Policy Framework and Strategy on Cancer in South Africa 2016-2021

Consolidated response from the Cancer Alliance - 27 April 2016

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Background

For almost 20 years, various parties have called on the National Department of Health (NDoH) to create a National Cancer Control Plan (NCCP).

Many attempts have been made to create such a plan, and diverse parties have invested many hundreds of hours, with no success. Individuals from many organizations have become involved, but have become disillusioned at the lack of progress. Many have withdrawn from discussions, preferring to concentrate on their own organizations.

The recent meeting of the Cancer Alliance with the Minister has given rise to new optimism; However, the issuing of yet another draft document, requesting comment within 7 calendar days has presented all parties with a serious problem: Even though extension was granted, it is patently impossible to obtain proper attention and input from all the affected parties within such a short time scale. This does not really constitute comprehensive stakeholder consultation that is inclusive and engaging of all the stakeholders involved in this arena.

Nevertheless we have made an attempt to assess the document provided. Six members of the Cancer Alliance have submitted detailed comments. Others have contributed in various ways according to time available. It is not practical within the current time constraints to consolidate all the responses into one document, so we have decided on the following:

1. Each member will submit their own response directly to the NDoH. The following members have submitted individual responses:
   a. CANSA
   b. CHOC
   c. HPCA
   d. People Living with Cancer (PLWC)
   e. Peter Hers - Coopted member from PLWC
   f. Salomé Meyer - Independent cancer advocate

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1 Refer document South African Cancer Control Roadmap.
2. The Cancer Alliance has extracted the major themes and issues which run through all the submissions, and is providing this document for consideration on behalf of all members.

The Cancer Alliance is committed to cancer control in South Africa, we are enthusiastic to work with the NDoH and provincial health departments to significantly reduce the incidence of cancer as well as providing support and care to those diagnosed with cancer and their families.

**Major Themes and Issues**

**Fundamental direction**

We are in full agreement with the general aims and objectives expressed in the draft document. This includes attention to cancer from risk reduction right through to eventual remission and living as a survivor, or demise.

We recognize that many different parties play roles in controlling and managing cancer, but that the NDoH, provincial health departments and other associated state bodies must exercise the leading role, having responsibility for the health of all South Africans.

We are however concerned that there seems to be too much optimism that cancer can be prevented or avoided, with a consequent downscaling of the importance of early detection, diagnosis and treatment.

Para. 1.2 misquotes the WHO document *Cancer Control - Knowledge into Action*, which reads:

"Cancer prevention is an essential component of all cancer control plans because about 40% of all cancer deaths can be prevented".

Cancer mortality is preventable by the full spectrum of primary prevention / avoidance, early detection and effective treatment.

Cancer cases, and subsequent deaths, can be reduced by prevention activities, but only when these prevention activities are properly carried out, and only after time have elapsed to allow the interventions to take effect. For example, actions to change behaviour, such as reduce smoking, get more exercise, etc may take many years to show noticeable changes, and even then there may be long delays before the effects appear. Similarly, the current excellent HPV vaccination campaign can only be expected to have a significant impact far in the future.

Estimates of National Health Expenditure 2015 by the Treasury states that:

'The baseline of the Health function is reduced by R5.1 billion over the MTEF period, from R488.6 billion to R483.5 billion. The function seeks to improve access to affordable quality health care by ensuring an appropriate balance
between preventative care and curative services. The function comprises 13.9 per cent of non-interest expenditure.'

The outputs for preventative services need to be quantified to justify a decreased budget.

**Research is essential**

We consider that research and surveillance are key activities. These are perhaps the first action plans that should be mapped out, funded and initiated. Every other action plan requires information on which to base its activities, and measurements will be essential to track progress.

Research and surveillance are not fully addressed. Primary responsibility should be identified, as should the additional key stakeholders.

Surveillance and research are essentially two different aspects of the cancer care continuum that warrant separate attention. Cancer surveillance in South Africa for years has been neglected and the lack of real time data from morbidity, mortality and survivorship perspective does not allow for proper planning for cancer care services. It is vitally important that surveillance and burden-of-disease measurement is appropriately addressed in a future plan.

Cancer Research in South Africa is mainly situated at academic institutions across the country. This is mainly funded by the Department of Science and Technology and/or international grants. The focus of this research includes: mechanisms of carcinogens, molecular epidemiology and drug and vaccine development. Cancer Association of South Africa (CANSA) also co-funds many scientific research projects. For risk reduction, treatment and palliation and social and public health research the Department of Health through the MRC should be responsible, however none of these types of research is initiated or undertaken. It remains unclear who is responsible for what research and who ensures that cancer research addresses the actual health needs of the country. In order to measure the true impact of a NCCP, research capacity should be enhanced and developed where needed with respect to fundamental, translational and applications research.

