

2016

# Bermuda National Tumour Registry Annual Report

with statistical data from 2015



**Bermuda Hospitals Board**

Bermuda National Tumour Registry  
Health Information Management Services  
King Edward VII Memorial Hospital





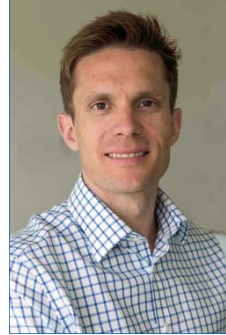




## Bermuda Hospitals Board



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The Bermuda National Tumour Registry is a cancer registration body, with the goal of improving outcomes of cancer diagnosis to ultimately increase survival of cancer patients. The registry began data collection in 1979 and has gathered 36 years of data. Each year it strives to improve the quality of cancer data collection and analysis. However, to truly have a positive impact on the healthcare of the island and improve cancer patients' quality of life and survival, the introduction of mandatory reporting is imperative.

With the support of Bermuda's local medical specialists, and the Bermuda Hospitals Board's Oncology Department and Health Information Management Services, the Bermuda National Tumour Registry has been able to compile data of cancer patients that has been used to monitor trends in research and to educate both the public and clinicians.

The 2016 Annual Report summarises most registered cases during this calendar year by site, gender and age group. It also includes a breakdown of the skin cancer incidences of 2015, which are of particular concern for our community with high rates of sun exposure. Finally, the report outlines the Bermuda National Tumour Registry's educational focus for the year, which is entitled 'A Closer Look at Prostate Cancer'. It is hoped that public education of this very prevalent disease will help improve the public's understanding.

Therefore, on behalf of the Bermuda Hospitals Board, we are pleased to endorse the Bermuda National Tumour Registry 2016 Annual Report.

Sein Aung, MD

Christopher Fosker, MD

## About Us

Cancer is a major burden of disease on our island. According to the Bermuda Health Council, cancer is the second leading cause of death in Bermuda, accounting for 31.2% of all deaths in 2014. Reducing the burden of this disease is a great and noble cause that involves many programmes, including a comprehensive database of all cancer cases island wide. This database is what is referred to as a tumour registry.

The importance of a tumour registry lies in the collection of accurate and complete cancer information that can be used for population-based research, public health programme planning, evaluation of current practices and patient care improvement. The information helps health professionals to better understand the disease and to use resources effectively for the prevention and treatment of cancer. It is a vital link in reducing the burden of cancer in Bermuda.

The Bermuda National Tumour Registry is Bermuda's first population-based, government-supported cancer registration body. The registry began data collection in 1979. It underwent restructuring in 2004 and was re-launched in September 2008. We are focused on improving outcomes in cancer diagnosis, treatment, care and, ultimately, survival.

The fundamental requirements of the registry are:

- Confidentiality
- Complete records
- Quality-controlled data
- Efficiency and usefulness

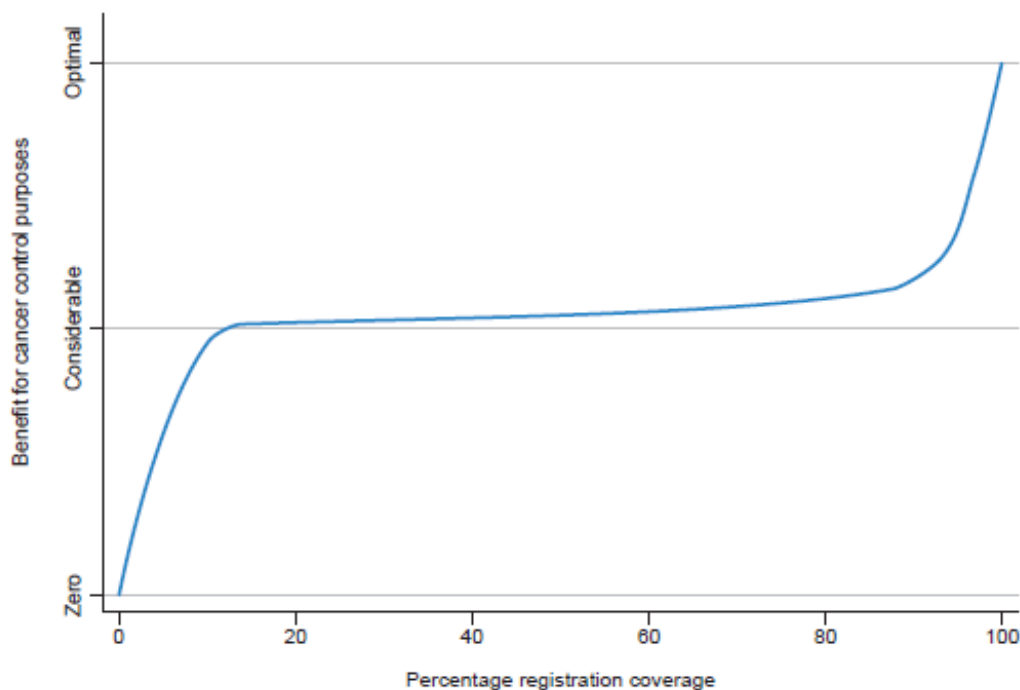
## How does the Bermuda National Tumour Registry work?

Systematic collection and storage of cancer data are essential to creating an accurate picture of the cancer burden affecting a population. A tumour registry is an organisation responsible for the collection of information about cancer patients using specialised reporting systems. It involves primary care physicians, specialists on island and overseas, pathology departments and healthcare planners in order to obtain the most current and concise data.

The data collected by the tumour registry includes: patient information (demographics, social habits and family history), tumour diagnosis specifics, treatment and hospital information, and follow-up particulars. The data can be analysed to compare the frequency and types of cancer between years, find patterns that identify possible risk factors and predict future incidence.

Bermuda's National Tumour Registry is a population-based registry, which means that it aims to collect information on every new case of cancer in Bermuda. The graph below, from the International Agency for Research on Cancer (IARC), shows the importance of registering as many new cancer cases as possible to increase benefits to the community.

