Cost of Cancer: Challenges for the next 10 years

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CONTENTS

ACRONYMS AND ABBREVIATIONS 4
DISCLAIMER & CONFLICT OF INTEREST 4
ACKNOWLEDGEMENT OF FINANCIAL CONTRIBUTIONS 4
FOREWORD 6

1. THE CANCER ALLIANCE 12
2. EXECUTIVE SUMMARY 12
3. THE CANCER BURDEN IN SOUTH AFRICA 14
   3.1. Cancer Incidence 14
   3.2. Projected cancer incidence 15

4. INVESTMENT IN CANCER IS A HUMAN RIGHTS IMPERATIVE 17
   4.1. The Legislative Framework 17
   4.2. The Policy Framework 18
   4.3. Legislative and other measures 20
   4.4. Implementation through co-operative governance 20
   4.5. Fostering Health Literacy, Demand and Implementation 20
   4.6. Investment 21

5. CANCER CARE IN SOUTH AFRICA 22

6. CANCER CONTINUUM OF CARE 24
   6.1. Cancer Surveillance 25
   6.2. Primary Prevention 26
   6.3. Secondary Prevention 26
   6.4. Diagnosis and Treatment 30
      6.4.1. Training of Cancer Health Care Providers 32
      6.4.2. Surgery 32
      6.4.3. Chemotherapy services 33
      6.4.4. Radiation therapy services 34
   6.5. Palliative and Supportive Care 36

7. CONCLUSION AND WAY FORWARD 38

8. APPENDIX A – REFERENCED LEGISLATION AND POLICY FRAMEWORK 39

9. APPENDIX B – REFERENCE LIST 40

10. APPENDIX C – GLOBAL AND LOCAL FRAMEWORK FOR CANCER 47

LIST OF TABLES

TABLE 1: The top cancers for females and males in 2017 14

LIST OF FIGURES

FIGURE 1: Total projected cancer incidence in South Africa, 2019-2030 15
FIGURE 2: Projected total costs to the public health sector, by cancer type, 2019-2030 16
FIGURE 3: An Analysis of the cancer continuum of care in South Africa 24
FIGURE 4: Money (in USD) required to finance elimination of cervical cancer 27
FIGURE 5: The investment required for cervical cancer elimination 28

ACRONYMS

A2M Access to Medicine
AGYW Adult Girls and Young Women
ASK Positive Attitudes, Appropriate Skills and Knowledge
CHW Community health workers
EML Essential Medicines
HBV Hepatitis B Vaccine
HCP Health care professionals
HPV Human papillomavirus
IAEA International Atomic Energy Agency
ICESCR International Covenant on Economic, Social and Cultural Rights
IUCC International Union of Cancer Control
LINAC Linear accelerator
LMIC Low-to-Middle-Income-Countries
MACC Ministerial Advisory Committee on Cancer Prevention and Control
MDT Multi-disciplinary team
NCCN National Comprehensive Cancer Network
NCCP National Cancer Control Plan
NCD Non-communicable disease
NCR National Cancer Registry
NCSF National Cancer Strategic Framework
NdH National Department of Health
NHI National Health Insurance
DISCLAIMER

We have obtained information from various sources as quoted to ensure that this document is correct at the time of publishing and have sought to ensure accuracy in this report to the best of our abilities through a process of peer review.

All references were checked for accuracy and availability on websites where applicable at the time of publication. Cancer Alliance cannot accept responsibility for links to references that are no longer available.

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CONFLICT OF INTEREST

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- ICON
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- National Council Against Smoking
- People’s Health Movement SA
- People Living With Cancer
- Project Flamingo
- Pink Trees for Pauline
- Reach for Recovery
- Rural Health Advocacy Project
- South African NCD Alliance
- Salomé Meyer
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- Vrede Foundation
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Cancer incidence is rising globally but proportionally faster in Low-to-Middle-Income-Countries (LMIC) where already approximately 70% of cancer related deaths are recorded. This Cost of Cancer report by the Cancer Alliance represents a compelling and well researched description of the current and projected cost of this cancer burden in South Africa. The cost of cancer is measured, not only in terms of Rands and cents but importantly, also the cost of the human lives affected and lost and the related impact this has on individuals, families and communities.

Infectious diseases such as HIV, TB and in the last 18 months, Covid-19, have already stretched and tested and, in some areas nearly collapsed, parts of the South African health system. In this context, a projected increase in cancer incidence from approximately 80,000 cases per year to over double this in 2030 is sobering. Treating cancer appropriately requires investment in specialised equipment, procurement of necessary drugs, training of skilled and specialised health workers and functional health systems to ensure secondary prevention. It also requires early diagnosis, treatment and support for survivorship and palliative care. To meet this need, the report projects that an additional R50 billion will be needed for cancer care by 2030.

The Cost of Cancer Report not only sounds the alarm in terms of the future of cancer care in South Africa. It also highlights the current and ongoing inequities in access to quality cancer care. Of the 200 radiation oncologists in the country, only 44 are employed in the state sector, a shocking indicator of disparities in the capacity to deliver cancer care.

The inequitable distribution of resources between public and private health sectors extends to other categories of health workers such as nurses, pharmacists, radiographers, physiotherapists, lymphoedema specialists, palliative care nurses and other critical human resources.

Even within the private sector, patients receive different standards of care depending on the specific medical insurance package they can afford and many are subjected to crippling co-payments to complete their treatment. Within the public sector, urban-rural and interprovincial disparities continue to disadvantage marginalised communities particularly in accessing specialised cancer care.

But this report is not simply a campaign for an extra R50 billion as a vertical investment in cancer. It recognises that the full continuum of cancer care can only occur within a health system that focuses on primary and secondary prevention, has strong referral pathways and has robust systems for education and training all health workers, not only those traditionally associated with cancer care such as oncologists and surgeons.

A particularly compelling call is made for the integration of cancer symptom recognition, survivorship and palliative care into the training of community health workers. After all, cancer patients are the same citizens who are at risk from diabetes, hypertension, HIV and TB, and an integrated, rather than disease specific approach, is not only logical but also cost effective.

The Cost of Cancer Report frames the need for standardised, quality cancer care within the constitutional right to health, highlighting that inequitable access means a violation of that right. The call is for a coming together of government and civil society partners, and health workers in public and private sectors, all centred on the patient voice, to create a road map for achieving quality, standardised and equitable access to cancer care for all.

We need a road map that goes beyond a policy framework and includes a detailed plan for funding, human resources, health system strengthening, and education across the continuum of cancer care.

Writing this foreword at the peak of the 3rd Covid-19 wave in South Africa feels like either the worst or the best possible time to make this call as the pandemic demonstrates simultaneously the deep fault lines and weaknesses of our health system but also the tremendous commitment and dedication of our health workers and resilience of some of our health systems.

Health workers and systems which, with support, good governance and appropriate resources, could bring this committed energy to the treatment of the tens of thousands of cancer patients who are in need of our best care.
**FOREWORD**

The scourge of cancer in South Africa is picking up speed. The rate of death from cancer continues to rise among both men and women, among all racial groups, and for many types of cancer, such as breast, prostate, colo-rectal, and lung cancers. Now that HIV positive patients have near normal lifespan, due to ARV treatment, we see more non-HIV defining cancers in the majority of our HIV positive patients. Unfortunately, this group of patients is excluded from most cancer treatment clinical trials. This anomaly needs to be addressed by public-private-patient partnerships which should steer cancer treatment research to include more HIV positive patients.

This report comes at a crucial time, when we need to be proactive if we want to turn this tide. If we don’t invest in personnel training and in cancer treatment research now then we are doomed. This report calls upon all stakeholders to prepare for the cancer war ahead. This steady increase in mortality from cancer reflects a lack of prevention and screening initiatives, and it also reflects poor diagnosis and lack of innovative treatment options. If nothing is done now, we will be engulfed by this cancer wave. This report is a clarion call for all stakeholders, both in the private and public sectors, to invest in cancer prevention, screening, and management.