In many places the draft framework points to a lack of information:

- On the incidence and demographics of cancer;
- On the services available;
- On the patient experience;
- And on the actual outcomes.

This lack of information seriously hampers the compilation of this plan. Research at every level should be amongst the most important actions from the outset.

Some examples from the draft document include:
Para. 2.4: "There is a paucity of data on exactly what type of childhood cancer facilities and activities exist at all levels of care in the private and public sector."

Para. 3.2.1: "There is a paucity of data on current Pap smear screening coverage nationally."

Para. 3.3: "There is a paucity of data on exactly what type and number of cancer facilities and activities exist at all levels of care in the private and public sector."

Development process is flawed and lacks necessary involvement of affected and affecting parties

Over the past few years we have seen continued attempts based on a faulty process for involvement and discussion with stakeholders. Each time a new draft policy document has been compiled initially without any discussion and then presented to stakeholders for comment, as an apparent once-off exercise. There is no mechanism for proper discussion of issues, which would lead to a more successful product as well as better acceptance by all stakeholders.

The development of this strategy / plan should be a consultative process. Extensive consultations with stakeholders initially would have been the preferred way of addressing this process as well as using a dedicated task team approach consisting of representatives from all facets of the cancer continuum of care.

Attempts at compiling a NCCP have continually excluded many affected parties. It would seem as if the product, IE: The delivery of a NCCP, is more important than the actual process of development of the plan. If this practice remains it will be difficult to obtain the required buy-in to ensure that cancer is regarded as a national priority.

This most recent attempt appears to have called only on the following:

- National Department of Health (NDoH)
- Provincial Departments of Health
- Medical Research Council (MRC)
- Ministerial Advisory Committee on Cancer Prevention and Control (MACC)
- National Cancer Registry (NCR)
- Cancer Alliance (CA)
- South African Non-Communicable Diseases Alliance (SANCD Alliance)

Conspicuous by their absence are:

- Individual patient voices, except via NGOs
- Office of Health Standards and Compliance
- Private sector
• Academia
• Service providers
• Health funders
• Other government departments, such as Social Development, Basic Education, Higher Education and Training, Science and Technology, Trade and Industry, Labour, Agriculture, Forestry and Fisheries, Minerals and Energy, Environmental Affairs
• International organizations
• Possible partners
• Radiation oncologists
• Medical oncologists
• Cancer surgeons
• Oncology social workers
• Oncology nurses

Many of the initiatives described for avoidance / prevention of cancers are outside of the control of the health departments. Other government departments and organizations should be included in this plan with accepted responsibility, as cancer prevention and control is not only vested in the NDoH.

Financial implications and transparency
There is no indication of the broader principles of budget allocations that should be applied, or how inequity should be addressed.

The draft strategy contains no information on the financial implications; no costing is performed for any of the action plans; no information is provided on how or when finances and other resources can or will be made available; no information is provided on future tracking of budgets and expenditure.

Ideally all financial implications should be transparent and visible to all parties, and in the public domain.

Action plans need extensive work, and disconnect with statements of intent
The Action Plans in Para. 4.5 are entirely unsatisfactory, and extensive work should be done to improve these before proceeding with this plan.
The following sub-headings detail the major points of issue.

➢ General statements of intent are not carried forward to the proposed Action Plans.
Many possible interventions are mentioned in the text, but not carried through to identified activities.

EG:

(Message from the Chairman of the Ministerial Advisory Committee on Cancer):
"In order to improve access and quality of care in both the diagnosis and the treatment of cancer, the strategy proposes the development and implementation of evidenced-based comprehensive cancer care packages and protocols for the ideal specialised cancer treatment center while providing a roadmap for how this can be achieved. A gold standard patient pathway experience is identified as a key criterion for improving the quality of care for cancer diagnosis and treatment. Palliative care and childhood cancers were further areas identified as requiring in-depth needs and situational assessment and the development of standard care protocols."

This does not appear in the Action Plans section.

➢ Measurements based on inputs, not outcomes or benefits

The majority of indicators and measurements proposed are inputs, and not end benefits or outcomes.

EG: Targets set include:
- No. of schools covered by ISHP;
- Numbers of screening tests conducted;
- Training of health practitioners;
- Etc.

These are all good measurements that should be made, but they do not measure the effect on patients, IE: the outcomes or benefits.

All measurements of progress will require initial measurements to be made, IE: "Where are we now?" This should be factored in with the development of a proper research strategy that is linked to the measurement and evaluation of implementation of a NCCP.

We suggest the development of a numerical model to describe the progression of patients through the whole system, and model the expected / predicted effects of each intervention. The summation of all these predictions would provide a view of the overall impact of all interventions.

