stakeholders to guide decision-making, planning of cancer initiatives, and intervention programmes, and provide important data for the evaluation of health interventions.

Methods

The EPBCR uses active (deploys surveillance officers to healthcare facilities to collect information from different sources) and passive (receives reports from facilities) surveillance methods to collect data on all cancer patients residing in the Ekurhuleni metropolitan municipality diagnosed by clinical, radiological, pathology, or any other means of investigation. Methods of data collection endorsed by the IARC, the International Association of Cancer Registries (IACR), and the African Cancer Registry Network (AFCRN) were employed. The inclusion criteria for both active and passive case-finding methods are: all confirmed cancer cases in persons who are residents of the Ekurhuleni metropolitan municipality and were diagnosed between 1 January and 31 December of the reporting year. Cancer cases include those considered malignant in the morphology section of the International Classification of Diseases for Oncology (ICD-O), by which behaviour code-3 is reported to the registry[11]. Cancers in metastatic sites (for example, lymph nodes) are registered with the primary tumour site topography. If this is not known, it is registered as an unknown primary site.

Data sources

The EPBCR has multiple data sources, including public and private hospitals/healthcare facilities, public and private laboratories, oncology networks, and associations. Data sources extend beyond the borders of the Ekurhuleni metropolitan municipality, as depending on the level of health services required, cancer patients may be referred out of the municipality to access further diagnosis and management. Furthermore, patients in SA tend to be highly mobile and may seek healthcare at a facility outside of the district in which they reside. Both public and private laboratories send reports (electronic or physical files) of patients diagnosed with cancer to the NCR's national pathology-based cancer registry. The EPBCR surveillance officers (SOs) use all the pathology reports received together with other data tools to identify, trace, and register patients from Ekurhuleni metropolitan municipality into the EPBCR. The South African Children's Study Cancer Group (SACCSG) and the South African Oncology Consortium (SAOC) also report their relevant data for residents of Ekurhuleni to the NCR. These data sources are used to consolidate missing information for patients already registered in the EPBCR database or to trace and notify the patient in conjunction with other data tools from different data sources. Finally, SOs use hospital registers, patient files, and mortuary records and visit hospices at regular intervals to identify new patients not already recorded in an existing database available to the NCR or to consolidate information missing for patients already registered from other data sources.

Data collection

The SOs visit healthcare facilities to review data-source tools such as medical files, pathology results, pharmacy prescriptions, cancer screenings, and admission and discharge books to identify, trace, and notify Ekurhuleni cancer patients. Identified cancer patients are notified using the South African Department of Health's cancer registration form[12]. The SOs extract data/variables required from data sources and code the cancer diagnosis according to the International classification of Oncology Diseases, version 3 (ICDO-3)[11]. Where available, a pathology report is filed with the corresponding notification form. The files are then captured onto the Research Electronic Data Capture (REDCap) database system, either remotely at surveillance sites by the SOs or centrally at the NCR by dedicated data capturers. The captured files are sent to the surveillance manager for quality assurance and quality control. The surveillance manager uses both the physical notification forms and electronic records on RedCap for each cancer case to check for duplicates, completeness, and consistency. The files are stored in a locked cabinet for 20 years as per the South Africa Protection of Personal Information Act (POPI Act) before they are permanently destroyed[13].

The electronic data are coded and incorporated into the REDCap database. To identify the cases that are missed by the SOs, SAOC, and the South African paediatric oncology network, national pathology-based cancer registry data for Ekurhuleni Metropolitan Municipality are extracted and linked to the REDCap database. Surveillance officers then trace the missing cases back to medical records at the relevant health facilities, and the medical records and the pathology records are consolidated and captured.

Data analysis

The complete, quality-assured dataset is extracted per calendar year. All malignant cases from all body sites are exported into Stata® statistical software (StataCorp LLC, Texas, USA) for cleaning and analysis. Benign growths, in-situ lesions and cancers of unknown behaviour are excluded from the analysis. The annual report includes cancer counts, frequencies, crude rates, lifetime risks and ASIRs by sex and population groups for each cancer. Including race (population group) in cancer data analysis is vital for identifying health disparities, tailoring interventions, and improving access to care. It ensures diverse representation and helps promote equitable health outcomes across populations. The Segi World Standard Population (WSP) is used for age standardisation and the mid-year population estimates from Statistics South Africa (STATS SA) are used as the population denominator[14,15]. Data quality indicators (proportions of cases diagnosed either by death certificate only, clinical investigation, or morphologically diagnosed) were calculated for each cancer case. Cases were classified as morphologically verified if a microscopic examination of a tissue sample confirmed the diagnosis. Those without morphological verification were identified through clinical evaluations and death certificates alone. In a PBCR, there should be a significant number of cases diagnosed clinically or at death, indicating reliance beyond just histological diagnosis. For this analysis, the proportions for each cancer site are presented, showing how many cases were diagnosed through morphological verification, clinical evaluation, or death certificate.

This report specifically addresses the 2022 surveillance results, focusing on the total number of cancer cases reported to the NCR for that year. It outlines the leading ten cancers in males and females, detailing their frequencies and ASIRs. Additionally, the report includes comparisons by population groups for the leading five cancers in both males and females, and it shows the distribution of childhood cancers for 2022.

Results

The statistics provided here are those of the Ekurhuleni population only and are not to be confused with the statistics of the national pathology-based cancer registry.

