



National Cancer Strategy

2012 - 2016

April 2012

Draft for ratification by the Higher Committee for Cancer Control

Version dated 4 April 2012

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Abbreviations

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|--|--|
| CBI: Community Based Initiatives | NCI: National Cancer Institute in Medani |
| CCP: Cancer Control Programme | NCR: National Cancer Registry |
| CPD: Continuing Professional Development | NGO: Non Governmental Organisation |
| CSR: Corporate Social Responsibility | NHL: National Health Laboratory |
| EMRO: Eastern Mediterranean Region | OVI: Objectively Verifiable Indicators |
| EPI: Expanded Programme of Immunisation | PHC: Primary Health Care |
| FMOH: Federal Ministry of Health | PHE: Public Health & Emergency Directorate: |
| HBV: Hepatitis B Virus | PHI: Public Health Institute |
| HIV/AIDS: Human immunodeficiency Virus/ Acquired Immunodeficiency Syndrome | RICK: Radiation and Isotope Centre in Khartoum |
| HPV: Human Papilloma Virus | SDG: Sudanese Pound |
| HRD: Human Resource Directorate | SMC: Sudan Medical Council |
| IAEA: International Atomic Energy Agency | SWOT: Strengths Weaknesses Opportunities and Threats |
| M&E: Monitoring and Evaluation | TOT: Training of trainers |
| MOV: Means of Verification | UV: Ultra violet |
| NCD: Non Communicable Diseases | WHO: World Health Organisation |

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CHAPTER 1: INTRODUCTION

1.1 Preamble

Cancer is one of the major ten killer diseases for many years in Sudan, and the number of people developing and dying from cancer is predicted to continue to increase steadily both in Sudan and worldwide. Although we have an increasing number of cancer patients every year, there is little improvement in our cancer services of which we should rightly be worried. In too many areas the reality of our cancer services fail to match the lower accepted level of services, The poor are still far less likely to get medical service and even awareness. Furthermore there is too much variation in the quality of care and treatment protocols across the country, leaving cancer patients frustrated by costly treatment and inaccessible services. At least forty percent of cancer can be prevented and early detection and effective treatment of a further third is also possible. Our ability to achieve what we know is possible depends to a great extent on our taking a more planned approach involving all activities and services related to cancer.

1.2. Why a National Cancer Strategy?

Cancer cases are on the rise in Sudan. There is a lot of effort, to control for cancer, by hospitals, clinicians, NGOs and communities but unfortunately they are fragmented and not coordinated. Furthermore, the Cancer Control Plan of 2002-2003 had lapsed without being updated. A lot of challenges are facing cancer control such as low population awareness, inequitable access to services, high cost of therapeutic medication and shortage in professional human resource. The limited resource resulted in unacceptable delay of framework to guide this work.

A strategy provides the framework and overall direction of work. It sets the most important priorities and ensures proper use of the scarce resources. Implementation of this strategy will require a major government and nongovernment commitment to cancer services in the coming years, strong collaboration between different partners and involving all stakeholders.

1.3 National policy context

The NCDs policy is currently under development. This strategy is in line with the following initiatives: Global Action against Cancer, Towards a Strategy for Cancer Control in EMRO, Sudan National Health Strategy (2005-2027), Sudan National Health Sector Strategic Plan (2012 – 2016), and the NCDs strategy (2010-2015). In May 2005 the World Health Assembly resolved that all countries should develop and implement national cancer control programs (3).

1.4 Methods of developing the National Cancer Strategy

The Public Health Institute (PHI) was consulted to help develop this strategy. A taskforce was formed with representation from the Directorate of Public Health and Emergency, the NCDs department, PHI, RICK, NCI in Gezira, the National Cancer Registry and from laboratories. Members of the taskforce are: Dr Muna I Abdel Aziz, Dr Zainab Omara, Dr Babiker ElMagboul, Dr Naeima Abdalla, Dr Ahmed Elhaj, Dr Manal Alemam, Dr Nazik M Nurelhuda, Dr Intisar Elfadil, Dr Shaza Abdelbagi, Dr Israa Mustafa Awad Alkarim, Dr Nageeb Suleiman, and Dr Nada Y Hamza.

The strategic planning process was initiated in July 2011. All key documents and literature available to the team were reviewed and summarized in the situational analysis section. The team brainstormed and developed the mission, vision, values and SWOT analysis. The first draft was written and then interviews with key informants were conducted to help generate a gap analysis. We are grateful to the key informants for their valuable input regarding their long experience and efforts in cancer control: Prof Ahmed Mohamed Elhassan, Prof Hussein Mohamed Ahmed, Dr Kamal Hamad, Dr Siddig Mohamed, Prof Ahmed Suleiman, Dr Mohamed Awad Elkhateb, and Dr Dafalla Omer Abuidris.

The draft was refined and presented to FMoH mid-level managers and heads of departments for initial comments. Two workshops were then held in December 2011 with wider stakeholders internal and external to Federal MOH: the Breast cancer multidisciplinary workshop and the FMoH stakeholder workshop (see Annex for reports of these workshops). The strategy was also presented to the National Breast Cancer Conference and to a multidisciplinary team on oral cancer. The purpose of these

workshops was to affirm the situation analysis, and clarify respective roles and responsibilities. This strategy document is intended to document all the findings from the strategy exercise, and avail this information to the Higher Committee for Cancer Control in March 2012 as a start for endorsement and ratification.

CHAPTER 2: Situation analysis

The health system analysis for cancer control is detailed in Annex 1; together with the gap analysis and the outline of the broad areas for actions (Annex 2). The following sections provide an overview and a summary SWOT.

2.1 Global Burden of Cancer

Cancer is a public health problem worldwide. It affects all people. Today, 24.6 million people are living with cancer and 6.7 million are dying of cancer each year. Cancer is the second leading cause of death in developed countries and is among the three leading causes of death for adults in developing countries. Almost 13% of all deaths are caused by cancer. That's more than the percentage of deaths caused by HIV/AIDS, tuberculosis, and malaria put together (1).

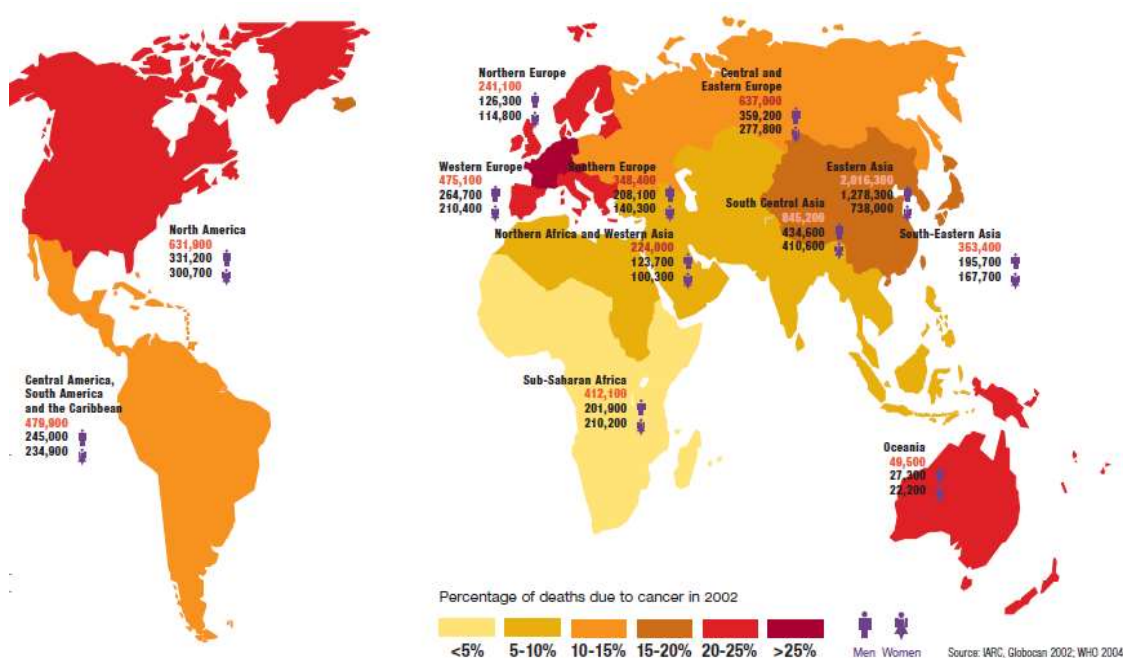


Figure 1: Global cancer situation (1)

Cancer is a multifaceted disease known to be caused by both internal and external risk factors including tobacco, alcohol, numerous chemical substances, radiation, and some infectious organisms. Lung cancer kills more people than any other cancer worldwide. More men than women get cancer of the lung, stomach, throat, and bladder. Cancers triggered by infections – liver, stomach and cervix cancers – are more prevalent in the developing world. In richer countries, prostate, breast and colon cancers are more common than in poorer countries. Cancers that are most often cured are breast, cervix, prostate, colon and skin, if they are diagnosed early (1).



Figure 2: Most common cancers worldwide (1).

Our knowledge about the prevention and treatment of cancer is increasing, yet the number of new cases grows every year. If the trend continues, 16 million people will discover they have cancer in 2020, two-thirds of them in newly-industrialized and developing countries. Cancer is preventable. Forty percent of all cancer can be avoided by avoiding risk factors you can control and make healthy lifestyle choices. Forty three

percent of cancer deaths are due to tobacco, diet and infection. Tobacco is the cause of 80% of lung cancer; it also causes cancer at many other sites including throat, mouth, pancreas, bladder, stomach, liver, and kidney cancer (1).

About one third of cancer deaths expected every year are related to nutrition, overweight, obesity and physical inactivity .Overweight and obesity are associated with colon, breast, uterus, esophagus, and kidney cancers.

Infectious agents, like hepatitis B virus (HBV), human papilloma virus (HPV), human immunodeficiency virus (HIV), Helicobacter pylori (H .Pylori), and others are related to certain cancers. Many of these could be prevented through behavioral changes, vaccines, or antibiotics. Certain occupational and environmental chemicals as asbestos, aniline dye and benzene are also related to cancer. Excessive solar ultra-violet radiation increases the risk of all types of skin cancer (1).

2.2 Burden of cancer in Sudan

NCDs are emerging as one of the major health problems in Sudan according to the Annual Health Statistical Records (2), Khartoum State STEPS survey (3), and the recent Sudan Household Health Survey (4). Furthermore, NCDs might be more prevalent than records show due to missed undiagnosed illness.

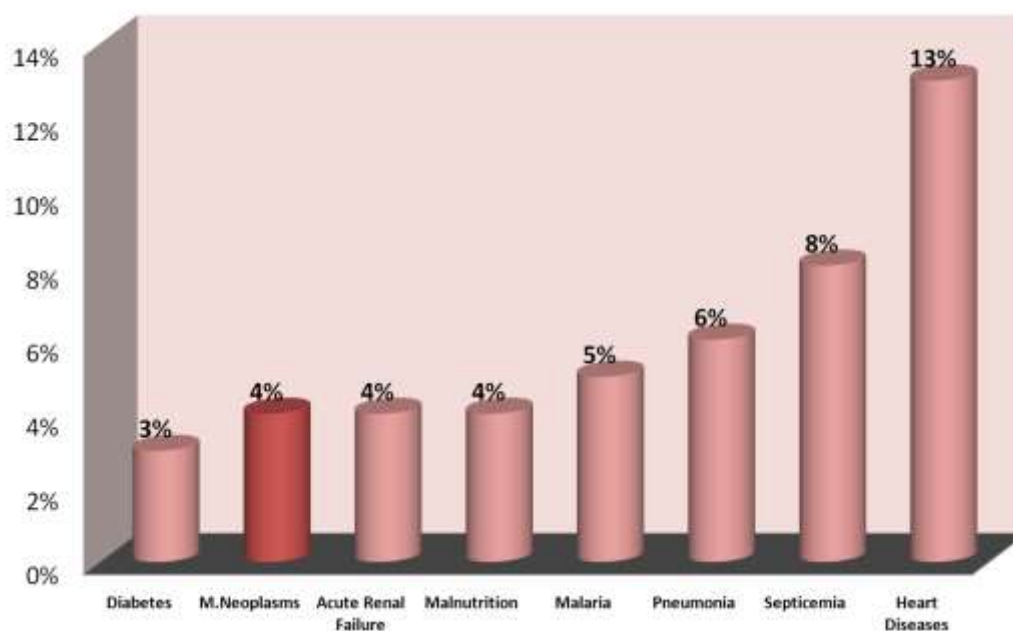


Figure 3: The leading causes of death in hospitals for 2009 (5)

Cancer has become one of the major ten killer diseases in recent years. The patients' registry at (RICK) which is the oldest and biggest center for managing cancer patients, witnessed more than two folds increase in the number of patients between the year 2000 and the year 2009 (2471 to 5739 respectively). There are two centers for cancer management; the cancer cases from these centers (RICK and NCI) are increasing annually as illustrated below.

