



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.
New therapies may potentially cause an exponential increase in the cost of cancer treatment.
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.

INTRODUCTION

National Cancer Registry Report in 2003 estimated a 1:4 risk of developing cancer for the Malaysian population [1].

Outcome of treatment for these patients is still largely unknown.

Malaysian Statistics on Medicines 2005 report [2] 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.

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[3].

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.

OBJECTIVES

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

CONCLUSION

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

REFERENCES

1. Gerard Lim CC, Yahya H. First Report of the National Cancer Registry, Cancer Incidence in Malaysia. National Cancer Registry, Ministry of Health, Kuala Lumpur, 2003.
2. Sameerah S.A.R, Sarojini S. (Eds). Malaysian Statistics on Medicine 2005. Kuala Lumpur 2007. Available at <http://www.crc.gov.my/nmus>
3. Bengt Jonsson, Nils Wilking. The burden and cost of Cancer. Annals of Oncology 2007; 18 (Supplement 3): iii8-iii22, 2007.

METHODOLOGY

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 2009. 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.

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.