

2015

Bermuda National Tumour Registry Annual Report

with statistical data from 2014



Bermuda Hospitals Board

Bermuda National Tumour Registry
Bermuda Hospitals Board
Office of the Chief of Staff, KEMH



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Bermuda Hospitals Board



Michael R Weitekamp, MD, MHA, Chief of Staff

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 35 years of data. Each year it strives to improve the quality of cancer data collection and analysis, which is essential to truly understanding the cancer burden affecting Bermuda.

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 2015 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 2014, 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 Breast Cancer'. It is hoped that public education of this very preventable disease will reduce future incidence rates.

Therefore, as Chief of Staff, on behalf of the Bermuda Hospitals Board, I am pleased to endorse the Bermuda National Tumour Registry 2015 Annual Report.

Michael Weitekamp, MD, MHA

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 30.2% of all deaths in 2009. 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

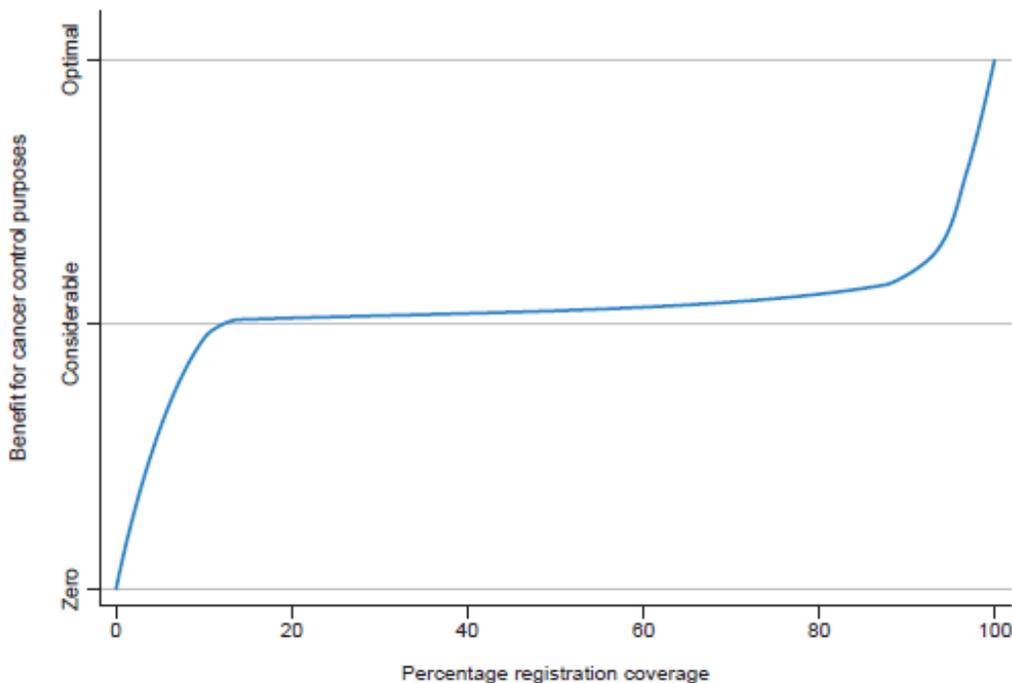
How does the Bermuda National Tumour Registry work?

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 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 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
- aid in making informed treatment choices based on precedent
- 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