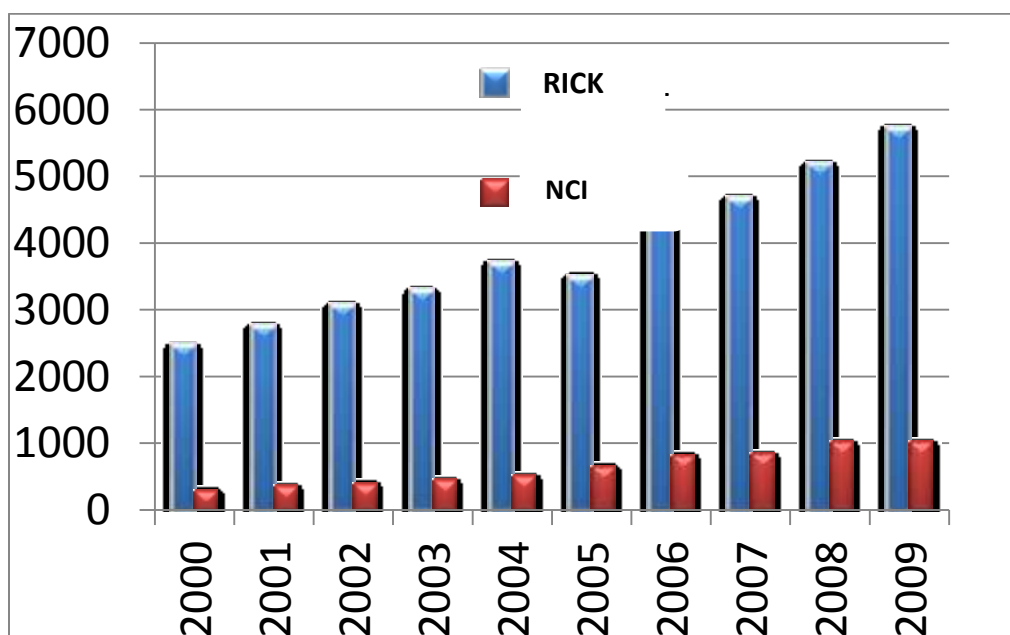


Figure 4: The total number of patients at RICK and NCI from 2000 to 2009 (5)

The top ten cancers in 2009 accounted for 59.8% (RICK). These were cancers of the breast, blood, spleen, lymph nodes, prostate, esophagus, cervix, ovary, bladder, liver and nasopharynx. The top five for male were blood, spleen, prostate, lymph node, liver and nasopharynx. For women they were breast, blood, spleen, cervix, ovary and lymph node cancers. Oral cancer is also often quoted as one of the common cancers but does not feature in NCR reports possibly due to underreporting resulting from cancer of the lips, tongue and others being reported separately (rather than one code for oral cancer).

Other data from the National Cancer Registry (NCR) are shown in Figures 5 and 6. One of its first activities was to map the distribution of cancer cases by States using its initial data regarding diagnoses made in 2007.

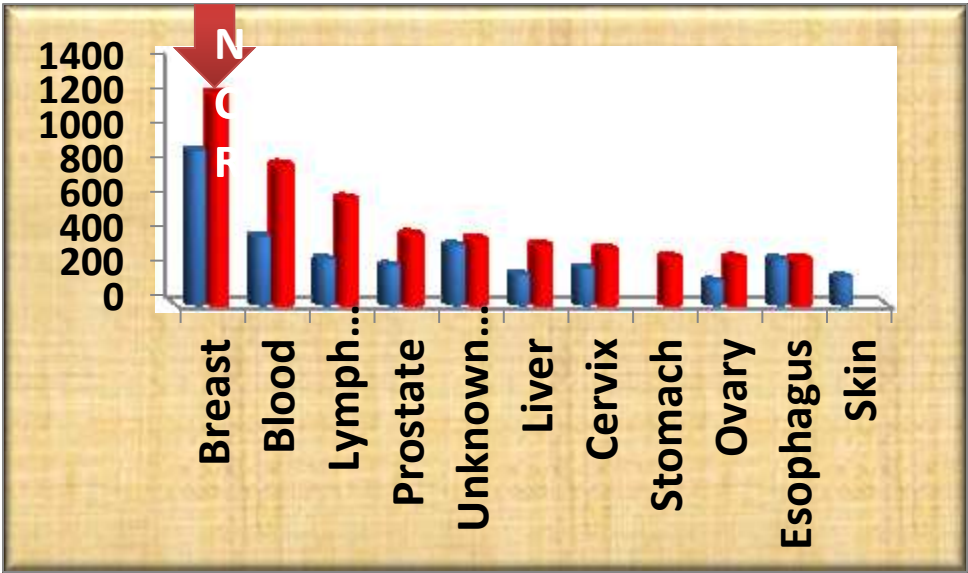


Figure 5: The ten most common types of cancer among Sudanese patients, 2009-10 (5)

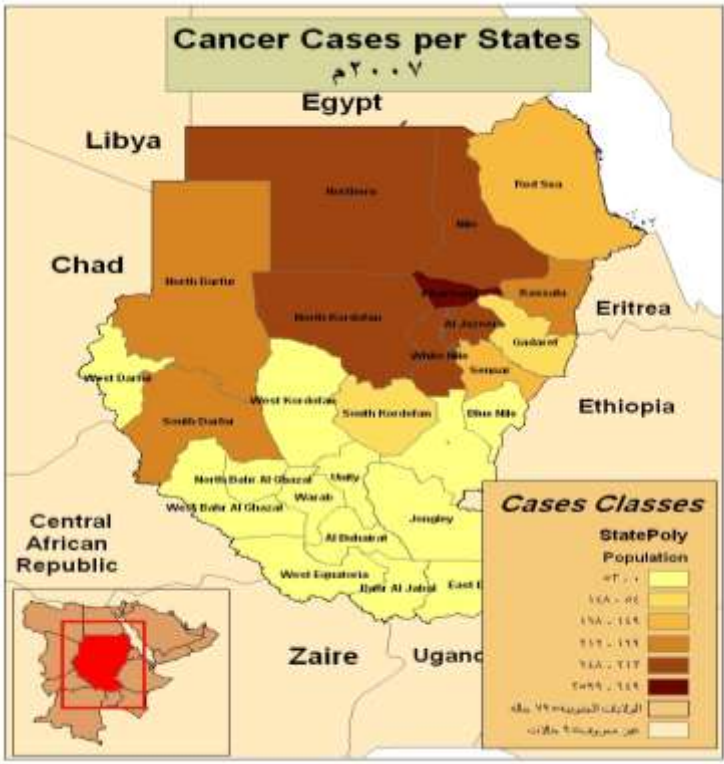


Figure 6: Distribution of cancer cases in Sudan for 2007 (Source: RICK)

2.3 SWOT analysis

Refer also to Annex 1

| Strengths | Weaknesses |
|--|--|
| <ul style="list-style-type: none"> • Commitment of current staff • Good relationships across stakeholders e.g. <ul style="list-style-type: none"> ➤ Cancer Advisory Committee ➤ Cancer Control Programme within NCD directorate in Ministry of Health • Two standard care management protocols for breast and prostate cancer • Prevention and early detection guideline for breast, oral & cervical cancer | <ul style="list-style-type: none"> • Budget challenge • National Shortage of specialist, chemotherapy pharmacist and nurses • Inadequate Facilities and few Specialized Cancer centers • Lack of population based cancer registries • No established Cancer Control Policy • Insufficient early detection effort • Shortage in histopathology services • No maintenance contract for machine • IT not integrated and problems with data quality • Few evidence based cancer research • Cancer not covered by health insurance |
| Opportunities | Threats |
| <ul style="list-style-type: none"> • Newly established National Cancer Registry • Professional development of staff • Private nonprofit cancer hospital • Development of new drugs and protocol • Global direction toward NCD control • Active NGOs | <ul style="list-style-type: none"> • Political instability • Lack of Cancer Awareness in Sudan • Low political commitment to cancer as a priority area • Overspent budgets - Lack of Accessibility to Treatment • Social inequity - affordability is an issue • High Cost of Treating Cancer • Sustainability of the National Cancer Registry is not guaranteed |

CHAPTER 3: THE STRATEGY

This draft of the Sudan National Cancer Strategy is a spearhead effort in the development and implementation of a comprehensive and coordinated programme to control cancer in Sudan. The strategy includes vision, mission, and principles to guide existing and future actions to control cancer. It also includes objectives and priority areas for action and research. To sustain commitment to this strategy, the NCD department will undertake wider engagement through the NCD policy and will follow up the implementation of the strategy as per the activities, timeline and indicators (specified below).

3.1 Vision

Sudanese people well aware of cancer predisposing factor, practice cancer preventing behavior, and have access to screening, early cancer detection, proper diagnosis, effective treatment and palliation.

3.2 Mission

The Federal Ministry of Health (NCD dept) are leading this work collaboratively with stakeholders to advocate for healthier lifestyles, reduce risk of cancer (prevention), and promote early detection of cancer. A core function is to improve equity, accessibility and quality of services for diagnosis, treatment and palliation.

3.3 Principles/values

- Adoption of a population health approach and reduce health inequalities.
- Prioritization of health promotion and disease prevention.
- Timely and equitable access to care
- Provision of the high quality effective care for cancer patients, using an evidence based approach
- Active involvement of patients, carers and communities
- Dignity
- Facilitated coordination and integrated multidisciplinary care across services, settings and sectors. Achievement of sustainable change.

3.4 The strategic objectives of the National Cancer Strategy

These are to:

- 1- Reduce the incidence of cancer through primary prevention
- 2 -Ensure early detection to reduce cancer morbidity and mortality
- 3 -Ensure effective diagnosis and treatment to reduce cancer morbidity and mortality
- 4 -Improve the quality of life for those with cancer, their family through support, rehabilitation and palliative care
- 5 -Improve the delivery of services across the continuum of cancer control through effective planning, co-ordination and integration of resources and activity, education activities, monitoring and evaluation
- 6- Improve the effectiveness of cancer control in Sudan through research and surveillance (and promotion of the role of the National Cancer Registry).

