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Training Requirements for the Competency of Rare Adult Solid Cancers

Preamble

The UEMS is a European-level non-governmental organisation representing national associations of medical specialists. With a current membership of 39 national associations and operating through 43 Specialist Sections and European Boards, the UEMS is committed to promoting the free movement of medical specialists across Europe while ensuring the highest level of training. Its work promises to pave the way to improved quality of care for the benefit of all European citizens. The UEMS areas of expertise notably encompass Continuing Medical Education, Post Graduate Training and Quality Assurance.

It is the UEMS' conviction that the quality of medical care and expertise is directly linked to the quality of training provided to medical professionals. Therefore the UEMS has committed itself to contributing to the improvement of medical training at the European level through the development of European standards in the different medical disciplines. No matter where doctors are trained, they should have at least the same core competencies. This is also essential for enabling free movement of medical specialists.

In 1994, the UEMS adopted its Charter on Post Graduate Training, which provided recommendations for good medical training throughout Europe. Made up of six chapters, this Charter set the basis for the European approach in the field of Post Graduate Training. The first five chapters established guidelines common to all specialties, while Chapter 6 was to be completed by each Specialist Section according to the specific needs of the discipline.

For more than a decade after the introduction of this Charter, the UEMS Specialist Sections and European Boards have continued to work on developing European standards in medical training that reflects modern medical practice and current scientific findings. In doing so, the UEMS Specialist Sections and European Boards do not aim to supersede the prerogatives of national authorities to define the content of postgraduate training in their own states, but rather to complement them and ensure that high quality training is provided across Europe.

At the European level, the legal mechanism ensuring the free movement of doctors through the recognition of their qualifications was established in the 1970s by the European Union. Sectorial Directives were adopted and one Directive addressed specifically the issue of medical training at the European level. However, in 2005, the European Commission proposed to the European Parliament

and Council to have a unique legal framework for the recognition of professional qualifications to facilitate and improve the mobility of all workers throughout Europe. This Directive, 2005/36/EC, established the mechanism of automatic mutual recognition of qualifications for medical doctors according to training requirements within all Member States; this is based on the length of training in the Competency and the title of qualification.

Given the long-standing experience of UEMS Specialist Sections and European Boards on the one hand and the European legal framework enabling Medical Specialists and Trainees to move from one country to another on the other hand, the UEMS is uniquely in position to provide competency-based recommendations. The UEMS values professional competence as "*the habitual and judicious use of communication, knowledge, technical skills, clinical reasoning, emotions, values, and reflection in daily practice for the benefit of the individual and community being served*"[1]. While professional activity is regulated by national law in EU Member States, UEMS understands that it has to comply with international treaties and UN Declarations on Human Rights as well as the WMA International Code of Medical Ethics.

This document derives from the previous Chapter 6 of the Training Charter and provides definitions of specialist competencies and procedures as well as how to document and assess them. For the sake of transparency and coherence, it has been renamed as "Training Requirements for the Competency of Rare Adult Solid Cancers". This document aims to provide the basic Training Requirements for each competency and it should be regularly updated by UEMS Specialist Sections and European Boards to reflect scientific and medical progress. Its three-part structure reflects the UEMS approach to have a coherent pragmatic document not only for medical specialists but also for decision-makers at national and European levels interested in knowing more about medical specialist training. . It is important to note that at the moment there is no such medical speciality recognized in the Annexe V. Therefore we use the term of "competency" instead of medical speciality, even if, hopefully, it will become an independent medical professional soon.

Rare adult solid cancers are a broad and diverse group of cancers with a wide range of survival outcomes. Rare adult solid cancers are defined by the European Union as malignancies with an incidence of less than 0.006%. Using incidence in this definition elucidates the difference between rare adult solid cancers with high cure rates and relatively common cancers with low cure rates. A rare adult solid cancer that is successfully cured has a rather high prevalence rate (such as testicular cancer) while a common cancer such as small-cell lung cancer has a low life-expectancy and hence a low prevalence in the population. It is estimated that there are 198 types of rare adult solid cancer. Some of these are unusual types of common cancers such as versions of bowel and breast cancer, while others are completely separate kind such as several sarcomas.

The public health challenge posed by rare adult solid cancers combines both the typical problems of rare diseases (such as limited relevant professional expertise available in the community, or the difficulties in clinical research) and those of cancer, with the need of a timely and appropriate diagnosis and optimal treatment from the very beginning of the patient's journey. An accurate

[1] Defining and Assessing Professional Competence, Dr Ronald M. Epstein and Dr Edward M. Houndert, Journal of American Medical Association, January 9, 2002, Vol 287 No 2

clinical, pathologic and biological assessment of the disease of the individual patient, as well as an expert and prompt clinical decision provided by a multidisciplinary team, is key to survival and cure.

Rare Adult Solid Cancer Training Aims (more details in the Description of Competency and the Syllabus)

A competent rare adult solid cancer specialist needs knowledge of the underlying disease processes, available diagnostic and therapeutic modalities, and also must appreciate the importance of epidemiology and the potential for prevention of these cancers. Rare adult solid cancer specialists who generally work in hospitals need as well to integrate their work with community based primary care colleagues and other hospital based physicians. The training requirements for the competency of rare adult solid cancers described below will ensure these competencies.

