

# The Malaysian National Cancer Registry - Experience in the First Year

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## **Summary**

This first annual report of the National Cancer Registry (NCR) has provided valuable insights into the seriousness of the cancer situation in Malaysia. Data such as the cumulative life time risk of getting cancer being 1 in 4, and that 40,000 new patients will be afflicted by cancer every year has important implications. This paper shares the experiences and challenges faced in the first year of the existence of the National Cancer Registry, and to invite greater participation from all parties so that subsequent reports will be even better.

The Advisory Committee of the NCR was formed with a wide representation from the public sector, universities, private sector and Non Government Organizations. The Advisory Committee endorsed the Governance Manual and designated the Clinical Research Centre (CRC) as the collaborating unit of the NCR. Marketing was actively carried out through the website, brochures, trade exhibitions, face-to-face talks and meetings. Over 99% of identified Source Data Producers (SDPs) had enrolled in 2002. Regular acknowledgements and contact was made with the SDPs. For Peninsular Malaysia, the data quality was encouraging due to the high notification rate of 1.9 per case. Expert Panels comprising various disciplines were responsible for the final quality assurance review of NCR data and interpretation of results.

It is encouraging that a World Health Organisation Consultant and Head of South Australia Cancer Registry has given a very positive, objective and constructive feedback soon after the First Report was published. The report is also available on the website (<http://www.crc.gov.my/ncr>). Chapters on "Methods" and "Evaluation of Quality of NCR Data" clearly stated the procedures and rules employed, as well as the limitations of the report. In line with recognized practices of cancer registries, certain data would best be reported only after a few years, such as in East Malaysia. Monthly submission of data is still very much needed from all source data producers so that a valid report may be published later. In addition to the oncologists, pathologists, haematologists, paediatric oncologists and palliative care staff identified as SDPs in 2002, radiologists, surgeons, gastroenterologists, neurosurgeons, chest physicians and hepatic surgeons have been identified to join as SDPs in 2003. The reporting of cancers to the National Cancer Registry by all who are involved in the diagnosis or treatment of patients with cancer is strongly urged.