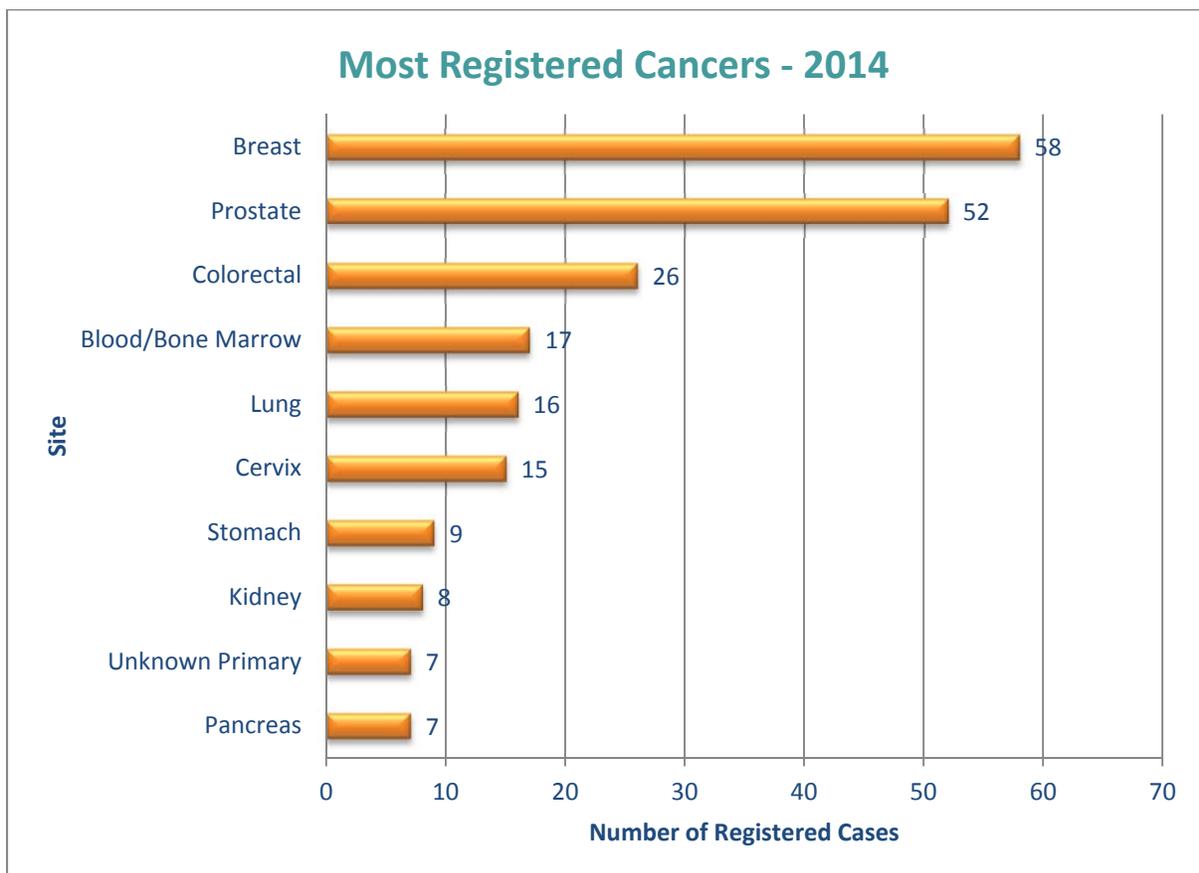
Caribbean Public Health Agency (CARPHA)