3.5 The priority strategies and actions

The priority actions are highlighted in the following table and demonstrating the link up to the National Health Sector Strategic plan 2012-16. The strategies to implement the Sudan Cancer Control Strategy include:

- Leadership for NCDs (Health is everyone's responsibility but FMoH should lead)
- Advocacy for cancer and attracting resources
- Encourage support from NGOs and through CBIs (present early & lifestyles)
- **THE priority is for accurate diagnosis.** *This includes any palpable lumps or symptoms suspicious of cancer like bleeding and ulceration. Self-examination and early presentation are included here as priorities for early detection.*
- Asymptomatic screening is not recommended at this time. *This includes lumps that are too small to be palpable and occult bleeding. Further work is recommended to assess whether/ when to introduce such asymptomatic screening.*
- **Development of the Service model** for cancer care in primary, secondary and tertiary levels (See Annex 3). *This includes diagnostics, network of oncology centres, referral mechanisms, multidisciplinary teams, guidelines, and palliative care.*
- Training (undergraduate, primary care and specialists)
- Information for Action: Sustain the National Cancer Registry, Priority Research

| National Health Sector Strategic Plan objectives | Cancer Strategic Objective | Priority actions of the National Cancer Strategy |
|---|---|---|
| Governance: Assure the health system is responsive to the population's health needs | Reduce the incidence of cancer through primary prevention | <p>Advocate for leadership of NCDs including NCDs integration into primary care and implementation of the tobacco control strategy.</p> <p>Support efforts for healthy eating & physical activity</p> <p>Study the role of aflatoxin, food additives and reuse of cooking oils</p> <p>Assess priority of HPV vaccine and Hep B for high risk groups</p> <p>Undertake risk assessment and risk mapping for priority carcinogens in the environment.</p> <p>Initiate health impact assessments and environmental impact assessments. Support efforts for occupational health & corporate social responsibility.</p> |
| Health services delivery: Strengthen primary health care, focusing at strengthening referral care and integrated patient centered approach | Ensure early detection to reduce cancer morbidity and mortality (including screening) | <p>Encourage early presentation to services – self examination, awareness raising, eg school curricula.</p> <p>Raise level of suspicion of cancer – undergraduate and primary care training</p> <p>Assess the case for cancer screening in Sudan (Wilson and Jungner criteria)</p> |
| Health technology: Improve cost-efficiencies by rationalizing the usage and cost of (equipment and) drugs | Ensure effective diagnosis to reduce cancer morbidity and mortality | <p>Standardise pathology request forms, reports and procedures</p> <p>Improve diagnostics – calibration, maintenance and operator training</p> <p>Avail staffing</p> <p>Training to ensure development and implementation of guidelines and availing diagnostic facilities in secondary care (equipment, consumables, staffing)</p> <p>Avail mammography machines for diagnosis</p> <p>Reduce the costs of diagnostics/ investigations through NGOs and expansion of insurance coverage</p> |
| Health services delivery: Strengthen primary health care, focusing at strengthening referral care and integrated patient centered approach | Ensure effective treatment to reduce cancer morbidity and mortality | <p>Develop and distribute further national standards, guidelines and protocols.</p> <p>Establish a 'model unit' in one hospital availing diagnostics and multidisciplinary team approach as per guidelines (further description of the clinical service model in Annex)</p> <p>Include cancer in general speciality training of all specialities</p> <p>Expand Oncology centres to all regions</p> <p>Explore opportunities for use of remote/mobile technology to support States (eg review telepathology project and task shifting to technicians/nurses)</p> <p>Undertake quality audits of cancer care</p> |
| Human resources for health: | Improve the quality of life for | Sustain the current effort on the model units for palliative care; not to lose staff. |

| National Health Sector Strategic Plan objectives | Cancer Strategic Objective | Priority actions of the National Cancer Strategy |
|---|--|--|
| Improve cost-efficiencies by rationalizing and improving HRH skill mix | those with cancer, their family through support, rehabilitation and palliative care | Ensuring each region has at least one local palliative care service. Health providers need to be trained in communication skills Role of social workers and NGOs to be expanded to counselling and psychosocial support for patients and carers. |
| Health financing: Ensure social protection by reducing O-o-P payment | Improve the delivery of services across the range of cancer control through effective planning, co-ordination and integration of resources and activity, education activities, monitoring & evaluation | Priority investment in diagnostics and early detection. Generation of funds should be under focus through NGOs and international collaborations. Involve the private sector. Initiate multidisciplinary audits and professional regulation (Sudan Medical Council assisted by the role of professional associations) Endorse the strategy through NHSSP processes and Higher Coordinating Council (and follow up its implementation) Undergraduate and primary care training |
| Information: Assure the means to measure improvement in the health outcomes; | Improve the effectiveness of cancer control in Sudan through research and surveillance (and promotion of the role of the National Cancer Registry). | Support and sustain the cancer registry Expand cancer registration to all states Explore opportunities in the eHealth project (Managed by the National Information Cooperation. It includes a hospital management information system) Training in data recording, verification and analysis (including accurate mortality data) Support the research function in the registry |

3.6 Priority research areas

1. Epidemiology and risk factors of the most common cancers in Sudan (source can be data from registry)
2. Priority carcinogens in the environment and risk mapping
3. Health impact assessment of major development projects and other economic sectors
4. Carcinogenicity of aflatoxin, food additives and reuse of cooking oils in the Sudan
5. Priority of HPV vaccine and Hep B for high risk groups in the immunisation programme in Sudan
6. Evidence on the impact of late detection of cancer on patients and the health system (including costs)
7. The scale of misdiagnosis for cancer contributing to late diagnosis.
8. Outcomes of investment on tertiary versus secondary and primary care
9. The economic business case for investment in early detection of cancer in primary health care (on the basis of future savings in secondary and tertiary care).
10. The case for screening for cancer in the Sudan (evidence based on the Wilson and Jungner criteria for screening) and feasibility.
11. Cost effectiveness of treatment abroad versus treatment in Sudan.
12. Opportunities for use of remote/mobile technology to support States (eg review telepathology project and task shifting to technicians/nurses)
13. Audit of service standards across secondary care services for cancer
14. Audit of patient satisfaction
15. Multidisciplinary Audits in tertiary care services for cancer
16. Feasibility for a cancer survival database in the Registry
17. Assessing the need for subspeciality in oncology eg surgical oncology, plastic surgery

4. Logframe, Phasing and M&E indicators

| Narrative Summary | Objectively Verifiable Indicators (OVI) | Means Of Verification (MOV) | Assumptions/risks |
|---|--|---|--|
| Goals (higher level objective, to be achieved together with other sectors/plans) 1. Reduce cancer incidence, morbidity and mortality | a. Incidence and outcomes of cancer in each State | a. Cancer registry | Registry sustained and covering all States |
| Purpose (the impact or development objective this plan will achieve) 1.1. Work collaboratively with stakeholders to advocate for healthier lifestyles, reduce risk of cancer (prevention), and promote early detection of cancer. | b. By 2016, partners in cancer prevention and cancer care are working together on shared programmes of work | b. Number of programmes led by multiagency multidisciplinary groups in each State (Target one in each State) | Purpose to goal Political commitment and availability of resources |
| Outputs or deliverables (strategic interventions) 1.1.1 Reduce the incidence of cancer through primary prevention 1.1.2. Ensure early detection to reduce cancer morbidity and mortality 1.1.3. Ensure effective diagnosis and treatment to reduce cancer morbidity and mortality 1.1.4. Improve the quality of life for those with cancer, their family through support, rehabilitation and palliative care 1.1.5. Improve the delivery of services across the continuum of cancer control through effective planning, co-ordination and integration of resources and activity, education activities, monitoring and evaluation 1.1.6. Improve the effectiveness of cancer control in Sudan through research and surveillance (and promotion of the role of the NCR). | a. Number of new prevention programmes set up each year b. Earlier stage of cancer at diagnosis c. Histopathology, haematology and radiology functioning in each State d. Regional oncology centres functioning (target 4 new) e. Palliative care unit in each State (minimum in each region) f. Multiagency cancer control group in each State (includes NGOs and private sector) g. National Cancer Registry collecting data from all States | a. NGO forum to be set up b. Cancer registry c. State MoH report d. Oncology centre reports/NCR e. Oncology centre reports/Palliative service reports f. State MoH reports g. NCR reports | Output to purpose i. Availability of adequate funds required ii. Availability of skilled staff iii. Political commitment to implement the strategic directions |

| Narrative Summary | Objectively Verifiable Indicators (OVI) | Means Of Verification (MOV) | Assumptions/ risks |
|---|--|---|---|
| Components (Inputs or activities) | | | Component to output |
| Primary prevention | 1.1.1.1 Run advocacy events for cancer prevention 1.1.1.2 Repeat Risk Factor Survey 1.1.1.3 Research into primary prevention | a. CCP report b. Survey report c. Registry report | i. Availability of adequate funds required ii. Availability of skilled staff. iii. Political commitment to implement the strategic directions |
| Early detection | 1.1.2.1 Campaigns for breast self examination, oral self examination 1.1.2.2 Training of primary health professionals | d. CCP report e. CPD report/CCP | |
| Diagnosis, treatment and palliative care | 1.1.3.1 Audit of MDT standards in each State ➤ Diagnostic access ➤ Oncologist access ➤ Guidelines availability ➤ Treatment modalities ➤ Palliative care access 1.1.4.1 Undertake patient/ carer satisfaction study | f. Multidisciplinary audits published g. Patient/carer satisfaction report | |
| Coordination | 1.1.5.1 Undergraduate training/Postgraduate training in cancer 1.1.5.2 Government and NGOs to fund diagnostics across States (new NGO initiatives or count of new money) | h. Curriculum amendments or number of sessions held i. CCP budget accounts/ CCP report from NGO forum | |
| Registry and research | 1.1.6.1 Annual summary report from the registry 1.1.6.2 Research into epidemiology trends and other priority research | j. NCR annual summary k. Numbers of research reports produced (publications, policy briefs, grey literature) | |

| TIME PLAN | 2012 | 2013 | 2014 | 2015 | 2016 |
|---|------|------|------|------|------|
| 1. Reduce the incidence of cancer through primary prevention | | | | | |
| i. Leadership for NCDs and partnership efforts | | | | | |
| ii. Risk assessment and risk mapping | | | | | |
| iii. Research into food and assessing priority vaccinations | | | | | |
| iv. Introduce new primary prevention programmes and cancer advocacy events | | | | | |
| 2. Ensure early detection to reduce cancer morbidity and mortality | | | | | |
| i. Run self examination and awareness campaigns | | | | | |
| ii. Review undergraduate curricula, including Academies of Health Science and run CPD training | | | | | |
| iii. Research into the impact of late detection and scale of misdiagnosis | | | | | |
| iv. Produce a business case for investment in early detection in primary care on the basis of future savings in secondary / tertiary care | | | | | |
| v. Assess the case for asymptomatic screening | | | | | |
| 3.1 Ensure effective diagnosis to reduce cancer morbidity and mortality | | | | | |
| i. Standardise pathology request forms and procedures | | | | | |
| ii. Improve diagnostics (calibration and training) | | | | | |
| iii. Avail staffing and diagnostic facilities in all States (histopathology, haematology, and radiology incl mammography) | | | | | |
| iv. Seek NGO support to avail diagnostics and absorb the cost from patients (support expansion of insurance) | | | | | |
| v. Explore opportunities for use of remote/mobile technology to support States | | | | | |
| 3.2 Ensure effective treatment to reduce cancer morbidity and mortality | | | | | |
| i. Develop and distribute further national standards, guidelines and protocols | | | | | |
| ii. Include cancer in general speciality training of all specialities | | | | | |

| TIME PLAN | 2012 | 2013 | 2014 | 2015 | 2016 |
|--|-------------|-------------|-------------|-------------|-------------|
| iii. Establish a 'model unit' in one hospital | | | | | |
| iv. Expand oncology centres to all regions | | | | | |
| v. Undertake audit of MDT standards in each State (diagnostics, ocology, guidelines, treatment modalities and palliative care access) | | | | | |
| vi. Assess the need for subspecialities in oncology | | | | | |
| 4. Improve the quality of life for those with cancer, their family through support, rehabilitation and palliative care | | | | | |
| i. Sustain the current palliative care model units | | | | | |
| ii. Ensure each region has a local palliative care service | | | | | |
| iii. Train health providers in communication skills | | | | | |
| iv. Expand the role of social workers and NGOs to counseling and psychosocial support | | | | | |
| v. Undertake patient/carer satisfaction study | | | | | |
| 5. Improve the delivery of services across the continuum of cancer control through effective planning, co-ordination and integration of resources and activity, education activities, monitoring and evaluation | | | | | |
| i. Endorse the strategy through NHSSP processes | | | | | |
| ii. Multiagency cancer control groups set up Federally and in each State | | | | | |
| iii. NGO Forum to be set up (and involvement of the private sector) | | | | | |
| iv. Attract government and NGO additional resource (especially for diagnostics and early detection) | | | | | |
| v. Involve partners in training and education initiatives | | | | | |
| vi. Initiate multidisciplinary audits and professional regulation through the Sudan Medical Council and professional associations | | | | | |
| vii. Investigate the cost effectiveness of treatment abroad | | | | | |

| TIME PLAN | 2012 | 2013 | 2014 | 2015 | 2016 |
|--|------|------|------|------|------|
| 6. Improve the effectiveness of cancer control in Sudan through research and surveillance (and promotion of the role of the NCR). | | | | | |
| i. Sustain and expand the cancer registry to all States | | | | | |
| ii. Explore opportunities in the eHealth project | | | | | |
| iii. Undertake training of doctors, statisticians and other staff in recording, verification and analysis | | | | | |
| iv. Explore opportunities for mortality recording and survival database in the registry | | | | | |
| v. Support the research function in the registry to lead priority research | | | | | |

