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24 July 2017

Written Submission to the **Parliamentary Portfolio Committee on Health** regarding the National Public Health Institute of South Africa Bill

TO:

The Chairperson Portfolio Committee on Health 2nd Floor, 9 Church Square **Parliament Street** Cape Town 8001

For Attention:

Luvuyo Ngwayishe **Administrative Assistant Parliamentary Monitoring Group**

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FROM:

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My Qualifications include:

Doctor of Literature and Philosophy [D Litt et Phil (Health Studies) - University of South Africa] Master of Arts and Science [M Art et Scien - Potchefstroom University for Christian Higher Education] Baccalaureus Curationis [BA Cur – University of South Africa] Diploma in Occupational Health [DBV - Potchefstroom University for Christian Higher Education] Diagnostic Radiographer



Imagine a world without cancer

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Dear Ms Mary-Ann Dunjwa

WRITTEN SUBMISSION ON THE NATIONAL PUBLIC HEALTH INSTITUTE OF SOUTH AFRICA BILL

I wish to thank the Portfolio Committee on Health for the opportunity to submit written comments, and to indicate my interest in making an oral submission, on the National Public Health Institute of South Africa Bill [B16 – 2017].

The Cancer Association of South Africa (CANSA) became aware of the envisaged establishment of the National Public Health Institute of South Africa (NAPHISA) during the course of 2015 and is pleased to see the publication of a Bill in support of the establishment of this very important institute. It is in the interest of all South Africans that the various divisions of the NAPHISA will deal individually with the following:

- Communicable Diseases
- Non-Communicable Diseases
- Occupational Health
- Cancer Surveillance
- Injury and Violence Prevention

As a Cancer Health Specialist and Occupational Health Specialist | wish to limit my comments to Cancer Surveillance and some aspects of Occupational Health pertaining to occupational cancers.

While infectious diseases were a major concern in the world during the 20th century, cancer has become the most dangerous health problem of the 21st century. Treatment of infectious diseases and overall health has improved dramatically over the past century, leading to prolonged life spans. However, with an aging world population, the incidence rates of cancer in low- and middle-income countries especially have increased and will continue to increase in the next few decades. In general, cancer is the disease of uncontrolled generation of abnormal cells in the body. The genetically unstable nature of cancer cells allows them to become highly resistant to treatment. One of many tools to combat this problem is cancer patient surveillance. The United States of America and other developed countries of the European Union are currently collecting clinically relevant information about each and every patient.

This data can be correlated with disease progression, treatment efficiency, environmental factors, or other variables. Scientific researchers in those countries have access to and analyse clinical samples for genetic mutations and gene expression profiling to identify other molecules of interest and compare it with disease stage and survival.

The proper surveillance system of cancer patients is a powerful tool that must be used to understand the disease and improve cancer therapy and patient survival. Therefore, generating a successful surveillance system for cancer patients in South Africa will have a profound effect on cancer control and potentially identify new ways to treat cancer patients in South Africa.



Unfortunately South Africa is not faring well. It has no current approved National Cancer Control Programme (NCCP).

In 2011, Regulation 380 of the National Health Act (Act 61 of 2003) formally established the South African National Cancer Registry (SANCR) as South Africa's main cancer surveillance agency; the legislation makes reporting all confirmed cancer diagnoses to the registry obligatory. Additionally, the Regulation mandated the SANCR to implement population-based cancer registration in South Africa – something that has still not materialised.

Cancer remains one of the leading causes of morbidity and mortality worldwide. It is predicted that by 2020, the number of new cases of cancer in the world will increase to more than 15 million, with deaths increasing to 12 million.⁽¹¹⁾

Much of the burden of cancer incidence, morbidity, and mortality will occur in the developing world. This forms part of a larger epidemiological transition in which the burden of chronic, non-communicable disease - once limited to industrialised nations - is now increasing in less developed countries. In addition to the accumulating risks associated with diet, tobacco, alcohol, lack of exercise, and industrial exposures, the developing world is already burdened by cancers some of which are attributable to infectious diseases.

