

# National Cancer Patient Registry-Breast Cancer (NCPR-Breast Cancer)

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## SUMMARY

**Breast cancer is the most common cancer in most part of the world and it is the most common cancer among Malaysian women. In order to estimate the overall survival and prognosis, it was decided that a National Cancer Patient Registry-Breast cancer be set up. It would be a tracking system form for breast cancer patients in Malaysia to help treatment outcomes. There would be useful for evaluating clinical management.**

## KEY WORDS:

*Patient registry, Breast cancer*

## INTRODUCTION

Breast cancer is the most common cancer in women in most part of the world and it is the most common cancer among Malaysian women. It is also the most common cause of cancer death<sup>1,2</sup>. In the year 2000, it was reported that there were 1,050,346 cases of breast cancer worldwide with 372,969 deaths. The average crude incidence rate was 94.93 per 100,000 in more developed country as compared to 19.66 per 100,000 in less developed country<sup>3</sup>. In Malaysia, there is difficulty in determining the exact incidence of breast cancer because of lack of a breast cancer registry<sup>1</sup>. In 2000, International Agency for Research in Cancers (IARC) estimated that there were 3835 new cases of breast cancer reported, with 1707 deaths. The crude incidence rate was estimated to be 34.86 per 100,000 in the world.

Management of breast cancer is usually based on multidisciplinary approach. As a good guide there is a Clinical Practice Guideline on Management of Breast Cancer prepared by a collaborative effort from Ministry of Health and Academy of Medicine issued in 2002. This evidence-based guideline provides a comprehensive outline on managing patient from confirming the diagnosis to specific treatment<sup>4</sup>. With the advent of new research findings, more modalities of therapy are made available such as targeted therapy e.g. Herceptin<sup>5</sup>. Another evidence-based guideline has been developed to address these newer regimes for breast as well as other type of cancers<sup>6</sup>. However, with the addition of these new drugs the cost of treatment will escalate tremendously. The outcome of breast cancer patients in general is based on the stage of the disease at the time of diagnosis. Overall prognosis is poor in patients with stage 3 and 4 disease.

For Malaysian women, due to lack of data collection and registry we do not know the overall survival and prognosis. We always quote western figures as our reference values that may not be exactly reflect our own population. With the launching of National Cancer Patient Registry by Ministry of Health, a more accurate figure could be obtained. It will be a valuable tool to provide timely and robust data on the real worldview of oncology practice, safety and cost effectiveness of treatment and most importantly the outcome of these patients.

## AIM OF THE STUDY

The aim of this registry is to provide a more accurate and refined prevalence estimates of breast cancer in Malaysia, help formulate screening and surveillance strategies that are relevant and facilitate clinically important research on breast cancer. All these aims can be achieve by the following objectives:

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

The objectives listed are implemented in phases. Building on the foundation laid by the early phase, the scope and coverage of the registry can then be expanded in later phases. The objectives above are listed in order of the scope and coverage of the registry to be implemented over time in phases.

## MATERIALS AND METHODS

### *Study design and patient selection*

NCPR-Breast cancer is a multi-centre, prospective study, which will register all patients with breast cancer who fit the inclusion criteria. Enrolment would be done from 2008 – 2010. Subject enrolment is universal whereby all new patients who are seen at the participating centres with confirmed diagnosis of breast cancer during the study period will be included. Existing patients on follow up may also be included in the registry.

### *Data collection*

With increasing operational experience and stability over time, NCPR-Breast cancer will be going to use a front-end

**Table I: Milestone of the Registry**

January 2008	NCPR-Breast cancer steering committee meeting to discuss about development of the Case Report Form (CRF)
April 2008	Site visit to Hospital Kuala Lumpur to understand the work-flow and process in the breast cancer clinic
June - July 2008	CRF is finalized and ready for web application development
June 2008	NCPR-Breast cancer meeting to discuss on access level & authorization list for e-NCPR Breast cancer web application
August 2008	Plan to official launch of e-NCPR Breast cancer web application

application and installed at source data provider (SDP) sites. The front-end application will be ready in mid of August 2008. Hence, data collection is expected to start in June 2008. The application will facilitate the patient registration and documentation process in the sites. It will add value to daily operations by improving efficient and effective management of information in the sites. The data captured is then electronically transferred to CRC for back end processing. Stringent information security policies had been implemented to maintain confidentiality. A report for the registry will be produced by end of this year 2008. Milestone of the registry is shown in Table I.

The principal investigator, co-investigators and the project manager will need to collaborate with individual source data provider (SDP) to identify key site coordinators (SC) responsible for the administration and management of registry data. The SC is responsible in providing timely and accurate data, and reports should be made to the centre registry office on a regular basis, detailing progress and any problem that needs to be addressed. Registry manager will be required to disseminate this information to all parties.

#### *Location of the study*

Participating sites include centres in the government and private centres. At the moment, the government centres are

Hospital Kuala Lumpur, Hospital Putrajaya, Hospital Sultan Ismail, Hospital Raja Perempuan Zainab II, Hospital Pulau Pinang. In future more centres are expected to participate.

#### **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 starting data collection. Generated data will be used for writing up scientific papers and publications.

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