MJC RUD

Béla Melegh

3 May, 2019

London

I. The UEMS in a nutshell (established in 1958)

info@uems.eu

Sections

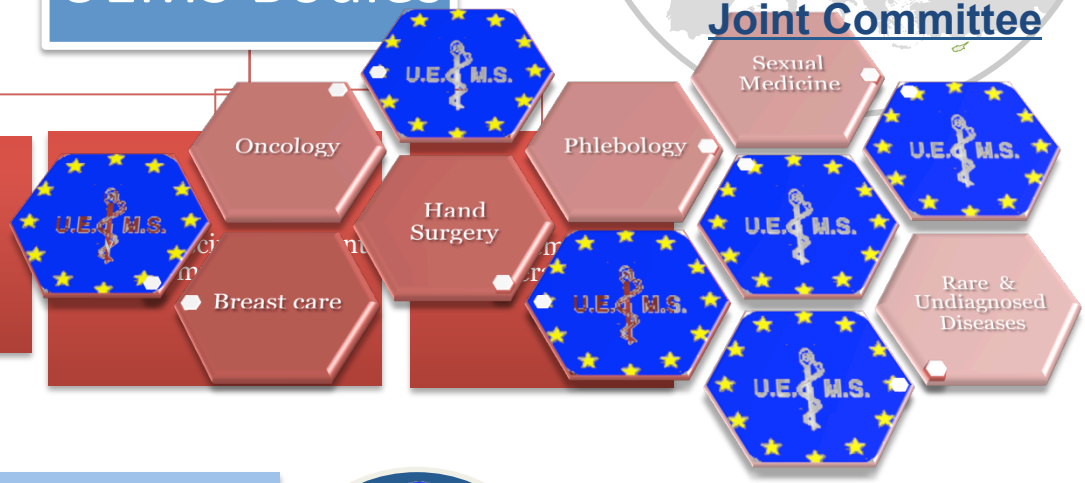
- Emergency Medicine
- Endocrinology
- Gastroenterology
- Geriatrics
- Gynaecology & Obstetrics
- Infectious Diseases
- Internal Medicine
- Ophthalmol
- Surgery
- Radiolog
- Cardiology
- Clinical pharmacology
- Psychiatry
- Neurology
- Pathology
- Rhematology
- Clinical Genetics

43 **Specialist Sections** & European Boards
21 **divisions** within Sections
14 **Multidisciplinary Joint Committees**
3 thematic federations

UEMS Bodies

Multidisciplinary Joint Committee

43 Specialist Sections



European Boards

Divisions

European Board

Role :
Specialty Representation & standards setting

II. MJC RUD

MULTIDISCIPLINARY JOINT COMMETTEE

OF

RARE AND UNDIAGNOSED DISEASES

info@uems.eu

Kickoff meeting of Multidisciplinary Joint Committee of Rare and Undiagnosed Diseases (MJC RUD); European Union of Medical Specialties (UEMS).
Brussels, 20th October, 2016

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III. Examles for the Partnering

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European Reference Networks

European Commission

Enrique Terol
DG SANTE
Directorate B
European Commission

European Reference Networks

Directive of patients' rights in cross-border healthcare

Health and Consumers

UEMS as a wide communication platform for the ERN activities, transfer of knowledge and training achievements towards the entire European community of medical specialists

RD-ACTION & DG Sante Workshop. 6-7 December, 2017 – Rome

Béla Melegh
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[2]Section of Clinical Genetics, & [3]Multidisciplinary Joint Commettee of Rare and Undiagnosed Diseases of the European Union of Medical Specialist (UEMS)

the Joint Action on Rare Cancers

FONDAZIONE IRCCS ISTITUTO NAZIONALE DEI TUMORI
UNIVERSITÀ DEGLI STUDI DI MILANO

Paolo G. Casali
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Objectives

With regard to RCs in the EU, to improve:

1. **Epidemiological surveillance**
2. **Quality of care through ERNs**
3. **Clinical practice guidelines**
4. **Innovation**
5. **Medical and Patient education**
6. **Health policy measures**
7. **Patient empowerement**

Work packages

WP		
1	Coordination	
2	Dissemination	*A, GR*
3	Evaluation	*CSF, FI*
4	Epidemiology	*INT, IT*
5	Assuring Quali	*OECI*
6	Clinical	*DKG, DE*
7	Inn ccess to innovation	*WIV-ISP, BE*
8	ucation	*UP, HU*
	hood Cancers	*SIOPE*
	Rare Cancer Policy	*ICO, ES*