A total of 4 116 cancer cases were registered by the EPBCR for the year 2022, with 1 741 cases (42.3%) occurring in males and 2 375 (57.7%) in females. Forty-three per cent of cases occurred within the White population, 55% within the Black population, and 1% each in the Coloured and Asian population groups. A detailed tabulation of cases registered in 2022 for males and females, including the total number of cases registered, crude rates per 100 000 population, age-adjusted incidence rates per 100 000 population, and lifetime risk for each cancer, is available in the full report[16]. Key findings include that the commonest cancers among males were prostate (24%), colorectal (6%) and lung (4%), whereas among women the commonest cancers were breast (25%), cervix (25%), and colorectal (4%).

Of the 4 116 cases reported, 89.8% were histologically diagnosed (morphologically verified) (Table 1). The EPBCR identified an additional 10.2% of cases through clinical diagnoses or death records. Notably, ovarian (59%), liver (35%), brain (31%), non-Hodgkin lymphoma (27%), lung (27%) and pancreatic cancers (22%) were diagnosed

clinically, indicating that these cases would not have been recorded in the registry without active cancer case finding through the PBCR. The rate of unknown primary sites was very low at 4.6%, which serves as a positive data indicator for a PBCR.

Table 1. Percentage of cases morphologically verified (MV), diagnosed clinically or diagnosed by death certificate only (DCO), Ekurhuleni population-based cancer registry (EPBCR) 2022.

			Basis of diagnosis		
ICD 10 Cancer site	**No. of cases**	**% Total**	**DCO**	**Clinical**	**MV**
C00 Lip	6	0.1	0.0	0.0	100.0
C02 Tongue	27	0.7	0.0	0.0	100.0
C03 Gum	1	0.0	0.0	0.0	100.0
C06 Mouth	13	0.3	0.0	7.7	92.3
C07 Salivary gland	9	0.2	0.0	11.1	88.9
C11 Naso-Oropharynx	24	0.6	0.0	4.2	95.8
C15 Oesophagus	55	1.3	1.8	16.4	81.8
C16 Stomach	39	0.9	0.0	10.3	89.7
C17 Small intestine	5	0.1	0.0	0.0	100.0
C18-20 Colorectal	213	5.2	0.0	13.6	85.9
C21 Anus	45	1.1	0.0	13.3	86.7
C22 Liver & Bile duct	43	1.0	2.3	34.9	62.8
C25 Pancreas	32	0.8	9.4	21.9	68.8
C26,C38,C48,C57,C58,C63,C68 Other specified	24	0.6	0.0	20.8	79.2
C32 Larynx	31	0.8	0.0	3.2	93.5
C34 Lung	107	2.6	0.0	27.1	72.9
C41 Bone	9	0.2	0.0	0.0	100.0
C43 Melanoma	90	2.2	0.0	4.4	95.6
C44 Basal cell carcinoma	645	15.7	0.0	0.6	98.9
C44 Squamous cell carcinoma of skin	222	5.4	0.0	0.0	100.0
C44 Skin other	26	0.6	0.0	7.7	92.3
C45 Mesothelioma	7	0.2	0.0	14.3	85.7
C46 Kaposi Sarcoma	48	1.2	2.1	8.3	89.6
C49 Connective tissue	20	0.5	0.0	10.0	90.0
C50 Breast	601	14.6	0.3	10.6	88.9
C51 Vulva	74	1.8	0.0	9.5	90.5
C52 Vagina	15	0.4	0.0	6.7	93.3
C53 Cervix	587	14.3	0.2	4.1	95.7
C54 Uterus	65	1.6	0.0	6.2	93.8
C56 Ovary	34	0.8	0.0	58.8	41.2
C60 Penis	12	0.3	0.0	0.0	100.0
C61 Prostate	426	10.3	0.2	12.7	87.1
C62 Testis	13	0.3	0.0	15.4	84.6
C64 Kidney	27	0.7	0.0	11.1	88.9
C67 Bladder	58	1.4	0.0	3.4	96.6
C69 Eye	20	0.5	0.0	15.0	85.0
C71 Brain, CNS	35	0.9	0.0	31.4	68.6
C73 Thyroid	18	0.4	0.0	5.6	94.4
C74 Endocrine	5	0.1	0.0	0.0	100.0
C76 Ill defined	19	0.5	0.0	5.3	94.7
C80 Primary site unknown	191	4.6	1.0	25.1	73.3
C81 Hodgkin lymphoma	35	0.9	0.0	11.4	88.6
C83 Burkitt lymphoma	2	0.0	50.0	0.0	50.0
C85 Non Hodgkin lymphoma	81	2.0	0.0	27.2	72.8
C90 Myeloma	22	0.5	0.0	4.5	95.5
C92 Leukaemia	33	0.8	0.0	12.1	87.9
C96 Haematology other	2	0.0	0.0	0.0	100.0
All sites	**4116**	**100**	**0.3**	**9.7**	**89.8**

Figures 1–4 illustrate the frequency and ASIRs of the commonest cancers registered in the EPBCR in 2022 for males and females. Prostate cancer was by far the commonest cancer amongst men, with 426 cases (24% of total new cases) identified and an ASIR of 27.53/100 000 population. Amongst women, the leading cancer was breast cancer, with 590 new cases (25% of total new cases) reported, with an ASIR of 33.63/100 000. Figures 5 and 6 illustrate the top five cancer ASIRs by population group. In males, the White population group had the highest ASR (36.21/100 000) in prostate cancer, followed by Black (30.56/100 000), Asian (14.52/100 000), and Coloured (8.45/100 000) population groups. In females, the White population group had the highest ASIR (42.76/100 000) in breast cancer, followed by Black (32.25/100 000), Asian (27.45/100 000), and Coloured (15.42/100 000) population groups.