This report is a call to action to the following vital areas of the cancer fight: prevention, early detection, diagnosis, treatment, life after cancer, and end of life. Government cannot do all this alone; it needs partners. Prevention of cancer requires lifestyle changes which should be voluntary, hence public education is a must. Early detection requires screening where applicable, and this needs government willingness and public education. Cancer diagnosis is crucial and health personnel training together with improved innovative ways of diagnosis are required. Cancer treatment has become so expensive that it is unaffordable, hence research investment by stakeholders is crucial. Life after cancer should be driven by survivor advocates who must be part of mass education and support groups. End of life involves preparing patients and families for the death from cancer of the loved ones, and here psychologists have an important role to play.

Proper planning and evidence-based cancer management is the key. This highly recommended report gives us both the data and the correct interpretation of this data. The projections are in keeping with what is seen in different clinics in South Africa. Let this report be the start of better planning and better utilisation of available evidence.

It is a proud moment for us to release our next report – Cost of Cancer: Challenges for the next 10 years, after 10 years of advocacy about cancer access. It forms part of a series of reports that we commissioned and developed to speak to the major challenges we face within the cancer landscape in South Africa.

The focus of these publications have been structured to give a broad spectrum view of the cancer challenges but more importantantly the reports have their foundation in scientific methodology. This will enable the development of creative, innovative ideas and solutions to the complexities that embrace the cancer care landscape within South Africa.

We see ourselves as the “Voice of the Cancer Community”. More particularly, we are the voice of cancer patients and their families who are dependent on cancer services provided within our inequitable two-tiered health care system – the public sector servicing 50 million of our 58 million population and the remaining 8 million who use private sector medical aid funded cancer services.

The main focus was to research the burden of disease in order to determine the associated costs with the projected increase in cancer incidence. With collective contributions we were able to contact Percept, a multi-disciplinary consultancy. A standardised Cost of Cancer Model is now available for cancer care units to plan effectively for cancer services to 2030. It is very clear from the Percept Technical Report and this Advocacy Report that we are facing a different pandemic.

Funding needs for cancer service can now be modelled and can assist clinical staff, health administrators and politicians to use validated peer reviewed data as the foundation to re-engineer of cancer services effectively for the future. In addition, the audit of childhood cancer services in South Africa, undertaken by St Jude will add to the body of evidence for effective forward planning. We cannot continue with what we have, as current cancer services are fragmented, inequitable and indifferent to needs of people being diagnosed and treated with cancer.

South Africa has the knowhow and resources to do better for its people. With collective effort we can utilise our legal framework, technology and human resources to enable equitable and affordable access within the proposed NHI and realise Universal Health Coverage.
The Cancer Alliance will remain vigilant in its effort to mobilise all stakeholders to become part of innovative think tanks that will focus on reshaping the cancer landscape in South Africa. We have to ensure that the human rights of all cancer patients are being protected. Cancer services must be delivered in an ethical manner, focusing on early detection and timeous treatment. With the use of technology and innovation we can provide cost-effective and patient-centred access for all.

We call on all stakeholders to become part of the innovation and re-engineering of Cancer Services in South Africa. Together with our partners, we remain committed to being the watchdog for cancer services in South Africa.

If you want to be part of this call: contact us at info@canceralliance.co.za
1. THE CANCER ALLIANCE

The Cancer Alliance is a group of non-profit organisations and advocates for the prevention and control of cancer. Its mandate is to provide a collaborative platform for cancer civil society to speak with one voice and thus become a powerful tool to affect change for all South African adults and children living with cancer.

The Cancer Alliance is a member of the Fix the Patent Law Campaign which focuses on the call for patent-law reform. The Access to Medicine Campaign, also known as the A2M Campaign of the Cancer Alliance is funded by the Open Society Foundation.

2. EXECUTIVE SUMMARY

In April 2019, the Cancer Alliance joined forces with the Treatment Action Campaign (TAC) to host a civil society stakeholder meeting to join in the fight back against cancer. The notice indicated “People are dying in increasing numbers. Medicines are too expensive and treatment and care seems to be only for the rich”. Mark Heywood, one of the founders of the TAC and facilitator of the meeting, noted that “Cancer is the new HIV”. At a follow-up meeting to discuss the way forward the challenge was clear – we needed facts to base our joint collective focus on this cause – and the Cancer Alliance took responsibility for gathering these facts.

We embarked on a very ambitious research path to predict the cancer increase with the associated costs for the next 10 years with Percept. Our expectation was to have this study completed in 2020 to initiate discussions with Treasury and the National Department of Health on the way forward. Covid-19 interrupted our plans and is expected to have an effect on how most of us will relate to health issues in the future.
3. THE CANCER BURDEN IN SOUTH AFRICA

3.1 - ASSUMPTIONS

In 2011, the Cancer Registration Regulation 380 of the National Health Act 61 of 2003 was promulgated as part of the health legislation to make cancer a registerable disease. The National Cancer Registry (NCR) currently only uses pathology-based data to record cancer incidence in South Africa, a practice which effectively results in underreporting. The most recent report available is from 2017, when the cancer incidence was recorded as a total of 81,607 cases. This is 7,030 cases more than in 2014.

In 2003, the National Health Register (NHR) was implemented with the aim of making pathology data the dominant source of cancer incidence information. However, due to the reluctance of some laboratories in the private sector to participate, the NCR data is still significantly underreported. The most recent NCR report available is for 2017.

The stand-alone Technical Report (packaged with this report) comes with an associated actuarial modelling tool which will allow the Treasury and Health departments to plan ahead. The focus of the advocacy report is to specifically highlight the issues that require attention.

For each of the six cancers, the burden of disease for South Africa has been projected from 2019 through to 2030. The estimates focus only on new cancer cases (incidence), as this is the only data available.

3.2 - PROJECTED CANCER INCIDENCE

The Cancer Alliance commissioned Percept in 2020 to research the burden of disease for cancer and project the estimated costs associated with the increase in the projected burden. The study focused specifically on cervical, breast, prostate, lung, haematological and childhood cancers.

The stand-alone Technical Report (packaged with this report) comes with an associated actuarial modelling tool which will allow the Treasury and Health departments to plan ahead. The focus of the advocacy report is to specifically highlight the issues that require attention.

For each of the six cancers, the burden of disease for South Africa has been projected from 2019 through to 2030. The estimates focus only on new cancer cases (incidence), as this is the only data available.