ECPC, EURORDIS, CCI E

Patient empowerement

Objectives

1. **using data of WP6**, **to delineate optimal resources for undergraduate medical education,** including paediatric oncology, that fits the European training requirements and standards; **to identify the educational resources available in Europe for post-graduate medical education**, with attention to those European regions where outcomes are statistically poorer;

2. to identify optimal ways and approaches to **connect the educational resources** available throughout Europe **with networked health care**, with special regard to **ERNs;**

3. **to promote the improvement** of European medical expert training instruments **via the European Union of Medical Specialists (UEMS), as well as SIOPE – European Society for Paediatric Oncology,** where paediatric oncology is concerned;

4. to provide recommendations on education of **non-medical experts, patient advocates and patient communities** involved in patient care, as a means to improve rare cancer patient empowerment in Europe.

Meeting notes: Joint Action for Rare Cancers & GENTURIS ERN

28 September 2017

Attendees:	Matt Bolz-Johnson, EURORDIS (Chair)
	Nicoline Hoogerbrugge, GENTURIS ERN Network Coordinator
	Nicoline Geverink, GENTURIS Network Manager
	Paolo Casali, Joint Action for Rare Cancer Lead
	Annalisa Trama, Joint Action for Rare Cancer Lead
	Bela Melegh, GENTURIS & JARC
	Ariane Weinman, EURORDIS
Apologies:	Claas Röhl, GENTURIS ePAG

- **2. Meeting objectives**
- The aim of the meeting was:
- Secure a detailed understanding of the scope and activities of GENTURIS European Reference Network (ERN) and the Joint Action for Rare Cancers (JARC).
- To explore the potential areas of collaboration between GENTURIS ERN and the JARC.

5. JARC & GENTRUIS Potential Areas of Collaboration

Collaboration Aims:

- **5.1 Clinical Practice Guidelines**
- **5.2 Training & Education**
- **5.3 Policy Areas**

5.3 Training & Education

- Bela Melegh was identified as the education and training lead that ‘bridge’ GENTURIS and the JARC. He agreed to coordinate the education and training activities between the 3 RC ERNs, GENTURIS and the JARC.
- **Action**: BM to coordinate medical education and training between the JARC and the 3 RC ERNs & GENTURIS.

Action Points

No.	Action	Lead
1.	JARC leads & GENTURIS agreed to identify experts working under initiative and to connect these experts up.	ALL
2.	To share the priority list of CPGs and the clinical leads with GENTUIRS.	PC
3.	To identify expertise in GENTURIS who can liaise with JARC clinical leads on the CPG.	NH
4.	To share rare cancers list with GENTURIS	AT
5.	Bela to coordinate medical education and training between the JARC and the 3 RC ERNs & GENTURIS.	B

Joint Action on Rare Cancers - Survey on Medical Education for Undergraduates and Postgraduates

1. Basics

Within the framework of Joint Action on Rare Cancer (http://jointactionrarecancers.eu/) WP8 you are invited to participate in the following survey. Our goal is to collect data on the education and training programs currently available for under- and postgraduates related to the rare cancers, including childhood cancers. In the present survey the current classification of the rare cancers is the reference material:

1. Head and neck cancers (cancers of nasal cavity and sinuses, nasopharynx, hypopharynx, larynx, salivary glands, oropharynx, oral cavity and lip, eye, middle ear)
2. Thoracic rare cancers (tumours of trachea, thymus, malignant mesothelioma)
3. Male genital and urogenital rare cancers (tumours of testis, penis, renal pelvis, ureter, urethra and extragonodal germ cell tumours)
4. Female genital rare cancers (tumours of vulva and vagina, non epithelial tumours of ovary, trophoblastic tumours of the placenta)
5. Neuroendocrine tumours
6. Tumours of the endocrine organs (cancers of thyroid, parathyroid, adrenal cortex, pituitary gland)
7. Central Nervous System tumours (Glial tumours, medulloblastoma, malignant meningioma)
8. Sarcomas (sort tissue sarcomas, bone sarcomas, gastrointestinal stromal tumours)
9. Digestive rare cancers (Tumours of small intestine, anal canal, gallbladder and extrahepatic biliary duct)
10. Rare skin cancers and non-cutaneous melanoma (melanoma of mucosae and of the uvea, adnexal skin carcinomas, Kaposi sarcoma)
11. Haematological rare malignancies (acute myeloid leukemia, myeloproliferative neoplasms, myelodisplastic and myeloproliferative neoplasms, histiocytic and dendritic cell neoplasms)
12. Pediatric cancers (all pediatric cancers are considered as rare cancers)