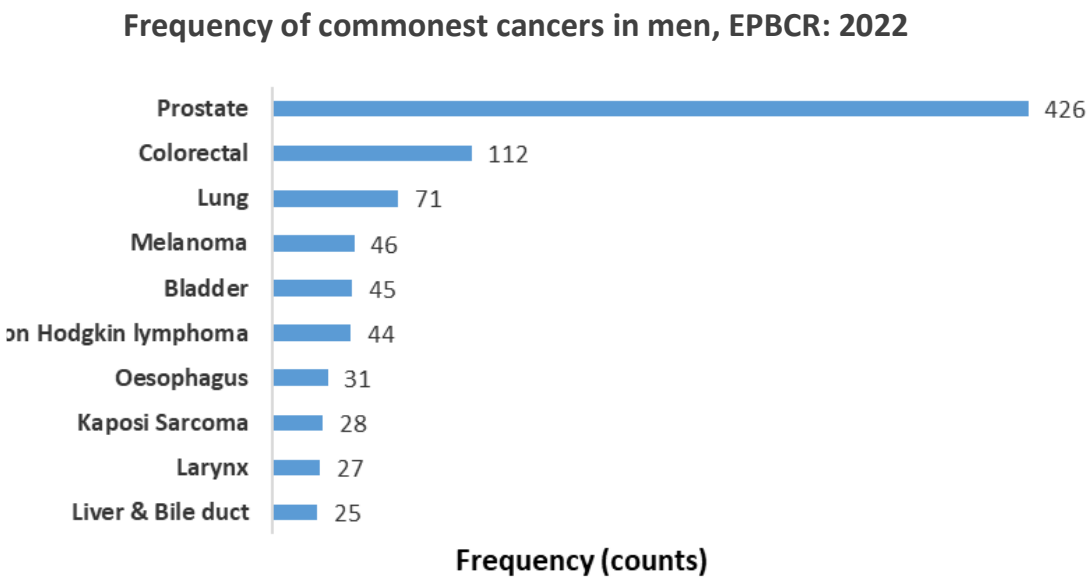

Figure 1. Frequency (counts) of the commonest cancers in males, Ekurhuleni population-based cancer registry (EPBCR), 2022.

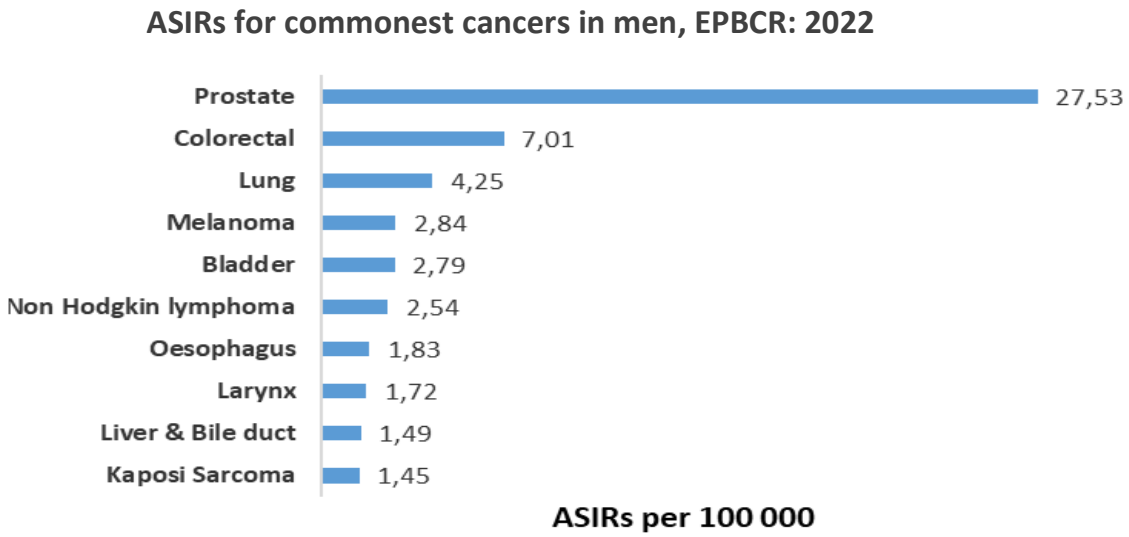

Figure 2. Age-standardised incidence rates (ASIRs) for the commonest cancers in males, Ekurhuleni population-based cancer registry (EPBCR), 2022.