### TABLE 1: WEIGHTING OF INCIDENCE DATA SOURCES FOR PUBLIC SECTOR

<table>
<thead>
<tr>
<th>#</th>
<th>FEMALE</th>
<th>NEW CASES</th>
<th>% OF ALL CANCERS</th>
<th>MALE</th>
<th>NEW CASES</th>
<th>% OF ALL CANCERS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Breast</td>
<td>9,624</td>
<td>23.11</td>
<td>Prostate</td>
<td>8,937</td>
<td>22.37</td>
</tr>
<tr>
<td>2</td>
<td>Cervix</td>
<td>6,600</td>
<td>15.85</td>
<td>Colorectal</td>
<td>2,182</td>
<td>5.46</td>
</tr>
<tr>
<td>3</td>
<td>Colorectal</td>
<td>1,981</td>
<td>4.76</td>
<td>Lung</td>
<td>1,879</td>
<td>4.70</td>
</tr>
<tr>
<td>4</td>
<td>Uterus</td>
<td>1,570</td>
<td>3.77</td>
<td>Non-Hodgkin’s Lymphoma</td>
<td>1,380</td>
<td>3.45</td>
</tr>
<tr>
<td>5</td>
<td>Lung</td>
<td>1,055</td>
<td>2.53</td>
<td>Melanoma</td>
<td>1,187</td>
<td>2.97</td>
</tr>
<tr>
<td>6</td>
<td>Non-Hodgkin’s Lymphoma</td>
<td>1,128</td>
<td>2.71</td>
<td>Bladder</td>
<td>1,018</td>
<td>2.65</td>
</tr>
<tr>
<td>7</td>
<td>Melanoma</td>
<td>1,024</td>
<td>2.46</td>
<td>Oesophagus</td>
<td>1,007</td>
<td>2.52</td>
</tr>
<tr>
<td>8</td>
<td>Oesophagus</td>
<td>787</td>
<td>1.90</td>
<td>Kaposi’s Sarcoma</td>
<td>986</td>
<td>2.47</td>
</tr>
<tr>
<td>9</td>
<td>Ovary</td>
<td>590</td>
<td>1.42</td>
<td>Stomach</td>
<td>827</td>
<td>2.07</td>
</tr>
<tr>
<td>10</td>
<td>Kaposi’s Sarcoma</td>
<td>578</td>
<td>1.39</td>
<td>Larynx</td>
<td>482</td>
<td>1.21</td>
</tr>
</tbody>
</table>

From these figures, it is not possible to determine how many patients received treatment in the public and private sectors respectively. The NCR receives the figures for cancer incidence in the public sector through pathology reports from the National Health Laboratory Service (NHLS). Several factors make reporting from the private sector more complicated, however. In the private sector, reports are received from many laboratories in the private sector, such as Ampath, Lancet and many smaller laboratories that render the reporting system fragmented. In addition, this reporting system is still paper based; private medical practitioners have little time to spend on administrative tasks, and the reported information is, therefore, not always comprehensive.
3. THE CANCER BURDEN IN SOUTH AFRICA

The Technical Report focuses on the costs of providing treatment for those who currently rely on the public sector for health care and are expected to need cancer treatment in the future, as compared to the 2020 baseline spending for those receiving care. This provides both the National Treasury and the NDhO with the first evidence-based model to cost the need for cancer treatment and services from 2021-2030. The report, however, does not take into account the number of dependants that will be added to the public sector once the NHl is implemented as there is not yet any clarity regarding medical schemes and their continuation within an NHl.

The costs associated with the increased burden for the public sector alone are reflected in Figure 2. The total cost reflects an investment of R50 billion over a 10-year period. This amount may, at first, sound enormous, but it is less than half of the R105.8 billion in medical legal claims paid out by the Provincial Health departments 2019/2020 alone.16 With proper planning and control measures it is not an impossible task to dramatically reduce these claims and free up the money needed for cancer treatment.

4. INVESTMENT IN CANCER IS A HUMAN RIGHTS IMPERATIVE

Chapter written by Baone Twala, Section27 and Salomé Meyer.

The South African government’s current approach to cancer policy development and implementation is sluggish and insufficient. Covid-19 has highlighted and exacerbated these issues and has overshadowed an already under-valued cancer policy reform agenda.

Government has a legal obligation to ensure the realisation of the right to access healthcare services by taking reasonable steps to this end. This obligation includes reform in both policy development and implementation.

A human rights-based approach to cancer would improve policy development and implementation; and ensure equality and access to services. Firstly, it would include updating current cancer policies and finalising the creation of cancer-specific policies through a transparent and participative process. Secondly, it would require streamlining public health finance for cancer programmes. And finally, it would require implementation of cancer programmes to meet needs and realise rights.

Taking such an approach would ensure the enjoyment of the rights to equitable access to healthcare services for people at risk or living with cancer.

4.1 - THE LEGISLATIVE FRAMEWORK

The Constitution enshrines everyone’s fundamental right to equality before the law and the enjoyment of all rights.17 This right includes the right not to be discriminated against. The Constitution also recognises and upholds the right to access healthcare services, which the state has an obligation to respect, protect, promote and fulfill.18 The right to healthcare is indivisible from the right to equality.

An example is in National Coalition for Gay and Lesbian Equality and Others v Minister of Home Affairs and Others 2000 (2) SA 1 (CC) where the Constitutional Court stated that an infringement of one right (“right A”) is indivisible from the right to equality, where the infringement on “right A” is comparably serious and where the individual belongs to a group that was previously disadvantaged. The State’s obligation is to take legislative and other measures to ensure that constitutional rights are respected, protected, promoted and fulfilled. Fulfilment of the state’s obligation is subject to the resources available to it, but the state must take reasonable steps to realise rights and make resources available. Rights may be justifiably limited, but such a limitation must satisfy a legal test to this effect.

In health, the National Health Act (NHA) 61 of 2003 and policies and programmes developed under that legislation are the starting point for the “legislative and other measures” that government must take to realise the right to access healthcare services.19 Simply passing legislation and policies is not enough. The Constitutional Court has found that the financial and human resources required for implementation must also be allocated to render the measures lawful, stating:

A reasonable programme therefore must clearly allocate responsibilities and tasks to the different spheres of government and ensure that the appropriate financial and human resources are available.
4. INVESTMENT IN CANCER IS A HUMAN RIGHTS IMPERATIVE

In addition to its own law, South Africa is party to international agreements that uphold the right to health. The International Covenant on Economic, Social and Cultural Rights (ICESCR) and the African Charter on Human and Peoples’ Rights recognise the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health”, to access to healthcare when needed; and places a duty on states to progressively take steps for the realisation of the right to health and access to healthcare\(^{(6)}\). It has also been acknowledged that:

\[\text{Human rights are interdependent, indivisible and interrelated. This means that violating the right to health may adversely impact the enjoyment of other human rights…} - \text{UN Office of the High Commissioner for Human Rights (OHCHR)~(A8).}\]

Equity and non-discrimination are key principles which are critical to the realisation of the right to healthcare services. Equity includes equality of opportunity and timely access to medicines\(^{(10)}\). Non-discrimination means that a person should not be discriminated against for any reason that effectively impairs or nullifies the enjoyment of their rights\(^{(8)}\). In relation to the right to health, historically marginalised groups in society are likely to suffer ill health or infringement of their right to health. In South Africa this includes groups historically marginalised due to race, sex and socio-economic status. A poor quality of healthcare services creates an added level of discrimination for people in these categories\(^{(8)}\). People at the centre of these overlapping and compounding elements of disadvantage make up most public health care users in South Africa.

Thus, the international, regional and domestic legislative frameworks recognise the right to health, the right to access healthcare services, and the State’s obligations to respect, protect, promote and fulfil the right to health progressively. Government is required to invest policy making, developmental, financial and human resources toward realising the right to health and access to healthcare services.

Currently, South Africa’s public healthcare system is failing to fulfil the right to access to health for cancer patients in South Africa. This failure is largely due to issues with policy creation and implementation, and the structure of public healthcare as well as the current funding model of healthcare in South Africa.

4.2 - THE POLICY FRAMEWORK

Currently, South Africa’s only policy framework on cancer comprises the Cervical Cancer Policy, Breast Cancer Policy and Palliative Care Strategic Framework. Despite the many calls of Civil Society for the development of a National Cancer Control Plan, only a Strategic Framework for Cancer Prevention and Control has been approved\(^{(9)}\).

Incidence projections are based on two main assumptions:

- The Cervical Cancer Policy\(^{(4)}\) was developed in 1998 and is the only cancer policy implemented in all provinces. It was updated in 2017 to make provision for screening HIV positive women, HPV vaccination, LBC cytology and HPV screening. These policy imperatives have not yet filtered down to provincial health departments.

