

National Cancer Patient Registry

A Patient Registry/ Clinical Database to Evaluate the Health Outcomes of Patients Undergoing Treatment for Cancers in Malaysia

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SUMMARY

Cancer burden in Malaysia is increasing. Although there have been improvements in cancer treatment, these new therapies may potentially cause an exponential increase in the cost of cancer treatment. Therefore, justification for the use of these treatments is mandated. Availability of local data will enable us to evaluate and compare the outcome of our patients. This will help to support our clinical decision making and local policy, improve access to treatment and improve the provision and delivery of oncology services in Malaysia. The National Cancer Patient Registry was proposed as a database for cancer patients who seek treatment in Malaysia. It will be a valuable tool to provide timely and robust data on the actual setting in oncology practice, safety and cost effectiveness of treatment and most importantly the outcome of these patients.

KEY WORDS:

Patient registry, Cancer

INTRODUCTION

Cancer burden in Malaysia is increasing. The latest National Cancer Registry Report in 2003 estimated a 1:4 risk of developing cancer for the Malaysian population¹. However as data in our local setting is scarce, the actual incidence and outcome of treatment for these patients is still largely unknown.

Given the increasing cancer burden in Malaysia, one would expect anti-neoplastic medicines to be widely used for cancer treatment in Malaysia. However, the most recent data from the Malaysian Statistics on Medicines 2005 report² shows that the utilization of anti-neoplastic drugs in the Malaysian population do not even rank among the top 30 by utilization level or by cost. In contrast, in Australia, a country with comparable population and cancer burden (although it is a wealthier nation), anti-neoplastic drugs ranked seventh by cost in its top ten therapeutic groups³. Anti-neoplastic drugs alone cost the Australian taxpayer RM600 million in 2004-5, while in Malaysia the total expenditure on all prescription drugs was only about RM2 billion in 2005.

This relative under treatment of cancer is of course not unique to Malaysia. A recent report⁴ shows that even among developed countries, the use of modern cancer drugs can vary by a factor of 10, demonstrating huge inequalities in access to cancer medicine around the world, which ultimately results in significant differences in patient survival. The biggest differences were seen in four innovator cancer drugs - bevacizumab (Avastin); cetuximab (Erbix); erlotinib (Tarceva); and pemetrexed (Alimta). For example, the use of Avastin for colorectal cancer in the United States was 10-times the European average, as was the use of Tarceva for lung cancer.

In the recent years there have been significant improvements in cancer treatment, including new chemotherapy regimes, targeted therapies and advanced radiotherapy techniques. However, these new treatments may potentially cause an exponential increase in the cost of cancer treatment. Therefore, justification for the usage of these treatments is mandated. Availability of local data will enable us to evaluate and compare the outcome of our patients. This will help to support our clinical decision making and local policy, improve access to treatment and improve the provision and delivery of oncology services in Malaysia.

The National Cancer Patient Registry was proposed as a database for cancer patients who seek treatment in Malaysia. It will be a valuable tool to provide timely and robust data on the actual setting in oncology practice, safety and cost effectiveness of treatment and most importantly the outcome of these patients.

OBJECTIVE

1. Describe the natural history of cancers in Malaysia.
2. Determine effectiveness of treatment for cancer.
3. Monitor safety of products and services used in the treatment of cancers.
4. Evaluate access to and quality of treatment services for cancer.

MATERIALS AND METHODS

Study Design

A multicentre observational cohort study

Patient Selection

All patients with a confirmed diagnosis of cancer at participating sites will be enrolled into the registry.

Duration of Study

The study is expected to start in early 2008. Patients will be followed up according to the standard of care of each participating site. The duration of follow up is anticipated to be about 10 years.

Location of Study

Participating sites include centers in the government and private centers. The government centers are Hospital Kuala Lumpur, Hospital Umum Sarawak and Hospital Sultan Ismail. Private centers consist of Nilai Cancer Institute, Hospital Mutiara Penang, Sabah Medical Centre, Damansara Specialist Hospital and Pantai Medical Centre. Participation from more centres is expected in the future.

Data Collection

All new cancer patients will be registered on attendance at participating sites. Existing patients on follow-up may also be included in the registry. Two datasets are defined, core dataset which is essential for data analysis and non core dataset which is additional data for further analysis.

Data collection will be done electronically. Stringent information security policies will be implemented to maintain confidentiality.

Data Analysis

Data analysis will be done by a third party biostatistical consulting vendor company. This will be done at least annually.

CONCLUSION

The National Cancer Patient Registry is the first database to record detailed information on cancer patients in Malaysia. Currently it is at the final planning stage and is expected to start data collection soon. Its first report is anticipated a year after data collection is started.

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