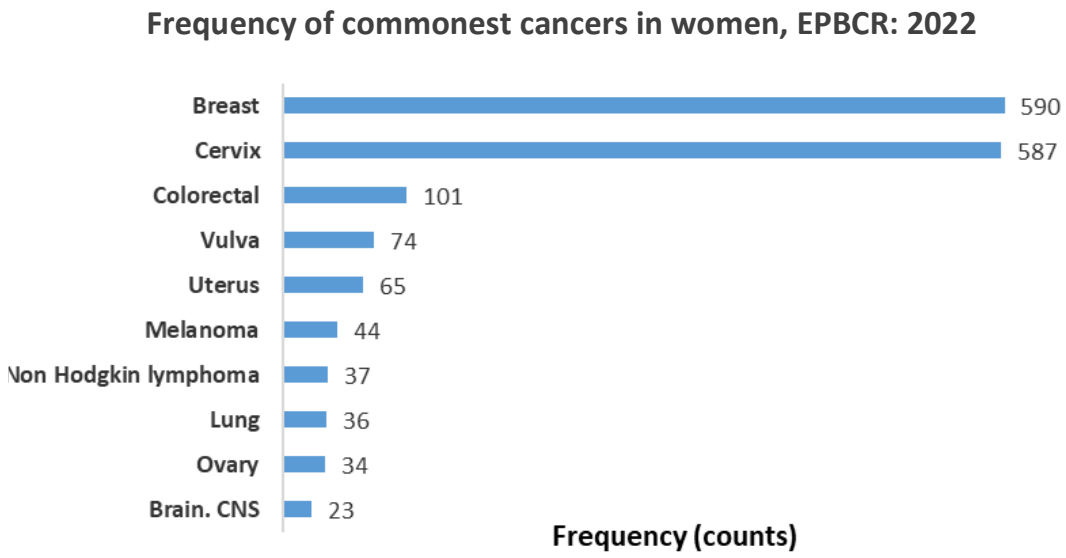

Figure 3. Frequency (counts) of the commonest cancers in females, Ekurhuleni population-based cancer registry (EPBCR), 2022. CNS: central nervous system

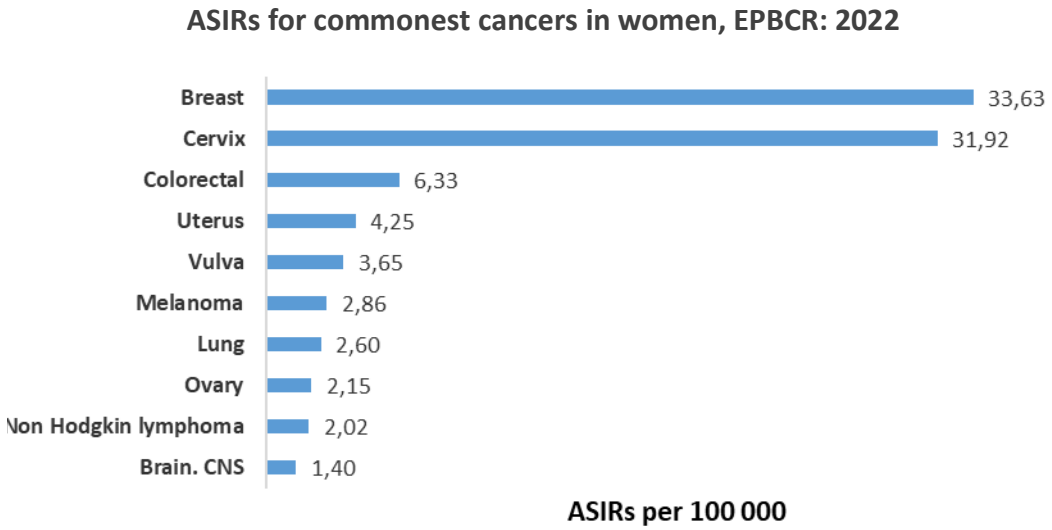

Figure 4. Age-standardised incidence rates (ASIRs) for the commonest cancers in females, Ekurhuleni population-based cancer registry (EPBCR), 2022.

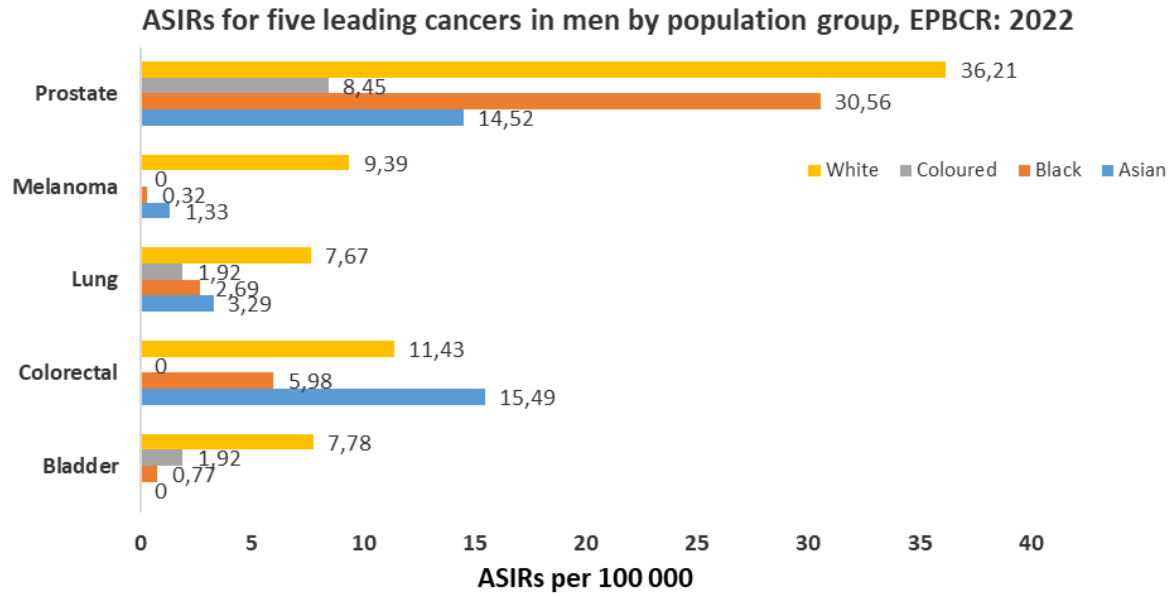

Figure 5. Age-standardised incidence rates (ASIRs) for the leading five cancers in men by population group, Ekurhuleni population-based cancer registry (EPBCR), 2022.

