



Overview of Hong Kong Breast Cancer Registry Activities

The success of HKBCR relies on participation of breast cancer patients and support of healthcare professionals. Since the inception in 2008, we first started collecting data at private clinics and at the same time explored the workflow collecting data at public hospitals.

Collaborating centers/doctors

The success of HKBCR also relies on the support of healthcare professionals to facilitate the participation of as many breast cancer patients as possible. They help in making the Registry known to their patients and urging them to participate by giving consent for the Registry to capture their medical data. There are more than 100 specialists and experts in breast cancer field indicating support to the Registry. Starting from 2009, HKBCR also collects patient data in several public and private hospitals, namely Princess Margaret Hospital, Prince of Wales Hospital, United Christian Hospital and Hong Kong Sanatorium & Hospital.

Participation of breast cancer patients

Currently, there are over 2000 breast cancer patients participating in the Registry (Figure 4). Majority of the participants are enrolled through private clinics.

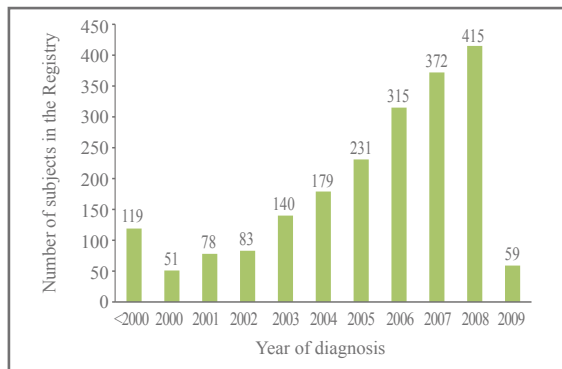


Figure 4. Total number of subjects participated in the Hong Kong Breast Cancer Registry by year of diagnosis

Data introduction

Over 200 data items are collected for each breast cancer case including but not limited to risk factors, diagnostic method, pathological and clinical data, types of treatment, physical and psychological effects. A very important component of the Registry is annual lifetime follow-up on patient status. It allows us to not only analyse clinical outcomes but also capture recurrence and survival information.

Part 1:

Personal information:

- Detailed contact information, demographics (age, race/ethnicity, household income etc)

Lifestyle factors:

- Smoking, alcohol use, exercise level, stress level

Past health:

- Weight, height, past breast health, history of tumor

Family history of breast cancer

- First / second degree relative etc

Reproductive history:

- Age at menarche, first delivery, menopause, use of hormonal replacement therapy etc

Part 2:

Clinical characteristics

- Tumor location (right, left, bilateral)
- Node involvement

Diagnostic characteristics

- Diagnostic methods
- Staging methods

Histological & molecular characteristics

- Histological type
- Molecular characteristics (ER, PR, c-erbB2, etc)

Treatment related information

- Surgery
- Radiation therapy
- Chemotherapy
- Endocrine therapy
- Targeted therapy

香港乳癌資料庫活動概要

香港乳癌資料庫的順利運作，有賴乳癌病人及各醫療人員的支持。由2008年起，我們於私家診所開展搜集病人資料工作，同時，並與各公共醫院聯絡，希望將搜集乳癌資料工作拓展至各醫院。

與醫生/醫療診所中心的合作

資料庫若要順利運作，便不可缺少各方醫護人員的支持，鼓勵及協助更多乳癌病人參加此項研究計劃。現時資料庫已獲得逾100位專科醫生或與乳癌相關的醫護人員的支持。自2009年起，資料庫已於公私兩方醫療機構開展資料搜集工作，參與機構包括瑪嘉烈醫院、威爾斯親王醫院、基督教聯合醫院及養和醫院等。