NEXT

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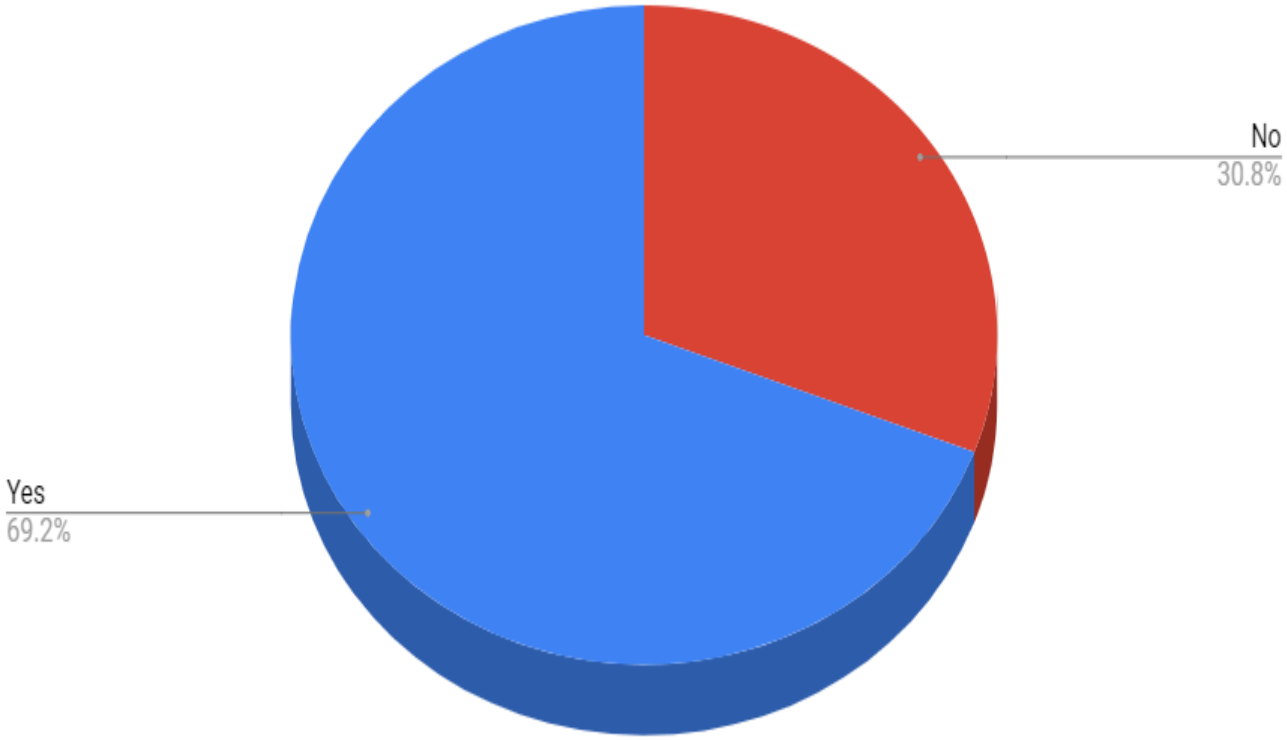
Austrian	4	Georgian	1	Portuguese	2
Belgian	9	German	9	Romanian	1
British	2	Greek	7	Russian	1
Bulgarian	1	Hungarian	5	Serbian	1
Croatian	3	Irish	2	Slovakian	1
Czech	3	Italian	6	Slovenian	1
Danish	2	Latvian	1	Spanish	7
Dutch	10	Lithuanian	1	Swedish	7
Estonian	1	Maltese	2	Swiss	1
Finnish	1	Norvegian	1	Turkish	2
French	5	Polish	3	Ukrainian	1

Total Responses: 108

6. Are you involved in any UEMS activity?



JARC
JOINT ACTION ON RARE CANCERS

JOINT ACTION ON RARE CANCERS

Joint Action on Rare Cancers - Survey on Medical Education for Undergraduates and Postgraduates

3. Undergraduate Training

7. Are you involved in the training of medical students?

- Yes
- No

8. Does your department have specially dedicated undergraduate training course on rare cancers?

- Yes
- No

9. To you knowledge, does your department have special teaching materials for rare cancer training of undergraduates?

- Yes
- No

10. In general, how can your knowledge and awareness of the rare cancers be characterized?

- Poor
- Acceptable
- Well informed

11. In general, how can the knowledge and awareness of other training personnel in your institution about the rare cancers be characterized?