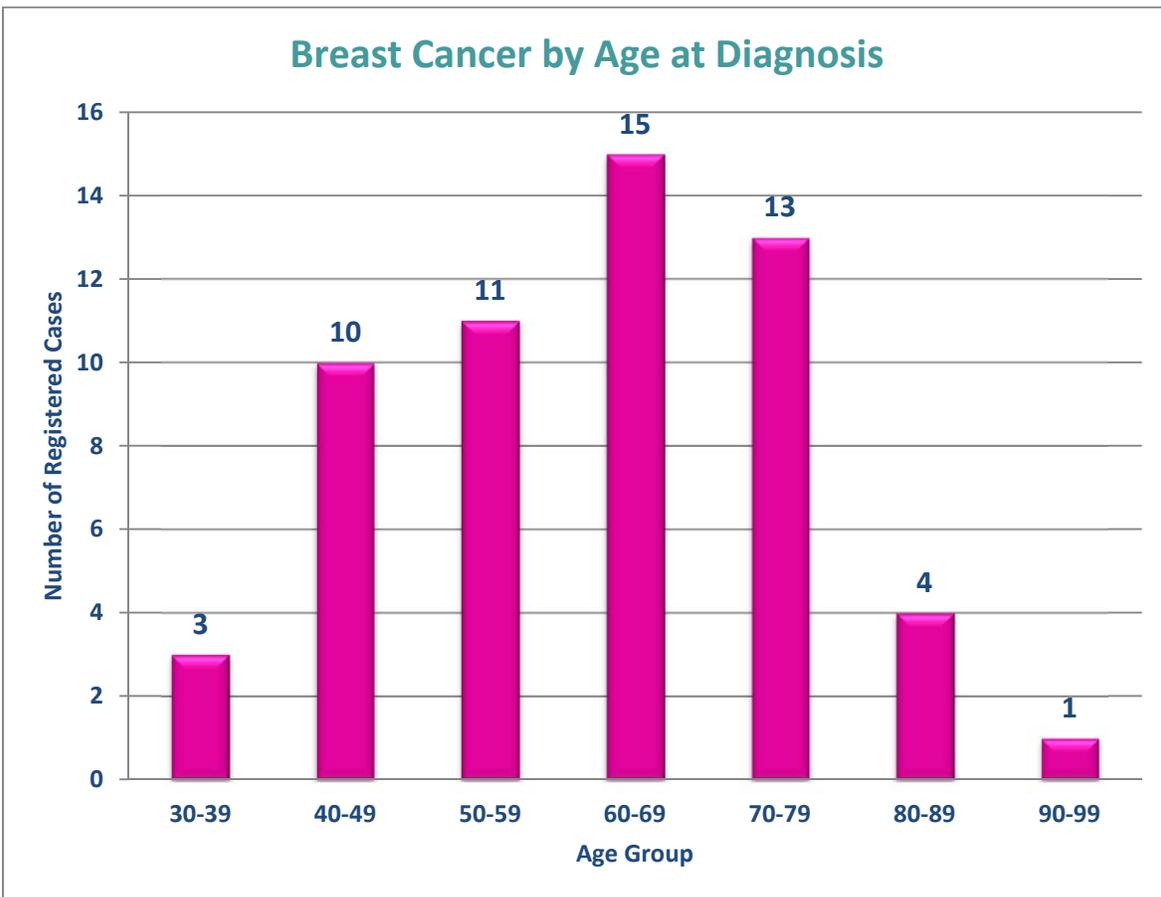
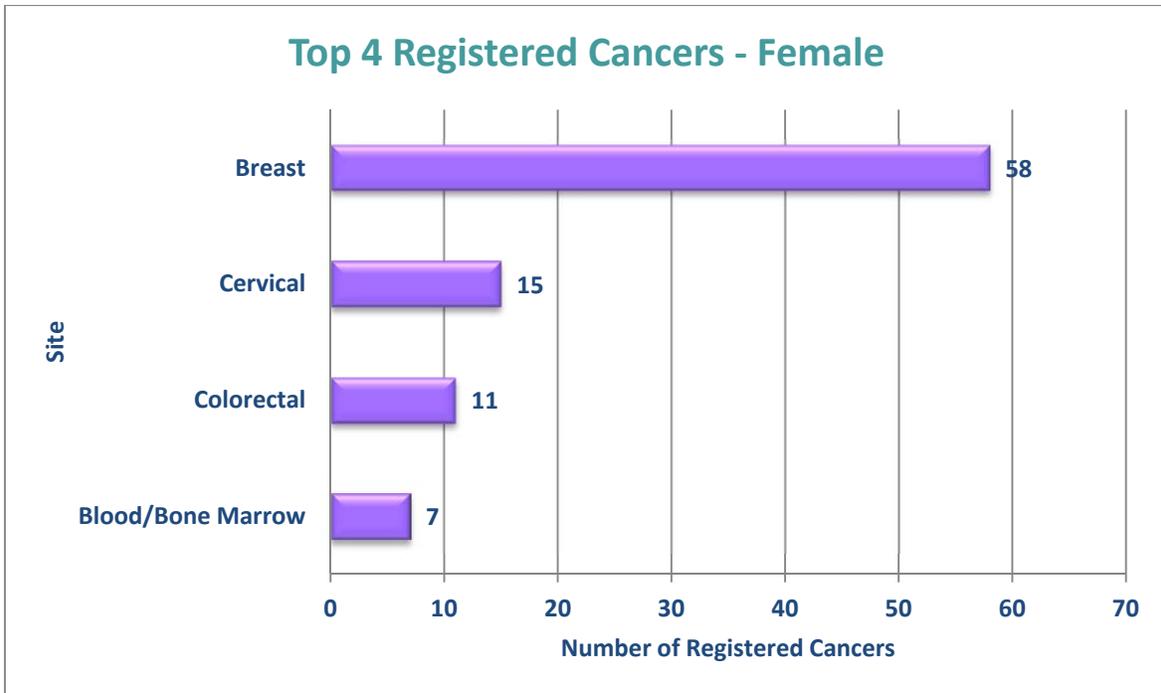
International Association of Cancer Registries (IACR)