### Benefits of Increasing Population Coverage by Cancer Registration



These benefits include better prevention methods and improved patient care as tumour registries can influence protocol, direct healthcare planning and resources, and evaluate the success of different care options.

## What is essential for an effective tumour registry?

Given these huge potential advantages of a tumour registry, it is important to establish a reliable and efficient system. According to the International Agency for Research on Cancer, there are several parameters that are essential to an effective population-based tumour registry.

- A clear population must be defined. This is easy for Bermuda, being a small island, however it means the registry must be able to distinguish between local residents and those who have immigrated to Bermuda, in addition to accounting for Bermudians who are diagnosed and/or receive treatment overseas.
- Effective medical care organisation. This is necessary so that cancer patients come into contact with the system, and there are specialists in diagnosis and treatment of cancer to care for these patients.
- A registry director. This is one of the most essential features of an effective tumour registry, as a director must take responsibility for the success of the registry by garnering support of other personnel and ensuring data quality. This is especially true in Bermuda, where there is active collection of the necessary tumour data by registry personnel.
- Cooperation with hospitals, hospices, private clinics, diagnostic services and death registries.

Other desirable factors for an effective tumour registry include a governmental healthcare system concerned with cancer prevention, treatment and care, and incorporation of the tumour registry as an integral part of the healthcare system. With these factors in place, a tumour registry can provide many cancer control benefits to a community.

## What are our objectives?

The objectives of the Bermuda National Tumour Registry are to:

- reduce the incidence of cancer in the community
- help identify potential environmental risk factors, genetic links and high-risk behaviours which may increase the likelihood of a cancer diagnosis
- assist in determining the efficacy of screening practices and ensuring that lifetime follow-up is conducted with every patient
- provide accurate island-wide data for the government, health service providers, medical researchers and the general community.

## How is the data used?

The data gathered by the tumour registry serves the following purposes within Bermuda and overseas:

- ongoing surveillance of cancer incidence and trends
- provision of information for public and professional education
- epidemiologic and academic research

## Professional Organisations

Caribbean Public Health Agency (CARPHA)

International Agency for Research on Cancer (IARC)

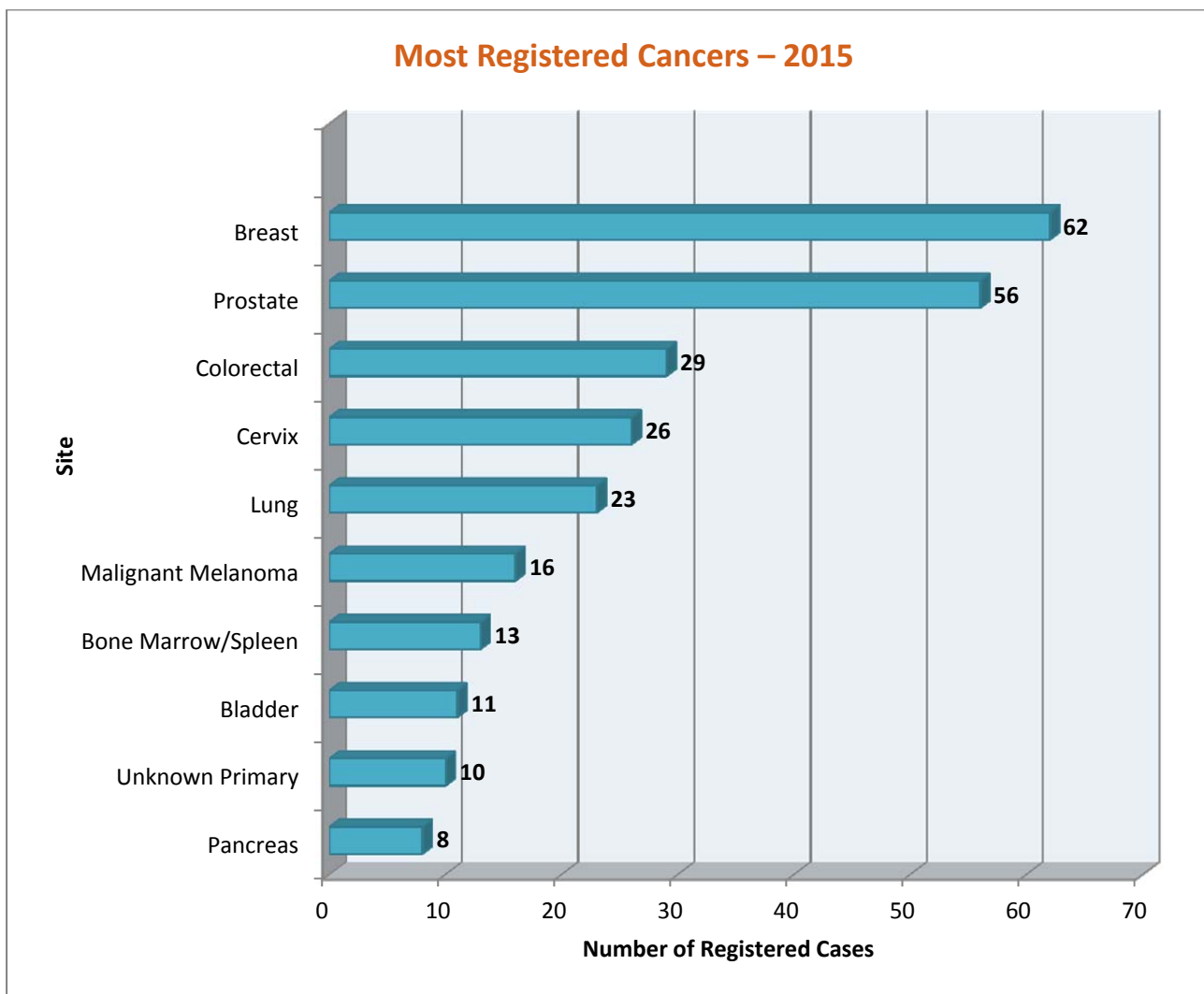
International Association of Cancer Registries (IACR)

