

## LETTER TO THE EDITOR

## THE STATE OF CANCER REGISTRATION IN PAKISTAN

Farhana Badar, Shahid Mahmood

Shaukat Khanum Memorial Cancer Hospital and Research Centre, Lahore-Pakistan

Sir,

Cancer registration is a neglected area in our part of the world. Therefore, it is difficult to compute the exact statistics on cancer incidence and mortality within our population. However, estimates on incidence, mortality, and prevalence have been generated and released recently by the International Agency for Research on Cancer (IARC), a sub-office of the World Health Organization, using the data from the Punjab Cancer Registry, Dr. Yasmin Bhurgri's paper, and the Federal Bureau of Statistics, Pakistan.<sup>1,2</sup> The purpose of writing this letter is to disseminate information on how to collect the data in an accurate and standardized format, thereby, facilitating population-based cancer registration in the country.

For an 'all-cancers' registry, the basic data items that need to be collected have long been defined by the International Agency for Research on Cancer.<sup>3</sup> Basic information is about items that are, in general, collected by all cancer registries. The purpose of collecting the minimum is to ensure that if some individuals are reported to the registry more than once, they will be recognized as being the same person. The basic data items include both the 'person' and 'tumour' characteristics. The items related to a person (patient) that need to be collected comprise the personal identifiers and the demographic information. The personal identifiers consist of the following: name, sex, and date of birth or age, whereas, items related to the demographics include the address of the usual place of residence and ethnic group. The information relevant to a tumour that is required encompasses the incidence date, the most valid basis of diagnosis, site of the primary tumour, histology, behaviour, and source of information (e.g. hospital record or name of physician). Further, two groups that are broadly used to classify the most valid basis of diagnosis are namely 'microscopic' and 'non-microscopic', apart from the death certificate only, as defined by IARC and the International Association of Cancer Registries (IACR).<sup>4</sup>

Details of codes corresponding to the most valid basis of diagnosis within the groups are as follows: 0-death certificate only; 1-clinical; 2-clinical investigation; 4-specific tumour markers; 5-cytology; 6-histology of metastasis; 7-histology

of primary tumour; and 9-unknown.<sup>4</sup> Other than the basic items, there are items of information (optional), which may also be collected.<sup>3</sup> Some of these are: the method of first detection, clinical extent of disease before treatment, surgical-cum-pathological extent of disease before treatment, TNM system, multiple primaries, laterality, initial treatment, information on last contact, and date of death.<sup>3</sup>

Keeping in perspective the recommendations given by IARC and IACR, along with our local needs, a comprehensive data capture form has been designed by the health-care professionals of Lahore. This form can be viewed by visiting the official website of the Punjab Cancer Registry, which is <http://punjabcancerregistry.org.pk>.<sup>5</sup>

The data collection form also includes a unique national identification card number as an exclusive personal identifier, a number allocated separately to every citizen of Pakistan. Once the practice of collecting the identification number sets in, it will be a major step towards checking for duplicate records through this identifier. Data collected on the prescribed form is likely to ensure uniformity in the way information is collected by professionals working in different districts or provinces of the country, thereby, facilitating region-wise comparisons of the results, once the results are standardized.<sup>6</sup> This may indeed be another way forward in the area of cancer registration in Pakistan.<sup>7</sup>

## REFERENCES

1. Ferlay J, Soerjomataram I, Ervik M, Forman D, Bray F, Dikshit R, *et al.* GLOBOCAN 2012 v1.0, Cancer Incidence and Mortality Worldwide: IARC Cancer Base No. 11. [Internet]. Lyon, France: International Agency for Research on Cancer; 2013 [cited 2014 Mar 5]. Available from: URL: <http://globocan.iarc.fr>
2. Bray F, Ren JS, Masuyer E, Ferlay J. Global estimates of cancer prevalence for 27 sites in the adult population in 2008. *Int J Cancer* 2013;132(5):1133-45.
3. MacLennan R. Items of patient information which may be collected by registries. In: Jensen OM, Parkin DM, MacLennan R, Muir CS, Skeet RG, editors. *Cancer Registration: Principles and Methods*. Lyon: International Agency for Research on Cancer; IARC Scientific Publications, No. 95. 1991;pp. 43-63. [Cited 2014 Apr 4]. Available from: URL: <http://www.iarc.fr/en/publications/pdfs-online/epi/sp95/SP95.pdf>.
4. International Association of Cancer Registries. In: IACR Standards-Basis of diagnosis-Table 1 [Internet]. 2014

- [cited 2014 Apr 8]. Available from: URL:  
[http://www.iacr.com.fr/index.php?option=com\\_content&view=article&id=105:standards&catid=82:support-for-registries&Itemid=472](http://www.iacr.com.fr/index.php?option=com_content&view=article&id=105:standards&catid=82:support-for-registries&Itemid=472).
5. Punjab Cancer Registry [Internet] 2011 [cited 2014 Mar 5]. Available from: URL:  
<http://punjabcancerregistry.org.pk>.
6. Ahmad OB, Boschi-Pinto Lozano R, Inoue M. Age-standardization of rates: A New WHO standard. GPE Discussion Paper Series: No. 31. EIP/GPE/EBD. World Health Organization 2001. [cited 2014 Apr 4]. Available from: URL: <http://www.who.int/healthinfo/paper31.pdf>
7. Badar F. Cancer Registration in Pakistan. J Coll Physicians Surg Pak 2013;23(8):611-12.
- 

**Address for Correspondence:**

**Dr. Farhana Badar**, Shaukat Khanum Memorial Cancer Hospital & Research Centre, 7-A, Block R-3, Johar Town, Lahore 54770-Pakistan

**Ph.** +92 42 35905000

**Email:** farhana@skm.org.pk