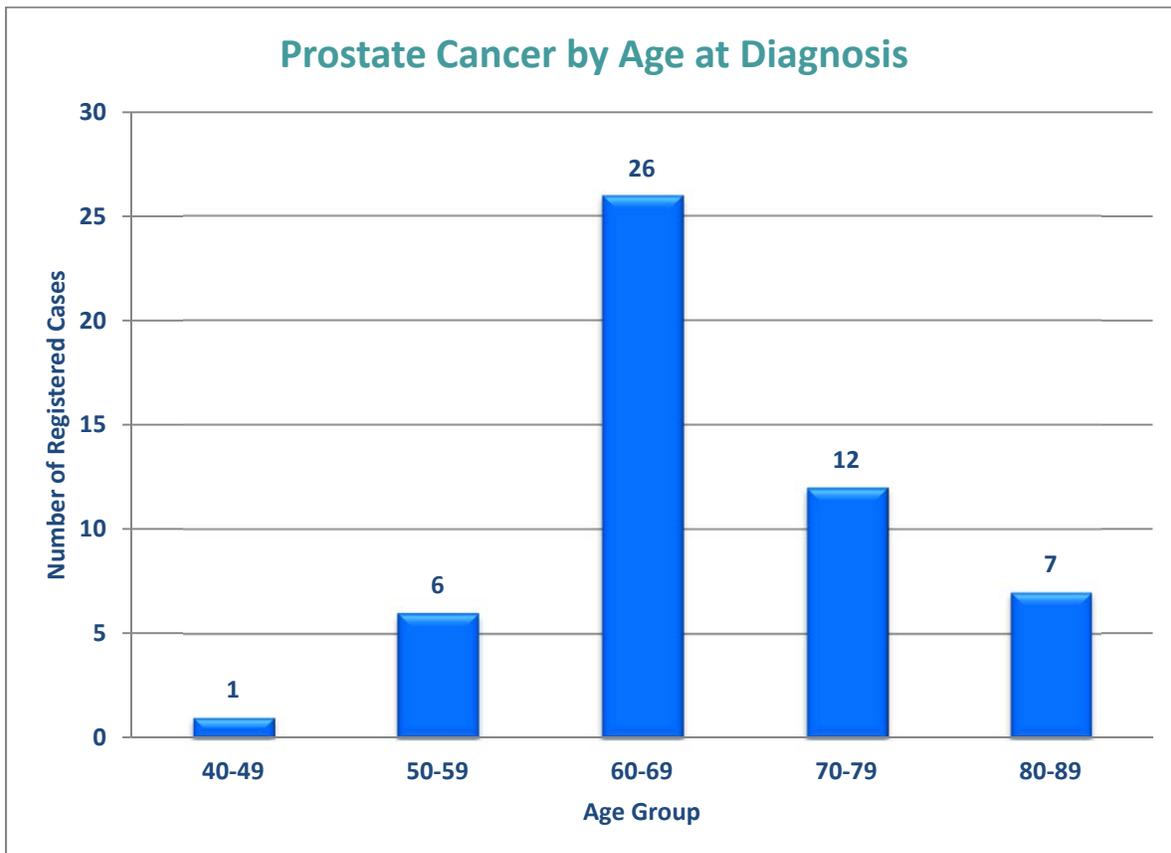
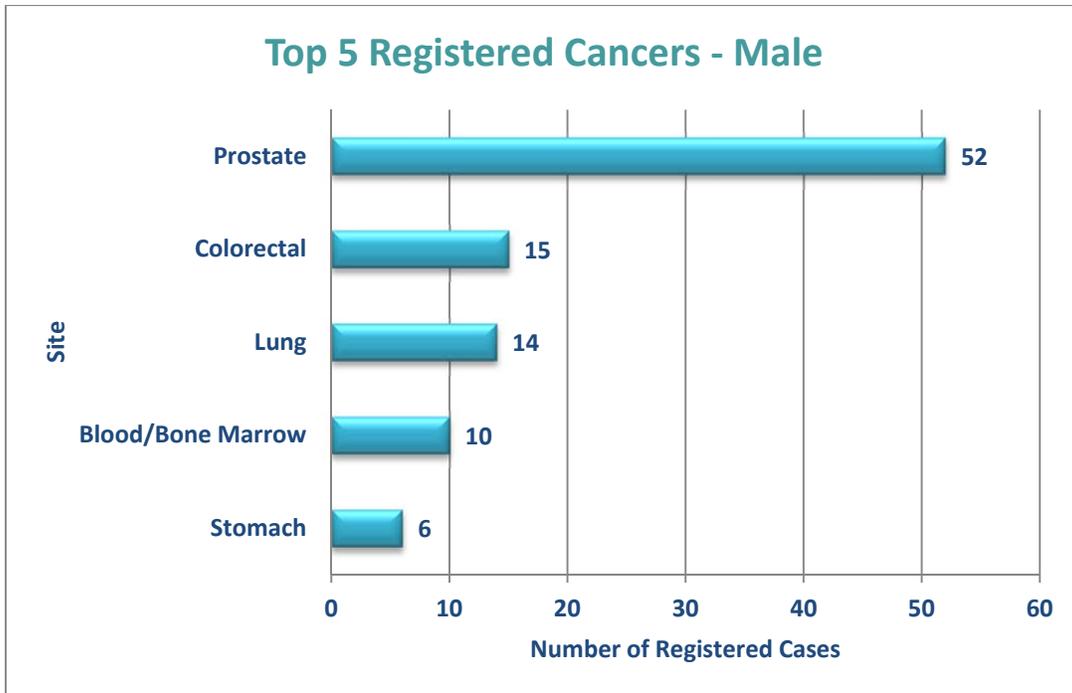
Pan-American Health Organization (PAHO)