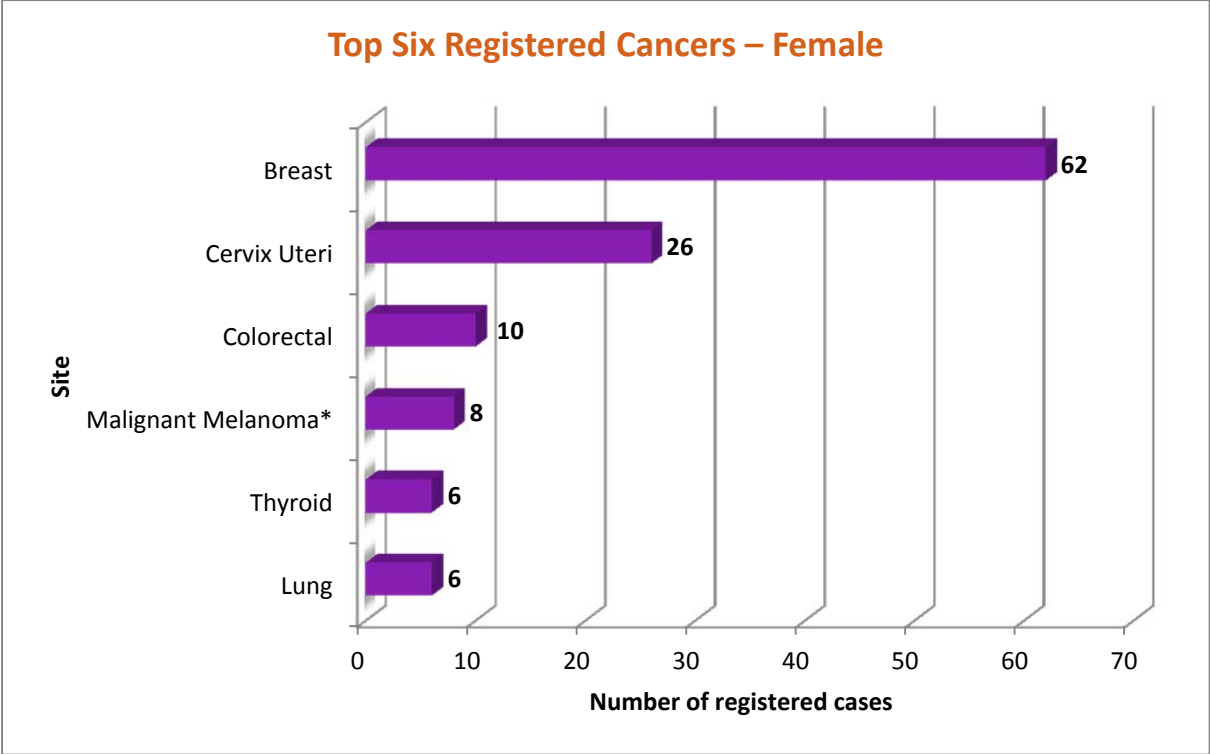
Pan-American Health Organization (PAHO)



