

National Mycetoma Control Program  
Policy outlines, Organ gram and description of staff responsibilities



# برنامج مكافحة المايستوما

## Mycetoma National Control Program

وزارة الصحة الإتحادية - جامعة الخرطوم

Federal Ministry of Health - University of Khartoum



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## Introduction

Mycetoma is a chronic specific granulomatous subcutaneous inflammatory disease that is recognized by its distinct appearance. It is caused by a variety of true fungi or by higher bacteria of the class actinomycete and hence it is classified as eumycetoma and actinomycetoma respectively.

Mycetoma is endemic in many tropical and sub-tropical regions and Sudan seems to be the homeland of the disease. It has a prolonged, progressive and indolent course and if untreated, it ultimately leads to destruction of the deeper tissues and bone resulting in deformity and disability that may necessitate amputation of the affected parts with all its social and economic implications.

It usually affects young population between the age of 15 - 40 years and this is the age of prime youth in the Sudan, but no age is exempted. Most of the patients are students, farmers, and workers of low socio-economic standards and eventually they lose their chance of education and jobs due to disability caused by a curable and preventable disease.

Due to ignorance and lack of health education, many patients present late with advanced disease and amputation may be the only available treatment modality for them.

Localized eumycetoma lesions are amenable to surgical excision, however, recurrence after surgery alone is high but it may be reduced with adjuvant medical treatment. Advanced cases usually require prolonged medical treatment as the response is slow. The available treatment is expensive and it may amount to more than 8,000 Sudanese pounds per year per patient with eumycetoma. The treatment is of a variable duration and may lapse for 2-3 years with a mean of 18 months. It proved to be expensive for the patient, family, community and health authorize.

In many centres, still amputation is the treatment of choice in the Sudan. Amputation is serious social stigma and it has many social and economic impacts on the individuals and community. In most centres, the artificial prosthesis is not available and if it is available, it is locally made of poor quality. Most of the amputees loss their jobs and become dependent on other members of the family.

Obviously, Mycetoma have prolong course of illness, associated with high morbidity, deformity and disabilities, the affected patients are of low socioeconomic status and the treatment requires a long duration to affect cure. Thus, these patients need attention from the medical community, society and donor organisations in the Sudan and worldwide.

Based on the priorities and guiding principles of the Health Sector 25 year strategic plan, the National Mycetoma Program is a good example of Intersectoral collaboration and partnership, teamwork enhancement for provision of care and Evidence-based policy and practice to disease control and prevention of its adverse effect. Joint collaboration between Ministry of Health (MoH) and University of Khartoum (UOFK) is an opportunity for the MoH to play its role in supporting successful existing projects and capitalize on its achievements for provision of better health care for whole country population.

With the good reputation of the Mycetoma Research Centre (MRC), University of Khartoum and the collaboration with MoH there is big potential for NMCP to be internationally recognized body. Especially, it is going to be the first initiative to deal with this disease in the world.

### **The Mycetoma Research Centre**

It was established in 1991 under the umbrella of the University of Khartoum. It was set up at Soba University Hospital to provide an integrated high quality medical care for Mycetoma patients, superb research and excellent education and teaching in the various aspects of Mycetoma. The center is recognized globally as a world leader and an authoritative advisor in Mycetoma management and research. It is the only specialized centre worldwide to deal with the Mycetoma patients. The centre is dedicated to the continuous discovery and development of scientific knowledge and clinical skills applied to the care of Mycetoma patients.

## **Mycetoma Research Centre Activities:**

### **Patients Management**

MRC prides itself on a multidisciplinary approach to individual patients and combines both medical and surgical expertise with specialist nursing and paramedical skills. MRC has a good history of providing exceptional care for the Mycetoma patients. By putting the welfare of patients first, MRC has achieved numerous national recognitions and it is a renowned worldwide as a referral centre for Mycetoma. The medical care at MRC is one of continuous change and challenge. During the last few years, 6200 patients with Mycetoma had been seen at MRC, most of them were young patients, 38.4% were jobless, 34% were students and 29.9% were farmers. Many of them presented with advanced disease due to lack of medical facilities at their localities and lack of health education and 12% of them had limb amputation. Most of the patients (84.1%) were of low socio-economic status, 40% of them had lost their jobs due to illness and 91% had no financial support for their treatment. MRC had managed through some donors to provide drugs to some of the patients. All patients had free medical consultation at the centre and some of them had free surgical treatment at Soba University Hospital.