1. To provide a service whose goal is to assess, investigate, and diagnose rare adult solid cancers and medical conditions
2. To provide a service that provides specialist information about rare adult solid cancers, including recommendations for screening where appropriate
3. To provide a service that investigates and offers counselling in relation to reproductive options and prenatal genetics, balancing the goal of preventing hereditary rare adult solid cancers with the personal choices of the individuals and families affected.
4. To contribute to the management and treatment of patients and families affected by rare adult solid cancers, in collaboration with other medical specialists
5. To be advocates, where necessary, for those affected by rare adult solid cancers
6. To conduct and contribute to clinical and genomic research aimed at improving knowledge of the causation and natural history of rare adult solid cancers and conditions
7. To teach and instruct medical undergraduates and postgraduates in rare adult solid cancers, in order to raise the knowledge base across all medical specialties
8. To provide a knowledge and skills resource to all medical specialties, including through multidisciplinary meetings
9. To contribute to public awareness about rare adult solid cancers

I. TRAINING REQUIREMENTS FOR TRAINEES

1. Content of training and learning outcome

The rare adult solid cancers speciality is a field of medicine concerned with the investigation, diagnosis, treatment, prevention, and research into rare adult solid cancers. The scope of patient care activities includes the recognition of rare adult solid cancers, the early identification of individuals and families at risk, the identification of possible causative genetic defects and the preventive care of affected family members, and prevention of intellectual and physical disability in those born with genetic disorders, in addition to the rehabilitation of such patients. This competency training is aimed at giving doctors appropriate qualifications in the field of rare adult solid cancers to enable them to treat patients and their families in the light of current and expanding knowledge on the subject, with particular emphasis on understanding the molecular and cellular pathogenic

mechanisms of such diseases, and their diagnosis and treatment. Rare adult solid cancer specialists must also be able to carry out screening for the early identification of individuals and families with a high risk of contracting common diseases that have a major social impact (malformations in general, familial cancers, inborn errors of metabolism, etc.). During the course of the training program classical methodologies will be applied. These include but are not limited to: lectures, seminars, bed side teaching, case reports, case scenario discussions, journal clubs, e-learning, webinars, computer assisted, self-instruction modules, problem-based learning, team-based learning, simulation etc.

Fields of rare adult solid cancers:

1. Head and neck cancers
1.1. Epithelial tumours of nasal cavity and sinuses
    1.1.1. Squamous cell carcinoma with variants of nasal cavity and sinuses
    1.1.2. Lymphoepithelial carcinoma of nasal cavity and sinuses
    1.1.3. Undifferentiated carcinoma of nasal cavity and sinuses
    1.1.4. Intestinal type adenocarcinoma of nasal cavity and sinuses
1.2. Epithelial tumours of nasopharynx
    1.2.1. Squamous cell carcinoma with variants of nasopharynx
    1.2.2. Papillary adenocarcinoma of nasopharynx
1.3. Epithelial tumours of major salivary glands and salivary-gland type tumours
    1.3.1. Epithelial tumours of major salivary glands
    1.3.2. Salivary gland type tumours of head and neck
1.4. Epithelial tumours of hypopharynx and larynx
    1.4.1. Squamous cell carcinoma with variants of hypopharynx
    1.4.2. Squamous cell carcinoma with variants of larynx
1.5. Epithelial tumours of oropharynx
    1.5.1. Squamous cell carcinoma with variants of oropharynx
1.6. Epithelial tumours of oral cavity and lip
    1.6.1. Squamous cell carcinoma with variants of oral cavity
    1.6.2. Squamous cell carcinoma with variants of lip
1.7. Epithelial tumours of eye and adnexa
    1.7.1. Squamous cell carcinoma with variants of eye and adnexa
    1.7.2. Adenocarcinoma with variants of eye and adnexa
1.8. Epithelial tumours of middle ear
    1.8.1. Squamous cell carcinoma with variants middle ear
    1.8.2. Adenocarcinoma with variants of middle ear
2. Thoracic rare cancers
2.1. Epithelial tumour of trachea
    2.1.1. Squamous cell carcinoma with variants of trachea
    2.1.2. Adenocarcinoma with variants of trachea
    2.1.3. Salivary gland type tumours of trachea
2.2. Rare epithelial tumours of lung
    2.2.1. Adenosquamous carcinoma of lung
    2.2.2. Large cell carcinoma of lung
    2.2.3. Salivary gland type tumours of lung