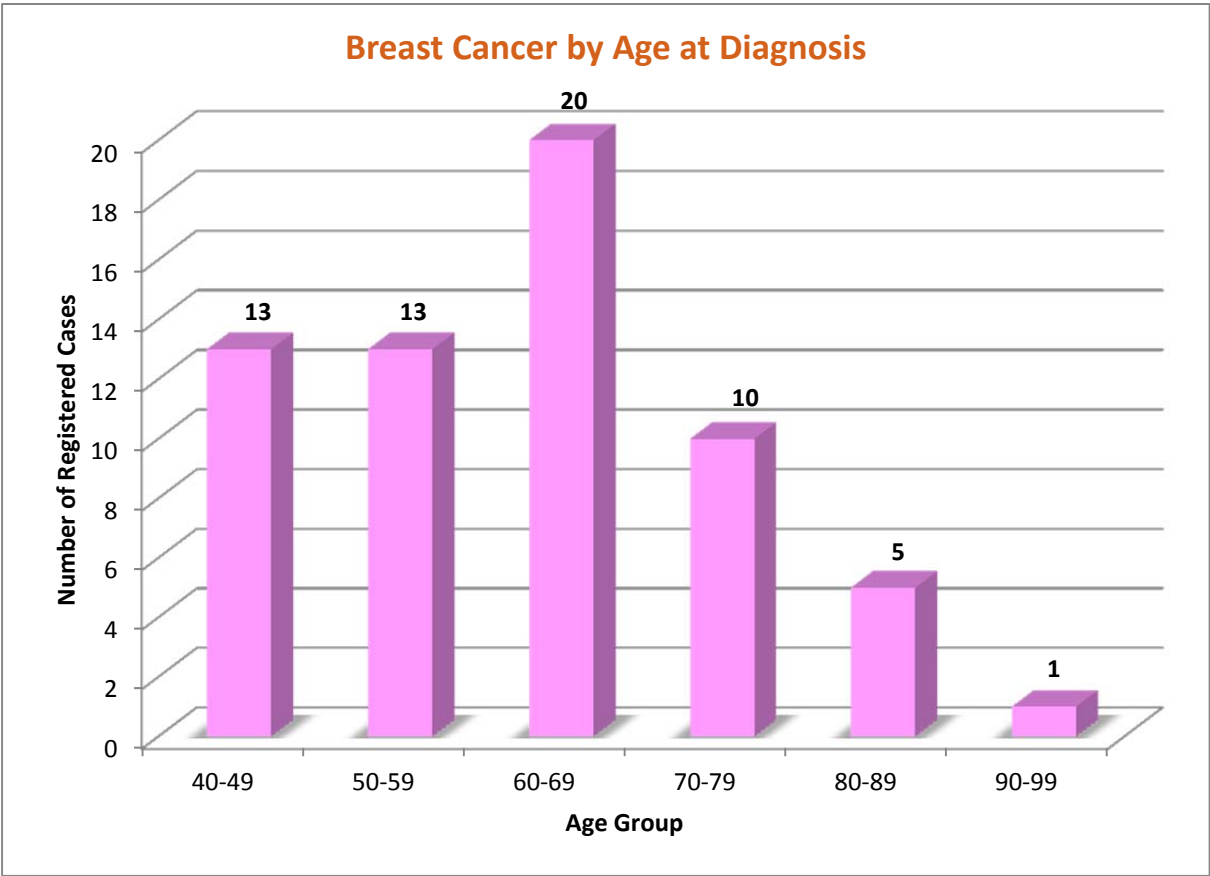
## Graphical Summary of Data

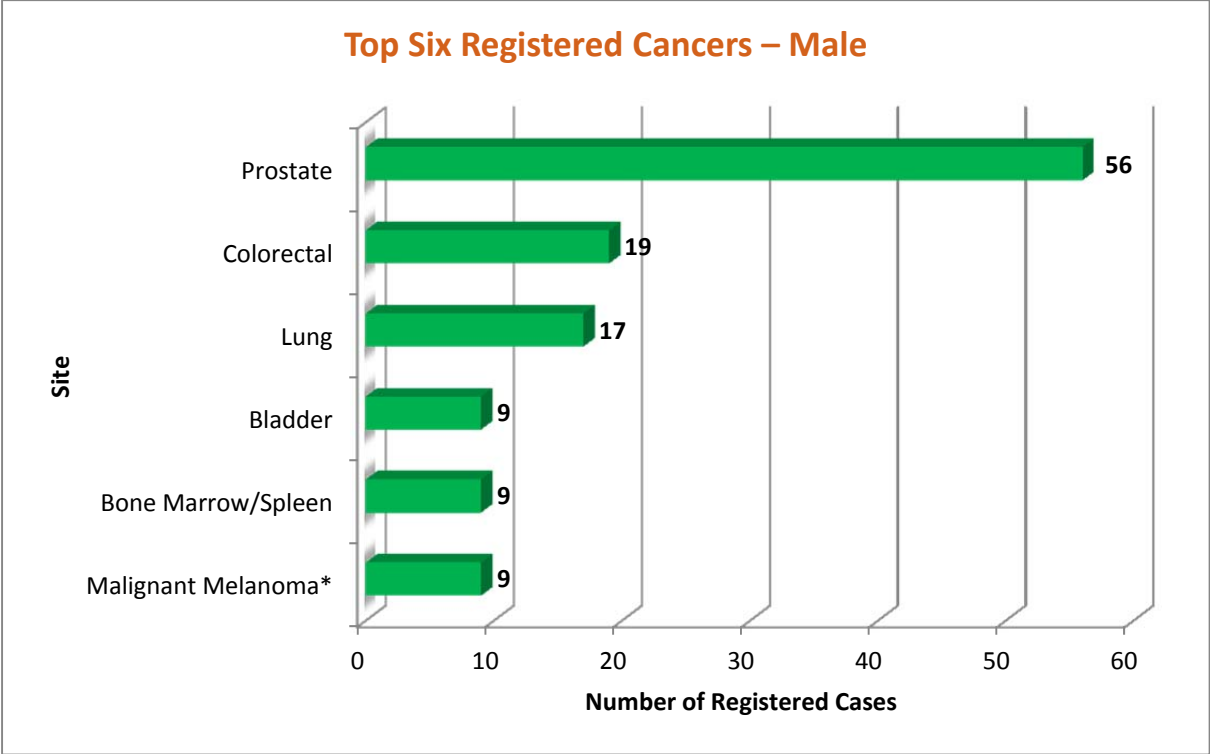
The Bermuda National Tumour Registry depends on physicians and pathology departments to report neoplasms as they arise. Because of lack of legislation, however, these particular bodies must self motivate to report diagnosed cancer cases to the registry. The graphs included in this report are representative of the number of *registered* cancer cases and may not be entirely representative of the *actual* number of cases.