### **Health Education & Community Development**

Staff members have conducted many field trips to various Mycetoma endemic areas to mention but few of them Eastern Sinnar and Khamlin and Dewam. In these areas out-patients clinics were established, house to house surveys were conducted and patients were encourage to attend these clinics. Patients were treated and complicated cases where referred to MRC for further treatment. In all these areas public health education sessions were conducted in collaboration with local health authorities and villages' leaders. The MRC had produced many CDs, video films on Mycetoma for health education and the problem was presented to the public through the Sudan National and Khartoum State TV, Sudan Broadcast and the press. To support the patients the centre had established the Mycetoma Patients Support Society aimed at the patients' financial, social and medical supports.

## **Medical & Paramedical Staff Training**

The centre had trained a core of medical, nursing and health personnel from different part of the country in various medical, health and nursing aspects of Mycetoma and now they are the change leaders in the management of Mycetoma patients.

## **Research & Publications**

The centre has executed an excellent clinical and basic research work in Mycetoma locally and in collaboration with many international centres. MRC had produced so far 55 original articles published in highly distinguished journals, one textbook, several chapters in textbooks, and a guideline for patients' treatment and that had contributed notably to the world literature.

## **International Collaboration**

The MRC has collaborated with many highly reputable international institutes and centres in the field of Mycetoma and other endemic and tropical diseases. This has resulted in knowledge and experience exchange and the conduction of high esteem research and publications.

## **Students Education**

The MRC staff is highly committed to provide enthused and inspired teaching for undergraduate and post-graduate students as well as continuing professional development for medical and health professionals. Many of these students have obtained post-doctoral

degrees. Currently the MRC has six research fellows. The MRC had organized with Gazira and Sinnar Universities and different academic associations many seminars on Mycetoma. The MRC has an educational website at [www.mycetoma.edu.sd](http://www.mycetoma.edu.sd)

### **Scientific Meetings Organization**

The MRC has organized many conferences, seminars and meetings which aimed to act as a media for medical and health members and scientists who are interested in Mycetoma to maintain contacts, to be a forum for informal discussion, to exchange and update knowledge and experience, to provide continuous medical education in Mycetoma and also to provide advisees and recommendations to the concerned authorities. Of these was the Third International Conference on Mycetoma which was organized in 2002 in Khartoum and the Fifth International Conference will be held in April 2011. The MRC had contributed to the organization of many local, regional and international meetings and conference on Mycetoma and other tropical diseases.

### **MRC Staff**

The staff members are of medical, health and science backgrounds who are interested in all facets related to Mycetoma. They have rich track records in patients' management, teaching, research and community development. The centre staff has continually explored new patients' management approaches through clinical and basic research.

## **National Health System in Sudan**

The introduction of federalism in Sudan fostered a three-layered health system structure. These are Federal Ministry of Health (FMOH), State Ministries of Health (SMOH) and Local Health System (locality level). The FMOH role is to provide technical support and guidance for the states, policymaking, strategic planning, co-ordination and international relations.

The second layer is composed of 26 State Ministries of Health (10 of which cover southern Sudan). The state governments are in charge of planning, policymaking, and implementation at state level. They take direct responsibility for the organization of health in the state and support of local health systems.

The third layer in the federal setup is composed of 134 localities (districts). They resemble the local health system. The localities are concerned mostly with policy implementation and service delivery. They are based on district health systems. They emphasize the principles of primary health care represented in decentralization, community participation, intersectoral co-ordination and integration of services. The local health system is composed of the primary health care unit (PHCU), dressing stations (DS), dispensaries, health centres (HC), rural hospital (RH) and locality general hospital (GH).