- 2.2.4. Sarcomatoid carcinoma of lung
- 2.3. Epithelial tumours of thymus
  - 2.3.1. Malignant thymoma
  - 2.3.2. Squamous cell carcinoma of thymus
  - 2.3.3. Undifferentiated carcinoma of thymus
  - 2.3.4. Lymphoepithelial carcinoma of thymus
  - 2.3.5. Adenocarcinoma with variants of thymus
- 2.4. Malignant mesothelioma
  - 2.4.1. Mesothelioma of pleura and pericardium
  - 2.4.2. Mesothelioma of peritoneum and tunica vaginalis
- 3. Male genital rare cancers
- 3.1. Rare epithelial tumours of prostate
  - 3.1.1. Squamous cell carcinoma with variants of prostate
  - 3.1.2. Infiltrating duct carcinoma of prostate
  - 3.1.3. Transitional cell carcinoma of prostate
  - 3.1.4. Salivary gland type tumours of prostate
- 3.2. Testicular and paratesticular cancers
  - 3.2.1. Paratesticular adenocarcinoma with variants
  - 3.2.2. Non seminomatous testicular cancer
  - 3.2.3. Seminomatous testicular cancer
  - 3.2.4. Spermatocytic seminoma
  - 3.2.5. Teratoma with malignant transformation
  - 3.2.6. Testicular sex cord cancer
- 3.3. Epithelial tumours of penis
  - 3.3.1. Squamous cell carcinoma with variants of penis
  - 3.3.2. Adenocarcinoma with variants of penis
- 3.4. Extragonadal germ cell tumours
  - 3.4.1. Non seminomatous germ cell tumours
  - 3.4.2. Seminomatous germ cell tumors
  - 3.4.3. Germ cell tumors of central nervous system (CNS)
- 4. Female genital rare cancers
- 4.1. Rare epithelial tumours of breast
  - 4.1.1. Mammary paget's disease of breast
  - 4.1.2. Special types of adenocarcinoma of breast
  - 4.1.3. Metaplastic carcinoma of breast
  - 4.1.4. Salivary gland type tumours of breast
  - 4.1.5. Epithelial tumour of male breast
- 4.2. Rare epithelial tumours of corpus uteri
  - 4.2.1. Squamous cell carcinoma with variants of corpus uteri
  - 4.2.2. Adenoid cystic carcinoma of corpus uteri
  - 4.2.3. Clear cell adenocarcinoma not otherwise specified (NOS) of corpus uteri
  - 4.2.4. Serous (papillary) carcinoma of corpus uteri
  - 4.2.5. Mullerian mixed tumour of corpus uteri
- 4.3. Epithelial tumours of cervix uteri
  - 4.3.1. Squamous cell carcinoma with variants of cervix uteri
  - 4.3.2. Adenocarcinoma with variants of cervix uteri

- 4.3.3. Undifferentiated carcinoma of cervix uteri
- 4.3.4. Mullerian mixed tumour of cervix uteri

4.4. Epithelial tumours of ovary and falloppian tube

- 4.4.1. Adenocarcinoma with variants of ovary
- 4.4.2. Mucinous adenocarcinoma of ovary
- 4.4.3. Clear cell adenocarcinoma of ovary
- 4.4.4. Primary peritoneal serous/papillary carcinoma of ovary
- 4.4.5. Mullerian mixed tumour of ovary
- 4.4.6. Adenocarcinoma with variant of falloppian tube

4.5. Non epithelial tumours of ovary

- 4.5.1. Sex cord tumours of ovary
- 4.5.2. Malignant/immature teratomas of ovary
- 4.5.3. Germ cell tumour of ovary

4.6. Epithelial tumours of vulva and vagina

- 4.6.1. Squamous cell carcinoma with variants of vulva and vagina
- 4.6.2. Adenocarcinoma with variants of vulva and vagina
- 4.6.3. Paget s disease of vulva and vagina
- 4.6.4.Undifferentiated carcinoma of vulva and vagina

4.7. Trophoblastic tumour of placenta

5. Urological / Urogenital rare cancers

5.1. Rare epithelial tumours of kidney

- 5.1.1. Squamous cell carcinoma spindle cell type of kidney
- 5.1.2. Squamous cell carcinoma with variants of kidney

5.2. Epithelial tumours of pelvis and ureter

- 5.2.1. Transitional cell carcinoma of pelvis and ureter
- 5.2.2. Squamous cell carcinoma with variants of pelvis and ureter
- 5.2.3. Adenocarcinoma with variants of pelvis and ureter

5.3. Epithelial tumours of urethra

- 5.3.1. Transitional cell carcinoma of urethra
- 5.3.2. Squamous cell carcinoma with variants of urethra
- 5.3.3. Adenocarcinoma with variants of urethra

5.4. Rare epithelial tumours of bladder

- 5.4.1. Squamous cell carcinoma with variants of bladder
- 5.4.2. Adenocarcinoma with variants of bladder
- 5.4.3. Salivary gland type tumours of bladder

6. Neuroendocrine tumours

6.1. Rare neuroendocrine tumours

- 6.1.1. GEP - well differentiated not functing endocrine carcinoma of pancreas and digestive system
- 6.1.2. GEP - well differentiated functing endocrine carcinoma of pancreas and digestive system
- 6.1.3. GEP - poorly differentiated endocrine carcinoma of pancreas and digestive system
- 6.1.4. GEP - mixed endocrine-exocrine carcinoma of pancreas and digestive system
- 6.1.5. Endocrine carcinoma of thyroid gland
- 6.1.6. Rare neuroendocrine carcinoma of skin
- 6.1.7. Typical and atypical carcinoid of the lung

- 6.1.8. Rare neuroendocrine carcinoma of other sites
- 6.1.9. Pheochromocytoma malignant
- 6.1.10. Paraganglioma