ANNEX 1. Health System Analysis for Cancer Control

Historical Background

In the early sixties, the Center for Cancer Treatment was set up in the Sudan under the auspices of the WHO, IAEA, and Sudan Government. WHO took the side of training for doctors and nurses with availing cytotoxic drugs. IAEA helped in stalling machines and equipments. The Government prepared the building and human recourses. It was the third center in Africa after Egypt and South Africa. Medical staff were sent abroad for training in this field. The first returnee was Dr. El-Sheikh Abdel Rahman in November 1964 and he supervised the inauguration of the buildings and machinery from an office in Khartoum Hospital, adjacent to the Department of Diagnostic Radiology. The buildings were completed by November 1965 and following that the equipments were installed. The next group of returnees, who joined Dr El-Sheikh Abdel Rahman were Dr Abdalla Hidayt Allah and Dr Khalid Hassan El-Tom. The center started working in 1967, but was officially opened on 18th October 1968 by President Ismaeel Alazhare and Minister of Health Dr Abdull Hameed Saleh.

The first program to combat cancer started in 1982 as a vertical programme managed by RICK under the auspices of WHO. The director of the program was Prof Hussein Mohammed Ahmed and the program coordinator was Mrs Illham Abdullah al-Bashir. There were initially limited objectives about early detection, training in the field of cancer, raising public awareness and updating the center. These objectives were later expanded as per WHO guidelines to encompass the whole spectrum of prevention as well as treatment. The program was adopted by FMoH in 2002. Until April 1999, the Radiation & Isotopes Centre (RICK) in Khartoum was the only specialized center for cancer patient management in Sudan. In April 1999 the Gezira Centre (NCI) was opened.

Historically, the first national cancer registry had been functioning in 1966-1980s in the National Health Laboratory (NHL) under the sponsorship of the International Union against Cancer (IUAC) (French organization). The data was collected from only two pathology laboratories, hence affecting the registry with bias Reports since cancer was based on a laboratory diagnosis only. This initiative concluded in the 80s due to the lack of sustaining funds. There is a pioneer group,(Professors: M Hammed Satti, Sied Hassan Daoud, Basheer I Mukhtar, Abdill Fatah A Algader, Mansoor A Hasseb,with prof. Ahmed M Elhassan) in the field of histopathology which is the gold standard for cancer diagnosis. The present cancer registry was established by a committee chaired by Prof Ahmed Mohamed Elhassan.

HEALTH SYSTEM AND SERVICES:

1- Governance and management:

The Radioisotope center Khartoum (RICK) started functioning at 1967 as a center for treatment of cancer using radiation, chemotherapy and hormone therapy. It has nuclear medicine for diagnosis. A vertical national cancer control program has been established at RICK since 1982, In 2002 NCCP became under the umbrella of the General Directorate of Primary health care at FMOH. Now the NCCP is within the General Directorate of Public Health and Emergency.

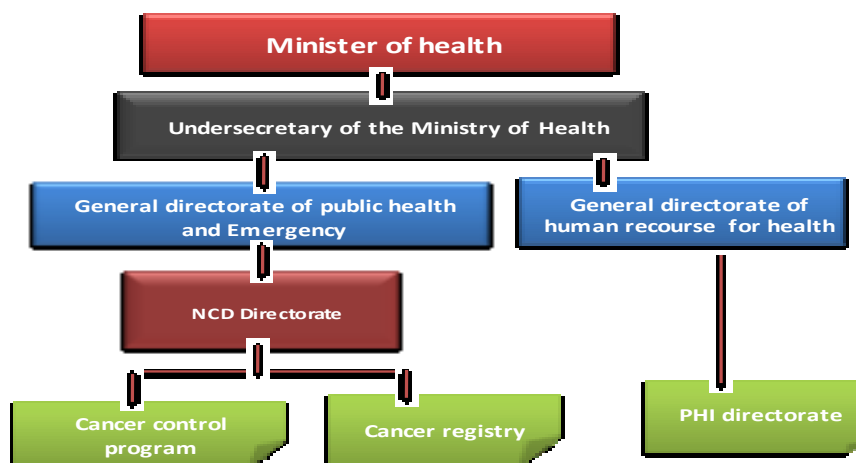
The Sudan NCCP at the Federal Ministry of Health (FMOH), is run by one community physician, and one registrar of community medicine, both also help in the other activities at the directorate. At the states level there are newly appointed NCDs coordinators who will deal with cancer control.

There are two bodies assisting the cancer control programme. The national cancer council (2008) of 28 different professionals, the other body is the Cancer Advisory Committee, belongs to the directorate of curative medicine. Both need to be activated.

The activities of the programme include development of strategies, plans, guidelines and protocols. It works on building the capacity of workers in the field of cancer control at different levels. It builds partnership with all related sectors. The awareness of public and care providers is a great concern to the programme.

A guideline on prevention and early detection of the most common cancers, breast, cervix, and oral cancers was developed and printed. There are two standard case management protocols for breast and prostate cancers for printing and dissemination.

There is a wide range of stakeholders and partners within the Federal Ministry of Health and outside. (See annex 4)



2. Cancer Control service delivery

Health Facilities

Health system in Sudan is composed of Federal, state (17 states) and local governments. Health care is delivered through primary health care (includes basic health units, health centers, and rural hospitals) secondary hospitals and tertiary hospitals. At the primary level there is no significant activity in cancer control. Some secondary and tertiary hospitals are doing some cancer care activities. The referral system is weak

Cancer is managed in three centers, Radiation and Isotope Center Khartoum (RICK), National Cancer Institute(NCI) Wad Medani, and Shandi Cancer Center in River Nile State.NCI, as RICK has radiotherapy, chemotherapy and nuclear medicine for diagnosis. In .Shandi cancer Center there is only chemotherapy and nuclear medicine.

The proposed centers are Marawe, AlFasher, and Suba centers. The military and police departments are planning to have their own centers. Two other centers at Alobied and AlGadaref are planned but no fund. Four nuclear medicine facilities, one is functioning, in the private sector.

Components of Cancer Control Services

The efforts of the highly qualified physicians in the field laid the foundation for the present cancer control programme. Nevertheless there is a rising trend in the reported cancer cases. This is attributed to the growth and aging of population, increased exposure to cancer risk factors, and increased knowledge and public awareness. It is therefore necessary to have good policies and plans, with more funds and facilities to cope with the recent developments and achieve the international standards in the management of cancer.

The elements of cancer control network are primary prevention, early detection, diagnosis, treatment, and palliative care (psychosocial and supportive care).

1 -Prevention

Prevention is elimination or minimizing exposure to known environmental risk factors of cancer. Tobacco use is responsible for up to 30% of cancer burden in developed countries. Obesity is a rapidly growing health problem. Unhealthy diet and obesity are important risk factors for cancer, accounting for 20-30% of cancer burden in the world. Chronic infections as Hepatitis B Virus, Human Papilloma virus, Helicobacter pylori and others can cause cancer. It is estimated that cancers due to infection represent 11% of the cancer burden in North Africa.

In Sudan, tobacco use, obesity and infections are prevalent. As yet unpublished NCR study in all the States highlighted poor lifestyles with high risk for cancer (7). More than a third respondents smoked cigarettes, one in four used toombak, one in five used shisha and nearly one in seven mentioned drinking alcohol. Half of these were long term users more than 15 years.

The public awareness regarding cancer prevention and control is poor. Expenditure on health is skewed towards curative and hospital care. There are limited cancer preventive activities.Hepatitis B vaccination in infancy started in 2006 but generally not offered to groups at high risk. There are few activities regarding community health education through some mass media and sporadic efforts. A guideline on prevention and early detection of the most common cancers, breast, cervix, and oral cancers was developed, with training of few health care providers.

The highest impact on prevention of cancer comes from the work of other sectors rather than the health sector per se e.g. industries and development projects, legislation, education and telecommunications, etc.

2-Early Detection

Early detection means detecting cancer prior to development of symptoms or as soon as is practicable after the development of symptoms, before it has time to spread to other parts of the body. Early detection is only effective if it is linked with diagnosis, treatment, and follow-up.

Early detection of cancer can involve strategies to promote early presentation, including education about symptoms and signs of cancer, and to improve access to primary care services for early diagnosis. Early detection in asymptomatic is done through screening.

Health education activities are scanty, primary health care workers are rarely provided with sufficient education about early signs of cancer, and when and where to refer, so cancer is diagnosed late. There is some effort to train primary health care workers in cancer awareness and suspicion e.g. that led by RICK, but these have not been scaled up or systematized. Early detection guidelines have been developed for breast, oral and cervical cancer (8).

There are no organized screening programs other than sporadic efforts in the private and NGO sectors (largely offering asymptomatic screening for breast cancer through mammography – without necessarily linking this to comprehensive treatment services). Some states as Gazera and River Nile practiced a small scale or pilot screening for breast cancer. At North Kordofan was a demonstration project for use of Visual Inspection with Acetic acid (VIA) test in cervical cancer.

The shortcomings in cancer diagnosis; especially early detection are demonstrated by the late detection of cancer; 80% of patients present late in Stages 3 and 4 which makes treatment more expensive and complicated, requiring multiple modalities of treatment, (surgery, radiotherapy, chemotherapy and hormone therapy), and a markedly low chance of success.

3-Diagnosis

Diagnosis of cancer involves clinical assessment and a range of investigations as endoscopy, imaging, histopathology, cytology and laboratory studies. Diagnostic tests at the initial are important in identifying the extent of spread of cancer which is necessary for choosing treatment options.

There is a shortage in histopathology services; there is one national health laboratory (NHL) at Khartoum state. Very few states have this service (4 states: Port Sudan, Atbara, Kassala, and Al-Obied), largely due to lack of retention of skilled staff. Training is needed to improve the quality of histopathology reports regarding cancer. The governmental hospitals with a histopathology laboratory in Khartoum State are 13 hospitals, at the private sector, about 12 histopathology labs at Khartoum state. There are endoscopic and imaging diagnostic facilities in some of the tertiary care hospitals.

This lack of accessible high quality diagnostic services undoubtedly contributes to the late treatment of cases with the resulting poor outcomes. There is anecdotal evidence of missed diagnosis and erroneous diagnosis (both missing the diagnosis of cancer or false positives). Records and pathology reports are individually designed by labs, and this contributes to lack of accurate information for patient management and for cancer registry records.

It is also worth mentioning that diagnostics are necessary for choosing treatment modality, and for routine follow up of patients on treatment to identify the extent of spread of cancer. Affordability of these investigations is an issue.

4-Treatment

Cancer treatment needs a well-established infrastructure, including radiotherapy machines, cytotoxic drugs, and trained personnel in surgery, radiation, clinical oncology and oncology nurses. Treatment of cancer is a complex, involving a range of therapies. These include surgery, radiotherapy, chemotherapy hormone therapy, or a combination of these. Treatment aims for cure or improvement of quality of life of patients with cancer.