The dispensary is the entry point for communication with the community. Theoretically, it provides health care for a 5,000 population, or covers an area of 5 km in diameter (half an hour walking distance), or a village of one thousand population where no other health facility is available. It is led by a medical assistant and provides and promotes curative and preventive health care activities. The HC is the primary referral point for PHCUs. HC are headed by a medical doctor and are managed by the SMOHs. They provide health care to 20,000 people and should be accessible to the Dispensaries around it. In addition to the activities offered by the dispensaries, they provide a basic laboratory and perform small surgical operations.

The RH provides health care for 100,000-250,000 people, according to the needs. On average, it has bed capacity of 40 to 100 and is managed by SMOHs. It is headed by a

general practitioner and works 24 hours per day. The GH is the secondary referral level in the local health system. It contains 200-250 beds, covers a population of 500,000. It is always available in urban setting.

The 21 tertiary hospitals and specialized centres, including teaching, specialized, and general hospitals, are located in State capitals and are operated by the SMOHs. State referral hospitals offer care to the whole state. They contain 300 beds and provide the entire major and some minor medical specialty services according to the needs. These structures are managed by the federal administration FMOH.

### **Description of the National Mycetoma Control Program:**

The National Mycetoma Control Program (NMCP) is a service integrated program. Its aim is to eradicate the Mycetoma from Sudan through disease provision of high quality treatment and averting disease complications. To do so, the program focus on improvement of Mycetoma patients treatment through provision of free treatment, capacity building of health providers in diagnosis and management of patients, provision of information about disease burden and impact of treatment to help in publishing and distribution of country's experience to the globe.

The program policy is focused a round six strategies:

- Early diagnosis and management of patient to prevent disease complications and reduce the disease toll to the patients and program.
- Training of health personnel to ensure adoption of the program guidelines and proper treatment of patients with competent teams
- Regular supervision to maintain good performance, problem solving and sharing of knowledge and experience.
- Timely and regular supply of drugs to ensure patient access to care and avoid interruption of treatment.

- Recording and reporting system to ensure flow of information about disease burden, appropriateness of used regimen and assessment of program performance to shape the appropriate strategies.
- Increase the community awareness on the disease and its complications through adequate health education

The program works directly and with close collaboration with the state CDC directorates to implement the above mentioned strategies. Team building is the underlying principle for the program policy, not only for planning program activities and its monitoring but, even at provision of service the program will focus on establishing multi-disciplinary team for diagnosis, management and patients follow up. The program will adopt the existing experience of Soba University Hospital Mycetoma Clinic where, patients care offered by a group of well trained team composed of general and orthopedic surgeons, pathologist, radiologist, mycologist, psychiatrist, pharmacist, physiotherapist, counseling nurse, secretary, social workers and paramedical staff. The clinic team will pursue good communication and hold regular meetings or any fast and reliable means of communication and information exchange about the individual patients and to plan management.

### **Structure of the program**

The NMCP is a national collaborative body, at national level it coordinates between the University of Khartoum Mycetoma Research centre (MRC) and Federal Ministry of Health Department of Communicable Diseases (CDC).

At state and locality levels NMCP works in close collaboration with Communicable Diseases Department to ensure the sufficient logistic and technical support is provided to health providers to implement the program activities as well as ensure that affected communities are aware of disease treatment and available services.

NMCP policy for eradication of Mycetoma is early diagnosis of disease through passive detection of the affected patients while seeking medical care in health services. The policy also entails insurance of management continuity through provision of free medication and patients follow up to reduce the economic burden of disease on the affected communities. In addition to, capacity building and community raising awareness programs are integral part of program policy for early diagnosis and to ensure that appropriate medical decision has been taken to manage the patients beside community support and participation in achieving the program targets.

Based on the above mentioned facts the NMCP focus on integrating its activities with curative care providers; surgical departments at hospitals for diagnosis, management and follow up of detected patients, health providers at lower level health facilities or among the community for suspecting the disease and directing the patients to the appropriate clinics. Surgical departments in hospitals are responsible of reporting directly to the National office about the detected patients and their treatment outcome through the program reporting forms and during the reporting system time frame. In collaboration with relevant national or state bodies the national office responsible of provide technical and logistic support to the health providers units in terms of capacity building, drugs, reporting format, ...etc.