7. Tumours of the endocrine organs
7.1. Carcinomas of pituitary gland
7.2. Carcinomas of thyroid gland
7.3. Carcinomas of parathyroid glan
7.4. Carcinoma of adrenal gland
8. CNS tumours
8.1. Tumours of central nervous system (CNS)

- 8.1.1. Astrocytic tumours of CNS
- 8.1.2. Oligodendroglial tumours of CNS
- 8.1.3. Ependymal tumours of CNS
- 8.1.4 Choroid plexus carcinoma of CNS
- 8.1.5. Malignant meningiomas

8.2. Embryonal tumours of central nervous system (CNS)
9. Sarcomas
9.1. Soft tissue sarcoma

- 9.1.1. Soft tissue sarcoma of head and neck
- 9.1.2. Soft tissue sarcoma of limbs
- 9.1.3. Soft tissue sarcoma of superficial trunk
- 9.1.4. Soft tissue sarcoma of mediastinum
- 9.1.5. Soft tissue sarcoma of heart
- 9.1.6. Soft tissue sarcoma of breast
- 9.1.7. Soft tissue sarcoma of uterus
- 9.1.8. Other soft tissue sarcomas of genitourinary tract
- 9.1.9. Soft tissue sarcoma of viscera
- 9.1.10. Soft tissue sarcoma of paratestis
- 9.1.11. Soft tissue sarcoma of retroperitoneum and peritoneum
- 9.1.12. Soft tissue sarcoma of pelvis
- 9.1.13. Soft tissue sarcoma of skin
- 9.1.14. Soft tissue sarcoma of paraorbit
- 9.1.15. Soft tissue sarcoma of brain and other parts of nervous system
- 9.1.16. Embryonal rhabdomyosarcoma of soft tissue
- 9.1.17. Alveolar rhabdomyosarcoma of soft tissue
- 9.1.18. Ewin's sarcoma of soft tissue

9.2. Bone sarcoma

- 9.2.1. Osteogenic sarcoma
- 9.2.2. Chondrogenic sarcomas
- 9.2.3. Notochordal sarcomas chordoma
- 9.2.4. Vascular sarcomas
- 9.2.5. Ewing's sarcoma
- 9.2.6. Epithelial tumours adamantinoma
- 9.2.7. Other high grade sarcomas (fibrosarcoma malignant fibrous histiocytoma)

9.3. Gastrointestinal stromal sarcoma
10. Digestive rare cancers

10.1. Epithelial tumours of oesophagus
- 10.1.1. Squamous cell carcinoma with variants of oesophagus
- 10.1.2. Adenocarcinoma with variants of oesophagus
- 10.1.3. Salivary gland type tumours of oesophagus
- 10.1.4. Undifferentiated carcinoma of oesophagus

10.2. Rare epithelial tumours of stomach
- 10.2.1. Squamous cell carcinoma with variants of stomach
- 10.2.2. Salivary gland-type tumours of stomach
- 10.2.3. Undifferentiated carcinoma of stomach

10.3. Epithelial tumours of small intestine
- 10.3.1. Adenocarcinoma with variants of small intestine
- 10.3.2. Squamous cell carcinoma with variants of small intestine

10.4. Rare epithelial tumours of colon
- 10.4.1. Squamous cell carcinoma with variants of colon
- 10.4.2. Fibromixoma and low grade mucinous adenocarcinoma of the appendix

10.5. Rare epithelial tumours of rectum
- 10.5.1. Squamous cell carcinoma with variants of rectum

10.6. Epithelial tumours of anal canal
- 10.6.1. Squamous cell carcinoma with variants of anal canal
- 10.6.2. Adenocarcinoma with variants of anal canal
- 10.6.3. Paget's disease of anal canal

10.7. Rare epithelial tumours of pancras
- 10.7.1. Squamous cell carcinoma with variants of pancreas
- 10.7.2. Acinar cell carcinoma of pancreas
- 10.7.3. Mucinous cystadenocarcinoma of pancreas
- 10.7.4. Intraductal papillary mucinous carcinoma invasive of pancreas
- 10.7.5. Solid pseudopapillary carcinoma of pancreas
- 10.7.6. Serous cystadenocarcinoma of pancreas
- 10.7.7. Carcinoma with osteoclast-like giant cells of pancreas

10.8. Epithelial tumours of liver and intrahepatic bile tract (IBT)
- 10.8.1. Hepatocellular carcinoma of liver and IBT
- 10.8.2. Hepatocellular carcinoma fibrolamellar of liver and IBT
- 10.8.3. Cholangiocarcinoma of IBT
- 10.8.4. Adenocarcinoma with variants of liver and IBT
- 10.8.5. Undifferentiated carcinoma of liver and IBT
- 10.8.6. Squamous cell carcinoma with variants of liver and IBT
- 10.8.7. Bile duct cystadenocarcinoma of IBT

10.9. Epithelial tumours of gallbladder and extrahepatic biliary tract (EBT)
- 10.9.1. Adenocarcinoma with variants of gallbladder
- 10.9.2. Adenocarcinoma with variants of EBT
- 10.9.3. Squamous cell carcinoma of gallbladder and EBT

Competencies required of the trainee

Rare adult solid cancer specialist need a wide range of clinical skills, as rare cancers can affect all body systems.