In Sudan there are only two centers equipped with radiotherapy machines and trained staff (RICK in Khartoum and NCI in Medani). There are 4 proposed centers, one in Khartoum (Suba), AlFasher (MOH), Merowe (MOH), and Shendi (University of Shendi). The latter has already started by a medical oncology unit, providing only chemotherapy and hormonal therapy.

RICK and NCI are both located in central Sudan with only 200 Km distance between them. This obviously limits access for patients who live far from them. This number of centers is definitely below the recommendation by IAEA which suggested one center for each 2-5 millions of population (9).

The other problem is lack of consistency in treating the same cancer at the same stage in different centers by different oncologists. The need for standard care management protocols is obvious. For breast and prostate cancers there are available guidelines for management (10); although not every oncologist is following them. There is some effort underway to formulate national management guidelines for all types of cancer.

There are two private hospitals dealing with cancer in Khartoum state, the Khartoum Breast Care Center (KBCC) and Khartoum Oncology Specialized center (KOSC). Beside treatment services, these centers also provide awareness raising and training activities for doctors and nurses.

5-Palliative care

Palliative care is not only for patients who do not have a curative option, but symptom control and psychosocial support to all cancer patients. Access to opioids is a major issue. Home care is a practical approach in palliative care. Late presentations of most of the patients make palliative care of importance. There are very limited rehabilitation and palliative care activities. At RICK there is a palliative care unit established February 2010, with one oncologist doctor, two nurses, two general practitioners, and one psychiatrist. There is shortage of trained staff, and inpatient beds. Another unit also recently started in Suba hospital. There is an urgent need to sustain this service and to enable the model to expand to other states. Access to opioids is a major issue, especially oral morphine (11). Home care is a practical approach in palliative care - a very limited home visiting service is available from RICK. At NCI they are doing palliative care but there is no dedicated unit for that.

6- Integration of cancer control services with PHC

The integration of cancer care at PHC is useful because PHC is accessible and affordable almost for everyone. This leads to sustainability of care. A high proportion of the community use PHC services, with prevention and care at same place, to ensure proper use of the scarce resources. Not all cancer control services can be done at PHC. Cancer care at PHC need (1) delineation of cancer services to be done at PHC as prevention, early detection, and palliative care, (2) development of prescribed range of essential drugs especially oral morphine, (3) guidelines and protocols, (4) a strong functioning referral system, (5) surveillance and information tools as format, patient record, referral cards, registration book, (6) equipments and supplies, (7) training of personnel on prevention, early detection and palliative care of cancer.

A pilot study for integration of NCDs at PHC was done at Khartoum and Gazera states. Plan is there to be expanded.

4. Medical products and technologies

The problems related to chemotherapy, hormonal therapy and new agents as targeted therapy include: estimation of real needs, availability and sustainability, rising cost, rising number of patients, inadequate budget to support poor patients, inadequate number of well trained staff: pharmacists, chemo-nurses and inadequate facilities to prepare chemotherapy agents.

The number of working radiotherapy units is greatly below the need of the country and the international standards. Only 3 cobalt machines and one linear accelerator exist; for a population of over 30 million. In Sudan, with the current number of cancer patients, the real need of radiotherapy machines is 16, according to the standard of 1 machine/ 500 cancer patients (12). With this limited number of radiotherapy machines, sometimes the machine may be out of order for nearly a year because there is no maintenance budget or maintenance contract, leading to very long waiting lists of patients.

The chemotherapy drugs are free of charge for all cases; targeted therapy, immunotherapy and other supportive treatments are not included.

5. Human Resources for Health

The trained staff members of oncologists, radiographers and oncology nurses are inadequate. The well-trained oncologists in the whole country are no more than 25 for almost 8000 new cancer cases every year. The IAEA recommend one oncologist for every 200 new cases in the developing countries. And the picture is the same for the other staff members. The shortage of trained human resources is worsened by massive brain drain.

Capacity building at federal, states, and care providers is needed. Curricula for under graduate and postgraduate education should be strengthened to bridge the gap in cancer knowledge.

6. Cancer information system and research

Cancer surveillance involves the routine and continuous collection of information on the incidence, prevalence, mortality, diagnostic methods, staging, and survival. Accurate cancer data are needed. Fully functioning and dedicated cancer registry is a corner stone of cancer surveillance.

The National Cancer Registry (NCR) was established in 2009. Its first report is to be endorsed shortly in 2012. some preliminary data from NCR have been used for this strategy (5). Previously, the only available data were from (RICK), and (NCI) in Wad Medani. It is estimated that the hospital data only registered 20-30% of the national cancer load. Information about cancer at RICK is hospital based. New Cancer cases contacted RICK were registered using Can. Tract data base system. There is need to introduce Can Reg4 data base system, training of the staff, and Quality control measures for completeness and keeping of patients records. At Gazeera state, NCI, cancer registry is population based using Can Reg4 data base system.

NCR started its activity by collecting cancer data from all governmental, private health facilities and histo-pathological laboratories in Khartoum State, after surveying all these facilities in 2009. It collects incidence data on all cancer patients who reside in or who are diagnosed and/ or treated for cancer in Khartoum and NCI Wad Medani services (only NCI hospital data feeds to NCR). Data collection depends mainly on passive and active case finding, and is carried out by cancer registry staff and statisticians in the hospitals. The NCR is planning for 6 more cancer registries to be distributed evenly across the Sudan. NCR currently lack information about cancer mortality, cancer survival and

age standardized cancer incidence rates. Aside from coverage, this is its greatest weakness as a registry. This is due to the general weakness of vital statistics and also that deaths certificates may not record cancer diagnosis as a contributing factor.

Research

Research is needed across the spectrum of cancer control to provide the basis for continual improvement. The research in cancer can be in these fields: epidemiology, clinical, laboratory, or health system and health policies. There is few researches in cancer. Indeed a comprehensive review of cancer research in Sudan highlighted the many gaps in this respect (12). NCR data are vital for this work; initially to map epidemiology and risk factors and also to stimulate other researches.

7. Cancer health systems financing

The government of Sudan, supported by WHO and IAEA are funding the cancer control expenses including buildings, equipment, radiotherapy services, supplies, drugs and continuous education and training.

Cancer is not a single disease, resources for cancer control are inadequate and directed to treatment, which is very costly. Free cancer treatment policy for chemotherapy does cover all cases, the costs of cancer treatment other than chemotherapy, are expected to be covered by patients, health insurance and others. However, free cancer treatment policy does not cover the costs of diagnosis or follow up investigations for patients undergoing treatment.

The monthly budget allocated to support chemotherapy at RICK and NCI are not adjusted to face the increasing number of patients and the rising cost of chemotherapy agents during the same period, i.e. there has been no annual increase. So the budget is inadequate, and made worse by the high cost for maintenance and repair of the machines.

Case study

In Sept 2011, some essential medications ran out in Central Medical Supplies despite availability of budget. Medications include Taxotere and Doxorubicin. Patients have to purchase their own medication privately at a cost of 3-4,000 SDG per dose and 800 -1,000 SDG per dose respectively.

Cancer is one of the conditions with catastrophic health expenditure for patients. A study was conducted in December 2010 for 231 patients at (RICK) to assess the socio-economic burden of cancer on patients attending the hospital and their families. Information about the direct and indirect cost of cancer was obtained. About 42% of patients received help from relatives and friends while 23% of them moved from their houses to pay for the cost of treatment or to live nearer to hospital. The Patients whose family income was over 700 SDG (US\$ 269.23) spent more; probably because they could afford it. The highest direct and indirect costs occurred within the first six months due to frequent visits and initial investigations and treatment. The costs of cancer are borne by families, health insurance and charity support to patients in this study was extremely limited (13).

Refer to SWOT Analysis

ANNEX 2. Gap analysis and areas of action

| Cancer control component | Situation | Gap | Areas for action (Source: multidisciplinary workshops for cancer strategy, Dec 2011) |
|--|--|---|--|
| Reduce the incidence of cancer through primary prevention | In a recent study by the cancer registry more than a third respondents smoked cigarettes, one in four used toombak, one in five used shisha and nearly one in seven mentioned drinking alcohol. Half of these were long term users more than 15 years. | Despite being a signatory to the Tobacco Convention, legislation and laws in tobacco control are disabled | <ul style="list-style-type: none"> • Legislation: smoke free environments, Alcohol related legislation • Taxation: Tax revenue should go to cancer control • Advocacy: innovative advocacy among the target teen group. Target young schoolchildren to persuade their parents against smoking. Use media in awareness messages for harmful lifestyles like smoking/toombak, harmful effects of alcohol. • Prevention programmes: increase health promotion activities, smoking cessation services. • Monitoring effectiveness of prevention programmes. |
| | Physical activity was not assessed in a standardized manner but more than 40% mentioned never exercise beyond normal day to day activities | Lack of awareness of lifestyle effects in cancer risk. | <ul style="list-style-type: none"> • support lifestyle modification • engage comprehensive media campaigns • promote action to prevent the development of obesity • augment rates of physical activity |
| | Sudanese use peanut butter which may contain aflatoxin due to storage conditions of the peanuts. It has been suggested that this may be associated with Hepatitis B in augmenting the risk of liver cancer | Recent increase in liver cancer (ref) and large percent of them hepatitis B positive. The role of aflatoxin is to be studied. | <p>Nutrition related cancers: improving access to acceptable and affordable healthy foods and food safety</p> <ul style="list-style-type: none"> • reducing the advertising of unhealthy food • raising awareness for healthy food • start prevention messages against food additives, reuse of cooking oil. |

| Cancer control component | Situation | Gap | Areas for action (Source: multidisciplinary workshops for cancer strategy, Dec 2011) |
|---|--|---|---|
| Reduce the incidence of cancer through primary prevention (contd) | Hepatitis B is now in the routine vaccination for children HPV vaccination not offered Other preventable cancers suggested to be linked to Helicobacter pylori, HPV, Schistosomiasis, HIV | No screening in high risk group for Hep B and no vaccination for them Priority of HPV vaccine has not been assessed against all other vaccines for EPI (cancer of cervix is one of the common cancers) | Increasing health promotion around infectious disease-related cancers <ul style="list-style-type: none"> • effective targeted screening for hepatitis B in high-prevalence populations • promoting hepatitis B vaccination • raising awareness of the risks associated with intravenous drug use • assess priority of HPV vaccine |
| | There are many potential carcinogens in the environment and occupational exposure eg pesticide, insecticide, Asbestos in water pipes and roofs/buildings, traffic pollution, factories and large development projects Waste disposal of equipment, batteries, radios, mobile phones etc industrial waste also contaminates the environment (pollution in air, land and water) | An assessment is needed of the priority carcinogens to address in the environment. It is likely to include sources of pollution including traffic, development projects, industrial waste pollution and general waste disposal. Also asbestos, pesticides, and occupational exposure in main industries (agriculture, petroleum and others) Assessment of priority of skin cancer due to UV exposure | <ul style="list-style-type: none"> • supporting international efforts to protect the ozone layer. • Health impact assessments and environmental impact assessments • Risk mapping |
| | There are regulations to protect workers against many known carcinogens. Hazards include pesticides in agriculture, lead in paints, mercury in gold mining, expansion in petroleum industry, etc. | Occupational and environmental health department responsibilities and authorities are distributed between different governmental bodies and not coordinated. Regulations are not enforced. | strengthening the legal framework to protect workers <ul style="list-style-type: none"> • reducing exposure to, and raising awareness of, carcinogenic compounds in the workplace • supporting research into occupational exposures • improving the reporting of occupational cancers. |

