

RARE MALIGNANT SKIN TUMOURS

PREFERRED MODEL OF CARE AND CRITERIA FOR REFERENCE CENTRES

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PREFERRED MODEL OF CARE AND CRITERIA FOR REFERENCE CENTRES

A. Types of cancer

1. Melanoma stage III & IV
2. Epitheliomas (basal cell and squamous cell carcinoma) that are:
 - o locally advanced and inoperable
 - o stage III-IV
3. Other rare skin tumours. These include Merkel cell tumour, angiosarcoma, dermatofibrosarcoma protuberans, atypical fibroxanthoma, malignant fibrous histiocytoma, leiomyosarcoma, Kaposi sarcoma
4. Primary cutaneous lymphomas

B. Short description of the skin cancer types

1) **Melanoma** is the most aggressive skin cancer arising from malignant transformation in the pigmented cells of the skin. It is currently the fifth most incident cancer in females and affects a relative young population (premature morbidity and mortality).

Melanoma stage III is a melanoma that has metastasized to regional lymph nodes or has developed in-transit metastases or satellites. There is no evidence of distant metastasis. Stage III disease is considered to be intermediate to high-risk for local recurrence or distant metastasis depending on specific sub-classification. Five-year overall survival varies between 26.7 to 69.5%. Melanoma stage IV is a melanoma that has metastasized to distant organs. Five-year overall survival is around 9.5%.

2) **Epitheliomas** are the most frequent types of skin cancer and even the most frequent cancer in Caucasians. It is expected that 1 in 6 people with this skin type will develop non-melanoma skin cancer during their life. In the majority of cases the treatment is simple and straightforward and the cure rate is very high. In a very small subgroup, the treatment can be less straightforward (locally advanced inoperable tumours) and/or these cancers can behave more aggressively (regional or systemic metastasis).

3) The **other** skin cancers are very rare (some dozens per year for Belgium, unfortunately no reliable figures available)

4) **Primary cutaneous lymphomas** are a group of rare lymphomas presenting in the skin without any evidence of extracutaneous disease at time of diagnosis. There is an estimated incidence of 1/100 000/year. There are different subgroups with different disease course and aggressiveness/prognosis. It is important to note that primary cutaneous lymphoma often has a completely different clinical behaviour and prognosis in comparison to their histologically similar systemic counterparts. For that reason the most recent classification systems (WHO, EORTC, ...) include primary cutaneous lymphomas as separate entities. A large part of the cutaneous lymphomas have an excellent prognosis and remain restricted to the skin. These need a totally different approach than the haematological lymphomas and usually their basic treatment is mainly skin directed. The diagnosis can be difficult and often needs integration of the clinical picture, the histopathological, immunophenotypic and sometimes molecular data.



C. Model of care pathway suggested for adult patients with skin cancers

Model of care pathway	Preferred model
1. <u>Model 1: Reference Centres exclusively (from diagnosis to follow-up).</u> Once there is a suspicion of skin tumour or a skin tumour has been diagnosed, the patient should be referred to a Reference Centre. A network with other Reference centres or with specific experts working in other centres is encouraged.	
2. <u>Model 2: Shared care between Reference Centres and peripheral hospitals.</u> Part of the care pathway is performed in the Reference Centre and for another part of the care pathway the patient is referred (back) to the regional hospital or private practice.	X

D. Phase(s) of the clinical pathway for which Reference Centres are required

Phase of the Clinical Pathway	Reference Centre	Peripheral centre
MOC	X	
Diagnostic confirmation	X	X
Comprehensive AP diagnosis	X	X
Therapeutic modalities	X	X
Follow-up	X	X
In case of relapse or progression: MOC	X	

Multidisciplinary Oncological Consult

All patients with a disease condition referred under A should have a specialized MOC in a Reference Centre to give advice on the management strategies needed / possible in the specific patient case. This is done either by the physical presence of the referring physician at the Reference Centre's MOC, by teleconsulting (tele-MOC) or after viewing the patient at a specialized consultation in the Reference Centre.

The Reference Centre will give a management advice (specialized written MOC report) within 2 weeks of first announcement of the patient file. The referring doctor is responsible for passing all available information to the Reference Centre at the moment of referral for advice. This MOC report should be sent to the referring doctor, the general practitioner of the patient and the patient himself. This MOC report should include standard of care procedures as well as possible clinical trials, including trials conducted in other centres. For the skin cancer types designated under A type 3 (other rare skin tumours) the specialized written MOC report has to document that the management plan is evidence-based (publications/reviews in peer-reviewed journals) or why it deviates from the guidelines suggested in literature.



The communication of this report to the patient can be done by the referring physician. Depending on the treatment chosen the referring physician can choose to start up the treatment himself or refer the patient for treatment to the Reference Centre (e.g. for study protocol that is not available in the referring centre). Treatment should be started preferably within 31 days of the report. In case of disease progression or relapse, a second opinion MOC has to be planned in a Reference Centre.

Diagnostic confirmation

In Reference Centre if advised by specialized written MOC report and agreed by referring centre. For skin cancer types as designated under A type 3 (other rare skin tumours) and type 4 (primary cutaneous lymphoma) it is advisable to have diagnostic confirmation in the Reference Centre.