A holistic vision of patients and good communication skills are particularly important for the trainee.

2. Organization of training

a. Schedule of training

A medical trainee (intern, resident, fellow or registrar) is a doctor who has completed their general professional training as a physician and is in an accredited training programme to become a recognised medical specialist. The trainee in rare adult solid cancer must be recognized as a trainee according to the regulations in force in each EU/EEA member state. The duration and curriculum of training in rare adult solid cancers should enable the trainee to become a fully independent specialist. The optimal rare adult solid cancer speciality training is 4 years consisting of 1 year of common trunk and 3 years training in an accredited program in a rare adult solid cancer centre.

b. Training curriculum

The general aim of the training program is to enable the rare adult solid cancer specialist to work effectively as a consultant. The trainee must demonstrate the ability to record and convey patient details of history, examination, and investigation findings to senior staff. The trainee must communicate effectively with patients and relatives, and be able to pass on both technical information in a way that it can be received with understanding, and distressing information in a sensitive and caring manner.

c. Assessment and evaluation

The MJC RUD aims to introduce an EU Board Exam in Rare Adult Solid Cancers. The successful candidates will gain an European Certificate in Rare Adult Solid Cancers (ECRASC), which is intended to be the main knowledge-based assessment tool for training and assessment across Europe and ultimately for all continent's experts, with the aim of establishing world class-leading standards in that competency throughout all countries. At the moment, there is no such national level exam anywhere in Europe. Later, countries may use their own assessment strategies appropriate to their needs, provided they introduce their own training and assessment systems. Knowledge will be assessed through a form of examination. This examination would use scenarios from an agreed list of core clinical conditions and test knowledge in the areas of relevant science and clinical practice (diagnosis, investigation, interpretation, prevention and treatment). As previously stated, we strongly rely on UEMS CESMA and NASCE during the introduction of EU Board Exam, therefore we will likely start with a simple 100-150 MCQ exam then we'll add further types of examination later.

Assessment of progress of education and training must include continuous assessment which tests whether the trainee has acquired the appropriate knowledge, skills, attitudes and professional qualities. This must include formal annual evaluations and final evaluations. The annual evaluation must formalize the assessment of a trainee's competence to promote the trainee's improvement. Final completion of a training program should be dependent upon review of the trainee's portfolio as well as success in the final examination. The Training program director must provide an overall judgment about the trainee's competence and fitness to practice as an independent specialist in Rare Adult Solid Cancer. We propose the following Assessment Protocol:

First Part (Theoretical)

- 100-150 Questions Multiple Choice

- 10 Gross description & Reducing Tech and modalities

Second Part (Practical) based on virtual Pathology report

- 5 whole exome and 5 whole genome report
- 5 rare tumor histopathology interpretation
- 5 FNA (fine needle aspiration) interpretation
- 15 Complete Surgical Pathology Reports (5 Oncology, 5 Reactive/Inflammatory, 2 Autopsy Slides, 3 Molecular Autopsy report Interpretation)
- 6 imaging (3 CT, 3 MR result interpretation)

Pass rate will employ the Angoff method, which calculates a cut-off mark based on the performance of candidates in relation to a defined standard (absolute) as opposed to how they perform in relation to their peers (relative). It involves a judgement being made on exam items (test-centered) as opposed to exam candidates (examinee-centered).

The ECRASC examination will be jointly developed by the UEMS Multidisciplinary Joint Committee (UEMS-MJC RUD) and the sections, MJCs, and national medical associations. European scientific societies, world networks, like the former Joint Action Rare Cancers (JARC) members, and the Undiagnosed Disease Network International (UDNI) are also expected to join this effort. The examination will be overseen and supervised by the Examination Steering Committee. It will be open to candidates who are trainees or fully trained experts from any nation. The ECRASC will be an excellence exam, and will be valid for practice only in countries where it is ratified as an official certificate for this purpose by national regulatory bodies or organisations.

Continuous medical education (CME) and continuous professional development (CPD) to keep updated with developments in diagnosis and management of rare adult cancer conditions as well as of global professional skills are obligations of the accredited expert. Type, duration, content and monitoring of CME/CPD activity will fall under the authority of national boards that need to be established, and these boards should consider the general recommendations of the UEMS. The UEMS provides European accreditation of CME (EACCME) for international events according to defined quality standards. It is recommended that trainees in rare adult solid cancer field are introduced to CME/CPD during their postgraduate training period.