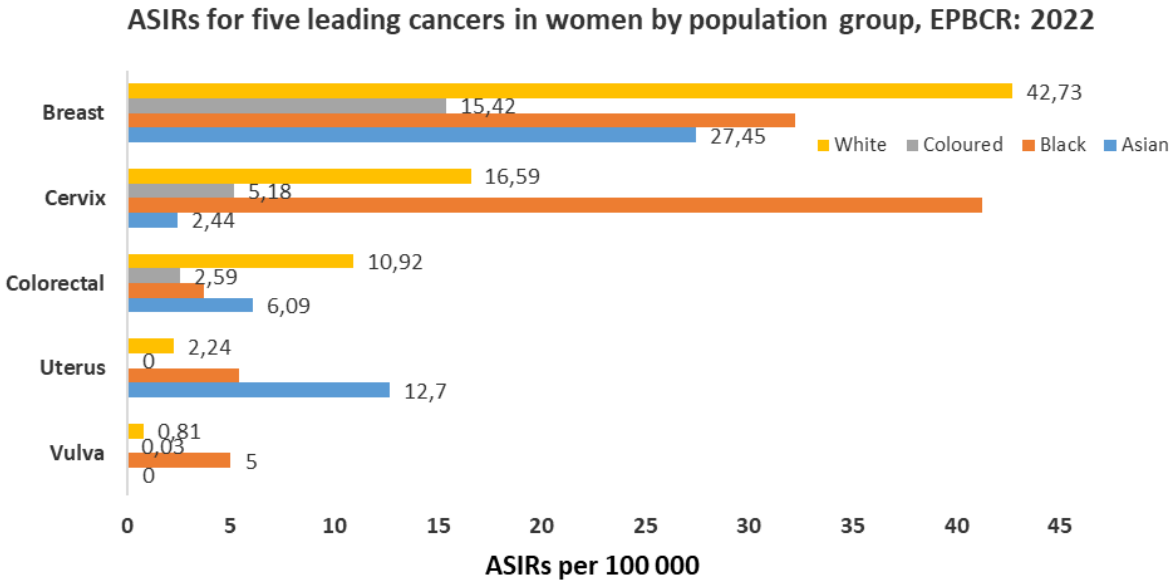

Figure 6. Age-standardised incidence rates (ASIRs) for leading five cancers in women by population group, Ekurhuleni population-based cancer registry (EPBCR), 2022.

Figures 7 and 8 show a comparison of ASIRs for common cancers reported from 2017 to 2022 by sex. Figure 9 shows comparisons of case numbers from 2017 to 2022. There was an 11% decrease in the overall number of cancer cases reported in 2022 (n=4 116) compared with 2021 (n=4 631). Among males, there was a 17% decrease from 2 105 cases in 2021 to 1 741 cases in 2022, while among females there was a 6% decrease from 2 526 in 2021 to 2 375 cases in 2022. The pattern of the five commonest cancers by age-standardised incidence rates by sex remained comparable between 2017 and 2022, with few exceptions for males, where melanoma and bladder cancers replaced non-Hodgkin lymphoma and oesophageal cancer in 2022.

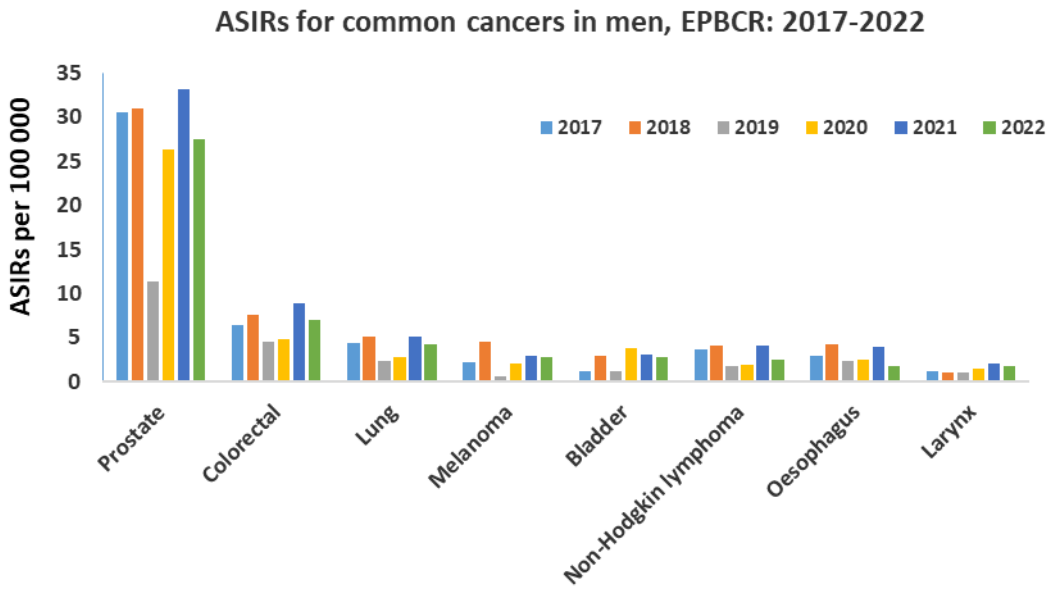

Figure 7. Age-standardised incidence rates (ASIRs) for the commonest cancers in men, Ekurhuleni population-based cancer registry (EPBCR), 2017-2022.