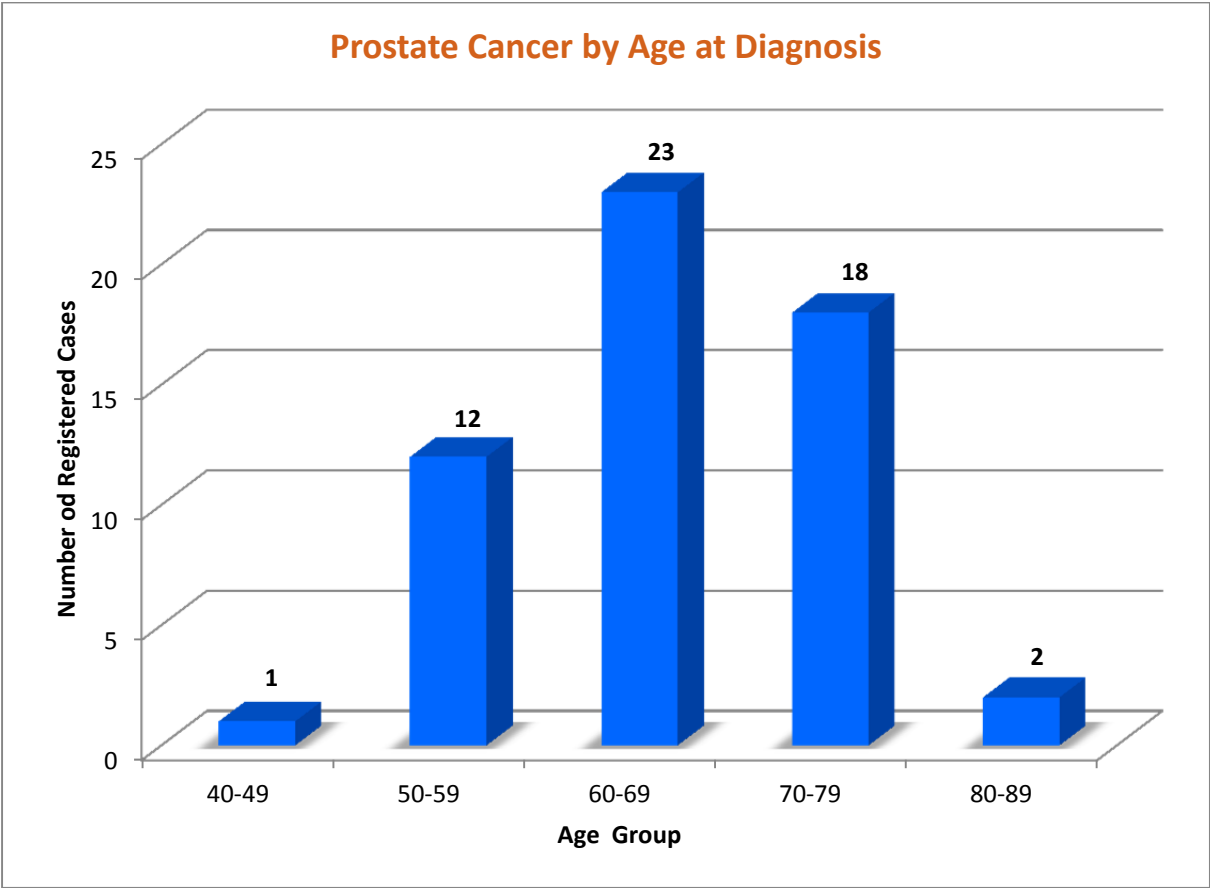


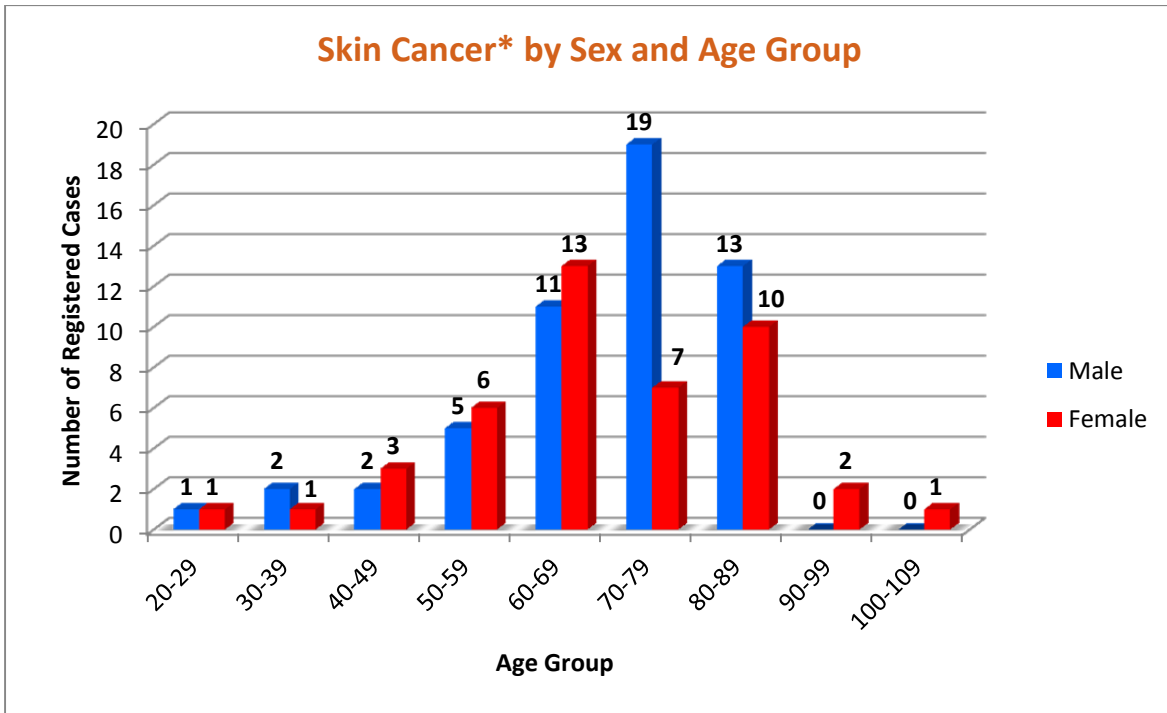
\*Invasive



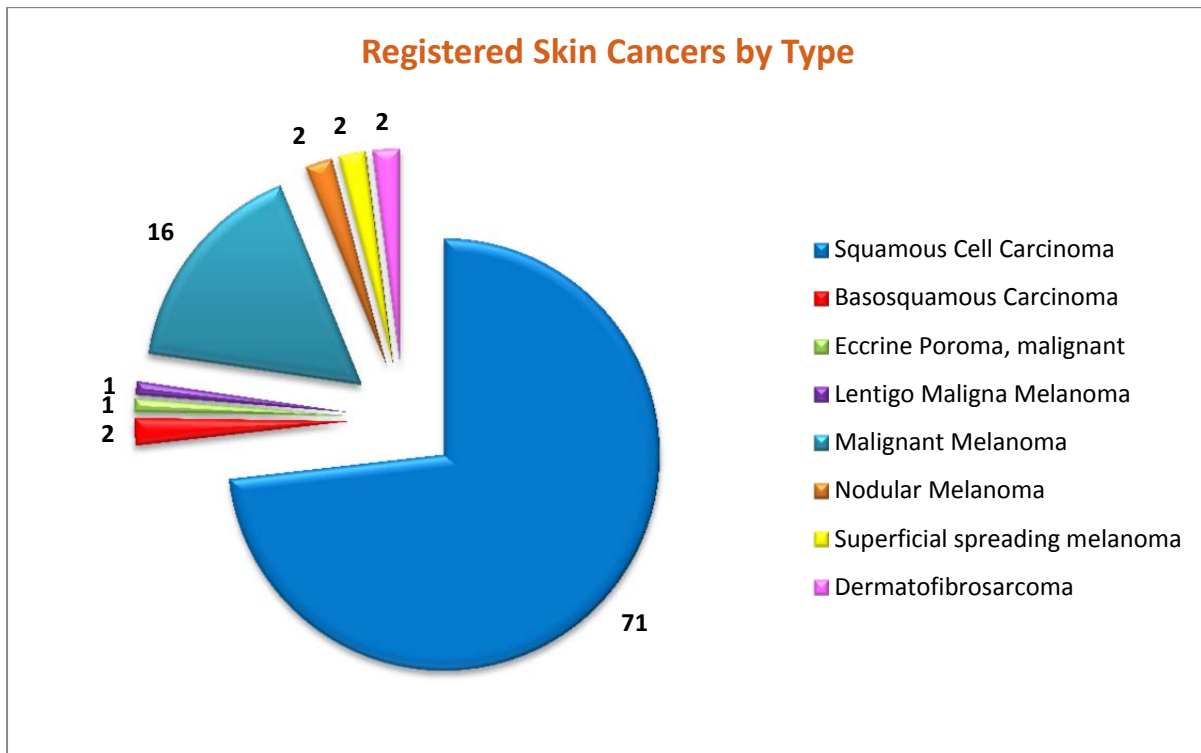


\*Invasive





\*In most registries, squamous cell carcinomas are not reportable. Our registry does register all forms of skin malignancies (with the sole exception of basal cell carcinomas) because of the increased sun exposure of our populace, and other environmental and demographic factors. The vast majority of registered skin cancers at the Bermuda National Tumour Registry are squamous cell carcinomas.



Descriptive Statistics for Each Value of Crosstable Variable: Sex vs Age						
	Observed	Mean Age			Variance	Standard Deviation
Male	200	66.595			147.1166	12.1292
Female	193	60.8601			286.0272	16.9123
	Minimum	25%	Median	75%	Maximum	Mode
Male	28	59	67	75	95	65
Female	19	50	63	72	100	63

The table above describes the relationship between age and sex in all observed cancer cases in 2015 within the registry database.