| Cancer control component | Situation | Gap | Areas for action (Source: multidisciplinary workshops for cancer strategy, Dec 2011) |
|--|--|--|--|
| Ensure early detection to reduce cancer morbidity and mortality (including screening) | No national screening programmes as in other countries for breast, cervix, colon, and prostate | <p>Introducing a new screening programme requires assessment of cost effectiveness and pragmatic option appraisal to cause more benefit than harm.</p> <p>No capacity of treatment services to accept additional patients and false positives.</p> <p>Eligibility for free management is reducing the costs for patients and families but not enough and we still see catastrophic health spending</p> | <p>We need to use success stories of cancer cure in the media to counteract the view that cancer=death. This is to encourage early presentation to health facility and thus early detection.</p> <p>Reduce the cost of investigations. Government subsidy needs to include investigations and diagnosis. Within the existing few resources, this is very difficult. Some work had already been started by NGOS and an approach to health insurance – this needs to be pursued.</p> |
| | <p>The main problem of cancer at that time the late diagnosis, 80-85% of pt diagnosed in stage 3 or 4.</p> <p>Too few cases found of lung cancer and cervical cancer than expected in hospital records (may be they die before they present)</p> | <p>Poor awareness of communities about cancer according to the national Cancer registry.</p> <p>Presenting late even if suspect cancer thinking that it cannot be managed or due to high cost of diagnosis and treatment or travel</p> <p>Low awareness of service provider and may miss the early signs -clinicians and allied cadres. Primary health care workers are the front line staff for early detection and better diagnosis and need to be trained.</p> <p>Possible defect in under graduate curriculum regarding early detection and control (only aware of overt cancers).</p> | <p>Self examination is to be promoted for early detection. Mammography machines should be available in public hospitals for diagnostic mammography (rather than screening of asymptomatic).</p> <p>Early detection: Teaching oncology/ basic principles in undergraduate and allied health professional training. Cancer unit in every hospital the same way as we have HIV unit. Increase awareness or training of health care workers/doctors. – if you suspect refer. Suspect the most harmful on top of the differential diagnosis and not the most common</p> <p>Training, guidelines, accountability. The Federal Ministry of Health should disseminate the current protocols/guidelines for breast and prostate cancer and ensure an accountability framework for implementation of these guidelines. It should involve the professional associations and the</p> |

| Cancer control component | Situation | Gap | Areas for action (Source: multidisciplinary workshops for cancer strategy, Dec 2011) |
|--|---|--|---|
| | | <p>Lack of postgraduate training in cancer</p> <p>Need to establish a process to assess the value of early detection of cancer.</p> <ul style="list-style-type: none"> • identify if the early detection of specific cancers reduces mortality and morbidity • recommend strategies to increase early detection , • assessment of the reasons for delays in early detection of these cancers in Sudan, focusing on who is affected & why | <p>Sudan Medical Council for professional and medico-legal regulation.</p> <p>For professional regulation and facilitating learning and dissemination of guidelines a group was recommended to be set up under the leadership of senior clinicians (pathologists, oncologists nad others) and building on the good practice demonstrated by Gezira. Audit is a starting point for professional regulation.</p> |
| Ensure effective diagnosis to reduce cancer morbidity and mortality | <p>Very few states have Histopathology labs (19%). While equipment provision may be adequate in States, still many of the states have no histopathologists</p> <p>Free of charge policy does not cover diagnosis,</p> <p>Similarly, lack of skills and numbers of other diagnosis modalities eg</p> <ol style="list-style-type: none"> 1. Endoscopy 2. Imaging. There are 6 mammography machine distributed in different states but technicians did not know how to use them 3. Immunohistochemistry 4. Haematology | <p>There is no uniform report and standards for quality assurance of labs (States and private)</p> <p>Gaps in numbers and skills of trained cadres in histopathologists, haematologists, endoscopy and imaging</p> <p>High costs of diagnosis are borne by patients which may contribute to delays in investigation and treatment</p> <p>Misdiagnosis is reported frequently eg TB and lung cancer</p> <p>Equipment: Calibration is a priority; the lack of this results in misdiagnosis. Maintenance: shortage in spare parts</p> | <p>Pathology request forms need to be standardized for better standards of diagnosis and cancer registration</p> <p>Ultrasound and imaging are operator dependent and need training</p> <p>This is also a quality issue for labs eg calibration of instruments</p> <p>Training to ensure implementation of the guidelines. This really needs resources therefore we need to advocate to a higher level and it is really the main priority of the strategy (to get diagnosis right).</p> |

| Cancer control component | Situation | Gap | Areas for action (Source: multidisciplinary workshops for cancer strategy, Dec 2011) |
|--|--|---|---|
| Ensure effective treatment to reduce cancer morbidity and mortality | <p>Management guidelines are available for breast and prostate cancer, although not every oncologist is following them</p> <p>Rising cost, rising number of patients, budget for supporting poor patients is inadequate</p> <p>Inadequate number of well trained staff –pharmacists, chemo nurses and inadequate facilities to prepare chemotherapy agents</p> | <p>Standard case management protocols do not exist for most cancers</p> <p>Estimation of real needs of treatment drugs is not known</p> <p>Inadequate number of well trained staff, oncologists, nurses, pharmacists etc</p> <p>Traditional healers are being used either to reduce cost of for beliefs and this affects early diagnosis and treatment of cancer.</p> <p>Treatment is costly.</p> | <p>Systematically assessing new treatment approaches.</p> <p>The Sudan National Cancer Strategy 2012-16 should recommend a ‘model unit’ in one hospital (eg Khartoum Teaching Hospital) availing mammography and multidisciplinary team approach as per above guidelines, with the necessary staffing and funding resources to be made available.</p> <p>To provide quality diagnostics and treatment, generation of funds should be under focus through: NGO’s and International collaborations</p> |
| | Only two oncology centers – these are in the centre of the Sudan. | Three more centres are needed which need to cover the wide geography of Sudan. This estimation is based on a standard of One center for each 2-5 millions of population (Ref) | <p>Establish necessary centres.</p> <p>Development of an infrastructure in oncology centres. These centres would require dedicated multidisciplinary teams</p> <p>Develop defined standards for diagnosis, treatment and care for those with cancer. The development, implementation and ongoing refinement of national and regional standards, guidelines and protocols. Multidisciplinary coordination of treatment.</p> <p>Multidisciplinary management of cases is the way forwards and no excuse for single person action.</p> <p>Development of a minimal data set to measure performance and outcome</p> |
| | Only 3 cobalt machines and one linear accelerator are available hence very long waiting lists of patients (no maintenance budget or maintenance contract) | Based on the current number of cancer patients the real need of radiotherapy machines is 16. This number is based on estimation that for every 500 cancer patients one machine is needed. | <p>Ensuring timely access to treatment</p> <p>Regular Maintenance of radiotherapy machines (spare parts).</p> |

| Cancer control component | Situation | Gap | Areas for action (Source: multidisciplinary workshops for cancer strategy, Dec 2011) |
|--|---|---|--|
| | The trained oncologists in the whole country do not exceed 20 oncologists for almost 8000 new cancer cases each year; and the picture is same for the other staff. | 20 oncologists are needed based on the estimate of one oncologist for every 200 new cases (estimation for developing countries – Ref) | Making use of remote/mobile technology to support States Increase number of human resources needed in cancer management |
| Improve the quality of life for those with cancer, their family through support, rehabilitation and palliative care | Only one palliative care unit in RICK and also operating in Soba. Palliative care taskforce and plan in place but funding needs to be secured for sustainability At NCI they are doing palliative care but there is no dedicated unit for that Carers are paying medical and non-medical costs of cancer as well as the social burden of cancer | Current palliative care is very small scale and its sustainability is not guaranteed. Each state to have a palliative care clinic. Palliative care should be included as an essential service in the regional cancer centres. Essential palliative care treatments (including pain relief) should be available across the country The carer's role is not recognized and supported Poor communication and counseling skills as well some patients and their families are not told of their diagnosis and prognosis. Dignity is not safeguarded in the crowded overloaded services Social and psychological support provided within hospitals is concerned with providing only financial support-role should include eg in oral cancer should include aesthetic surgery support | Ensure all people with cancer and their families are able to access the appropriate resources for support and rehabilitation that they need, including access to high-quality information on treatment and care Preserving a patient's right to be told about their diagnosis. Health providers need to be trained in communication skills Facilities for health care to have good reception and signposting of where to go for the service. Sustain the current effort on palliative care not to lose staff. Advocate for palliative care and raise awareness of patients that this service exists Ensuring each region has at least one local palliative care service - palliative care as routine care anywhere and not just small units in tertiary centre. Role of social worker to be expanded to counselling and psycho social support for patients and carers Availing home palliative care services |

| Cancer control component | Situation | Gap | Areas for action (Source: multidisciplinary workshops for cancer strategy, Dec 2011) |
|---|---|---|---|
| Improve the delivery of services across the range of cancer control through effective planning, co-ordination and integration of resources and activity, education activities, monitoring and evaluation | 25 year strategy for health does not include cancer. This translates to low commitment from decision makers and the fragmented services show lack of coordination and harmony (NGOs, public and private sector services) | Fragmented services and lack of coordination between NGOs, public and private sector | <u>Develop a co-ordinated national cancer strategy</u> Setting up a professional website for breast cancer to help facilitate networks, sharing of guidelines, and evidence based practice |
| | No specific budget for the early detection and prevention of cancer or the cancer control programme | Lack of coordination in resource allocation according to need | Review of free of charge policy and options of how this can be rebudgeted to cover investigations/ earlier diagnosis |
| | No annual increase in budgets to face the increasing number of patients and the rising costs of chemotherapy agents. A few patients are able to travel abroad or get treatments from abroad | Diagnosis is expensive and falls upon the patients. Free of charge policy is not adequate to cover the costs of cancer treatment and not included in health insurance. Catastrophic health spending by patients on cancer include the costs of travel from far states to the few oncology centres | Making use of remote/mobile technology to support States |
| Improve the effectiveness of cancer control in Sudan through research and surveillance (and promotion of | There are two regional registry (Khartoum, WadMedani) There are few proper researches in cancer Lack of funds for data collection and production of the report Scarcity of training for registry cadre in medical statistics & cancer epidemiology | Patients from States do not have a register so only those patients who present to RICK, Medani or Northern State are reported. Lack of funds for research Lack of awareness & coordination of medical doctor & pathologists& oncologists in the importance of cancer registration | Improve national cancer data quality Cancer registration: Must expand to all states to ensure completeness of data for patients; and records to include suspected cases not just those which are confirmed late stages in tertiary centres. The plan is to start in five oncology centres having diagnostic facilities. Explore opportunities in the E-Health project. Improve registration by |

| Cancer control component | Situation | Gap | Areas for action (Source: multidisciplinary workshops for cancer strategy, Dec 2011) |
|---|--|---|--|
| the role of the National Cancer Registry). | Lack of registry for those travelling abroad for treatment | <p>Lack of training for statisticians in cancer registration</p> <p>Sustainability of the cancer registry is under threat due to finances.</p> <p>Lack of awareness of policy makers and health personnel in the importance of cancer registration</p> <p>lack of surveys and screening of cancer</p> <p>Research in cancer is inadequate (lack of evidence –based data)</p> | <p>training on data analysis from the register (more likely to improve it if they are using it). Training for doctors to include the diagnosis on patient files, and for statistic clerks to complete the full record (not just name and age). The cancer registry are doing all this and need to be supported and sustained.</p> <p>Standardization of pathological report</p> <p>Establishment of cancer information networking</p> <p>Publicity (published annual report 2009-2010)</p> <p>Surveys and screening in breast cancer</p> <p>Extend and enhance research programmes</p> <p>Coordination between stakeholders eg NGOs etc</p> <p>Use data from NGOs to augment the register eg WIG data on early detection/screened women</p> |

ANNEX 3. Service Model for Cancer Care

Levels of care:

Primary care: This includes health centres and rural hospitals. Early detection (high level of suspicion), immediate referral of suspected cases to secondary care, training of primary care staff and awareness raising

Secondary care: Proper diagnosis and initial management. Can treat high volume low risk cancers based on guidelines and local expertise. Multidisciplinary team approach (minimum standards – below)

Tertiary care: Specialist management in Oncology centres (expansion in number to cover regions)

Secondary care minimum standards:

These standards have been recommended by the Multidisciplinary workshop and are subject to further clinical discussion and refinement

Standard: Any suspected case of cancer to be dealt with by a multidisciplinary team. If there is no team locally available, then discuss over phone or take to multidisciplinary clinic in the nearest facility. Suspected cases from primary or rural hospital should be referred to MDT.