Due to the current covid-19 virus outbreak pandemic, our lives and activities have been changed and are changing right now. We are facing a new situation on a global scale and we are reorganizing our work, many events have been canceled, postponed or re-organized in online format in order to keep everybody safe and collaborate all together to overcome this crisis. This also effects examinations worldwide. Taking this into consideration it is important for the future that we develop a system for doing the exam online and possible parts of the training as well, all according to UEMS CESMA guidelines.

d. List[2] of comprehensive Entrustable Professional Activities (EPAs)[3]

- Evaluate and manage a new medical condition in an ambulatory patient and coordinate care between healthcare providers across multiple care settings
- Manage the care of patients with rare cancers across multiple care settings
- Manage the care of patients with complex medical conditions, and/or comorbidities, across multiple care settings
- Manage transition of care for adult patients transferring to another care setting
- Manage transition of care for young patients transferring from pediatric to adult services
- Provide medical consultation to nonmedical specialties
- Lead a family meeting to discuss serious news (bad news, end of life care) with a patient and/or family and other health providers
- Obtain initial history, perform physical examination, and formulate a management plan for a new ambulatory patient in continuing care
- Manage the care of patients with chronic conditions across multiple care settings
- Access medical information to provide evidence-based care
- Facilitate the understanding of patients, their families, and members of the multidisciplinary team
- Recognize and diagnose common nonmedical conditions (i.e., surgical, neurological, dermatologic, psychiatric etc.) and refer appropriately to other specialty care
- Diagnose and comanage patients with complex conditions needing other specialty care (inpatient or outpatient)
- Organize and maintain information and knowledge through medical practice to improve personal development when delivering care and educating others (journal club, etc.)
- Recognize when palliative care is needed and liaise with palliative care specialists
- Counsel patients appropriately
- Advocate for individual patients by representing them, supporting them and working for them
- Improve patient safety
- Provide age appropriate screening and preventative care
- Identify and address any need for quality improvement in a clinical setting
- Improve the quality and safety of healthcare at both individual and systems levels
- Provide telephone management for an ambulatory rare disease patient
- Provide care to nonnative speakers in an inpatient or outpatient setting through the use of appropriate translation services
- Develop and implement a management plan based on review of outcome data for ambulatory patient population
- Provide inpatient and outpatient care for patients with difficulty in accessing appropriate

[2] Adopted with revisions from Karen. E. Hauer, Jeffrey Kohlwes, Patricia Cornett, Harry Hollander, Olle ten Cate, Sumant R. Ranji, Krishan Soni, William Iobst, and Patricia O'Sullivan (2013) Identifying Entrustable Professional Activities in Internal Medicine Training. Journal of Graduate Medical Education: March 2013, Vol. 5, No. 1, pp. 54-59 and the Alliance for Academic Internal Medicine. Internal Medicine End of training EPAs, 2012

[3] Definition: An EPA is 'a critical part of professional work that can be identified as a **unit** to be ***entrusted*** to a trainee once sufficient competence has been reached'. An EPA goes a level higher than the traditional 4th level of competence which is the 'independence competency'. The key factor is ***Entrustment.*** The trainee is not only capable of tackling the particular procedures or units independently, but he can be ***trusted*** to do this by his tutors.

healthcare; advocate for individual patients where needed
- Participate in an in-hospital cardiopulmonary resuscitation
- Perform common procedures in internal medicine (lumbar puncture, thoracocentesis, central line insertion, joint aspiration)
- Undertake a research project (e.g., a degree or diploma, quality improvement, educational opportunity, other)
- Develop the practice of lifelong learning
- Demonstrate professional behavior at all time

e. Logbook Recommendation:

Purpose: The purpose of the logbook is to document that the applicant has had direct and meaningful involvement in the rare disease evaluation, counseling and management of patients and/or families, and has received appropriate clinical supervision.

The EPA is a Unit and units can be counted. The certified Logbook with a category for EPA included is the key. Because the emphasis and attitudes regarding the spectrum of competences and education within any medical area vary significantly in the individual states, one cannot expect applicants to have attained EPA competency in each and every item listed in the Syllabus/Curriculum. In other words, one cannot expect Eligible Candidates to have attained must have attained 100% of the possible EPA Units in the Syllabus / Curriculum. The Eligibility Committee applies the correct degree of flexibility allowing for equivalence of some procedures. To give an example, the percentage of items in the Syllabus to be expected of an applicant attaining the EPA grade of competence, for the EBSQ General Surgery, is presently set at 65%. This is an arbitrary figure which was reached by evaluating the previous year's candidates' data but will obviously vary with each particular Competency Assessment and possibly from year to year. Another important legal point is that each Competency Examination Board has to establish this threshold when the Exam Webpage goes online.

Requirements: Logbook must be completed in accordance with the instructions provided in this summary and anticipates ongoing review of cases between the trainee and their program director, the applicant should assure that all requirements have been fulfilled before submitting the final logbook for review.

Case Selection:

All cases must be obtained through accredited residency and/or training program.
All cases must be obtained during the inclusive dates of the applicant's training.
Each logbook entry must document a face-to-face interaction between the applicant and an individual patient and/or family.
A given patient or family may appear only once in an applicant's logbook, regardless of the number of encounters with that patient or family.