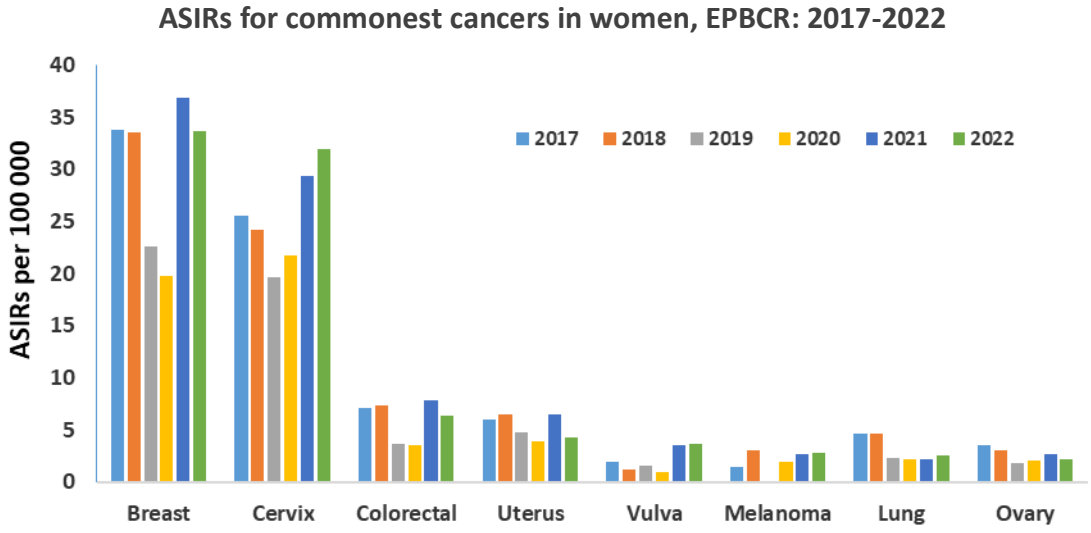

Figure 8. Age-standardised incidence rates (ASIRs) for the commonest cancers in women, Ekurhuleni population-based cancer registry (EPBCR), 2017-2022.

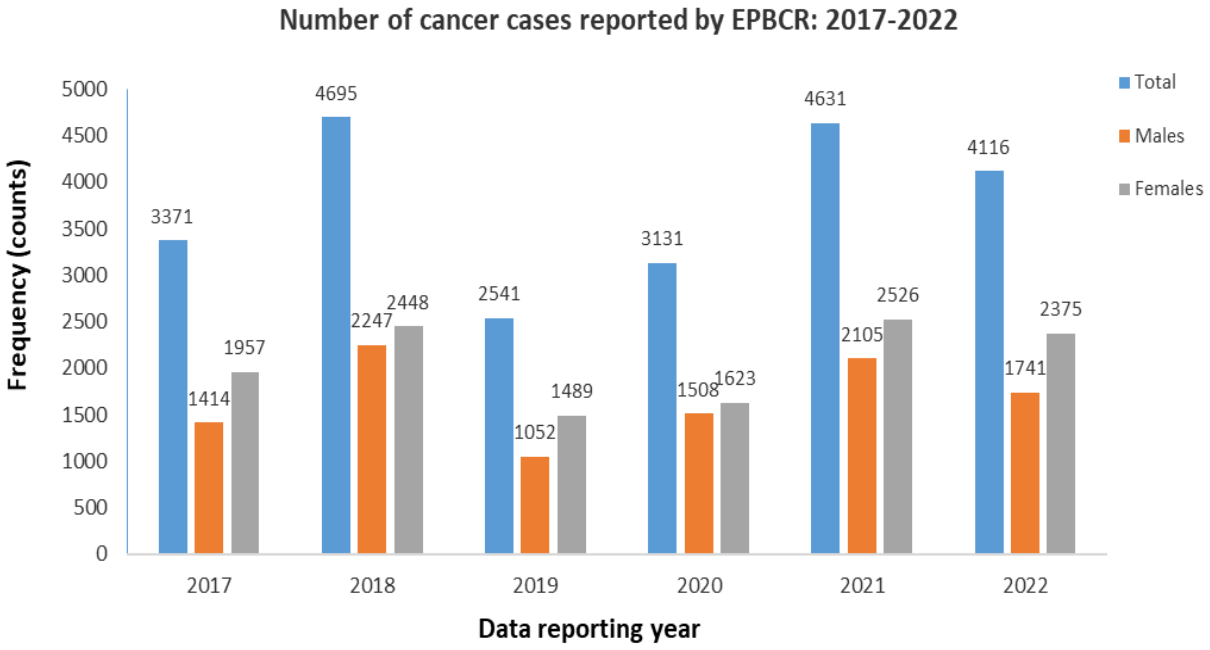

Figure 9. Frequency (counts) of cancer cases reported by year and sex, Ekurhuleni population-based cancer registry (EPBCR), 2017-2022.

Table 2 shows the leading ten cancers in children aged 0–14 years in the Ekurhuleni area. Thirty-three cancers were registered in 2022 among children, accounting for 0.8% of all cancers registered in 2022. There were 17 cancers in boys and 16 cancers in girls. Leukaemia, lymphoma, CNS neoplasms, soft tissue sarcomas, retinoblastoma, and nephroblastoma were the commonest cancers in children.