- The Breast Cancer Policy\(^{(3)}\) was developed and approved at national level in 2017. It is yet to be approved and implemented by the nine provincial health departments, and there are inequities in breast health services between provinces. Some provinces have access to Special Breast Units that can diagnose and fraige patients for further treatment. Some provinces provide access to specific medicines, such as trastuzumab, that can treat specific breast cancers while provinces such as Western Cape regard this as an unfunded mandate. Women that have had breast amputations through mastectomies are not entitled to a breast prosthesis even though a limb amputee is entitled to a prosthesis.

- The Palliative Care Strategic Policy Framework\(^{(3)}\) was also developed and approved in 2017. It is specifically designed to deal with the very sensitive management of dread diseases from diagnosis until the end of life, within communities as most patients with dread diseases will die in their own homes. Because the framework has not been implemented, there rests an onus upon us to ensure that we will provide the appropriate care for people in their last phase of life, ensuring a dignified death and including access to pain medication and palliative care services at community level. The policy framework is yet to be implemented in the provinces, thus affecting many patients’ right to access palliative care including pain medication at end-of-life.

A number of other policies remain at the development stage, including the Prostate Cancer Policy; the Childhood Cancer Policy and the Lung Cancer Policy.

- The Prostate Cancer Policy has been on the drafting table for nearly four years. Lack of funding to determine the costs of implementation of the policy has delayed its finalisation. All policies have to be costed before they can be approved by the National Health Council. It is likely to be a few more years before this policy will be implemented at provincial level. The research shows that prostate cancer is growing exponentially.

- The Lung Cancer Policy should be finalised in 2021. Funding for policy implementation, however, remains an issue at provincial health level.

- The Childhood Cancer policy development process will hopefully be initiated in 2021.

We thus have an incomplete policy framework with policy implementation lagging even further behind.
4. INVESTMENT IN CANCER IS A HUMAN RIGHTS IMPERATIVE

4.3 - LEGISLATIVE AND OTHER MEASURES

What, then, would be required to meet government’s obligation to take legislative and other measures to realise the rights to health and equality of people with cancer?

While a move towards NHI is government’s ultimate goal, implementation thereof seems some way off and the extent to which NHI and related legislation would cater for cancer services at different levels of the health care system is unclear and cannot be relied upon.

We need legislative and policy certainty in relation to cancer, now and in the future.

The rule of law is a democratic principle that requires policy makers to review the laws, policies and processes in place to ensure an enabling environment for the realisation of the right to access to healthcare. Policies must be in line with the constitutional framework and must provide for emergency situations and for the needs of the most vulnerable.1,2

While not in themselves sufficient to realise rights, law and policy play an important role in developing the content of rights. The obligation to take legislative and other measures for cancer requires as a start, the review, updating and finalisation of cancer-related policies.

4.4 - IMPLEMENTATION THROUGH CO-OPERATIVE GOVERNANCE

Policies are developed by the NDoH in consultation with provincial health departments. All policies must be costed before submission to the National Health Council which comprises all nine provinces’ MEC’s for Health as well as the Heads of Departments.

Once approved at this level it is expected that policies will be implemented by the provincial health departments. The problem is that human and financial resources are often not made available for policy implementation.3,4

A human rights approach to cancer would require national and provincial departments of health to work together in policy development and to ensure that the financial and human resources that are required for implementation are available equitably across all provinces.

4.5 - FOSTERING HEALTH LITERACY, DEMAND AND IMPLEMENTATION

Community leaders, health activists and community health workers play a pivotal role in translating policy into understandable language. Cancer prevention, early detection and treatment all rely on such accessible information and on the availability of care. These stakeholders are also responsible for monitoring and evaluation of policy implementation at community level.

4.6 - INVESTMENT IN THE LEVELS OF CARE REQUIRED TO REALISE THE RIGHT TO ACCESS HEALTH CARE SERVICES

Cancer cannot be managed at primary health care level only. It requires an integrated approach across the cancer continuum of care. The National Cancer Strategic Framework for 2017-2022 describes the role and requirements of each of the different levels of care as well as the specific relationship between them. However, we need to go further than the description. It is only through re-engineering a plan for developing, establishing and funding the required levels of care that the right to access health care services for people with cancer can be realised.

No substantial progress has been made to address these critical but dysfunctional systems. The result is that oncology services are at a critical point of disaster. Urgent redesign and re-engineering is required to find innovative strategies and interventions to address this emergency with immediate effect. This needs to be done by developing a national emergency plan for developing, establishing and funding of cancer services across the required levels of care. The new cancer care model will have to ensure that the right of people with cancer to access health care services can be realised going forward for the next 20 to 30 years.

If constitutional and human rights obligations to people with, and at risk of cancer are to be met, more than a collection of policies are required. Government has an obligation to develop law and policy within the constitutional framework; to fund the implementation of those laws and policies; and to ensure their implementation. Investment (of time, human resources and money) in cancer is a human rights imperative to serve all South African equitably.

Broad participation is vital for the implementation of prevention strategies. South Africa has been very successful in primary prevention strategies such as tobacco control, sugar taxation, HBV vaccination, food labelling and the recent HPV vaccination. Secondary prevention strategies include awareness and education, early detection, and screening. While the successful primary prevention strategies operate at national level, the secondary strategies must operate provincially and require allocation of financial and human resources.

Civil society organisations can be partners in this work, but they cannot remain largely responsible for the work, particularly in the absence of funding from government. Participation of, and real partnership with, affected people is key to implementation.
5. CANCER CARE IN SOUTH AFRICA

Cancer is a specialised, non-communicable disease (NCD). It is one of the most expensive NCDs to treat, requiring various treatment modalities and highly technical specialist care. While there have been major advances in treatment outcomes during the last 20 years, these are offset by major disparities between high income and low-income countries. Nearly 70% of cancer-related deaths occur in LMIC countries. There has been a major focus on the prevention of cancer from the International Union of Cancer Control (UICC), and the American Cancer Society, UN agencies such as the WHO (together with the International Atomic Energy Agency (IAEA) have pushed for the integration of cancer control planning by countries to effectively manage cancer across the cancer continuum of care. Sadly, despite various calls from civil society since 2002, South Africa still does not have an approved National Cancer Control Plan (NCCP) that will allow for effective planning for cancer. In 2017 the NDoH published the National Cancer Strategic Framework which does not allow for a legal framework for cancer care.

We are lagging behind other countries, such as the United States of America which passed its National Cancer Act in 1971 in an attempt to ensure integrated planning and management of cancer. Japan first developed a 10-year Comprehensive Cancer Strategy in 1984 and in 2007 implemented the Cancer Act after a call from civil society and survivors to heed their “right to health”. South Africa is on a similar path to Japan.

One of the stumbling blocks to coordinated cancer care is the current delegation of power in South Africa. The NDoH only has the authority to develop health policies with the associated guidelines and standards and to monitor the performance of health services across the different provinces. Provincial Health Departments, on the other hand, must deliver health services in their specific areas of jurisdiction. This delegated authority to provinces presupposes that they must budget sufficiently for their services, and implement policies in accordance with the need of the specific province.

The interpretation has a negative impact, as provinces may not necessarily understand their human rights obligation and thus cut the cloth according to their budget allocation which in turn leads to inequitable services between provinces. The cervical cancer policy has been implemented since 2000 and thus has an algorithm for primary health care clinic services. The recent breast and palliative care policies have not been incorporated into the Ideal Clinic Framework, again leaving cancer care behind. The reality is that cancer is a disease that spans over nearly 200 different cancers so developing a cancer policy for each of the different cancers is clearly an impossible task. The requirement would rather be for the urgent development of standardised care for the different cancers and the different treatment modalities to ensure that everyone has access to equitable health care services irrespective of whether accessed via private or public health systems. The question, however, is whose responsibility it would be to develop and approve such standard of care policies and guidelines in an NHI. The current health system allows for different standards of care between provinces in the public sector, and different standards of care in the private sector between managed care organisations as well as the 78 different medical schemes.