Multidisciplinary team approach should include

- Input by an oncologist (either as part of the team or remote advice)
- specialist clinicians (eg surgeons, obstetricians, paediatricians etc)
- radiologists, histopathologists, hematologists
- palliative care specialist; pharmacist input
- nursing and allied health professionals, including social worker; and
- trainees in various fields;

Diagnostic facilities: Biopsy facilities, radiology, mammography

Availability of guidelines: MDT team refers to protocols and guidelines and evidence of best practice.

Treatment facilities: Decisions to manage at this level should be made by the MDT according to guidelines.

Referral pathways are clear through protocols and guidelines and advice of oncologist. Secondary level accepts back-referral.

ANNEX 4. Stakeholder roles and responsibilities for action

| Cancer Strategic Objective | Priority actions of the Sudan Cancer Control Strategy | Lead within MoH | Partners outside MOH |
|--|---|---|--|
| Reduce the incidence of cancer through primary prevention | <p>Advocate for leadership of NCDs and specifically the tobacco control strategy. Support efforts for healthy eating & physical activity</p> <p>Study the role of aflatoxin, food additives and reuse of cooking oils</p> <p>Assess priority of HPV vaccine and Hep B for high risk groups</p> <p>Undertake risk assessment and risk mapping for priority carcinogens in the environment. Initiate health impact assessments and environmental impact assessments. Support efforts for occupational health and corporate social responsibility (CSR).</p> | <p>PHE dir, NCD, tobacco coordinator</p> <p>Health promotion</p> <p>Food safety</p> <p>EPI</p> <p>Env health</p> <p>Occupational health</p> <p>CCP with PHI for CSR</p> | <ul style="list-style-type: none"> • NGOs • Legislative body • Consumer Protection • Specifications and standards • Ministry of Water and Irrigation • Ministry of Agriculture • Ministry of Industry • Ministry of Roads and Bridges • Ministry of Environment and Forests and Urban Development • Ministry of Higher Education and Scientific Research • Ministry of Public Education • Ministry of Youth and Sports • Ministry of Labor • |
| Ensure early detection to reduce cancer morbidity and mortality | <p>Encourage early presentation to services – self-examination, awareness raising, eg school curricula.</p> <p>Raise level of suspicion of cancer – undergraduate and primary care training</p> <p>Assess the case for cancer screening in Sudan (Wilson and Jungner criteria)</p> | <p>CCP with Health promotion</p> <p>CCP with RICK and NCI</p> <p>HRD with PHC</p> <p>CCP/NCR with health economics</p> | <ul style="list-style-type: none"> • Ministry of Education • NGOs • CBI • Civil organizations • Telecommunication companies • Universities and institutes |

| Cancer Strategic Objective | Priority actions of the Sudan Cancer Control Strategy | Lead within MoH | Partners outside MOH |
|--|--|---|--|
| Ensure effective diagnosis to reduce cancer morbidity and mortality | <p>Standardise pathology request forms and procedures</p> <p>Improve diagnostics – calibration, maintenance and operator training</p> <p>Avail staffing</p> <p>Training to ensure implementation of guidelines and availing diagnostic facilities in secondary care (equipment, consumables, staffing)</p> <p>Avail mammography machines for diagnosis</p> <p>Reduce the costs of diagnostics/ investigations through NGOs and expansion of insurance coverage</p> | <p>Labs with NCR</p> <p>Quality with labs</p> <p>Labs with HRD</p> <p>HRD with CCP</p> <p>Curative med</p> <p>Projects and development</p> <p>CCP</p> | <ul style="list-style-type: none"> • NGOs • CBI • Civil organizations • Telecommunication companies • National Health Insurance Fund • Private sector • Speciality associations |
| Ensure effective treatment to reduce cancer morbidity and mortality | <p>Distribute and develop further national standards, guidelines and protocols.</p> <p>Establish a ‘model unit’ in one hospital availing diagnostics and multidisciplinary team approach as per guidelines (further description of the clinical service model in Annex)</p> <p>Include cancer in general speciality training of all specialities</p> <p>Expand Oncology centres to all regions</p> <p>Explore opportunities for use of remote/mobile technology to support States (eg review telepathology project and task shifting to technicians/nurses)</p> <p>Undertake quality audits of cancer care</p> | <p>Curative med</p> <p>Curative med</p> <p>HRD with SMSB</p> <p>Planning, Projects and development with State MoH</p> <p>Labs with HRD</p> <p>Curative med with Quality</p> | <ul style="list-style-type: none"> • The Council of the Pharmacy and Poisons • Ministry of Finance • Civil organizations • Private sector • Treatment abroad • Telecommunication companies • Sudan Medical Specialisation Board • Sudan Medical Council • Speciality associations • National Council for Allied Health Professionals |
| Improve the quality of life for those with cancer, their family through support, rehabilitation and palliative care | <p>Sustain the current effort on the model units for palliative care; not to lose staff.</p> <p>Ensuring each region has at least one local palliative care service.</p> <p>Health providers need to be trained in</p> | <p>CCP with RICK</p> <p>State MoH</p> <p>CPD</p> | <ul style="list-style-type: none"> • NGOs • Ministry of Welfare and Social Security • Sudan Medical Council • Speciality associations |

| Cancer Strategic Objective | Priority actions of the Sudan Cancer Control Strategy | Lead within MoH | Partners outside MOH |
|---|--|--|---|
| | communication skills Role of social workers and NGOs to be expanded to counselling and psychosocial support for patients and carers. | CCP with curative med | <ul style="list-style-type: none"> National Council for Allied Health Professionals |
| Improve the delivery of services across the range of cancer control through effective planning, co-ordination and integration of resources and activity, education activities, monitoring & evaluation | Priority investment in diagnostics and early detection. Generation of funds should be under focus through NGOs and international collaborations. Initiate multidisciplinary audits and professional regulation Endorse the strategy through NHSSP processes and Higher Coordinating Council | CCP and PHE dir and health economics CCP with international health Curative med and quality PHE directorate with Planning | <ul style="list-style-type: none"> NGOs universities and institutes Ministry of Higher Education and Scientific Research Sudan Medical Council Speciality associations |
| Improve the effectiveness of cancer control in Sudan through research and surveillance (and promotion of the role of the National Cancer Registry). | Support and sustain the cancer registry Expand cancer registration to all states Explore opportunities in the eHealth project Training in data recording, verification and analysis (including accurate mortality data) Support the research function in the registry | PHE directorate NCR with state MOH NCR with National eHealth NCR with health informatics NCR with research and PHI | <ul style="list-style-type: none"> Universities and institutes Ministry of Oil Ministry of Mines Ministry of Agriculture Ministry of Industry Ministry of Science and Technology International NGOs Central Bureau of Statistics National information Cooperation Telecommunication companies |

ANNEX 5. Participants in the three stakeholder workshops

Minutes of FMOH workshop, 10 Oct 2011.

Agenda

1. Discuss progress to date on strategic planning
2. Identify critical issues for cancer
3. Identify the gaps and strategic objectives

Participants

Ahmed Hassan Mohamed – Director of Blood bank (FMOH), Amani Abdelmoneim - Director of Immunisation (FMOH), Nada Hamza, (WHO), Muna I Abdel Aziz, Zainab Amara, Manal Emam, Nazik Nurelhuda , Intisar Elfadil, Nageeb Suleiman, Babiker Magboul, Naima Abdalla, Suad Altahir Ali – coordinator of RTA, Amani Ahmed Osman- mental health ,

Recommendations

1. Comments made on the wording of the vision and mission
2. Gap analysis: consider stratifying the prevalence of risk factors by states etc
3. HPV vaccination as a form of protection from Cancer cervix – situation is that the vaccine is available, and it can be supported (GAVI and government in Sudan) but implementation should be according to burden of disease analysis and based on good baseline data ... also there are priority vaccines before this such as pneumonia.
4. Carcinogen analysis should be undergone in depth. Oil/gas/benzene added to the carcinogens
5. Awareness of service provider – in terms of early detection, management etc Strategy objectives- education is mentioned – but it should be elaborated to target medical schools, paramedical schools etc.
6. This seems to be a very long term strategy – would like to emphasize that all stakeholders need to be involved to achieve this. Influential partners – community participation .. youth etc in control , prevention etc. Need to focus on areas where you can get quick results.
7. Consider introduction of a sin tax to fund cancer ttt – all industries eg factories, pesticides, cigarette... and also to remember corporate social responsibility.
8. Highlighted that there are some missing directorate representatives but these were included as key informants... others were invited but did not make it to the meeting. The Strategy needs advocacy. Endorsement from the ministry is mandatory – invitation to partners from the Minister or Undersecretary
9. We need competent diagnosticians and laboratories – to get these personnel trained and to retain them is problematic - the system lacks organization. The Ministry of Finance easily responds to equipment requests but there are no staff to run them.
10. Diagnosis is expensive – free of charge ttt is not included in the diagnosis, misdiagnosis is common for this reason – what is the solution?
11. Other stakeholders suggested by the group include Road and traffic authorities, Ministry of Finance, potential sponsors eg from private sector eg. Oil and telecom companies

Cancer Strategy Stakeholders Workshop

Venue: Continuing Professional Development (CPD) Center– FMOH

Day: 7th December, 9:30 to 1:30pm

*Sponsored by Public Health Institute and Non Communicable Disease dept, Federal
Ministry of Health*

Stakeholders' workshop

Coordinator: Dr. Muna I Abdel Aziz

Cancer Strategy scribe: Dr Nazik Nurelhuda

| | | |
|---------------|--|--|
| 9:30 – 10:30 | Registration | |
| 10:30 – 10:40 | Opening Overview of strategy and gap analysis Open discussion | Dr Babiker ElMagboul Dr Muna I Abdel Aziz Dr Nazik Nurelhuda |
| 10:10 – 12:00 | Scenarios for discussion: 1. Prevention 2. Early detection and screening 3. Diagnosis 4. Treatment 5. Palliative care 6. Access to services (information, equity) | Open discussion of scenarios |
| 12:00 – 12:30 | Breakfast | |
| 12:30 - 01:30 | Wrap up and recommendations | Dr Muna I Abdel Aziz & Dr Babiker ElMagboul |

Invitations to this event had been issued to stakeholders and organizations interested in cancer and also through the Breast Cancer Conference. It was attended by 35 participants from various departments of the ministry of health, different clinical specialities, NGOs, Ministry of irrigation, media and a patient rep.