Table 2. Childhood cancers, Ekurhuleni population-based cancer registry (EPBCR), 2022.

	Number of cases					Rates per Million Age-Specific Rates						
Cancer	**Age 0-4**	**Age 5-9**	**Age 10-14**	**All Ages**	**Male/ Female ratio**	**Age 0-4**	**Age 5-9**	**Age 10-14**	**Crude Rates**	**Age-Standardised Rates**	**Lower Confidence Level**	**Upper Confidence Level**
Leukaemia	2	2	1	5		7	8	4	6.52	6.53	2.12	15.23
Lymphoma	3	2	1	6	2	10	8	4	7.82	7.88	2.89	17.13
Central Nervous System Neoplasms	2	1	1	4	1	7	4	4	5.22	5.25	1.43	13.43
Neuroblastoma	1	0	0	1		3	0	0	1.30	1.35	0.03	7.39
Retinoblastoma	3	0	0	3	1	10	0	0	3.91	4.05	0.84	11.74
Nephroblastoma - Wilms Tumour	1	2	0	3	1	3	8	0	3.91	3.90	0.80	11.41
Bone Tumours	0	1	0	1		0	4	0	1.30	1.28	0.03	7.18
Soft Tissue Sarcomas	0	1	1	2	1	0	4	4	2.61	2.55	0.31	9.28
Germ Cell Tumours	0	0	0	0		0	0	0	0.00	0.00	0.00	4.80
Primary site Unknown	1	0	1	2		3	0	4	2.61	2.63	0.32	9.46
Other, specified	4	2	0	6	2	14	8	0	7.82	7.95	2.92	17.27
All sites	**17**	**11**	**5**	**33**	**7**	**59**	**43**	**22**	**43.04**	**43.38**	**11.69**	**124.32**

Discussion

This report describes cancer cases that were diagnosed among residents of Ekurhuleni metropolitan municipality in Gauteng province between 1 January and 31 December 2022, and compares the ASIRs of the commonest cancers in adults between 2017 and 2022. In cancer surveillance, data are always collected retrospectively due to the long turnaround time for diagnosis, with a universal standard of a two-year reporting lag[17]. Overall, the cancer case numbers have remained approximately 4 000 annually across 2017 to 2022, except during the COVID-19 pandemic (2019 and 2020), which affected cancer diagnosis and data collection negatively. This report suggests that surveillance activities have returned to normal post-pandemic.

The frequency and ASIRs analysis for 2022 in EPBCR show that the commonest cancers among males were prostate, colorectal and lung, whereas among women the commonest cancers were breast, cervix and colorectal, respectively. These proportions of cancer cases are useful for determining the burden on the country's healthcare system for screening, diagnosis, treatment, and care of cancer patients. On the other hand, ASIRs are used to compare rates of cancer between different geographic regions and populations. The general pattern of cancer among men and women remained similar to previous years, with a few exceptions, such as non-hodgkin's lymphoma and oesophageal cancers replacing melanoma and bladder cancers in the top five cancers among men from 2017 to 2022. Estimates available on the IARC's Globocan show that lung cancer was the most commonly occurring cancer globally in 2022 (12.4% of an estimated 20 million total new cases), followed by

female breast cancer (11.6%), colorectal cancer (9.6%), prostate cancer (7.3%), and stomach cancer (4.9%)[2]. There were some differences in incidence by sex. For women, the most commonly diagnosed cancer was breast cancer, followed by lung and colorectal cancer, whereas for men lung cancer had the highest number of new cases, followed by prostate and colorectal cancers. Cervical cancer was the eighth most commonly occurring cancer globally[2]. The IARC's Global Cancer Observatory data shows similar patterns, with lung cancer being the commonest globally, followed by female breast, colorectal, prostate, and stomach cancers[18]. This concordance between the two reports highlights the consistency in cancer incidence patterns and reinforces the importance of comprehensive cancer registration and surveillance systems in understanding the burden of cancer on healthcare systems.

The differences observed in the commonest cancer types between the EPBCR data and the Globocan global estimates can be attributed to several factors. Firstly, the EPBCR data represents the cancer incidence specifically within the SA sub-population, whereas the Globocan data provides estimates for the global population, which can reflect regional variations in cancer epidemiology. Secondly, the demographic and risk factor profiles of the SA population may differ from the global averages, influencing the relative burden of different cancer types. Thirdly, the EPBCR may have higher completeness and accuracy in cancer reporting compared to the modelling and estimation methods used by Globocan, which could lead to discrepancies in case identification and reporting.

Cancer in children under 15 years of age is rare, comprising less than one percent of all malignancies diagnosed globally[19]. In children, lymphomas were the commonest cancers. Global literature highlights leukaemia, particularly acute lymphoblastic leukaemia, as the most frequently diagnosed cancer in children[20]. The discrepancy in prognosis between developed and lower-income countries is striking. In developed countries, the overall survival rate for childhood cancers is approximately 80%, largely due to advanced diagnostic methods that facilitate early detection and treatment[20]. In contrast, lower-income countries experience a significantly poorer prognosis of only 20% overall survival rate, often attributed to late diagnoses and limited access to healthcare resources[20]. In SA, there is an urgent need to generate robust evidence regarding childhood cancers to better inform policies and improve outcomes for affected children. By understanding the specific challenges and trends in our context, we can work towards enhancing early detection and treatment strategies, ultimately bridging the gap in cancer care between regions.