The inequities and inequalities between the public and private sector are a stark reality, as was highlighted in the Cancer Alliance’s Advocacy Toolkit released in 2017. The lack of a dedicated legislative framework regulating how cancer should be managed on an equitable basis impacts policy implementation at a provincial level in the public sector. Because there is no standardised document that details what the cancer policy implications are, the onus falls on provinces to devise their own implementation strategies and to provide the associated human and technical resources. The logical consequence of a policy, once adopted, would be that provinces have to make provision for the deployment of trained human resources and equipment at all levels, including diagnostic services. Additionally the allocation of appropriate budget to sustain treatment services across the cancer continuum of care would be required. This aspect is lacking in most of the provinces and requires urgent intervention if the projected cancer incidence increase is to be managed effectively.

Cancer care in the private sector, on the other hand, is within the hands of private sector practices that are mainly situated in the main centres of the various provinces. Although they only serve 16% of the population, more than 80% of the country’s oncology specialists are accessed by private patients who contribute to medical schemes. This sector is also plagued with inequities within the various oncology benefit packages, between the various schemes and between the two managed care organisations. A dedicated research report on this sector will be published shortly by the Cancer Alliance.

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6. THE CANCER CONTINUUM OF CARE

It is well recognised that the cancer continuum of care is the pathway required for the effective management of the disease. This continuum of care also spells out the various areas of focus and responsibility levels and eases the referral pathways and assignment of health care professionals for each phase of the continuum. The cancer continuum of care speaks about seven specific categories ranging from aetiology (describing the primary causes of cancer); primary prevention (mainly associated with legislative frameworks across all sectors of government); and secondary prevention (focusing on cancer awareness and early detection strategies, including the education and screening of the general population).

Early detection and screening takes place at primary health care level and aims to ensure that cancer is detected at an early stage, rather than a more challenging late stage of disease. This requires a clear referral pathway from the primary health care level to the next level of care for diagnostic services. Standardised guidelines ensure that the referral pathways and methods of treatment are compliant with the length of time between the various categories of the continuum. In the private sector it takes less than 14 days from screening to treatment. In the public sector this can be anything from one month to nine months and longer depending on where the patient lives[7]. To ensure that the patient’s treatment outcomes are met, it is vital that each patient is subjected to a treatment plan that is compiled by a multidisciplinary team consisting of specialists across the three modalities of treatment – namely surgery, chemo and radiation therapy. Currently this is not happening between the various levels of care, resulting in considerable delays. These delays impact the potentially curative nature of an early-detected cancer and can radically impact the patient’s survival.

Cancer patients are followed up at their specific specialist treatment centres. But referral back to the community primary health care clinic for monitoring and evaluation in terms of survivalship, palliative care requirements and end-of-life care support is an important part of the health care system that is completely ignored. This is an aspect that needs attention to ensure that the cancer patient is integrated into the health care system and managed appropriately. Cross-cutting areas that need to be included at each point on the continuum are: epidemiology, communications, quality of care, attention to health disparities and decision making. It is a useful framework to map our plan, measure our progress and determine our priorities.

6.1 - CANCER SURVEILLANCE

The core function of cancer surveillance is the measurement of incidence, morbidity, survival and mortality for people with cancer[8]. Effective disease control and management is dependent on the surveillance and monitoring systems that are implemented. It is a truism that what gets measured gets done, and equally what is not counted does not matter. The current manner in which cancer surveillance is conducted bears evidence to this. It is imperative to measure what matters to the patient and the system in order to improve on what we have. This will provide policy and decision makers with the information required to make informed decisions about the specific disease[9].

Cancer surveillance in South Africa has been part of the NHLS’s National Cancer Registry since the early 1980’s[10]. In 2011, the Cancer Registration Regulation[11] was promulgated, allowing for a pathology-based register as well as population-based registries. The regulation however, does not make the person diagnosing cancer responsible for registration, thus delegating the responsibility to a person who has no interest in the planning and management of the disease. Not all cancers are diagnosed with pathology, with the result that those particular cancers are not being recorded. The way in which mortality or death data is captured in South Africa contributes to the underreporting of many cancer deaths. Data is not submitted electronically which makes it difficult for the private sector to participate in this registry. Nevertheless, the registry does provide some insight to the cancer burden in South Africa.

Accurate information regarding incidence, management of the disease across the cancer continuum of care, survival and death data is required for monitoring and evaluation of effective cancer control. We do not have any of these. Data on diagnosis and staging of patients and how soon they are treated will reveal the effectiveness of secondary prevention measures as well as the referral pathway. Survival data after treatment will inform us about the effectiveness of treatment, how the patient is living with their cancer and adapting to the challenges they face. Cancer surveillance should provide a quantitative portrait of cancer and its determinants in a defined population.

The funding of a cancer registry remains a primary function of government. Hospital and treatment facility-based cancer registries should be compulsory to ensure that data across the cancer continuum is recorded and maintained. It is concerning that the budget allocation of the NCR has been decreased – thus affecting our ability to report on cancer incidence even further. Act 1 of 2020 established a new authority that will be responsible for disease surveillance and will inform planning and budgeting for effective management at national and provincial level[12]. There is still no clarity on when and how this new body will become a reality and how cancer surveillance will fit into this structure. It is evident that we may once again have a brilliant policy hampered in effectiveness by a lack of implementation. Additionally, we need to support the acquisition of South African peer-reviewed data which has been collected in line with quality assurance measures.

If we want to successfully control and manage cancer, we will have to ReThink- ReDesign- ReEngineer our surveillance system to be an integrated system across the continuum of care.
6. THE CANCER CONTINUUM OF CARE

6.2 - PRIMARY PREVENTION

South Africa has been successful in the implementation of Primary Prevention Strategies with the following:

- Tobacco Control Act, Act 83 of 1993[^23] It is however, concerning that tobacco continues to pose the biggest threat as a causative cancer factor[^24]. It is widely recognised that stopping smoking is one of the most important ways to reduce deaths from non-communicable diseases. The smoking trend amongst different population groups and its effect were recorded in 2012, highlighting the need for intervention strategies[^25]. There is only one tobacco cessation clinic in South Africa, and even this is unfunded[^26].
- HBV vaccination since 1995[^27]
- HPV vaccination since 2016[^28]
- Tobacco and Alcohol Taxation since the early 1960’s[^29] Interesting that no African country to date has used monies collected from sin tax for health. The total amount collected from Sin Tax in 2019/2020 was R14.5 billion[^30]. In comparison, tobacco’s cost to the economy is still R42 Billion per year[^31].
- The Health Promotion Levy since 2017[^32] Once again, the amount used for health is minimal[^33].

6.3 - SECONDARY PREVENTION

Most secondary prevention activities are conducted and self-funded by cancer non-profit organisations in South Africa. No subsidies are made available to do crucial work. Unlike with HIV/AIDS and TB, cancer is not regarded as a priority disease of focus. This is confirmed in the non-negotiable list of the goods and services budget, where AIDS and TB are specifically highlighted thus strengthening the silo approach[^34].

The implication is that health promotion activities assigned to the NDoH and community health workers (CHWs) are only assigned to HIV/AIDS and TB. CHWs are not trained in cancer early warning signs and symptoms. Non-profit organisations do not have the same footprint as the CHWs assigned to primary health care clinics. NCD education and monitoring should become part of the curriculum of CHWs who are the foot soldiers who ensure that communities are well informed and are able to access secondary prevention strategies such as earlier screening to detect cancer. Traditional healers should also be included in health education and awareness training, given the importance of this cadre of health care workers in the various populations represented in South Africa. This would also contribute to reducing cancer stigma.

An additional factor is that health-seeking behaviour in men is poor. Given our patriarchal society, there is little room for education and awareness-creation by women in the household or even in the community.

