

## **New regulations on cancer notification in South Africa**

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### *UN Declaration on Non-communicable Diseases*

The UN Declaration on non-communicable diseases (NCD's) ratified in September 2011 acknowledged that of the 36 million global deaths due to NCD's, nearly 80% occurred in developing countries. It also recognised that by 2030, NCD's would become the most common cause of death, even in Africa (1).

While previously in South Africa NCD's, including cancers, were relegated to a lower priority behind communicable diseases, HIV/TB in particular, the changing epidemiology of NCD's has suddenly propelled it into the spotlight. Cancers, once perceived as a problem of developed countries and the socio-economically advantaged communities in South Africa, is now the fourth leading cause of death in South Africa accounting for 7% of mortality (2).

### *National Cancer Registry*

The National Cancer Registry (NCR) is South Africa's main source of cancer statistics, currently containing 850 000 individual patient records. It was established in 1986 as pathology based cancer registry relying on voluntary reporting from public and private pathology laboratories. Approximately 90 000 pathology based reports are submitted to the NCR each year with 30 000 being duplicates that are subsequently excluded from the database.

The NCR staff collate and analyse cancer cases diagnosed in pathology laboratories (both public and private) nationwide and report annual cancer incidence rates stratified by sex, age and population groups.

The published data from the NCR has been used extensively to inform the development of the draft national policy guidelines for cancer prevention and control, to inform cancer research and for teaching purposes. These data are also used by many other sectors with a keen interest in cancers to inform their policy decision-making processes and/or intervention programmes.

Being a pathology based cancer registry, the reports generated are an underestimation of the true cancer incidence in the country. Cancer cases that are not diagnosed by histology or cytology are not reported. Furthermore, as cancer reporting was not a legal requirement, information was not received from certain private pathology services in the past.

### *New Regulations on Cancer Registration*

In April 2011, new regulations on the registration of cancers were promulgated. These regulations make it compulsory for every health care worker who has diagnosed a new case of cancer to notify the case on the prescribed form (3) (Act No. 61 of 2006- Regulations related to

Cancer Registration No. R.380). The regulations make provision for the establishment of a population-based cancer registry, which is defined as “the registration of the details of every cancer that occurs in a defined population, usually in those persons resident within the boundaries of a defined geographical region or country”.

The responsibility for managing the pathology, specialised and population based registries was given to the National Health Laboratory Service (NHLS). The Chief Executive Officer of the NHLS was tasked with ensuring that the NCR (an institute within the NHLS) conformed to the norms and standards as set in the regulations. The regulations also include penalties for non-reporting.

The notification form, which has also been gazetted, includes patient demographic information, risk factors (occupation, smoking, alcohol use, HIV status), and clinical and laboratory details.

#### *Responsibility of the NCR*

The NCR’s role will be to publicise the cancer regulations, conduct outreach activities and develop mechanisms for the receipt of cancer registration forms. It is envisioned that health care workers will be able to perform manual as well as electronic submissions.

The NCR personnel will then code and capture the data, and delete duplicates. It is anticipated that multiple notifications will be received for single cases and information will be collated into one case before analysis. This is to ensure that details received are as complete as possible from multiple sources. Finally, the NCR will analyse the information received, produce and disseminate reports.

#### *Responsibility of Health Care Workers*

South African health care providers are responsible for ensuring that the notification form is completed for every new case of malignancy diagnosed. Furthermore, the health care worker is requested to fill in as much detail as is available at the time of the consultation. Notification forms should be submitted to NCR within 3 months of the diagnosis.

#### *Why cancer registration?*

Cancer registration is an integral element of any cancer control program. It informs etiological and epidemiological research, policy development and health-care planning, primary and secondary prevention and patient care. Thus, it has the ability to impact on population care as well as individual patient care (4).

A cancer registry is able to determine the incidence of cancer in populations as well as to track cancer trends over many years. The new notification form in South Africa will provide a wealth of information on the prevalence of risk factors. The inclusion of HIV status is a significant step in the right direction for South African health care.

Furthermore, the introduction of a population-based cancer registry will ensure that South African statistics are now included in global cancer reports produced by the International Agency for Research on Cancer (IARC). Previously, South Africa was omitted as pathology based surveillance data were not included in IARC reports. South Africa will now become one of 7 African countries included in the report, the others being Uganda, Nigeria, Zimbabwe, Gambia, Mali, Reunion and Algeria.

### *Role of Public Health Practitioners*

Public Health Practitioners have an essential role to play in ensuring the success of the new population based cancer registry. They could assist with informing and training colleagues on the new regulations and notification form and emphasising the value of accurate cancer data to clinicians. In addition, the introduction of undergraduate healthcare workers to the new notification process can form part of the medical curriculum in public health.

### *Conclusion*

The UN Declaration commits itself to strengthening “information systems for health planning and management, including through the collection, disaggregation, analysis, interpretation, and dissemination of data and the development of population-based national registries and surveys, where appropriate, to facilitate appropriate and timely interventions for the entire population”. As a signatory to this declaration, the South African government has already ensured that it is acting on this commitment. We will need the input of every South African healthcare worker to continue the momentum.

*Note that the views expressed in this article are those of the author(s) and do not necessarily represent the views of PHASA.*

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