There were 200 observed male cases and 193 observed female cases. The mean age for newly diagnosed male cancers was approximately 66.60 years, while the mean age for female neoplasms was approximately 60.86 years. The standard deviation for men is +/- 12.1292 years and for women is +/- 16.9123 years. With respect to the range of ages, the youngest reported malignancy for males was 28 years and the oldest was 95. For females, the lower limit was 19 years while the upper limit was 100.

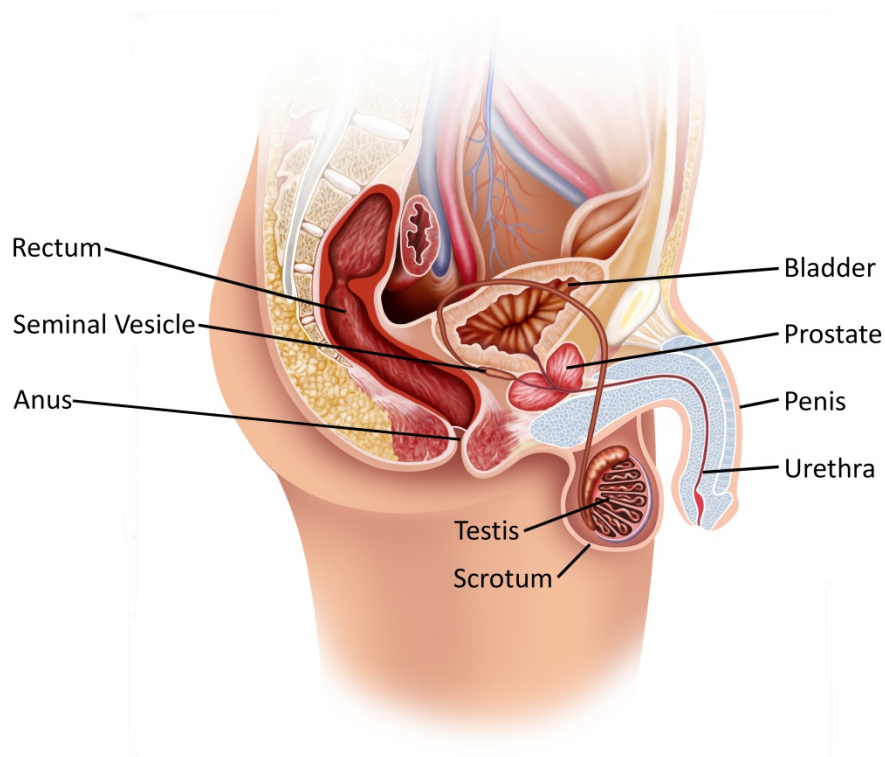
## 2015 Focus: A Closer Look at Prostate Cancer

The Bermuda National Tumour Registry aims to educate the public on various cancers. Each year, one cancer site is chosen in order to raise awareness and provide more in-depth information. This year's annual report focuses on prostate cancer.

Prostate cancer is the uncontrolled growth of cells within the prostate gland. The prostate gland is found only in males. It is located below the bladder, in front of the rectum. As a man ages, the prostate gland will change in size – it can start at about the size of a walnut but can become larger with age.

