

Surveillance Evaluation of the National Cancer Registry in Sabah, Malaysia

ABSTRACT

Background: Cancer is the fourth leading cause of death in Sabah Malaysia with a reported age-standardized incidence rate was 104.9 per 100,000 in 2007. The incidence rate depends on non-mandatory notification in the registry. Under-reporting will provide the false picture of cancer control program effectiveness. The present study was to evaluate the performance of the cancer registry system in terms of representativeness, data quality, simplicity, acceptability and timeliness and provision of recommendations for improvement. Materials and Methods: The evaluation was conducted among key informants in the National Cancer Registry (NCR) and reporting facilities from Feb-May 2012 and was based on US CDC guidelines. Representativeness was assessed by matching cancer case in the Health Information System (HIS) and state pathology records with those in NCR. Data quality was measured through case finding and re-abstracting of medical records by independent auditors. The re-abstracting portion comprised 15 data items. Self-administered questionnaires were used to assess simplicity and acceptability. Timeliness was measured from date of diagnosis to date of notification received and data dissemination. Results: Of 4613 cancer cases reported in HIS, 83.3% were matched with cancer registry. In the state pathology centre, 99.8% was notified to registry. Duplication of notification was 3%. Data completeness calculated for 104 samples was 63.4%. Registrars perceived simplicity in coding diagnosis as moderate. Notification process was moderately acceptable. Median duration of interval 1 was 5.7 months. Conclusions: The performances of registry's attributes are fairly positive in terms of simplicity, case reporting sensitivity, and predictive value positive. It is moderately acceptable, data completeness and inflexible. The usefulness of registry is the area of concern to achieve registry objectives. Timeliness of reporting is within international standard, whereas timeliness to data dissemination was longer up to 4 years. Integration between existing HIS and national registration department will improve data quality.