These disparities in cancer risk combined with poor access to epidemiological data, research, treatment, and cancer control and prevention combine to result in significantly poorer survival rates in developing countries for a range of specific malignancies. (11)

Cancer Surveillance

Cancer registration is the fundamental method by which information is systematically collected about the incidence and types of cancer, the anatomic location, the extent of disease at the time of diagnosis, the kinds of treatment received by cancer patients, and the outcomes of treatment and clinical management. (12)

South Africa currently does not have a functional National Cancer Control Programme (NCCP). Cancer Surveillance in South Africa, therefore, is functioning in a vacuum. A well-structured and Parliamentary approved National Cancer Control Programme is crucial to the success or failure of cancer control in South Africa.

A national cancer control programme (NCCP) is a public health programme designed to:

- reduce the number of cancer cases
- reduce the number of cancer deaths; and
- improve the quality of life of cancer patients (cancer survivors)^(1;7)

This is done by implementing systematic, equitable and evidence-based strategies for prevention, early detection, diagnosis, treatment and palliation using all available resources. No matter what resource constraints a country faces, when well-conceived and well-managed, a NCCP helps reduce the cancer burden and improve services for cancer patients, their families and carers.



National cancer control plans should be goal-oriented, realistic, carefully prepared and appropriately funded through a participatory process in order to be effectively implemented. Cancer control planning requires accurate data, including reliable cancer registries and monitoring and evaluation programmes to ensure programmes are appropriately prioritised and to assure quality.^(5;7)

For a NCCP to be successful, the following questions need to be asked and answered during the planning phase:

Where are we now?
Where do we want to be?
How are we going to get there?

This is to be followed by a policy implementation phase. (1;5)

Another crucial part of a successful NCCP is the availability of a reliable National Cancer Registry. (6)

As stated above, cancer control aims to reduce the incidence, morbidity, and mortality of cancer and to improve the quality of life of cancer patients through the systematic implementation of evidence-based interventions in prevention, early diagnosis, treatment, and palliative care. In the context of a national cancer control program (NCCP), a cancer surveillance programme (CSP), built around a population-based cancer registry, is an essential element.^(2;3)

<u>A Population-based Cancer Registry</u> - systematically collects information on all new cancer cases in a particular geographic area and is determined by multiple sources. The main sources of information for these registries are (a) public and private hospitals and medical centres; (b) public and private outpatient surgery centres; (c) public and private anatomical pathology laboratories; (d) civil registry offices that issue death certificates, particularly lists of certificates of residents whose cause of death was cancer or probable tumour or those in which cancer is referenced in some manner; (e) public and private specialty cancer diagnostic centres; (f) public and private hospice centres; and (g) public and private nursing homes. These registries provide a more reliable cancer profile for estimating population indicators of incidence, mortality, survival rates, and prevalence. (3)

It pains to acknowledge that South Africa fails as far as this is concerned as well. South Africa does not currently have a population-based cancer registry — it has a poorly functional histology-based National Cancer Registry. This boils down to a registry only reflecting cancer diagnoses that have been confirmed by tissue biopsy in a pathology laboratory.

<u>A Histology-based Cancer Registry</u> - collects information from one or more pathology laboratories and is useful for laboratory needs. It provides an incomplete and skewed cancer profile, essentially determined by the types of tissues that the laboratory can process.⁽³⁾

<u>Valid instruments to diagnose cancer</u> - the following are all valid instruments used to diagnose cancer, but if the diagnosis is not based on a pathology report, it is not taken up in the current South African National Cancer Registry:



- Physical examination
- Laboratory tests (blood, urine, tissue biopsy etc.)
- Imaging tests (X-ray, PET/CT, MRI, ultrasound, etc.)
- Nuclear medicine scans (bone scans, etc.)
- Endoscopy
- Genetic tests.⁽⁴⁾

<u>Criteria to confirm a valid and reliable national cancer registry</u> - according to the International Agency for Research on Cancer (IARC)⁽¹⁰⁾ cancer registries should be able to provide some objective indication of the quality of the data that they have collected. The methods available have been described and updated, and cover four dimensions of quality: comparability, validity, timeliness, and completeness. The SANCR provides no information as to sources or quality of data. The latest cancer statistics available from the SANCR are those for 2012.

