

Abstract

Background: Consequences of cancer research depend on wealthy cancer information. Many Sri Lankan research publications highlight the importance of web-based cancer information for research purposes which can provide information rich in completeness, validity, timeliness and comparability. Under the circumstances, identifying the information requirements of the cancer researchers in Sri Lanka and automating cancer patient information de-identification can terminate the fragmentation of the cancer information sources in the country.

Method: This study adopted an Action Research Strategy to design and develop a prototype for a web-based cancer information portal for research purposes. Relevant data from the major cancer repositories of the country have been extracted to provide quality improved clinical data for local cancer researchers. Automation of the cancer information de-identification has been facilitated without compromising the informational needs of the researchers. User feedback were obtained using two surveys during the user training, and analysed using descriptive statistics. Records of the observations made during the pilot study were analysed under key thematic areas.

Result: Initial survey indicated, 87.8% of the local cancer researchers have recognised the use of Information Communication Technology for research purposes. The majority (92.5%) were interested in tumour details. Patient records were the most preferred source of information in 87.4% of the researchers. Integration of all the available local cancer sources for the promotion of local cancer research has been recommended by 73.9%. Overall satisfaction of the cancer information portal was indicated by 87.0% of positive responses, 1.7% of the negative responses and 11.3% of not declared information (n=53). Furthermore, portal was comprehensively analysed using usability, maintainability, reliability, security, interoperability, quality and information utilization parameters by the second survey. Thematic analysis of the observation records resulted positive user perceptions about the data quality, data organization, functionalities of the web portal and arrangement of user training. There has been an increasing trend in cancer incidence, mortality, survival, and quality of care from year 1985 to 2018, according to the national statistics delivered by the portal.

Conclusion: This study highlights the strategies of cancer surveillance informatics which can be adopted to enhance cancer information utilization for research purposes in the Sri Lankan setting.