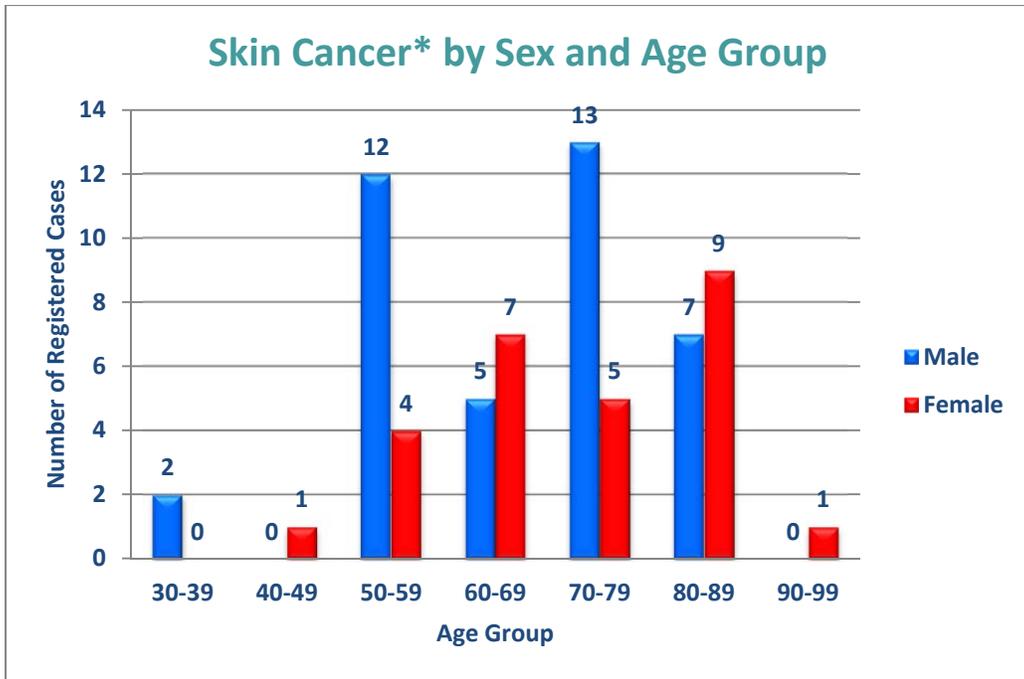
Graphical Summary of Data

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.