The International Statistical Classification of Diseases and Related Health Problems, 10th Revision — or ICD-10 for short — is an internationally used document which translates the written description of all medical diagnoses into a coded format. The World Health Organization (WHO) owns and maintains these codes and they are the standard way of indicating the reason for a visit to a healthcare provider. The purpose of ICD-10 coding is to translate diagnoses of diseases and other health related problems from descriptions into an alphanumerical code, which permits easy storage, retrieval and analysis of the data. It also allows for the establishment of the systematic recording, analysis, interpretation and comparison of morbidity and mortality data collected within the country but also with other countries. ICD-10 coding communicates health data in a predictable, consistent and reproducible manner.⁽⁸⁾

Even though the ICD-10 has been adopted by the National Department of Health as the diagnostic coding standard for South Africa, the South African National Cancer Registry (SANCR) seems to be oblivious to its existence. In the ICD-10 Coding System, tumours (cancers) are classified under codes C-00 to C-96 and under codes D-00 to D-49, yet the current SANCR records all cancers under the following number of headings (not ICD-10 related)⁽⁸⁾

Cancers (neoplasms) related to females 45 headings
Cancers (neoplasms) related to males 42 headings

A further example is that according to the ICD-10 coding system, leukaemias (blood cancers) are classified under thirty-four (34) codes, whereas in the SANCR all leukaemias are grouped together under one single heading of 'leukaemia', whereas the ICD-10 Coding System has 34 codes.

Similarly Lymphomas, even though they are categorised under several headings in the ICD-10 coding system, are categorised under only three (3) headings in the SANCR, namely: Hodgkin's lymphoma, non-Hodgkin's lymphoma and Burkitt's Lymphoma.

Neoplasms of the liver and bile ducts, for example, are all grouped together in the National Cancer Registry under one heading – although there are ten (10) codes in the ICD-10 Coding System. (9)

Without a proper ICD-10 aligned National Cancer Registry, proper and adequate cancer surveillance is not possible.



<u>Examples of Errors Occurring in the National Cancer Registry</u> – I would like to take this opportunity of pointing out critical errors that occurred in the National Cancer Registries of 2011 and 2012.

National Cancer Registry (NCR) 2011

Annexure I (Page 1 of the 2011 NCR) with reference to the column "N(ADJ)" — N(ADJ) refers to the number of cases adjusted for those with sex unknown. This particular column, throughout the whole of the NCR, indicates percentages of the total number of cases as follows:

- Number of new cases with sex known 8000 cases of Basal Cell Carcinoma (BCC), when adjusted becomes 8286.04 cases
- Number of new cases with sex known 3386 cases of Squamous Cell Carcinoma (SCC) of the skin, when adjusted becomes; 3514.67 cases
- Number of new cases with sex known 1552 cases of Lung Cancer, when adjusted becomes 1590.63 cases
- Etc

The question is: how can one have 8286.04 persons? When this was pointed out to the NCR, the response was that this is normal when adjusting figures. I totally disagree with such a response - one can never have 8286.04 persons! The particular NCR was eventually removed from the Website, corrected and re-posted. How many researchers were confused by this?

National Cancer Registry (NCR) 2012

Annexure II and Annexure III (Page 12 and Page 14 of the 2012 NCR). Both these pages provide frequency data of histologically diagnosed cancer in South Africa, 2012 among <u>All Males</u> (Page 12) and <u>Asian Males</u> (Page 14), yet comments at the bottom of the pages have the following inscriptions:

(Page 12) SEX KNOWN (FEMALES), POPULATION GROUP

(Page 14) SEX KNOWN (FEMALE), POPULATION GROUP UNKNOWN

Errors of this nature are not acceptable. Are these real errors where female data was included in frequency data of males or is it possibly a typographical error? This causes major confusion among individuals conducting research of cancer incidence in South Africa!

Occupational Health

More than half of the world's population is engaged in work, and so the socio-economic development of each country relies on its workers' health, safety, work ability and well-being. Healthy workers are productive workers. Absenteeism due to work-related disease and disability disrupts the operation of enterprises and tarnishes their reputation, adds costs such as the recruiting and training of replacement workers, and increases social and health-care costs.

Thus safety and health at work are important not only for individual workers, but also for enterprises, communities and countries. The safety and health of workers affect the overall quality of life of working people, and the harmony of society. Safety and health at work also contribute positively to enterprise profitability and national economies through improved productivity, product quality, work ability and job satisfaction.

Data on diseases caused by work and their effects on workers' health are essential for national policy-makers and organisations responsible for workplace safety and health to formulate evidence-based occupational safety and health policies, and to set priorities and targets for action.