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[^A10]: Tobacco Control Act, Act 83 of 1993
[^23]: Tobacco Control Act, Act 83 of 1993
[^24]: Tobacco Control Act, Act 83 of 1993
[^25]: Tobacco Control Act, Act 83 of 1993
[^26]: Tobacco Control Act, Act 83 of 1993
[^27]: Tobacco Control Act, Act 83 of 1993
[^28]: Tobacco Control Act, Act 83 of 1993
[^29]: Tobacco Control Act, Act 83 of 1993
[^30]: Tobacco Control Act, Act 83 of 1993
[^31]: Tobacco Control Act, Act 83 of 1993
[^32]: Tobacco Control Act, Act 83 of 1993
[^33]: Tobacco Control Act, Act 83 of 1993
[^34]: Tobacco Control Act, Act 83 of 1993
6. THE CANCER CONTINUUM OF CARE

The referral pathway also has to make provision for the referral back to the primary health care level to ensure that patients comply with their follow-up care and are appropriately supported in their own communities. Survivorship management should be based on a standard reporting form that links primary health care clinics with tertiary treatment centres.

In the private sector, screening for certain cancers such as cervical, breast and prostate cancer are linked to loyalty programmes. Baseline screening for cancer is low and these were even impacted more as a result of Covid-19 lockdown. Discovery Health recorded an overall 16% drop in cancer screening in 2020, with a specific drop of 17% for breast cancer and 18% for cervical cancer. An increase in cancer recorded at late stage of disease (Stage 4) was also recorded. Medscheme and GEMS reported similar trends.

Timely cancer screening is associated with health care professionals who have positive attitudes, appropriate skills and knowledge (known as ASK). Many patients are faced with the attitude that timely screening is not part of the normal visit of a patient to their health care provider. It remains a topic that is avoided by both the patient and the health care provider. Only when a patient asks for cancer screening will a health care provider decide if it is warranted. In an ideal situation, health care providers would ensure that cancer screening is performed as a routine standard. Many cervical cancer patients in the public sector who present with signs and symptoms that require follow-up will be turned away on the basis that they have been screened for cervical cancer in the recent past. The cancer curriculum for health care professionals is limited and does not address future needs. It should be revised to ensure that all health care professionals receive appropriate training on the signs and symptoms of cancer.

Ensuring that traditional healers are part of the ASK training for cancer prevention and management will contribute to the destigmatising of cancer in communities. The Childhood Cancer Foundation South Africa (CHOC) has done extensive work with traditional healers which has paid off. This model should be replicated.

The WHO Global Strategy estimates that US$3.20 will be returned to the economy for every dollar invested in health owing to the increases in women’s workforce participation, with this rising to US$26.00 if societal benefits are incorporated. The NHLS together with the NDoH should investigate the cost of HPV testing as the preferred screening method to build an investment case coupled with increased ability to treat cervical cancer at early stage.

Screening for breast, prostate, lung, childhood and haematological cancers at primary health care facilities is dependent on 1) the ability of the health care worker to recognise the early warning signs with which a patient may present at a clinic level and 2) the availability of a clear referral pathway for triaging a patient to the next appropriate level of care. The Ideal Clinic Framework version 19, July 2020 only makes provision under element 65 in the NCD category for diabetes and hypertension.

This effectively negates the clear need for basic screening of cancer by fully qualified health care professionals at a primary care level. The lack of convergence between policy documents in the NDoH needs to be addressed.

For provinces to implement cancer screening effectively, a budget allocation for training health care professionals (HPCs) and CHWs is needed, to ensure that community members are able to do self-examination, where applicable, and patients are properly triaged to the next appropriate level of care for diagnostic screening and treatment. It also requires each primary health care clinic to have the appropriate equipment associated with the specific screening method. Most patients have to return to the clinics for their screening results. Most patients are not followed up properly, contributing to disease spread. By involving CHWs in the follow-up care of potential cancer patients, patient compliance can be achieved and it will further impact the time it will take to refer patients for treatment.

Referral pathways between the Primary Health Care clinics, secondary level diagnostic centres and tertiary treatment centres are not clearly mapped out for each of the cancers. A clear referral pathway needs to indicate the maximum time allowed for the work-up of a patient to each level of care as well as take into account the transport arrangements between the various levels of care, to minimise the out-of-pocket expenditure of patients.
6. THE CANCER CONTINUUM OF CARE

6.4 - DIAGNOSIS AND TREATMENT

Cancer diagnosis is confirmed with a biopsy, endoscopy, diagnostic imaging and blood tests\(^{(31)}\).

All of these require specifically trained health care professionals with specialised equipment. It is crucial that this competency is established in each province to minimise the impact of late diagnosis and referral for treatment. Where diagnostic facilities are not available, Public Private Partnerships (PPP) should be investigated in order to save costs instead of developing new capacity. They should also be developed within a specific framework with the ability to monitor and evaluate the services to curb corruption.

Once diagnosis has been confirmed, staging of the disease must be carried out by a qualified health care worker. Staging should be in accordance with the International Standards. The TNM classification is a unified standard and is a prerequisite for ensuring the quality of care in all resource settings. It goes beyond the clinician’s practice and professionals can communicate the extent of cancer for individual patients as well as a basis for decision making on treatment management and individual prognosis. It can also be used to inform and evaluate treatment guidelines, national cancer planning and research.

More specifically, the objectives of the TNM classification are the following:

- Aid treatment planning;
- Provide an indication of prognosis;
- Assist in the evaluation of treatment results;
- Facilitate the exchange of information between treatment centres;
- Contribute to continuing investigations of human malignancies; and
- Support cancer control activities, including through cancer registries.

The TNM classification is a unified standard and is a prerequisite for ensuring the quality of care in all resource settings. It goes beyond the clinician’s practice and constitutes vital information for policymakers developing or implementing cancer control and prevention plans, hence its need to be incorporated into cancer registration\(^{(32)}\).

Adopting the TNM as the universal standard for staging in South Africa will assist in standardising treatment for oncology patients. It is vital that treatment plans for oncology are determined by a multi-disciplinary team (MDT) that will consist of the specialists in surgery, radiation and chemotherapy from the tertiary treatment centres. Such MDTs should be established for each of the provinces. This will also ensure a seamless transition between the various modalities and the prioritisation of any surgeries required. Ideally surgeries should take place at secondary hospitals at provincial level within a maximum of 8 weeks after diagnosis.

Most cancers are highly treatable at an early stage of the disease, a fact that contributes to a survival rate of five years or more where timely diagnosis and high-quality treatment are applied. Common treatment-related effects experienced by long-term cancer survivors that affect quality of life include bladder dysfunction, bowel dysfunction, sexual dysfunction, lymphoedema and psychosocial problems. Lack of social support, most importantly from spouses, has the greatest adverse impact on quality of life of women cancer survivors in sub-Saharan Africa. Cancer stigma also plays a role. In addition to managing pain and other distressing symptoms, care should encompass psychosocial and spiritual support for cancer patients and their families\(^{(33,34)}\).

The Photovoice Research project\(^{(35)}\) provides us with the lived experiences of 316 cancer patients in South Africa. These voices represent many, and cannot be ignored within the context of the right to health.\(^{(36,37)}\)

It is crucial that palliative care is integrated into the treatment plan and provided throughout the course of the disease. Although the Palliative Care Framework\(^{(38)}\) was approved in 2017, it has still not been implemented by provinces, a fact that highlights the need for convergence between policy development and implementation.