- Poor
- Acceptable
- Well informed

12. In general, how can the knowledge and awareness of the training personnel in your country about the rare cancers be characterized?

- Poor
- Acceptable
- Well informed

13. Please evaluate the contribution of the individual disciplines to the rare cancer training.

	1 - Poor	2 - Acceptable	3 - Excellent	4 - Not applicable
Biophysics	○	○	○	○
Molecular Cell Biology	○	○	○	○
Behavioural Science	○	○	○	○
Medical Chemistry	○	○	○	○
Anatomy	○	○	○	○
Biochemistry	○	○	○	○
Pharmacology	○	○	○	○
Pathophysiology	○	○	○	○
Microbiology	○	○	○	○
Dermatology	○	○	○	○
Otolaryngology	○	○	○	○
Internal Medicine	○	○	○	○
Clinical Biochemistry	○	○	○	○
Clinical Radiology	○	○	○	○
Public Health	○	○	○	○
Oncology	○	○	○	○
Oral Medicine	○	○	○	○
Orthopaedics	○	○	○	○
Urology	○	○	○	○
Surgery	○	○	○	○
Traumatology	○	○	○	○
Paediatrics	○	○	○	○
Neurology	○	○	○	○
Psychiatry	○	○	○	○
Obstetrics and Gynaecology	○	○	○	○
Ophthalmology	○	○	○	○
Anaesthesia and intensive care	○	○	○	○
Family Medicine	○	○	○	○
Medical Genetics	○	○	○	○
Psychiatry	○	○	○	○

14. Which disciplines should definitely enhance their performance in the rare cancer training?

	1 - Not at all	2 - Moderately	3 - Strongly	4 - Not applicable
Biophysics	○	○	○	○
Molecular Cell Biology	○	○	○	○
Behavioural Science	○	○	○	○
Medical Chemistry	○	○	○	○
Anatomy	○	○	○	○
Biochemistry	○	○	○	○
Pharmacology	○	○	○	○
Pathophysiology	○	○	○	○
Microbiology	○	○	○	○
Dermatology	○	○	○	○
Otolaryngology	○	○	○	○
Internal Medicine	○	○	○	○
Clinical Biochemistry	○	○	○	○
Clinical Radiology	○	○	○	○
Public Health	○	○	○	○
Oncology	○	○	○	○
Oral Medicine	○	○	○	○
Orthopaedics	○	○	○	○
Urology	○	○	○	○
Surgery	○	○	○	○
Traumatology	○	○	○	○
Paediatrics	○	○	○	○
Neurology	○	○	○	○
Psychiatry	○	○	○	○
Obstetrics and Gynaecology	○	○	○	○
Ophthalmology	○	○	○	○
Anaesthesia and intensive care	○	○	○	○
Family Medicine	○	○	○	○
Medical Genetics	○	○	○	○
Psychiatry	○	○	○	○

15. How can the knowledge and awareness of the new MD graduates about the rare cancers be characterized?

- Well informed
- Acceptable
- Poor

16. To your knowledge how fragmented is the European training in undergraduate level comparing the nations?

- Very fragmented
- Medium fragmented
- Well-harmonized
- Do not know

17. Do you see rationale in the pan-European harmonization of the training?

- Disagree
- Agree
- Strongly agree
- Do not know

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JOINT ACTION ON RARE CANCERS

JOINT ACTION ON RARE CANCERS

Joint Action on Rare Cancers - Survey on Medical Education for Undergraduates and Postgraduates

* Required

4. Postgraduates

18. Are you involved in the specialist training and/or CME CPD services?

- Yes
- No

19. What kind of board exam do you have? *

Your answer

20. I feel that the different specialists in my university (for non university employees: in my country) have up to date knowledge and expertise in rare cancers.

- Agree very much
- Agree
- Neither agree nor disagree
- Disagree
- Disagree very much

21. I feel that general practitioners in my country are aware and well informed about rare cancers.

- Agree very much
- Agree
- Neither agree nor disagree
- Disagree
- Disagree very much

22. I feel that pediatricians in my country are aware and well informed about rare cancers.

- Agree very much
- Agree
- Neither agree nor disagree
- Disagree
- Disagree very much

23. I feel that the real significance of rare cancer in the training schedule of the following medical disciplines are appropriate.