National occupational disease data are also important for international comparisons, to fit the national OSH profile into the international picture, and can be used to calculate regional and global estimates of the burden of occupational diseases.⁽¹³⁾

During the month of July, 2017, researcher conducted research in an effort to collect data to prepare a <u>Fact Sheet on Occupational Cancers in South Africa</u> and could not find any evidence or record of incidence of occupational cancers in South Africa.

The National Cancer Registry (2012) does not differentiate the cause or origin of cancers. It is, therefore, not possible to determine from the National Cancer Registry how many individuals have been diagnosed with an occupational cancer.

The researcher was also unable to find evidence of statistics on occupational cancers in publications of the following:

- Statistics SA
- National Health Laboratory Service
- South African Institute of Occupational Health
- The South African Department of Labour
- The South African Department of Energy
- The South African Department of Transport
- The Chamber of Mines of South Africa
- The Compensation Commissioner

No country can ensure a healthy and safe working environment for its workforce without proper and adequate surveillance and statistics on occupational diseases. It rests in the hands of responsible people, such as the ministries of labour, health, and social security; at those in occupational safety and health inspection, occupational safety and health services, national social security institutions, compensation boards, employers, workers and their organisations to ensure adequate health and safety surveillance and availability of accurate and relevant occupational health statistics and information.



Recommendations:

I wish to make the following recommendations, trusting that they will be forwarded to the appropriate divisions of the proposed National Public Health Institute, for urgent attention:

1.

The National Department of Health must be instructed to provide, as a matter of urgency, an approved, functional, relevant, and current National Cancer Control Programme (NCCP) for South Africa, without which no cancer control is possible.

- 2.
- The National Department of Health and the National Cancer Registry must ensure that all individuals responsible to report cases of cancer diagnoses are effectively trained in how to complete the prescribed notification of cancer cases so as to ensure that all relevant statistics are received by the National Cancer Registry for inclusion in the Registry.
- 3. The National Cancer Registry must ensure that all diagnoses of all cancer cases are reported to ensure inclusion in the National Cancer Registry.
- 4. The National Department of Health and the National Cancer Registry must ensure that cancer diagnoses on the prescribed notification of cancer cases be done in terms of the ICD-10 Coding System.
- 5. The National Department of Health and the National Cancer Registry must, as soon as possible, introduce a Population-based National Cancer Registry instead of continuing with the current Histology-based National Cancer Registry.
- 6.
 The National Cancer Registry must urgently introduce an intensive training programme for its staff in statistics and other relevant topics to ensure that no unacceptable and erroneous statistics or inclusions are published in the National Cancer Registry.
- 7. The National Cancer Registry must introduce a system of careful scrutiny (editing) of the content of the National Cancer Registry to prevent typographical errors (as those pointed out having appeared in the 2012 National Cancer Registry).
- The National Cancer Registry must be urged to hasten the publication of more recent cancer statistics. It is impossible to adequately plan for cancer control with statistics that are 5 years old.
- 9. The National Cancer Registry must revise and expand the manner in which cancer statistics are currently presented to be more in line with the ICD-10 Coding System and not, for example, post all the different types of leukaemia under one heading.



10.

An effort must be made to ensure that accurate statistics become available concerning occupational cancers in an effort to better protect the workforce of South Africa from exposure to carcinogens in the workplace. This should be available from at least the following:

- Statistics South Africa
- National Health Laboratory Service
- South African Institute of Occupational Health
- The Chamber of Mines of South Africa
- The Compensation Commissioner

11.

International research indicates that low- and middle-income countries bear the greatest burden of new cancer cases as well as deaths, amid an ever-increasing total number of affected individuals worldwide. Since cancer kills more people worldwide than HIV/AIDS, tuberculosis, and malaria combined, it needs to be a global health priority. (14;15) It is, therefore, recommended that the Cancer Surveillance Division of the proposed Institute investigate this to determine why South African health statistics do not reflect this, even though South Africa has the skewed burden of Aids, Tuberculosis and Malaria.

wish to thank the Portfolio Committee on Health for the opportunity to submit written comments on the National Public Health Institute of South Africa Bill.

Sincerely
Michael C Herbst (Prof)

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SUMMARY STATISTICS OF CANCER DIAGNOSED HISTOLOGICALLY IN SOUTH AFRICA IN 2011 ALL POPULATION GROUPS: MALE



ANNEXURE II - Page 12 of the 2012 National Cancer Registry

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ANNEXURE III - Page 14 of the 2012 National Cancer Registry

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