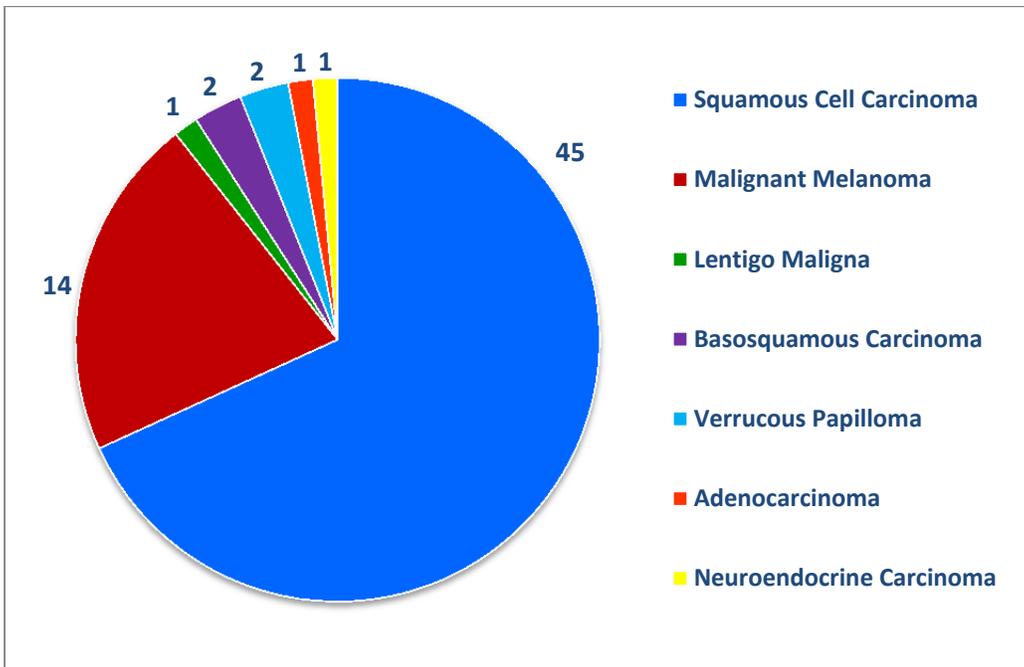








*In most registries, squamous cell carcinomas are not reportable. Our registry does register all forms of skin malignancies (with the sole exception of basal cell carcinomas) because of the increased sun exposure of our populace, and other environmental and demographic factors. The vast majority of registered 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	169.0000	67.2426		133.6729	11.5617	
Female	153.0000	61.3137		287.2299	16.9479	
	Minimum	25%	Median	75%	Maximum	Mode
Male	31.0000	60.0000	68.0000	76.0000	87.0000	67.0000
Female	21.0000	51.0000	62.0000	73.0000	94.0000	69.0000

The table above describes the relationship between age and sex in all observed cancer cases in 2014 within the registry database.

There were 169 observed male cases and 153 observed female cases. The mean age for newly diagnosed male cancers was approximately 67.24 years, while the mean age for female neoplasms was approximately 61.31 years. The standard deviation for men is +/- 11.5617 years and for women is +/- 16.9479 years. With respect to the range of ages, the youngest reported malignancy for males was 31 years and the oldest was 87. For females, the lower limit was 21 years while the upper limit was 94.

2015 Focus: A Closer Look at Breast Cancer

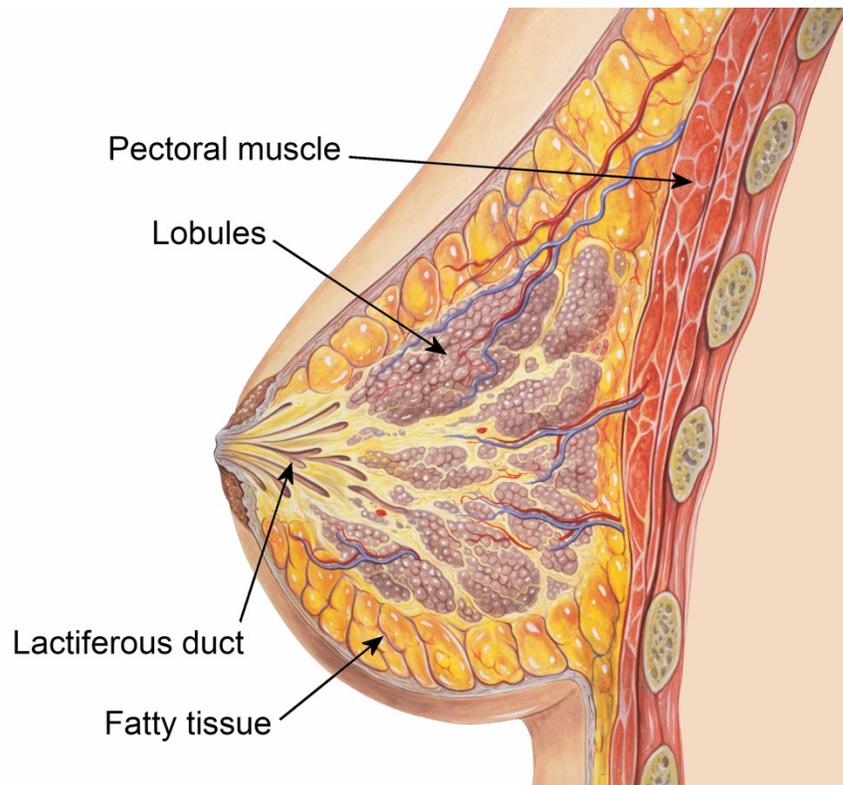
Each year, the Bermuda National Tumour Registry chooses one cancer type for which to raise awareness and provide special education. For this year's annual report, the focus is on breast cancer.

Breast cancer is a malignant tumour that starts in the cells of the breast. Malignant tumours are groups of cancer cells that can invade surrounding tissues or spread to distant areas of the body. For the most part, this disease affects women but breast cancer can, and does, afflict men as well.

The lion's share of breast cancers begin in the cells that line the ducts of the breast and are referred to as 'ductal carcinomas'. Of the breast cancers registered in 2014, 86.20% were ductal carcinomas of different stages.