The analysis of the 4 116 cancer cases reported reveals that 89.8% were histologically diagnosed (morphologically verified), highlighting a strong foundation of morphological verification in the dataset (Table 1). However, the EPBCR's identification of an additional 10.2% of cases through clinical diagnoses or death records emphasises the critical role of active cancer case finding in achieving comprehensive cancer surveillance. Notably, a higher percentage of clinical diagnoses, particularly for ovarian (59%), liver (35%), brain (31%), non-Hodgkin lymphoma (27%), lung (27%) and pancreatic cancers (22%), indicates effective case finding by the EPBCR. These cases, which would have likely gone unrecorded if the registry solely relied on pathology results, demonstrate the importance of integrating clinical investigations, such as X-rays and other diagnostic methods, into cancer

registries. The low rate of unknown primary sites at 4.6% also serves as a positive indicator of the registry's effectiveness in capturing complete diagnostic information.

The data collection process encountered several challenges. The COVID-19 pandemic had a substantial impact on all aspects of cancer service delivery globally, including disruptions in cancer screening, early diagnosis, access to treatment, and repurposing of health facilities and healthcare workforce for COVID-19 services[21,22]. The implementation of COVID-19 protocols prevented data collectors from accessing health facilities and restricted data collection activities, necessitating a retrospective compilation of cases once services returned to normalcy. In addition, the implementation of the POPI Act, which restricts data sharing, especially concerning personal identifiers, added another layer of complexity to data collection efforts[23]. Some healthcare practitioners misinterpreted the POPI act and were reluctant to share data due to concerns about breaching patient confidentiality. Access to mortality data remains a challenge. The Department of Home Affairs (DHA) is the custodian of vital statistics (death registration) for SA. Although Statistics South Africa (STATS SA) also has cleaned vital statistics data for South Africans that can be used to consolidate vital status (dead/alive) in the EPBCR, they are unable to legally share patient-level data with other organisations. To compensate for this challenge, the surveillance officers visit the mortuaries within healthcare facilities to trace and report cases of cancer for patients who may have been missed while alive. The lack of access to mortality data also posed a significant obstacle in completing the analysis. Although aggregated data provided by STATSSA can be used to consolidate vital status (dead/alive) in the FPBCR, individual-level data is crucial for accurate survival analysis in cancer research, and without it, meaningful assessments of cancer outcomes cannot be conducted.

Historically, due to limitations in data availability and quality in SA, cancer incidence estimates provided for SA by sources like GLOBOCAN often had to rely on extrapolations and modelling techniques, using data from neighbouring countries. The NCR has now successfully submitted the EPBCR 2020 data to GLOBOCAN. Thus, for the first time, South African data will be used in the compilation of global cancer statistics, truly reflecting the unique epidemiological landscape of the country. The NCR will continue to strengthen the EPBCR system and set a benchmark for the other PBCRs in SA to gather comprehensive, representative, and best-quality cancer data to inform prevention and control. The NCR, in partnership with the University of KwaZulu-Natal's Cancer & Infectious Diseases Epidemiology Research Unit, launched the KwaZulu-Natal population-based cancer registry (KZN PBCR) in 2023, and in the near future, the cancer incidence data from both registries will be computed together to increase the accuracy of cancer-related estimates.

Conclusion

This EPBCR report shows that the commonest cancers among males are prostate, colorectal and lung, while among females the commonest are breast, cervix, and colorectal cancers. The report also shows that cancer in children under 15 years of age is rare, with lymphomas being the commonest in this age group. These results are valuable for determining the burden on the healthcare system for cancer screening, diagnosis, treatment, and care. Additionally, the analysis highlights the importance of a PBCR in capturing non-pathologically diagnosed cancers. PBCRs are critical for countries to effectively drive cancer policy, decision-making, and intervention programmes aimed at reducing cancer cases and deaths. The EPBCR has set a benchmark for the implementation of additional PBCRs in SA.

Recommendations

NCR should:

- Continue providing robust cancer surveillance data to inform cancer prevention and control policies, intervention programs, and strategies by implementing and strengthening more PBCRs in South Africa.
- Ensure the PBCRs meet the IARC's international standards for data quality and completeness by leveraging existing cancer registry infrastructure and expertise, and regularly submit updated and expanded PBCR data to the IARC.
- Improve access to mortality data by implementing appropriate data sharing agreements that secure access to comprehensive national mortality data. This will enable the NCR to better understand the full burden of cancer and evaluate the impact of interventions.
- Strengthen strategic partnerships between public and private stakeholders, increase the number of active partnerships, and engage with these partners to identify and leverage all possible data sources that can enhance the cancer surveillance capabilities in South Africa. Collaborative partnerships are essential for building a comprehensive and sustainable national cancer surveillance system.

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Ethical considerations

The enactment of Regulation No. 380 of the National Health Act (Act 61 of 2003) formally established the NCR as the delegated agency for the collection of cancer surveillance information on behalf of the National Department of Health. This regulation made cancer a reportable disease and mandated the NCR to establish population-based cancer registration for the country. The NCR adheres to the NHLS, the IARC/IACR guidelines, and the POPI Act to ensure the preservation of privacy during the EPBCR surveillance processes. The statistics of cancer data are released in an aggregated format through the annual reports published on the NCR website.

Conflict of interest

The authors declare that there are no conflicts of interest regarding the publication of this article. They have no financial relationships or affiliations with any organisations that could influence the research presented. All the work was conducted independently without any external influence.

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