Description of Logbook Headings/Columns:
Entry Number: The logbook spreadsheet allows a trainee to enter an unlimited number of cases while in training. For the final logbook that may be requested for audit, you must select 100 cases to

submit that fulfill all of the defined requirements. The applicant must be able to identify each case by its entry number if questions arise about a logbook entry
Date: The date in month/day/year [MM/DD/YYYY] format identifies when the patient was seen
Patient Age Category: For each case, the patient's age must be given. Age refers to age of the patient on the date of the clinic visit.
Diagnosis: The cases seen should reflect the heterogeneity of Rare Adult Solid Cancers.

f. Grades of Competence:

1. Knowledge
1.1. knows of
1.2. knows basic concepts
1.3. knows generally
1.4. knows specifically and broadly
2. Clinical Skills
2.1. Has observed – the trainee acts as an 'Assistant'. From complete novice through to being a competent assistant. At end of level 1 the trainee:
2.2. Has adequate knowledge of the steps through direct observation.
2.3. Demonstrates that he/she can handle the apparatus relevant to the procedure appropriately and safely.
2.4. Can perform some parts of the procedure with reasonable fluency
2.5. Can do with assistance - a trainee is able to carry out the procedure 'Directly Supervised'. From being able to carry out parts of the procedure under direct supervision, through to being able to complete the whole procedure under lesser degrees of direct supervision (e.g. trainer immediately available). At the end of level 2 the trainee
2.6. Knows all the steps - and the reasons that lie behind the methodology.
2.7. Can carry out a straightforward procedure fluently from start to finish
2.8. Knows and demonstrates when to call for assistance/advice from the supervisor (knows personal limitations).
2.9. Can do the whole procedure but may need assistance – a trainee is able to do the procedure 'indirectly supervised'. From being able to carry out the whole procedure under direct supervision (trainer immediately available) through to being able to carry out the whole procedure without direct supervision i.e. trainer available but not in direct contact with the trainee. At the end of level 3 the trainee
2.10. Can adapt to well-known variations in the procedure encountered, without direct input from the trainer.
2.11. Recognizes and makes a correct assessment of common problems that are encountered.
2.12. Is able to deal with most of the common problems.
2.13. Knows and demonstrates when he/she needs help.
2.14. Requires advice rather than help that requires the trainer to intervene
2.15. Competent to do without assistance, including complications. The trainee can deal with the majority of procedures, problems and complications, but may need occasional help or advice.
2.16. Can be ***trusted*** to carry out the procedure, independently, without assistance or need for advice. This concept would constitute one Entrustable Professional Activity (EPA). An EPA is 'a

critical part of professional work that can be identified as a unit to be entrusted to a trainee once sufficient competence has been reached'. This would indicate whether one could *trust* the individual to perform the job and not whether he is just competent to do it. At the end of level 5 the trainee:

2.17. Can deal with straightforward and difficult cases to a satisfactory level and without the requirement for external input to the level at which one would expect a consultant to function.
2.18. Is capable of instructing and supervising trainees.
3. Technical Skills
3.1. Has observed.
3.2. Can do with assistance.
3.3. Can do whole but may need assistance.
3.4. Competent to do without assistance, including complications, but may need advice or help.
3.5. **Can be *trusted* to carry out the procedure, independently, without assistance or need for advice (EPA).** EPAs have been explained previously.

The above detailed classification of Competence Levels could be useful during the process of formative training, when it comes to deciding when an applicant is eligible to sit an eventual Specialist Exit examination, it is the evaluation of the EPAs which is essential. In this sense, the Eligibility Assessment Process is really the first part of the Examination and that explains the suggestion that the '5th level of Technical Skills competence' should be included in a standardized Logbook Template for all trainees

g. Governance
Governance of each training program will be the responsibility of the Program or Course Director and the institution(s) in which the training program is being delivered. A trainer (who will have satisfied the requirements laid out below, Section II) will be responsible to the Program Director for delivering the required training in their area of practice. Naturally everything will be conducted under supervision of CESMA, EACCME and NASCE.

II. TRAINING REQUIREMENTS FOR TRAINERS

1. Process for recognition as trainer

a. Requested qualification and experience
Trainers should be certified rare adult solid cancer specialists and must be recognized by the national authority. Trainers should provide evidence of academic activities (clinical and/or basic research, publications in peer reviewed journals and participation in clinical genetic scientific meetings) and professional experience. They should possess the necessary administrative, communicative, teaching and clinical skills and commitment to conduct the program. Trainers and Training Program Directors must be in active clinical practice and engaged in training in the training center. A Training Program Director must be a certified specialist for a minimum of 5 years. He/she organizes the activities of the educational program in all institutions that participate in the program. As in other parts of the training it is strongly recommended to follow the UEMS regulations, thus connection with accredited CME/CPD courses for trainees is recommended under the supervision of the

training institution. In the EU Board Exam level the training of trainers and training of examiners will be a special duty of the EU board.

b. Core competencies for trainers

1. Familiar with all aspects of rare adult solid cancers
2. Experienced in teaching and in supporting learners
3. Trained in the principles and practice of medical education
4. Lectures to a peer-audience on a regular basis, attends national meetings and is able to demonstrate appropriate participation in continuing professional development
5. Able to recognize trainers whose professional behavior is unsatisfactory and to initiate corrective and supportive measures as needed

2. Quality management for trainers

Trainers and Program Directors will have their job descriptions agreed with their employer, which will allow them sufficient time for support of trainees. Feedback from trainees is necessary for optimal training. The educational work of trainers and Program Directors will be appraised no less than on an annual basis within their institution as local circumstances determines.