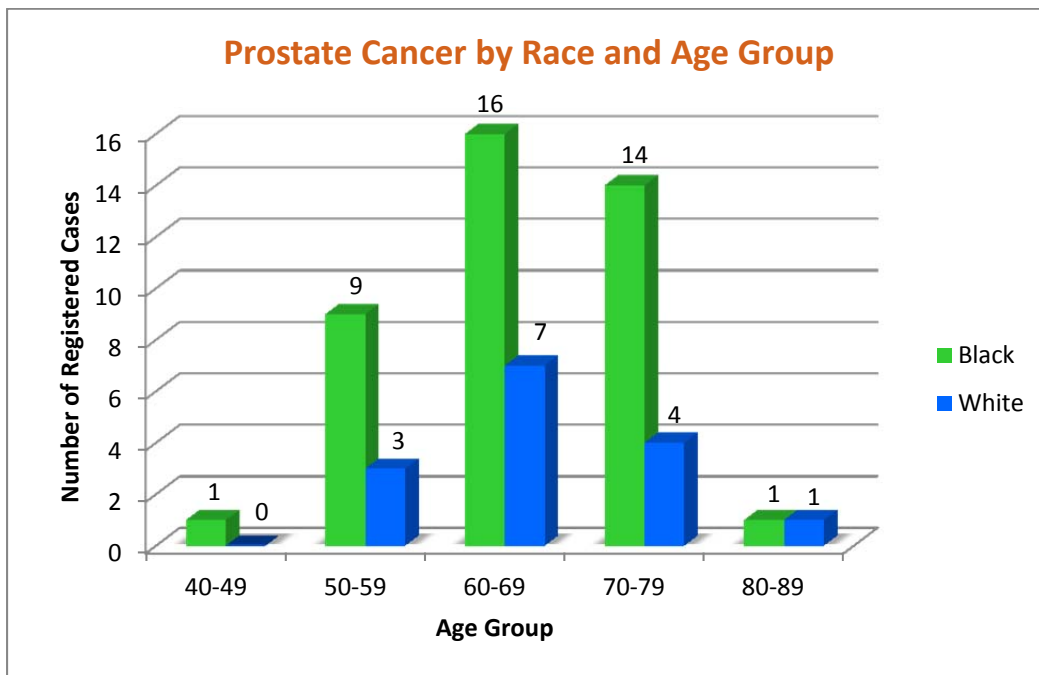
The vast majority of prostate cancers are adenocarcinomas, which develop in the gland cells. These cells produce the prostate fluid that is contained within the semen. In 2015, all of the prostate cancers reported to the registry were adenocarcinomas at various stages. There are several other types of prostate cancer, which are considered rare: sarcomas, small cell carcinomas, neuroendocrine tumors (other than small cell carcinomas) and transitional cell carcinomas.

### Male Reproductive System



According to the American Cancer Society, one in every seven men will be diagnosed with prostate cancer in his lifetime. In general, prostate cancer is considered to be a slow-growing cancer. However, in some cases it can grow and spread rapidly. Diagnosing prostate cancer in males younger than 40 is considered rare, but there is a rapid increase in cancer development as males reach the age of 50. Most prostate cancers are diagnosed in males aged 65 or older. In 2015, the average age at diagnosis was 66.2 years among Bermuda’s male populace.

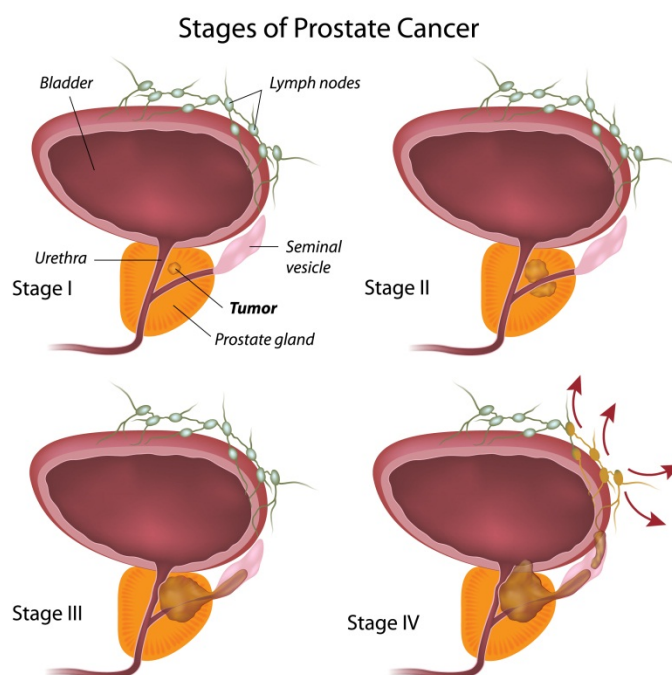
A risk factor is an attribution, condition or behaviour that affects the possibility of developing a disease, in this case, prostate cancer. Some risk factors can be controlled while others cannot. The greatest risk factor for prostate cancer is age. As previously stated, the chance of developing and being diagnosed with prostate cancer greatly increases after the age of 50. One’s race is also a risk factor, with black men being more likely to develop prostate cancer. There is currently no clear understanding of the reason for this racial difference. Family history and inherited genes contribute as well. Within a family, if a father or brother has been diagnosed with prostate cancer, it more than doubles a man’s risk of being diagnosed with prostate cancer as well. For this reason, inherited gene changes in men, such as mutations of the BRCA1, BRCA2 or MMR gene, have indicated a marked increase in the development of prostate cancer. Other risk factors that play a lesser role are: dietary habits, being overweight or obese, and smoking.



As previously mentioned, race influences the development of prostate cancer. Black men have a higher chance of developing prostate cancer and, when it is diagnosed, it tends to be more advanced or aggressive in nature. The Bermudian population has a higher ratio of black men, and for this reason it would appear that more black males in Bermuda have prostate cancer. However, due to the expansion of racial categories in the 2010 Bermuda Census (black, white, black & white, black & other, white & other, etcetera), we were unable to properly adjust along racial lines for prostate cancer.

Prostate cancer remained the most registered type of cancer cases in men for 2015, and the second most registered cancer in Bermuda.

Cancers are categorized by not only morphology or “type”, but also by stage of disease.



**Stage I:** The tumour may be felt through a digital rectal exam, but can be seen with an imaging test (transrectal ultrasound). It remains within the confines of the prostate gland and is considered small.

**Stage II:** By this stage, the tumour has grown in size and may involve both sides, but still remains within the confines of the prostate gland.

**Stage III:** The tumour has grown outside of the prostate gland and may involve the seminal vesicles, but has not spread to the lymph nodes that are nearby or to other parts of the body.

**Stage IV:** Cancer has grown in size and spread beyond the confines of the prostate. There is now involvement by the nearby lymph nodes and it has spread (metastasized) to organs throughout the body.