	1 - Agree very much	2 - Agree	3 - Neither agree nor disagree	4 - Disagree	5 - Disagree very much
Allergology	○	○	○	○	○
Anaesthesiology	○	○	○	○	○
Cardiology	○	○	○	○	○
Cardiothoracic Surgery	○	○	○	○	○
Child and Adolescent Psysichiatry	○	○	○	○	○
Clinical Genetics	○	○	○	○	○
Clinical Neurophysiology	○	○	○	○	○
Dermatology and Venereology	○	○	○	○	○
Emergency Medicine	○	○	○	○	○
Endocrinology	○	○	○	○	○
Gastroenterology	○	○	○	○	○
Geriatrics	○	○	○	○	○
Gynaecology and Obstetrics	○	○	○	○	○
Infectious Diseases	○	○	○	○	○
Internal Medicine	○	○	○	○	○
Laboratory Medicine / Medical Biopathology	○	○	○	○	○
Medical Microbiology	○	○	○	○	○
Medical Oncology	○	○	○	○	○
Nephrology	○	○	○	○	○
Neurology	○	○	○	○	○
Neurosurgery	○	○	○	○	○
Nuclear Medicine	○	○	○	○	○
Occupational Medicine	○	○	○	○	○
Ophthalmology	○	○	○	○	○
Oro-Maxillo-Facial Surgery	○	○	○	○	○
Orthopaedics	○	○	○	○	○
Otorhinolaryngology	○	○	○	○	○
Paediatric Surgery	○	○	○	○	○
Paediatrics	○	○	○	○	○
Pathology	○	○	○	○	○
Pharmacology	○	○	○	○	○
Physical Medicine and Rehabilitation	○	○	○	○	○
Plastic, Reconstructive and Aesthetic Surgery	○	○	○	○	○
Pneumology	○	○	○	○	○
Psychiatry	○	○	○	○	○
Public Health Medicine	○	○	○	○	○
Radiology	○	○	○	○	○
Radiation Oncology and Radiotherapy	○	○	○	○	○
Rheumatology	○	○	○	○	○
Surgery	○	○	○	○	○
Thoracic Surgery	○	○	○	○	○
Urology	○	○	○	○	○
Vascular Surgery	○	○	○	○	○

24. Do you suggest introduction of new training projects and improvement of the current specialist training in EU-harmonized manner?

- Yes
- No
- Do not know

25. If you suggest introduction of new training programs what are the criteria for prioritizing programs?

	Low	Medium	High	Not applicable
Number of affected people	○	○	○	○
Morbidity/mortality	○	○	○	○
Economical and individual burden	○	○	○	○
Potential for economic exploitation	○	○	○	○
Obvious gaps in health care	○	○	○	○
Social burden of diseases	○	○	○	○
Economical significance for the health care system	○	○	○	○
Potential for scientific and technological innovations	○	○	○	○
Other*	○	○	○	○