Comprehensive AP diagnosis

In Reference Centre if advised by specialized written MOC report. A Reference Centre also must have the possibility to send the histological slides to specific reference pathology laboratories (national or international) that can help to establish the diagnosis.

Therapeutic modalities

In Reference Centre if advised by specialized written MOC report.

Follow-up

In Reference Centre if advised by specialized written MOC report.

E. General and specific criteria for Reference Centres

Human Resources and dedicated team

The multidisciplinary team at the Reference Centre should have the following members:

- Dermatologists: minimum of 2 dermatologists, covering a major interest in skin cancer, including skin cancer surgery and cutaneous lymphoma
- Medical oncologists/haematologists: minimum 2 medical oncologists (or haematologists in case of skin cancer type designated under A point 4 (primary cutaneous lymphoma)), covering a major interest in skin cancer.
- Specialist reconstructive surgeons: minimum of 2 surgeons with a designated interest and training in skin cancer surgery. Surgeons undertaking block dissections must perform at least 10 block dissections per year.
- Pathologist: minimum 1 pathologist with special interest in dermato-pathology
- Radiotherapist with knowledge of the latest radiotherapy (RT) techniques including intensity modulated radiotherapy (IMRT), rotational IMRT, stereotactic RT, 3D-image guided RT(IGRT), particle therapy, total skin RT.
- Dedicated nurse / psychologist
- Palliative support team
- Cosmetic camouflage service advisers



- Liaison psychiatrist

The presence of at least one member of each specialty during the specialized MOC is advised.

Required facilities and equipment

The Reference Centre should also be able to offer:

- Molecular analysis important for diagnostic or treatment work-up: detection of tumour mutations, detection of clonality
- Imaging: all appropriate imaging including PET-CT facility and image-guided biopsy modalities are available to patients in a timely manner
- Specific surgical techniques such as sentinel node biopsy, block dissections (minimum of 10 per surgeon per year), Mohs surgery
- State of the art radiotherapy: electron therapy, 3D-conformal RT, IMRT, rotational IMRT, stereotactic RT, 3D IGRT
- Information leaflets for the patients with information on the disease, its management and the specific treatment options proposed to the patient
- Facilities for clinical trial conduct and support, including research nurse and data manager involved in oncology trials according to existing standards (International Conference on Harmonisation Good Clinical Practice (ICH-GCP))
- Facility of prosthetics and orthotics

Patient centred care

- National and international networking with other Reference Centres for second opinion or referral of patients for other options not available at the Reference Centre (specific clinical trials, specialized surgical procedures, specialized radiation therapies)
- There is a national cutaneous lymphoma working group where primary cutaneous lymphomas that are difficult to diagnose or treat can be discussed.

Minimal volume of patients

- A Reference Centre should manage (actually diagnose and/or treat outside second opinion in specialized MOC conditions) at least 5% of all patient subtypes registered by the National Cancer Registry. As some skin cancer subtypes are most probably underestimated, estimations could be made by the Cancer Registry based on international data.
- Surgeons undertaking block dissections must perform at least 10 block dissections per year.

Quality Assurance

- Identification of a care program with standardized working procedures and clear, up-to-date guidelines for stage III and IV melanoma patients at the Reference Centre. For the skin cancer types designated under A type 3 (other rare skin tumours) the specialized written MOC report has to document that the management plan is evidence-based (publications/reviews in peer-reviewed journals) or why it deviates from the guidelines suggested in literature.
- A specialized written MOC report should be available within 2 weeks of first announcement in 90% of the referrals. This report should be sent to the referring physician, the general practitioner and the patient himself. In case of delay of the report, the reason for delay must be clearly documented.
- The referring physician should report back to the Reference Centre the treatment that has been chosen based on the specialized MOC report after discussion with the patient. S/he also reports if and when the treatment will be started at the referring centre or if the patient will be referred back to the



Reference Centre for treatment. A treatment should be initiated within 31 days of the written report, either in or out the Reference Centre in 85% of the cases. In case of delay of the start of treatment (> 31 days), the reason for delay must be clearly documented by the referring physician or the Reference Centre in case the patient was sent back for treatment.

- The Reference Centre must report all specialized MOCs to the National Cancer Registry.
- There will be an annual report by the Reference Centre with the number of all specialized MOCs and their through-put times (time to MOC report, time to start of the treatment).

Research and other scientific activities

For a Reference Centre for skin cancer, research activities resulting in publication in peer-reviewed journals (reported in pubmed) are encouraged.

Educational activities: Teaching and dissemination

All members of the multidisciplinary team of the Reference Centre must attend national and international meetings with skin cancer-specific topics at least once a year e.g. ASCO, ESMO, EADO, EORTC melanoma / cutaneous lymphoma subgroup meeting, visit to international excellence centres,

Membership of at least one member of the multidisciplinary team to national or international scientific skin cancer organizations is encouraged.

The Reference Centre itself is involved in training and continuous education programs for physicians, nurses, supportive disciplines and communication in scientific congresses.

Additional comments

- In order to make this operable, the working group believes that a quality control program will be necessary as well as additional financial support for these dedicated MOC.
- The members of the working group think it would be advisable to have a transition period of 1 to 2 years.