In the early stages, most prostate cancers present no symptoms. However, as the cancer progresses one might experience: problems urinating (slow or weak urinary stream or an increase need to urinate); blood in the urine or semen; erectile dysfunction; a loss of bladder or bowel control; a weakness or numbness in the legs or feet; and/or pain in the hips, back or chest. Most commonly, prostate cancer spreads (metastases) to bone, which leads to pain or fractures throughout the body. This proves to be the presentation of a more advanced stage prostate cancer when a male feels “hip discomfort” or “back pain”.

According to the American Cancer Society, the survival statistics by stage\* are:

Stage	5-year Relative Survival Rate
I	100%
II	100%
III	100%
IV	28%

\*Based on the American Joint Committee on Cancer (AJCC) staging standards.

The SEER database, based on survival statistics collected by the US National Cancer Institute (NCI), groups cancers into local, regional and distant stages.

**Local stage** corresponds to the American Joint Committee on Cancer stages I and II. There is no sign of cancer outside of the prostate.

**Regional stage** includes stage III cancers and stage IV cancers that do not involve distant parts of the body.

**Distant stage** includes the remaining stage IV cancers which have spread to the lymph nodes, bones or other organs throughout the body.

In the case of prostate cancer, screening can be used to detect the formation of cancer at an early stage, which will likely make it easier to treat. In many cases, prostate cancer can be found prior to the presentation of symptoms. Bermuda is guided by the recommendations set forth by the American Cancer Society, which suggest screening for prostate cancer beginning at the age of 40. These screening procedures include a digital rectal exam (DRE) and/or a prostate-specific antigen (PSA) test (blood test).

In an effort to provide screening and education opportunities to the male population aged 40 and above, Bermuda Cancer and Health Centre holds a free men's health screening event in November each year. For several years, in partnership with other healthcare organisations and professionals around the island, men are able to receive free of charge: foot exams, HIV testing, lung function tests, blood glucose screening, body composition analysis, blood pressure screening, and consultation with a physician about any of health concerns and risk factors. This annual event aims to increase awareness and improve the overall health and wellness of the male population in Bermuda.

## Looking Forward

The Bermuda National Tumour Registry attended the International Agency for Research on Cancer (IARC) Caribbean Hub meeting in Turks and Caicos in June 2016. The goal of the meeting was to pool manpower and resources to devise action plans ensuring every country in the region would be supported to develop its own population-based cancer registry. Population-based cancer registries monitor the frequency of new cancer cases in well-defined populations by collecting information from treatment facilities, laboratories and death certificates. They also follow patients from diagnosis to death, whether from cancer, old age or otherwise. These registries are an instrumental notch in the belt of comprehensive cancer care and have the potential to be a real game changer with respect to the state of public health both within individual countries and within regions.

Although regionally Bermuda is near the forefront in cancer registration, there is always room for improvement. The Bermuda National Tumour Registry implemented the CanReg 5 system, which will better allow us to collect and analyse our data along with increasing our ability to share data with other countries and the international agencies to which we report.

Oncologists, both full time and locum, act as clinical advisors for the tumour registry. Representatives from the registry attend all tumour board meetings and conduct rigorous chart reviews to ensure completion. We also work closely with Bermuda's Epidemiology and Surveillance Unit and hope to be able to provide reliable survival statistics in our annual reports in the near future.

The pathology departments at both King Edward VII Memorial Hospital (KEMH) and outside facilities are instrumental in providing neoplasms for registration. They are often the first point of diagnosis, so rigorous reporting practices are imperative. The KEMH Pathology Department in particular has diligently reported to the tumour registry, ensuring we have the most up-to-date diagnoses and amendments to those diagnoses.

Data from the Bermuda registry can be used to monitor cancer trends over time, and to guide planning and evaluation of cancer control interventions. Ideally, this data can assist in setting priorities for allocating health resources, no matter how scarce they may be, and serve as a basis for clinical, epidemiological and health services research. Outcome data is imperative for setting

policies and guidelines with respect to best practices for treatment. Being able to compare our data with data from the region will aid immensely in our quest for better cancer screening, treatment, and even post-disease rehabilitation. Ensuring completeness and quality control in our cancer registration process will only assist in that quest. We need to do better with data collection and analysis of that data.

This year, with increased support from the Bermuda Hospitals Board, the tumour registry has added a staff member and implemented the CanReg 5 software system we needed to move our registry forward. These two issues have existed for some time and it was a team effort to resolve them. In addition, however, two main issues make comprehensive data collection particularly challenging in Bermuda:

## Legislation

In order to effectively collect data, mandatory reporting is imperative. Currently, Bermuda mandates the reporting of all communicable diseases under the Public Health Act of 1949. Cancer has a growing burden of disease in Bermuda, and it is of the utmost importance that we collect thorough and meaningful data. Most jurisdictions that require the reporting of cancer cases to a population-based registry (such as the Bermuda National Tumour Registry) have legislation in the form of a comprehensive Cancer Act. The United States has a separate National Cancer Act (1971), and the UK has provided for confidential cancer registration under Section 60 of the Health and Social Care Act (2002). Regionally, several countries, including Bahamas, Jamaica and Trinidad & Tobago, mandate reporting of cancer cases.

## Electronic Medical Records

Because a physical chart can only be located in one place at any one time, it is very difficult to stay up to date with incoming new registrations. Electronic medical records (EMRs) would assist greatly with tumour registration as information would be consolidated in one place (digitally), which makes remote registration much easier. Additionally, as many patients are seen by many different physicians with different areas of expertise and, sometimes, at many different facilities, the EMR makes tracking patient movement through different healthcare systems much more efficient.

## Acknowledgements

Ministry of Health and Seniors  
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Dr Deborah J Daly and staff  
Staff of the Bermuda National Tumour Registry



GOVERNMENT OF BERMUDA  
Ministry of Health and Seniors





# **Bermuda Hospitals Board**

## **Bermuda National Tumour Registry**

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