A lesser number of breast cancers begin in the cells that line the lobules of the breast. These are classified as lobular cancers. Only 5.17% of registered breast cancers last year were lobular in nature. Very few cancers arise outside the ducts or the lobules.

Side View of Breast



Patrick J Lynch, medical illustrator; C Carl Jaffe, MD, cardiologist

In 2014, breast cancer remained the most registered type of cancer case in Bermuda's populace. Not only is it number one in women, but it is number one overall. This has traditionally been the case throughout recent years amongst cases registered by the Bermuda National Tumour Registry.

Breast cancers are not simply classified morphologically or 'by type'. They are also assigned a stage on diagnosis. The stage of cancer indicates whether or not the cancer is located in one area of the breast or if it has spread beyond the primary site of diagnosis. There are five stages of breast cancer. A tumour is staged based on whether or not it is invasive, the size of the tumour, whether or not lymph nodes are involved, and whether or not the cancer has spread or 'metastasized' to areas of the body outside the breast.

The stages of breast cancer are:

Stage 0 or In Situ: No evidence of cancer cells anywhere outside the area of the breast in which they started. This stage of cancer does not invade any other normal tissue.

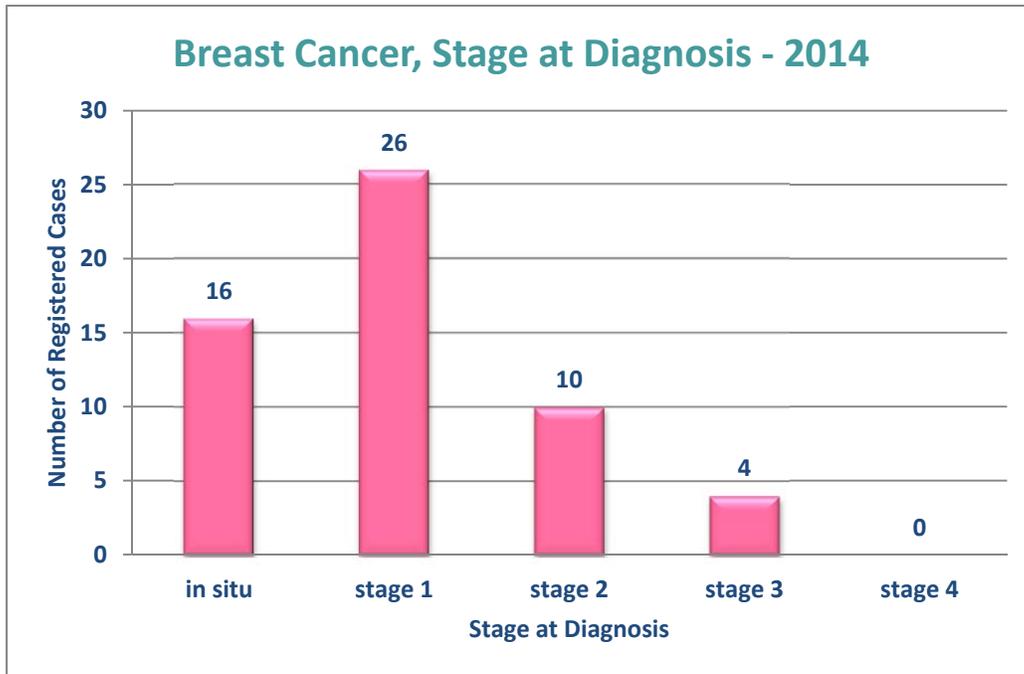
Stage 1: Invasive cancer cells, which are breaking through to or invading normal surrounding breast tissue. The tumour is no larger than two centimetres (3/4in) and no lymph nodes are involved.

Stage 2: The tumour measures between two and five centimetres. In some cases, the cancer has spread to the lymph nodes under the arm on the same side as the breast cancer.

Stage 3: The tumour in the breast is more than two inches and the cancer is extensive in the underarm lymph nodes, or has spread to other lymph nodes or tissues near the breast.

Stage 4: Cancer has spread beyond the breast, underarm and internal mammary lymph nodes to other parts of the body near to or distant from the breast.

Interestingly, the majority of registered breast cancer cases in 2014 (72.4%) were diagnosed as in situ or stage 1.