RECOMMENDATIONS OF THE STAKEHOLDER WORKSHOP

- 1) We should focus on all cancers not just breast cancer in the strategy – agree the priorities and phase the work (step by step)
- 2) Cancer registration is important to get the current evidence base, accurate information of the most common cancer, and priority research for cancer (eg why do people from the East have high head and neck/oesophageal cancer?, why do we get cancer at younger age than developed countries?)
- 3) Some solutions do not need much resource. Coordination reduces duplication and more efficient use of resource
- 4) We need to use success stories of cancer cure in the media to counteract the view that cancer=death. This is to encourage early detection.
- 5) We can use data from NGOs to augment the register eg WIG data on early detection/screened women
- 6) NGOs can learn from each other (form a network that works closely with the Ministry to coordinate).
- 7) Free investigations instead of free treatment.
- 8) Training health workers and medics (eg university curricula) as there are many delays due to missed diagnosis
- 9) Facilities for health care to have good reception and signposting of where to go for the service.
- 10) Prevention: role of media in scare messages for harmful lifestyles like smoking/toombak. Tax won't work but may release funds for cancer control. Coordinating the role of NGOs is important here. Start prevention messages early eg school children. Enabling legislation. Remember food additives, reusable oil.
- 11) Early detection: Teaching oncology/ basic principles in undergraduate and allied health professional training. Cancer unit in every hospital the same way as we have an HIV programme. Increase awareness of patients (give case studies of survivors), increase awareness or training of health care workers/doctors. – if you suspect refer. Suspect the most harmful on top of the differential diagnosis and not the most common
- 12) Diagnosis: Training to ensure implementation of the guidelines. This really needs resources therefore we need to advocate to a higher level and it is really the main priority of the strategy (get diagnosis right). Gap in finance, numbers and training of staff. Needs high level/senior clinicians to put in an action plan. This is also a quality issue for labs eg calibration of instruments
- 13) Treatment: Availability of treatment in the first place, Registration of cancer drugs is now a priority 90 drugs are registered (were only 60 last year)). Advocacy is important and more resource is needed for treatments which run out. Multidisciplinary coordination of treatment. Maintenance of radiotherapy machines (spare parts). Discontinued treatment wastes resource and also lives.
- 14) Palliative and supportive care: This is not just at end of life. Some resource from Social workers but their time is spent getting funding poor patients – could focus some of this time on psycho social support. Need palliative care as routine care anywhere and not just small units in tertiary centre. This is important because now 80% of patients present late. Sustain the current effort on palliative care not to lose staff. Advocate for palliative care and raise awareness of patients that this service exists
- 15) Cancer registration: Must expand to all states to ensure completeness of data for patients; and records to include suspected cases not just those which are confirmed late stages in tertiary centres. The plan is to start in five oncology centres having diagnostic facilities. Explore

opportunities in the E-Health project. Improve registration by training on data analysis from the register (more likely to improve it if they are using it). Training for doctors to include the diagnosis on patient files, and for statistic clerks to complete the full record (not just name and age). The cancer registry are doing all this and need to be supported and sustained.

Registered participants in the Cancer Strategy Stakeholders Workshop

| No. | Name | Institution |
|------------|-------------------------|---|
| 1- | Samia Adam Yahia | FMoH/ Health Economics Depart. |
| 2- | Widad Awad El Baloula | FMoH/ Curative Medicine |
| 3- | Fatma Mohamed Fadol | FMoH/ Curative Medicine |
| 4- | Ammar A. Alsalam Osman | Kuwaiti Specialized Hospital |
| 5- | Amr Osman Abdelrahim | Kuwaiti Specialized Hospital |
| 6- | Khalid A. Alsamea | Elshiekh Specialized Hospital |
| 7- | Salah A. Allah | Ministry of Irrigation |
| 8- | Babiker Magboul | FMoH/ Epidemiology Depart. |
| 9- | Fatima Hassan Salih | Military Hospital |
| 10- | Hiba Ibrahim Mohamed | Military Hospital |
| 11- | Eman Ahmed Mohamed | Military Hospital |
| 12- | Rihab Abdelate Saad | RICK |
| 13- | Aida Abdel Wahab | FMoH/ NCD |
| 14- | Nuha Ibrahim Elsayed | Sudanese Standards and Metrology Organization |
| 15- | Naiema Abdalla Wagialla | FMoH/ NCD |
| 16- | Hala Fouad Younis | FMoH/ Curative Medicine |
| 17- | Izadeen Gaffar Salim | National Cancer Institute |
| 18- | Rabha Hammad | General Corp. for National TV |
| 19- | Mohamed Omer Gamie | Alzaieem Alazhari Univ./ Fac. Of Medicine |
| 20- | Samia Osman Eltahir | National Council of Drugs and Poisons |
| 21- | Fatima Mohamed Ahmed | Military Hospital |
| 22- | Alhadaya Suliman Abbas | Military Hospital |
| 23- | Waheeba Mustafa Ali | Military Hospital |
| 24- | Amani Ahmed Osman | FMoH/ NCD |
| 25- | Suad Eltahir Ali | FMoH/ NCD |
| 26- | Patient advocate | Patient rep |
| 27- | Ahmed Mohamed Ahmed | Radio Omdurman |
| 28- | Intisar Elfadil Saeed | National cancer registry director |
| 29- | Yousra A. Almoniem | Military Hospital |
| 30- | Doaa Hassan A. Algalil | Khart. Dental Teaching Hospital |
| 31- | Ruaa Hamza Gasim | Khart. Dental Teaching Hospital |
| 32- | Nada Yahia | WHO |
| 33- | Mugahid Sayed Taha | Zain |
| 34 | Arafa Abdalla Elshiekh | Ministry of Finance and Nat. Economy |

University of Medical Sciences & Technology

1st International Conference on Breast Cancer

5th – 7th December 2011

“All together against Breast Cancer”

Venue: Continuing Professional Development (CPD) Center– FMOH

Day: 7th December, 9:00 to 4:00pm

Sponsored by Federal Ministry of Health

Clinicians’ workshop

Facilitators: Dr. Ahmed Elhaj and Dr Faisal Mehaimeed

Cancer Strategy scribe: Dr Manal AlEmam

| | | |
|---------------|---|--|
| 9:00 – 9:10 | Cancer strategy – diagnosis, treatment & palliation | Dr Muna I Abdel Aziz |
| 9:10 - 9:50 | Case Presentation: Local cases | Dr. Ahmed Elhaj |
| 9:50 - 10:30 | Case Presentation: UK cases | Dr. Faisal Mehaimeed |
| 10:30 -11:00 | Breakfast | |
| 11:00-01:00 | Controversial Issues: 1- Clinical & Radiological aspects. 2- Resection Margins. 3- FNAC versus CNB. 4- Immune Markers. 5- Management Options. | Experts Panel |
| 01:00 -01:20 | Pray & Coffee Break | |
| 01:20 -03:00 | Speciality comments | Experts Panel (contd.) |
| 03:00 – 04:00 | Overview of Sudan Cancer Control Group Strategy | Dr Muna I Abdel Aziz and Dr Manal Elimam |

Registration to this event was organized by the Breast Cancer Conference. It was attended by over 60 clinicians for many specialties and expert contribution by colleagues from AORTIC and abroad.

RECOMMENDATIONS OF THE MULTIDISCIPLINARY WORKSHOP

- 1) The Federal Ministry of Health should disseminate the protocols/guidelines for breast and prostate cancer that were developed a year ago and ensure an accountability framework for implementation of these guidelines. It should involve the professional associations and the Sudan Medical Council for professional and medico-legal regulation.
- 2) For professional regulation and facilitating learning and dissemination of guidelines a group was recommended to be set up under the leadership of senior clinicians (pathologists, oncologists and others) and building on the good practice demonstrated by Gezira. Audit is a starting point for professional regulation.
- 3) The Sudan National Cancer Strategy 2012-16 should recommend a 'model unit' in one hospital (eg Khartoum Teaching Hospital) availing mammography and multidisciplinary team approach as per above guidelines, with the necessary staffing and funding resources to be made available.
- 4) Mammography machines should be available in public hospitals for diagnostic mammography (rather than screening of asymptomatic which it had been commented before that it is a luxury). Self-examination is to be promoted for early detection.
- 5) Private sector should be accountable and regulated.
- 6) The role of NGOs is welcomed and indeed they are doing a lot, but government is expected to shoulder some key responsibilities.
- 7) Eligibility for free treatment is reducing the costs for patients and families but not enough and we still see catastrophic health spending. Government subsidy needs to include investigations and diagnosis. Within the existing few resources, this is very difficult. Some work had already been started by NGOS and an approach to health insurance – this needs to be pursued.
- 8) Advocacy was generally agreed for cancer prevention, better services and to get more funds in; as well as better coordination between sectors (government/NGO/specialities)
- 9) Multidisciplinary management of cases is the way forwards and no excuse for single person action. The cancer strategy needs to include this eg Breast cancer clinic in Khartoum to be institutionalised and to continue with multidisciplinary workshops
- 10) Setting up a professional website for breast cancer or Facebook to help facilitate networks, sharing of guidelines, and evidence based practice
- 11) Ultrasound and imaging are operator dependent and need training
- 12) Pathology request forms need to be standardized for better standards of diagnosis and cancer registration
- 13) Get the diagnosis right (overtreatment of patients who may not need it)
- 14) Primary health care workers are the front line staff for early detection and better diagnosis and need to be trained.
- 15) Counselling and psycho social support for patients and carers, being told about their diagnosis

Registered participants in the Multidisciplinary workshop

| | |
|--|---------------------------------------|
| 1. Dr Ahmed ElHaj | 42. Walaa Ahmed Farah Mohamed |
| 2. Prof Ahmed Mohammadani | 43. Mohammedsuror B.M.Alsammani |
| 3. Mr Faisal Mihameed | 44. Alsammani Widaa Mhd.Alameen |
| 4. Dr Ishrak Hamo | 45. Rashid Abdelhaleem Khaleel |
| 5. Dr Anas Hamdoun | 46. Waleed Musa Basheer |
| 6. Mr Ahmed Elamin Elsheikh | 47. Jihad Ali Osman |
| 7. Dr Abdalmonim Alataya | 48. Hala Al-Nasif |
| 8. Dr Ali Abdalsatir | 49. Sarah Mustafa |
| 9. Dr Lamya Ahmed Mohd Elhassan | 50. Husameldin Mahmoud Osman Nafi |
| 10. Dr Salwa Hassan Maki | 51. Albagir Elkheir |
| 11. Dr Muna I Abdel Aziz | 52. Mutasim Mursi |
| 12. Manal Alemam | 53. Tasneem Ahmed |
| 13. Nazik Nurelhuda | 54. Manal Mohemed Almaki |
| 14. Israa Mustafa | 55. Mohammed Khair Yousuf |
| 15. Abeer Hassan | 56. Gehan Ali |
| 16. Eman Mukhtar | 57. Samah Izzeldin |
| 17. Amr Osman Abdelrahim | 58. Wiaum Nasrallah |
| 18. Ammar Abdelsalam Osman | 59. Emtithal Alamin |
| 19. Khalid Abdelsamea | 60. Tasneem M.Elshiekh |
| 20. Mohja Ibraheem Alkhedir | 61. Mohamed Ahmed Mahgoub Ahmed |
| 21. Sara Yousf Mohamed | 62. Mazin Mukhtar Hamed Mohd Ahmed |
| 22. Malaz Abdel Mutal | 63. Nafeesa Khalid Musa |
| 23. Wafa Mudathir Elbashir | 64. Ahmed Abdelrahim Khalil |
| 24. Mohammed Yousif | 65. Reem Yassin Saeed |
| 25. Mohammed Abdulla Elawad | 66. Sareen Mahgoub Mahmoud Alzayat |
| 26. Eslam Mustafa Mukhtar | 67. Sara Hassan |
| 27. Nada Ismeil Mergheni | 68. Huda Alteb Ahmed |
| 28. Ala'a Ibrahim Bakri | 69. Izzadeen Gaffar Salim Salh |
| 29. Sheenaz Ahmed Mohamed | 70. Abdelazeem Ahmed Khalifa |
| 30. Elzehour Hashim Eltom | 71. Elwathig Sidahmed Mustafa Seliman |
| 31. Omaina Hashim Al-Tayeb | 72. Ammar Abdelhameed Alshareef |
| 32. Talal Mohamed Jergandi | 73. Mostafa Yousif Alnakli |
| 33. Sahar Elsmani Hassan | 74. Sara Mohammed Osman |
| 34. Zeinab Abdel Monaiem | 75. Hiba Atta Alhussein Ali |
| 35. Nouf Elfaki | 76. Tasneem Ahmed Abass |
| 36. Hadia Arzoun | |
| 37. Ahmed Hashim | |
| 38. Awad Ali M.Ahmed | |
| 39. Mohammed Elzein Eltayib | |
| 40. Abdu Elraheim Elmaleeh | |
| 41. Ghofran Mohamed Elhafiz | |

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