The inputs to such a model would include:
- Population statistics derived from census and interim population predictions;
- Predicted cancer incidence rates, obtained from the most current information available - NCR statistics; mortality statistics;
- Sample information obtained from population-based cancer registries; etc.
• Predicted effects of each intervention;

For example: The programme to vaccinate against HPV has been in existence for some time, and progress is being monitored. There are probably plans for improvement, to increase the coverage, to ensure equity and possible other features to make it more effective. It should be possible to predict what impact this will have on cases of cervical cancer on a year-by-year basis into the future.

Doing this for all planned interventions should provide a basis for future planning, and a model against which to measure actual experience.

➢ Responsibilities for executing projects and activities are not identified
This section is the perfect platform to integrate other government departments, private sector, non-profit organisations and civil society into the implementation of a NCCP as a collective effort and responsibility.

➢ Costs and other resources required are not identified or evaluated

See also comments on financial issues above.

Significant issues not addressed
Short list of some important issues that are not addressed: (Note: Not a complete list!)

• Processes for awareness programmes, early diagnosis and treatment.
• Carcinogens and nutrition aspects of inter alia: salt and sugar; red meat; processed foods;
• Aflatoxins (contributory factor for oesophageal cancer in South Africa)
• Health technologies and access to medicines and devices EG: Increased PSA testing ability, increased colposcopy facilities, essential drug lists
• Scope, practice and processes for palliative care
• Psychosocial support - No recognition is given to the importance of psychosocial care of cancer patients during the cancer trajectory of care
• Support for cancer survivors through tertiary prevention
• Communication – public awareness and empowerment
• Monitoring, evaluation and quality control processes
• Allocation of budgets
• Nowhere is there mention of ensuring an integrated/holistic/multidisciplinary approach.
• There is also no mention of re-training/education of health care professionals across the board - these are the enablers to implement the cancer control plan.
• The South African Nursing Council has rescinded the training of the oncology nursing specialization and stoma care. This needs to be of primary concern and should be addressed in the strategic plan.
• Lymphoedema care - No provision is made for this essential care for many cancer patients affected after cancer surgery.
• Prosthetic services – No provision is made for essential prosthetic services for mastectomy patients. Even though there is mention of a Breast Cancer Prevention and Control policy this should be recognised here.
• The adequate provision of pain control in palliative care needs to be addressed urgently.
• Referral pathways in cancer care are a core concern for effective implementation of an effective cancer plan:
  o From primary care clinic to diagnostic centers for tests and staging
  o From diagnostic centers to tertiary treatment hospitals
  o From treatment hospitals back for follow-up cancer care at primary care clinics
  o From treatment hospitals for palliative care for patients with incurable cancer

**Traditional healers omitted**
This document does not even mention the role of Traditional Healers. This large group both affects and is affected by cancer in our society, and cannot and should not be ignored.

Research has been done on the roles of traditional healers; on their pervasive influence on society; and also on the number of people who consult a traditional healer in place of, or in addition to the formal health sector. There are large numbers of traditional healers spread throughout the country, and they can be more accessible than formal health workers.

**Stigma omitted**
We know that patients are subject to severe effects from stigma; whether in the family, the community or in the workplace. Apart from the psychosocial problems, this can and does have serious consequences for adherence to treatment etc.

Stigma is one of the biggest challenges in identification, reporting and treatment of Childhood Cancers, and can also be significant for adults and young adults.

**Effects of proposed NHI**
The Cancer Alliance is currently studying the White Paper on National Health Insurance (NHI) for South Africa dated 10th December 2015. It is not possible to comment on this White Paper or its possible impact on this draft cancer control plan at this stage.
Para. 2.2: "The NHI will facilitate more equitable cancer care as currently skilled staff, equipment and other resources are inequitably distributed in favour of patients receiving care in the private sector."

The above statement indicates a misunderstanding of how the private sector works. There is no conceivable way in which the resources that are currently available and paid for within the private sector can be "redistributed" into the public sector. This is also subject to the outcome of the Competition Commission Market Inquiry into the Private Health Sector.

An integrated NCCP can address inequity in cancer care access through effective Public Private Partnerships. The PPP for the George District is a perfect example of how cancer treatment can be shared on an equitable basis.

Relationship to other associated plans and strategies
Para. 1.0 state:

"The PFCSA is aligned with and should also be utilized in conjunction with the following cancer related policy, strategic documents and clinical guidelines:

- The Strategic Plan for the Prevention and Control of NCDs
- National Strategic Plan on HIV, STI’s and TB
- Strategy for the Prevention of Obesity and Overweight
- Cervical Cancer Policy
- Breast Cancer Prevention and Control Policy
- Childhood Cancer Policy
- Palliative Care Policy
- HPV and HBV vaccination Program"

We understand that more focused plans will be compiled to deal with major areas of concern. However, our comments herein in regard to the PFCSA should apply equally to these, including the ways in which these plans are developed, and the content and detail of these plans.