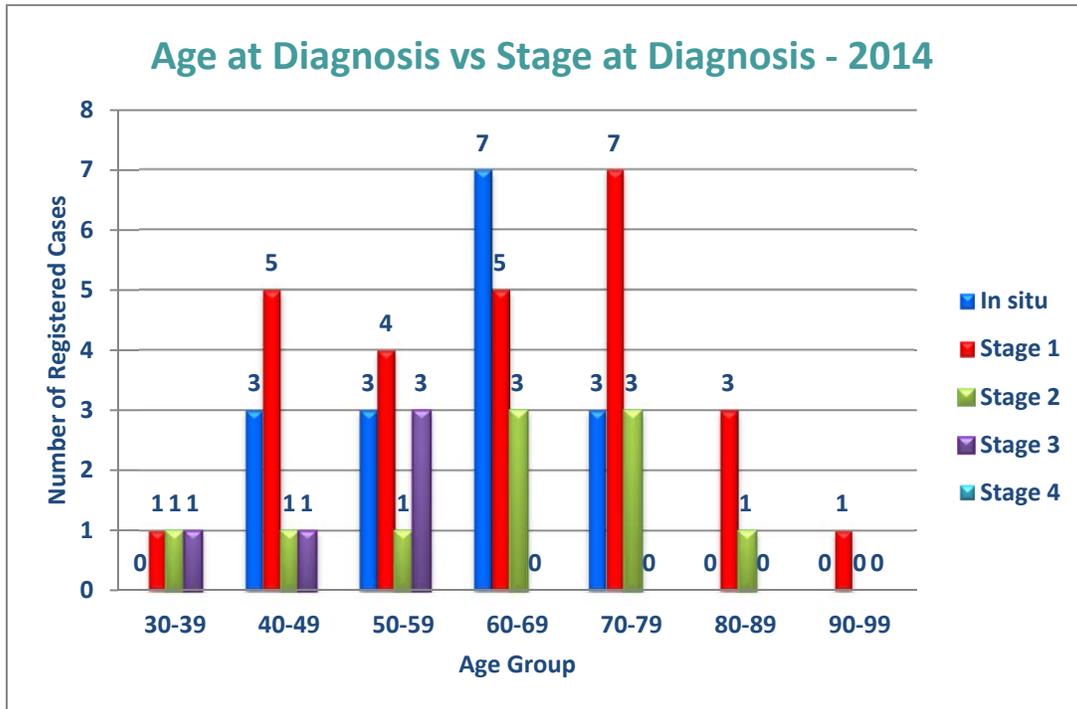


According to the American Cancer Society, the survival statistics by stage are:

Stage	5-year Relative Survival Rate
0	100%
1	100%
2	93%
3	72%
4	22%

Bermuda's average age at diagnosis amongst registered cases for the 2014 period is 61.7 years.

The Ministry of Health, Seniors and Environment recommends that all women over the age of 40 are screened annually using mammography.



Looking Forward

The Bermuda National Tumour Registry presented at the Caribbean Public Health Agency's (CARPHA) 2014 Annual Conference in Aruba. Participating in the conference brought about great discussion on how to bring awareness and change attitudes toward favourable support of cancer registries. 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 death is from cancer, old age or otherwise.

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, epidemiologic and health services research. Outcome data is imperative for setting policy 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.

Regionally, Bermuda is definitely near the forefront in cancer registration, which is encouraging. However, there is always room for improvement. Ensuring completion 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 will aid in the country's ability to conduct epidemiological research which, clearly, has the potential to impact the health of the population and how we spend health dollars.

Most of 2015 has been spent acclimating to the newest version of registry software, CanReg 5. This is a relational database structure, unlike the flat database structure that was used up until now in the previous versions of the software. This will better allow registrars to link (via data) patients who have multiple cancers to tumours and treatment facilities.

For the next annual report we hope, with the help of this software, to be able to do an even more rigorous workup of the newly registered cases.

The Bermuda National Tumour Registry was honoured to be invited to submit a dataset for volume XI of Cancer Incidence in Five Continents (CI5). This longstanding collaboration between IARC (International Association of Cancer Registries) and IACR (International Association for Research on Cancer) serves as a unique source of cancer incidence data from high-quality population-based cancer registries around the world. It continues to be an invaluable resource for cancer research and cancer control worldwide, and is the primary source of GLOBOCAN and national estimates in 184 countries by cancer, sex and age, presently for the year 2012.

The registry experiences similar challenges to those suffered by other registries. Amount of qualified manpower, minimal funding and difficulty finding robust, cost-effective software are challenges that many jurisdictions face. 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 with tumour registration greatly 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

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Bermuda Cancer and Health Centre

PALS

Dr Deborah J Daly and staff

Staff of the Bermuda National Tumour Registry



GOVERNMENT OF BERMUDA

Ministry of Health, Seniors and Environment





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