The National Cancer Strategic Framework (NCSF)\(^{(39)}\) set out some milestones for achieving some specific targets. Sadly its assertion that the targets are there for guidance of provinces means that the NCSF is just an exercise on paper and is in fact toothless as the NDoH has no jurisdiction over provinces in terms of implementation of policies. As mentioned earlier, when Japan faced a similar situation, advocacy and activism led to the development of a Cancer Act in 2006\(^{(40)}\). Only with a dedicated Cancer Act were they able to ensure that comprehensive services, including long-term insurance for cancer patients were implemented. We may face the same reality despite the specific legal framework that is in place. An additional concern is that the Labour Act does not make provision for cancer to be regarded as a dread disease. Many cancer patients have to undergo debilitating treatment over a long period. Cancer treatment is toxic, but many patients face financial toxicity as well\(^{(41)}\) with job losses and loss of income.
6. THE CANCER CONTINUUM OF CARE

6.4.1 - TRAINING OF CANCER HEALTH CARE PROVIDERS

Most of the training of health care service providers, including specialised oncology, health care workers, falls under South Africa’s tertiary academic institutions. Health faculties are responsible for the further education and training of health care professionals. Most of the curriculums make provision for the inclusion of cancer in undergraduate programs. This is however very limited and will need to be extended to address the need for improved early diagnosis by all health care professionals. It is vital that this competency be retained and invested in to ensure the next generation of cancer specialists.

Oncology nursing, like oncology social workers and oncology pharmacists are also specialised fields. There however is a severe shortage of both adult and paediatric oncology nurses. Staff retention strategies will need to be developed to ensure a capable workforce.

6.4.2 - SURGERY

Surgical intervention remains the first line of treatment for many cancers. If patients are diagnosed early, surgical intervention can effectively save on further cancer treatments. This is specifically relevant for cervical cancer where patients can be cured. This saving is only possible with specially-trained oncological surgeons and access to facilities at secondary hospital level.

Surgery for breast, prostate and lung cancer also requires specialist oncologic surgeons, who are not always available at all secondary hospitals. Oncology surgeons often have to “compete” with other surgical priorities, resulting to backlogs that can lead to cancer spread. The Amabale Project Flamingo arranges “catch-up” surgeries at two provincial hospitals in the Western Cape to deal with surgical backlogs. This organisation fundraises for the payment of theatre staff on a Saturday, thereby taking over the work that government should be doing. Lack of public funding does not allow for this initiative to be duplicated in other provinces. A total of 738 surgeries have already been performed with their involvement. Similarly, Project Peacock, a new non-profit, aims to support prostate cancer surgeries and brachytherapy for prostate cancer. However, these initiatives are not the solution to the problem. Breast cancer patients in the public service with mastectomies are faced with the reality that their amputation is not recognised as an amputation that requires a prosthesis in the same way as a limb amputation. The devastating impact on women is thus ignored. Again, the non-profit community steps in to fundraise for this service.

Many of the oncological surgeries in the public sector are also faced with the lack of state-of-the-art technology due to their cost. This includes intraoperative radiation therapy for breast cancer and robotic surgery for prostatectomy surgeries, which are available in the private sector and some public facilities. However, lack of funding and forward thinking means that our health care professionals are not adequately trained in these techniques and many patients do not have access to these less invasive treatments.

Provinces need to ensure that the required surgical capacity and appropriately equipped theatres are available to perform the various interventions required for the main cancers and to manage the projected increase in demand.

6.4.3 - CHEMOTHERAPY SERVICES

These services are more readily available at decentralised secondary hospitals in provinces, but some still do not have the competency to provide these services for all types of cancers. Most chemotherapy treatments in the public sector are referred to tertiary hospitals situated in five of the nine provinces. This requires transportation of patients between provinces – a gruelling journey that can start long before dawn and end late at night. Patients, many of whom face language barriers, have to navigate the system themselves as patient navigators are not available.

Chemotherapy admixing requires the recruitment of oncology pharmacists and oncology pharmacy assistants. They require access to a specialised protective environment and clothing in order to tailor-make and dispense chemotherapy dosages for treatments. In South Africa oncology pharmacists have to mix oncology prescriptions of patients but the standards available for oncology pharmaceutical practices are very limited and oncology pharmacy is not a recognised speciality of pharmacy in South Africa. These standards have to be set in accordance with international guidelines and best practise by the Pharmaceutical Council of South Africa.

Qualified oncology nurses administer chemotherapy and monitor patients throughout their therapy in a dedicated, fully equipped chemotherapy ward. There are, however, private sector practices where oncology nurses are mixing oncology prescriptions, which is not compliant with international standards.

Chemotherapy services require a dedicated budget for the procurement of medicines. The Essential Medicines List (EML) determines which medicines are available for cancer treatments in the public sector. There is however no equity between provinces as each province and Pharmaceutical Therapeutic Committee (PTC) of a specific facility may make a recommendation for the buy-out of medicines not on the EML, citing the provisions of Section 21 of the Constitution.

In the private sector, patients have access to medicines in accordance with their medical scheme benefits. These will differ between the various benefit packages and even between schemes. Even the guidelines for oncology treatment set by the managed care organisations are different. These systems are being maintained at a high cost for relatively a small number of patients.

A policy for the treatment of haematological cancers as well as colorectal cancers should be considered to ensure that treatments across provinces are equitable and also to make provision for the prescribed minimum benefits (PMBs) applicable in the private sector. Standardisation of treatment guidelines for the main cancers is therefore an urgent requirement to ensure that all patients can access equitable health care.
6. THE CANCER CONTINUUM OF CARE

The priority needs to be multidisciplinary therapy of localised and locally advanced cancer with surgery, radiation and simple adjuvant hormonal and simple chemotherapy therapy should be prioritised. This approach allows women to save their breast and can thus encourage earlier presentation. World renowned epidemiologist Richard Peto, who worked with Richard Doll on revealing smoking as a cause of lung cancer, also identified tamoxifen as the agent which has saved more lives in oncology that any other drug. It is very cheap – a few rand for a month’s supply.[32]

The Access to Medicine report CA03/21[1] highlighted the specific issues relating to access to cancer medicines and made very specific recommendations for considering cancer medicines within the NHI. Some of the medicines that need to be considered for addition to the EML are lenalidomide, bendamustine, abiraterone and erlotinib. All four products were included on the WHO Model EML in 2019[33].

There is also an urgent need to discuss the concept of value-based care for cancer within the NHI. We cannot perpetuate the inequalities of the current health system by allowing value-based treatment opportunities in the private sector whilst lifesaving treatments remains out of reach for many patients in the private and the public sector. Currently in the private system two managed care organisations are maintained to set standards for oncology care. Each of the medical schemes also have their own oncology benefit sections that evaluate and approve treatment according to their standards of care, resulting in various standards of care for treatment of cancer available in South Africa. A better system would be similar to the National Comprehensive Cancer Network (NCCN) in the USA.[34]

As a starting point, the value-based care discussion should investigate specific medicines and diagnostic tests associated with the cancers. Specific criteria for value-based treatments and specific diagnostic tests should be set, and these should be the same for all patients, regardless of their ability to pay for treatment. Patient selection should be submitted to an independent body for approval of treatments with value-based care products.

6.4.4 - RADIATION THERAPY

The IAEA sets standards for radiation and nuclear medicine. South Africa has been a member of the IAEA since 1957[35]. South Africa has been audited twice by the IAEA[36]. It is this field of treatment where the inequities between the private and public sector is most visible.

There are 200 registered clinical and radiation oncologists in South Africa. Of these, 160 are in the private sector servicing 16% of the population and 40 specialists serve the remaining 84% of the population. It goes without saying that there is an opportunity for PPPs that has to be investigated. Currently only one PPP in in place. It was set up in 2004 and is between Groote Schuur and George Hospitals with Cancercare George for palliative care services. This PPP was the result of an investigation into the radiation capability of the Western Cape Health Department, coupled with a request to investigate the amalgamation of the services. At the time, Groote Schuur needed new radiation machines and amalgamation seemed the only option.

The success of this PPP is the very clear framework, with set criteria that are monitored and evaluated on an annual basis. A successful short-term PPP was established between Frere Hospital and Cancercare East London when the private sector radiotherapy bunker required upgrading[36].