Existing health systems challenges
Our experience confirms that substantial challenges exist in the existing health services provided, and we have previously communicated some of our major concerns to the Minister. Many anecdotal reports point to severely lacking services. However, we have no hard information or statistical information.

Refer to our comments above under Research: Efforts should be made to audit and assess all these challenges as early as possible to form a basis for further projects and activities.
Lack of single owner regarding cancer
To date there has been no single owner charged with responsibility for all activities regarding cancer.

Para. 4.3 - Principles speaks to this in the "Leadership" role.

The Cancer Alliance recommends that a custodian or head coordinator be appointed to oversee the planning and implementation of the cancer prevention and control strategy, and to act as the single point of contact for all matters relating to this PFSCSA. To date the lack of such a dedicated person within the NDoH could be attributed to cancer not receiving the needed priority status. If cancer is regarded as a national priority then it should be treated as such at all levels.

National Cancer Registry
Much has been made of the past and current problems of the existing National Cancer Registry (NCR). However, no information is forthcoming on plans to improve the situation.

The NCR is outdated and there are minimal resources for its upkeep and maintenance in future. There is very little confidence in the NCR data. The most recent statistics are in respect of 2010, and there is no communication strategy to obtain other cancer specific data such as mortality rates. It has become difficult to extrapolate the Statistics South Africa (StatsSA) underlying causes of death, as it may not be a true reflection due to the quality of death certificate information received from the Department of Home Affairs.

The Regulation for the mandatory registration of cancer was promulgated on 26th April 2011; this is not yet reflected in current statistics and will only be reflected in figures for 2012 at the earliest. We have absolutely no idea what will be found, but we suspect that compliance on reporting will be found to be lacking.

We draw attention to the apparent lack of any enforcement in terms of Sub-Regulation 11, and no regulations have been promulgated to determine penalties for non-compliance.

The information published by the NCR on the National Institute for Occupational Health (NIOH) website is somewhat limited, and only provides information broken down by high-level grouping of cancer site, sex, age and population group. No facility is provided to allow public exploration of further details of the information held. The document detailing the NCR methodology does not appear to have been reviewed since 2001.
It is important to understand what information is provided by the NCR and how this is actually applied in practice.

No information is provided on the reliability of the information, which is presented, or confidence levels. Attention is drawn in the draft PFSCSA to disparities between NCR statistics and GLOBOCAN estimates. These questions would appear to be irrelevant at this stage, given that the NDoH does not have any other reliable source of information.

A Strategic Plan for the improvement of the NCR has been previously mentioned but has not been made public.

Mention is made of extending the operations of the NCR to include one or more population-based cancer registries (PBCRs). There appears to be some misunderstanding of what these would entail. Our understanding is that a PBCR would collect more extensive information from a defined population where reliable sources of information are available, and which can be used to extrapolate to the larger population. Such a PBCR would be more complex than the existing NCR, and more costly per cancer patient to operate, hence the restriction to defined populations.

No mention is made of the South African Children’s Cancer Tumour Registry.

It is suggested that there are readily available statistics of cancer care in the private sector e-authorization systems as well as from medical aids regarding the cost of cancer treatment of their members. This data could be used for the construction of a more comprehensive cancer plan and could be audited to provide us with much needed data.

**Survivorship and Palliative Care should be separated**

We are against combining the concepts of Survivorship and Palliative Care under one heading. While we understand the need for palliative care at many stages of the cancer patient’s experience, from the patient viewpoint we need to separate components, which could be associated with (negative) end of life issues from (positive issues) of possible cure or remission.

- **Survivorship**
Survivorship starts from the point at which a diagnosis is made, and concerns all the issues of managing treatment, coping with life and doing everything possible or necessary to obtain the best possible outcome. Therefore a positive but pragmatic outlook must be engendered. Palliative care may be required during this process.
In this draft, no recognition is given to the importance of psychosocial care of cancer patients during treatment and survivorship. This phase is a care phase: All patients should be followed up post treatment to assist with long term management of side effects as well as monitor for recurrence of illness or secondary cancers. This needs specialized skill and resources.

- **Palliative Care**
  Palliative care services are lacking or under-funded in many parts of the health system. There is research that shows improvement in quality of life when palliative care is provided, especially in the treatment of oncology emergencies such as hemorrhage, pathological fractures, spinal cord compression and other metabolic events. Palliative care services should be situated in the primary care clinic and will need more resources: staff, medication, pharmacists, nurses specialized in palliative care, etc.

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