#### **Role of CDC directorate and FMoH in general:**

Since its establishment Mycetoma Research Centre has been good example of collaborating centre. The centre was able to coordinate with some international as well as national stakeholders for the sake of provision of good services to Mycetoma patients care and support. One example is it collaboration with WHO, Zakhat, States health authorities, and recently the MoH through the direct Undersecretary promised support. However, the centre currently is looking for providing permanent and continuous support to Mycetoma care, widening treatment coverage, improve management and prevent disease side effects. With regard to these issues the roles are:

1. Establishment of National Mycetoma Control Program as an entity responsible of ensuring that Mycetoma patients get access to high quality of care and help in preventing the disease late presentation and complications.
2. Maintain the available staff in Mycetoma Research Centre by providing them with salaries and other welfare scheme like their colleagues in other programs.
3. The MoH had hired the program national program staff (except program director) to run the program activities at national or state levels in coordination with the Mycetoma Research Centre Director.
4. The MoH is responsible of providing sufficient budget for the drugs, implementation of the program training and supervision activities and car for running the activities in the states.

#### **Role of Mycetoma Research Centre:**

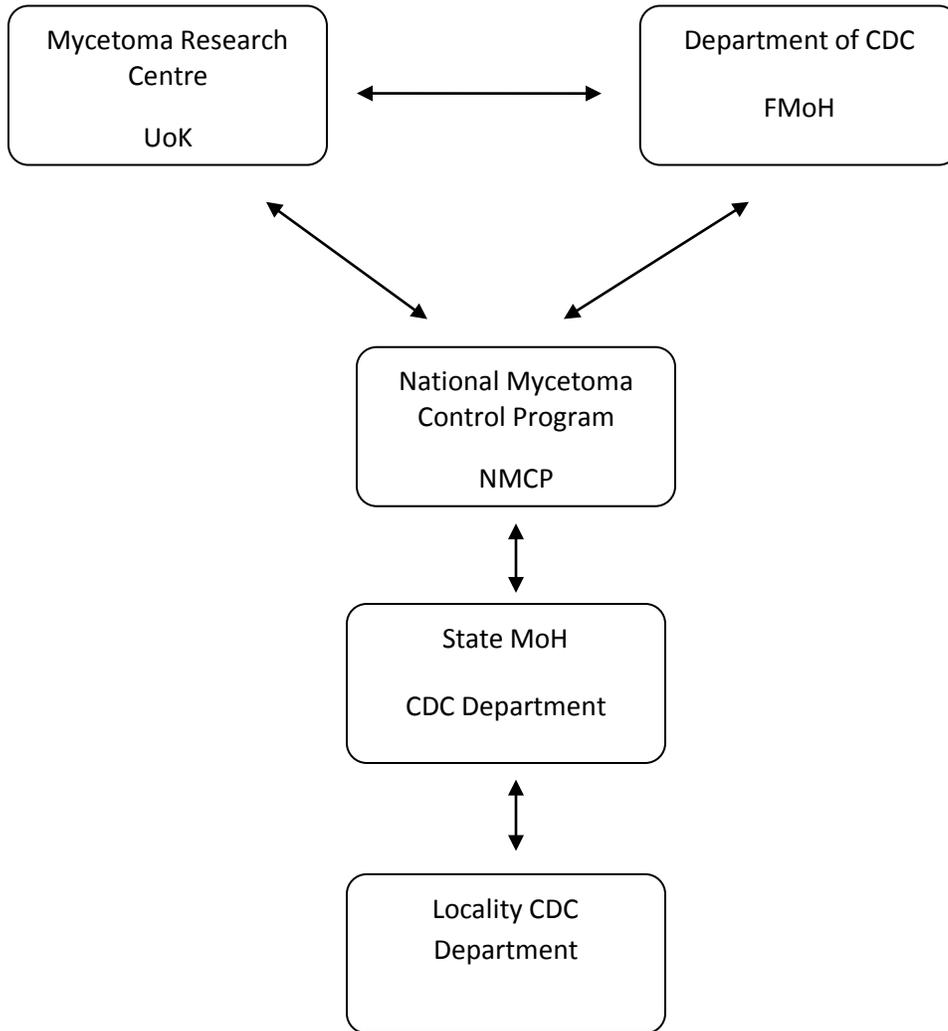
With the vision of establishment of National Mycetoma Control Program and the partnership with the National Ministry of Health the centre will be ready to tackle the following responsibilities:

1. Hosting of the National Program at the centre premises at Soba Hospital, the centre will build separate section to accommodate extra national program staff.
2. Hiring the national program director; the Mycetoma Research centre director by his/her status is the NMCP program director. University of Khartoum is expected to consider MoH criteria of selection of national program directors.
3. The center supports the program with the sufficient laboratory equipments and materials and trained staff to establish The National Program Reference Laboratory
4. The center provides its technical support to the program and help in developing the training manuals, program guidelines and any other necessary documents either by its available resource persons or its collaborating entities.

5. The center provides seed amount of money to cover the running cost of the program daily activities e.g. stationeries, computers, communications tools and others.

The MoH and university of Khartoum had signed memorandum of understanding describing each party responsibilities, system of coordination and follow up.

**National Mycetoma Control Program Organogram:**



**National office**

**National Mycetoma Control Program Coordinator:**

**Title of position: National Mycetoma Control Program Coordinator**

**Responsible of: National office staff**

**Responsible to: Director of Communicable Diseases Directorate**

**Qualification: Degree of MD Public Health or any equivalent degree**

The major responsibility of program coordinator is to coordinate NMCP activities and ensure the collaboration between MoH and MRC is on place, furthermore he/she is responsible of:

1. Coordinate process of policy making and update program policies and strategies
2. Coordinate program planning process, plans for training of program cadres monitoring and evaluation of progress made on planned activities
3. Prepare the program annual budget estimates including cost of drugs.
4. Supervision of states performance, provide technical and moral support to the staff at state to ensure standardization of method of interventions (diagnosis, management, reporting ...ect).
5. Collection of reports from states and coordinate with Mycetoma Research Centre the process of its analysis and ensure that feedback reports is timely and regularly provided to states
6. Coordinate with MRC, states, CDC directorate and other relevant national or international bodies to ensure that the program is able to perform its planned activities.
7. Report in systematic manner about the program achievements, challenges and disease burden to MRC, CDC directorate or any other potential partners.

***Training and supervision officer***

**Title of position:** National Training and supervision officer, NMCP  
**Responsible to:** National Mycetoma Control Program Coordinator  
**Qualification:** Degree of MPH

1. Coordinate design or update of training courses design, content and materials for NMCP activities
2. Plan for training and supervision activities annually and quarterly
3. M&E of training plan progress and provide regular reports about states performance
4. Supervision of health providers' performance and conduction of on job training.

***Health Education officer:***

**Title of position:** National Health Education officer, NMCP  
**Responsible to:** National Mycetoma Control Program Coordinator  
**Qualification:** Degree of MPH

1. Coordinate design of health education materials for NMCP activities
2. Plan for health education activities with relevant state bodies annually and quarterly and ensure contribution of the community and civil society
3. M&E of health education plan progress

***Information officer:***

**Title of position:** National Information officer, NMCP  
**Responsible to:** National Mycetoma Control Program Coordinator  
**Qualification:** Master Degree on Statistic

1. Collection of reports from clinics
2. Data entry
3. Send feedback to states

***Surveillance officer:***

**Title of position:** National Surveillance officer, NMCP

**Responsible to:** National Mycetoma Control Program Coordinator

**Qualification:** Master Degree on PH or epidemiology or Statistic

1. Analysis of data and interpretation of the disease trend and burden
2. Provide regular reports

**Logistic officer:**

**Title of position:** National Surveillance officer, NMCP

**Responsible to:** National Mycetoma Control Program Coordinator

**Qualification:** Degree in Pharmacology or Laboratory

- Responsible of management of materials and machines for the laboratories and other program equipments.
- Management of drugs its store, dispatch to states and collection of inventory lists from the states
- Provide regular feedback reports to states and national office about the situation of drugs and other program materials

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