The KZN radiation therapy crisis of 2018 resulted in a PPP[37]. The tender was awarded to Wits Health Consortium (WHC). It remains unclear how this tender was advertised, and awarded and what the specific criteria are for this PPP. It is also not clear whether there is monitoring and evaluation built into the contract. Similar contracts are seemingly now in place in Mpumalanga and Limpopo.

The April 2021 fire at Charlotte Maxeke Johannesburg Academic Hospital left an already struggling department crippled[38], with huge backlogs PPPs would offer a solution to a very obvious problem, but outreaches from the private sector were ignored. The radiation department also does not have enough human resources to effectively deal with the backlog.

At NDoH however, the procurement of nine machines for various provinces is already underway. It seems as if planning and procurement is done without proper consultation and coordinated planning. The role of the Ministerial Advisory Committee on Cancer Prevention and Control (MACC) as an advisory mechanism is also questioned as recommendations from this group are seemingly ignored. In the light of the projected cancer increases there is need to analyse the impact these increases will have and rather to make these decisions with new information that is sustainable and affordable.

The importance of radiation services seems not to be understood by policy and decision makers. Like oncologic surgery and medical oncology, specialists need to plan and manage the service. Radiation equipment is highly specialised and requires regular calibration and maintenance. If maintenance contracts are not renewed, equipment will fail and require replacement sooner.

In addition to radiation oncologists, this service also requires radiation therapy technicians, medical physicists, linear accelerator (LINAC) engineers and radiation oncology nurses. Equipment will include LINAC machines, brachytherapy units, CT simulators with treatment planning computers and dosimetry packages. When the US-based National Cancer Institute published the human resources required for treating new cancer cases in South Africa in 2015, based on a cancer incidence of 7740[39], a total of 388 radiation oncologists were required for the number of new cases. We have half of that capacity now. The same document also indicates the numbers required for all other associated cancer specialists. If the incidence is increased to as predicted there is an urgent need to ReThink-ReDesign-ReEngineer cancer services in South Africa.

For cervical cancer specifically, curative radiation therapy for moderate and advanced localised cervical cancer remains possibly the most cost-effective treatment available in oncology with an enormous societal impact. The long-term cure rate for patients with stage three disease (disease which stretches from the cervix to the pelvic sidewall) is around 50%. Earlier disease will be cured with radiation in between 70 to 95% of patients.[40]
6. THE CANCER CONTINUUM OF CARE

6.5. PALLIATIVE AND SUPPORTIVE CARE

Palliative care is a key component of the cancer continuum of care. It is not only associated with cancer, as many other life-threatening diseases also require palliative care services. Providing this basic care should therefore be non-negotiable in a health system that values health equity.

For cervical cancer specifically, 38% of women in high-middle income countries with late-stage disease, which causes suffering and embarrassment for many women. Cervical cancer in particular is a gynaecological issue for women. Women are the victims then turn them into patients. Their condition is one of emotional needs.

Many cancers are hidden from society, however cervical cancer is the one disease that is exposed in the public sector. Women require palliative care, as do their care givers, even after the treatment phase. Their care should be holistic and supportive. They need care that is comprehensive, that is, physical, psychological, social and spiritual.

Palliative care is not only associated with cancer, as many other life-threatening diseases also require palliative care services. Providing this basic care should therefore be non-negotiable in a health system that values health equity.

At provincial level of care where palliative care is falling short to address the needs of many people who require palliative care is the most dire of all. The presence of a network of palliative care services is essential to provide quality care to all patients in need.

The National Policy Framework and Strategy for Palliative Care 2017-2022 provides the required framework, however it lacks specific guidelines and implementation policies for palliative care.

The National Policy Framework and Strategy for Palliative Care 2017-2022 provides the required framework, however it lacks specific guidelines and implementation policies for palliative care. Palliative care and supportive care for cancer needs to be designed for each specific patient needs.

Any patient that falls out of this will have need. A further essential package of palliative care for cancer is needed, consisting of an oncology social worker not only psychologically but also physically, socially and emotionally.

Palliative and supportive care for cancer needs to be designed for each specific patient needs. Palliative care and supportive care for cancer needs to be designed for each specific patient needs.

The NDoH in 2019 published the Mandatory Palliative Care Service Provider Policies to ensure a seamless social security system that is supportive of the patients' needs. 

In the public sector, where this valuable asset is not available, patient navigators should become a standard requirement with units that are accredited.

This will facilitate the move towards value-based care model for oncology.

Supportive care by non-profit organisations is available from a variety of non-profit organisations that have a physical presence in all provinces and has the ability to attend to patients in their own language. It would require extensive training of Lifeline operators to ensure that they are conversant in cancer care

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Many cancers can be hidden from society, however cervical cancer is the one disease that is exposed in the public sector. Women require palliative care, as do their care givers, even after the treatment phase. Their care should be holistic and supportive. They need care that is comprehensive, that is, physical, psychological, social and spiritual.

The National Policy Framework and Strategy for Palliative Care 2017-2022 provides the required framework, however it lacks specific guidelines and implementation policies for palliative care. Palliative care and supportive care for cancer needs to be designed for each specific patient needs.

Any patient that falls out of this will have need. A further essential package of palliative care for cancer is needed, consisting of an oncology social worker not only psychologically but also physically, socially and emotionally.

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7. CONCLUSION AND THE WAY FORWARD

Given the growing burden of cancer in South Africa, the cost of cancer to the health system has been increasing and is expected to continue to grow over the next ten years, according to model forecasts and the results documented in this report. Cost will increase in both the public and private sector. This increasing cost coincides with a period of fiscal constraint on the national budget as a whole, and health spend specifically.

The impact of the Covid-19 pandemic cannot be ignored when considering current and future availability of funds for health services in the public sector. Not only is the Government dealing with the existing quadruple burden of disease, but also fighting a new pandemic which requires funds to be mobilized for equipping health facilities to treat Covid-19 patients, as well as the procurement of vaccines. This is in the context of a national budget which is already under strain due to poor economic growth. Limited resources and budget constraints highlight the importance of health policy and interventions being cost-effective and enabling synergies across disease groups and levels of care as far as possible.

We can have an equitable health system if we collaboratively apply our minds in the ReThink-ReDesign-ReEngineer debate for cancer care within an NHI.

What has been highlighted in this report is known to everyone that works within the cancer community. It is not new news. We can make many recommendations for solutions, but what we really need are solutions that have been developed in a consensus. That is why the Cancer Alliance will be undertaking a series of high-level discussions with selected influencers, focusing on:

1. Cancer within the Public Service
2. Financing Cancer within the NHI
3. Public Private Partnerships for Cancer Services: Radiation Oncology /Surgery/Medical Oncology
4. Cancer medicines pricing and access
5. Value-based Care in cancer care
6. Legal and policy frameworks
7. Synergies with NCD policies and other prevention strategies
8. Data collection and surveillance systems to enhance the NHI
9. Cancer research needs and requirements to serve the future health needs.

The outcomes of these discussions will be presented as recommendations to be shared with decision-makers on how cancer can be incorporated within the NHI, sooner rather than later.

"KNOWING IS NOT ENOUGH; WE MUST APPLY. WILLING IS NOT ENOUGH; WE MUST DO.”

- GOETHE
REFERENCE LIST


APPENDIX B: REFERENCE LIST

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doi: https://doi.org/10.2147/8CTT.S112516


APPENDIX B: REFERENCE LIST


APPENDIX C: GLOBAL AND LOCAL FRAMEWORKS

GLOBAL

WORLD HEALTH ORGANISATION


INTERNATIONAL AGENCIES AND NON-PROFIT ORGANISATIONS


LOCAL

South Africa. Medicines and Related Substances Act 101 of 1965. (Previously Drugs Control Act)