乳癌病人的參與

現時共有逾2000名乳癌病人已參加香港乳癌資料庫（圖4），參加者主要來自私家診所。

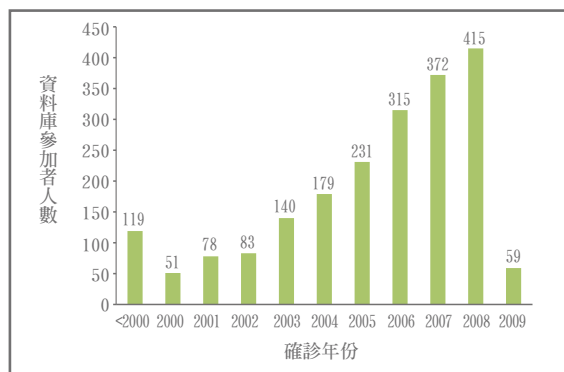


圖4. 按確診年份劃分的參與香港乳癌資料庫的人數

搜集數據簡介

資料庫搜集逾200項乳癌相關的資料，包括其風險因素、診斷方法、病理學及臨床數據、治療種類、生理及心理影響等。資料庫其中一個重要的元素，就是為所有參加者作每年度病況的跟進，能讓我們分析病人治療後的健康狀況，以及復發風險及存活率相關的資料。

第1部份

個人資料

- 詳細聯絡方法、個人資料（年齡、種族、家庭入息等）

生活習慣

- 吸煙、飲酒、運動習慣及壓力狀況等

過往健康狀況

- 體重、身高、病前乳房健康及過往腫瘤病歷等

乳癌家族病史

- 直系親屬、次系親屬等

生育紀錄

- 月經、生育資料、更年期、賀爾蒙補充治療等

第2部份

臨床資料

- 腫瘤位置（右乳/左乳/雙邊乳房）

- 淋巴擴散

診斷資料

- 確診方式

- 斷定期數方法

組織學及分子學特性

- 組織學分類

- 分子學特性（ER、PR及 c-erbB2等）

治療方法

- 外科手術

- 電療

- 化療

- 賀爾蒙治療

- 針對性治療



Part 2:

Follow up on patient status

- Recurrence (local/ distant)
- Metastasis
- Patient status (no evidence of disease, alive with disease, death)
- Date of death
- Death from breast cancer/ death from unrelated cause

The Registry is used to collect, manage and analyse data on breast cancer cases. To ensure data quality, the Registry staff, now consists a team of 3, are trained to coordinate and collect medical data at sites. The system is protected with security measure. The data are validated, verified and analysed in aggregate. Patient confidentiality is assured.

About this Report

A population-based breast cancer registry requires patient participation from private clinics and public hospitals. The dataset consisting of 1006 cases in this Report was collected during the period from February 2008 - January 2009 upon the project commencement. Over 95% of the breast cancer cases in this dataset were collected from private clinics. In this connection, the facts reported should be interpreted with special attention. The data collection is a long drawn process. With support and participation from various parties, the Breast Cancer Registry shall be able to review an overall picture of the breast cancer facts in Hong Kong in the long run.

第2部份

病人狀況跟進

- 復發(局部/遠端)
- 轉移擴散
- 病人狀況(沒有乳癌徵狀、與癌症共存、去世)
- 去世時期
- 去世原因：乳癌/其他病症

資料庫將會搜集、管理及分析乳癌病人提供的資料。為確保數據的質素，資料庫的3位職員均接受過專業訓練，並定期到訪醫院或診所進行資料搜集工作，而資料庫系統亦由嚴密保安系統保護，而所取得的資料數據將作綜合分析，參加者的個人資料絕對保密。

關於此報告

一個全民性的乳癌資料庫，需同時得到來自公私立醫院與私家診所的病人支持參與。自2008年2月至2009年1月期間，資料庫已完成處理1006宗個案資料分析，其中超過95%的參加病人來自私家診所，因此，本報告闡述的數據及乳癌趨勢等，亦應作出相應的解讀調整。

搜集資料往往是一個漫長的過程，然而，隨著各醫院、醫護人員及相關的熱心人士踴躍支持，不久將來，香港乳癌資料庫將可確切反映本港整體的乳癌概況。