III. TRAINING REQUIREMENTS FOR TRAINING INSTITUTIONS

1. Process for recognition as training center

a. Requirement on staff and clinical activities

A training center is a place, or number of places, where trainees are able to develop their competences in rare adult solid cancers. Thus, training may take place in a single institution, or in a network of institutions working together, to provide training in the full spectrum of clinical conditions and skills detailed in the curriculum. A training institution must have national accreditation, in agreement with UEMS standards, and should possess an adequate infrastructure and offer qualitative and quantitative clinical exposure. Optimally, they are member(s) of one or more European Reference Networks (ERNs).

Each participating institution in a network must be individually recognized as a provider of a defined section of the curriculum. Training centers must have a sufficient throughput of patients, an appropriate case-mix to meet training objectives, and be adequately resourced with teaching staff.

The training must expose the trainee to a broad range of clinical experience. The training of a trainee will be led and managed by a specialist. This specialist will be active in the practice, with personal responsibility for the management of patients with a wide range of rare adult solid cancers. Within a training center there should be a team of specialists, each with subspecialty expertise and able to supervise and train a trainee. Allied specialties must be present to a sufficient extent to provide the trainee with the opportunity of developing his/her skills in a multidisciplinary approach to patient care. There is no specific trainee/trainer ratio required, but there should be a minimum of two trainers in a training center, and it is likely that non-medical healthcare professionals will also be engaged.

The trainee should be involved in the diagnosis and management process of new patients (outpatients and in-patients), as well as their follow up. A trainee must demonstrate personal responsibility for the global care of patients with rare adult solid cancers. There should be written general guidelines within the training institution concerning patient care and patient information (including informed consent), referrals, medical records, documentation, on-call and back-up schedules, attendance at conferences and educational/training courses.

The staff of a training center should engage collaboratively in regular reviews and audit of the center's clinical activity and performance. There should be regular multi-disciplinary meetings to determine optimal care for patients, involving both medical and other healthcare professionals.

Specialist staff appointed to a training center will have completed all training requirements themselves and will have been trained also in teaching and mentoring trainee staff, staff as well as in working in a multidisciplinary team with lab and genetic counsellors.

b. Requirement on equipment, accommodation
A training center should have sufficient equipment and support to enable the clinical practice that would be expected of a training center and thus provide the necessary educational opportunities for trainees. The trainee must have adequate time and opportunities for practical and theoretical study and have access to adequate professional literature. Computing, Information Technology and library resources must be available. All trainees must engage in clinical audit and have the opportunity to engage in research.

2. Quality Management within Training Institutions
Participation of the training institution in a certified quality management program with an external auditing process on a regular basis is consistent with good governance. Naturally everything will be conducted in accordance to CESMA, EACCME and NASCE guidelines. Criteria of quality management at competency training institutions include the following:

Accreditation
Training institutions need to be accredited with competent National Medical Boards. Additional accreditation on a supra-national level, such as that provided by some professional societies, and in an European Board, is strongly recommended. A training institution must have an internal system of medical audit or quality assurance. Quality assurance must be an integral part of the training program of all training institutions and networks. A national register of approved institutions and networks should be available. Internal regulations: There should be written general guidelines within the training institution concerning patient care and patient information (including informed consent), referrals, medical records, documentation, leave (annual, study, maternity/paternity), residents' working schedules, conference attendance and educational activities. These should be available to staff and trainees.

Clinical governance
Employee structure at training institutions needs to be designed in a way to accommodate for competency training. Workload has to be managed with a priority on training.

Manpower planning
Training institutions should appoint a coordinator responsible for the composition, implementation and supervision of a competency training program. Roles of trainer and trainee need to be clearly defined. Allotted time of at least one day per workweek should be implemented for competency training interaction. Manpower planning is under the jurisdiction of each member state according to their needs for rare adult solid cancer specialists.

Regular report
Annual reports on various aspects of an institution's competency training program should be made publically available.

External audit
Training institutions should appoint a coordinator who is also responsible for compliance of the training program with current guidelines, directives or regulations of competent medical boards, as well as the local medical school.

Transparency of training programs
Based on national and regional guidelines, UEMS strongly encourages training institutions to formulate defined training programs and make them publicly available, for example, on their website. It would be expected that a training center would publish details of the training provision available with details of the clinical service it provides and the names of the trainers. Such information would include the training programs, the nature of the clinical or laboratory experiences in which a trainee would be engaged, and the support and interaction with the trainer and Program Director. There would be a named individual whom a prospective trainee might contact and discuss the program.

Framework of approval
As part of training programs it should also be made clear how and by whom key achievements of training will be ascertained, leading the trainee to a higher level of clinical responsibility and new assignments. To assist a European medical specialist with additional clinical competence moving from one EU country to another it would be expected that they have satisfactorily completed a training program. After the examination in rare adult solid cancers they may be able to demonstrate that they have the required knowledge, clinical and laboratory skills and competences, as well as having demonstrated appropriate professional behaviors. Such accomplishments would be verified both by relevant documents and by the testimony of trainers and other staff who have worked with the trainee.

Feedback from trainers and trainees
Feedback about program quality from both trainers and trainees must be systematically sought, analyzed and acted upon. Trainers and trainees should be actively involved in using its results for program improvement and development.