*Please specify

Your answer

BACK SUBMIT

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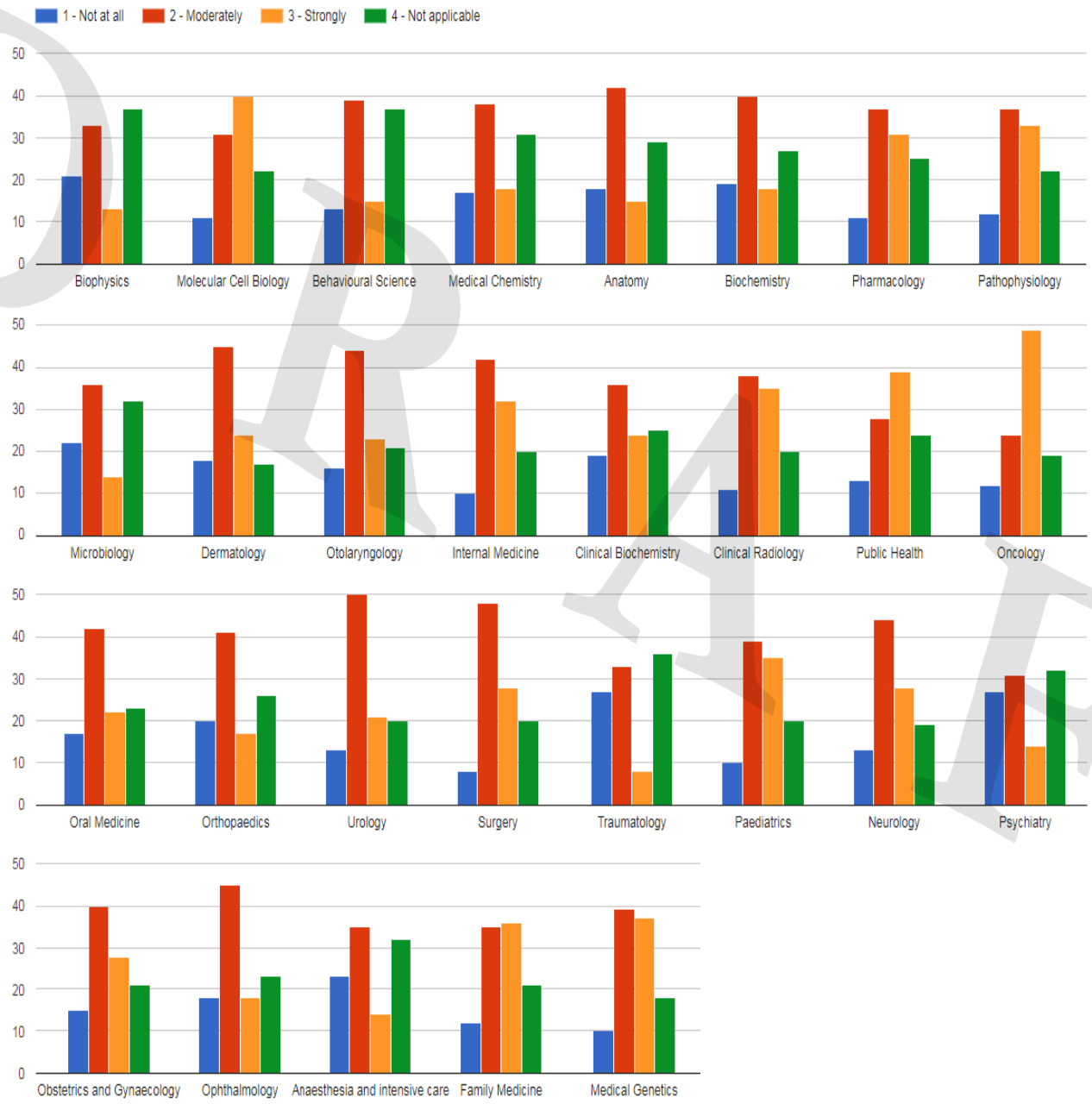
14. Which disciplines should definitely enhance their performance in the rare cancer training?



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JOINT ACTION ON RARE CANCERS

IV. The EU Exam system

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Areas of Expertise

CME - CPD

Postgraduate Training

European Standards in Medical Training - ETRs

Competence-Based training and assessment

CESMA

CESMA Appraisals

CESMA Meetings

CESMA Meeting Glasgow

The Council for European Specialists Medical Assessment

The CESMA is an advisory body of the UEMS created in 2007 with an aim to provide recommendation and advice on the organisation of European examinations for medical specialists at the European level.

It was called in the beginning the "Glasgow group" referring to the first meeting held in Glasgow. It was then decided to adopt the name CESME (Council of European Specialist Medical Examinations). This name was finally changed to CESMA (Council of European Specialist Medical Assessment)

Its main role is to:

- To promote harmonisation of European Board assessments
- To provide guidelines to the Boards on the conduct of assessments
- To encourage take up of Board assessments as a quality mark
- To offer an alternative to National assessments, where appropriate

Existing EU Exams

1. Allergology and Clinical Immunology
2. Anesthesiology
3. Cardiology
4. Dermatology & Venereology
5. Otorhinolaryingology
6. Hand Surgery
7. Intensive Care
8. Internal Medicine
9. Neurology
10. Neurosurgery
11. Nuclear Medicine
12. Ophthalmology
13. Oromaxillofacial Surgery
14. Orthopaedics and Traumatology
15. Pathology
16. Pediatric Surgery
17. Physical and Rehabilitation Medicine
18. Plastic, Reconstructive and Aesthetic Surgery
19. Radiology
20. Respiratory Medicine
21. Surgery (General Surgery)
22. Coloproctology
23. Endocrine Surgery
24. Surgical Oncology
25. Thoracic Surgery
26. Transplantation
27. Trauma Surgery
28. Thoracic and Cardiovascular Surgery
29. Urology
30. Vascular Surgery
31. Angiology
32. Emergency Medicine

Glasgow Declaration

- European Board Examinations are regarded as a quality mark for independent practice at the end of specialist training. Passing a European Board Examination does not give a right to practise in any UEMS country. Such rights are granted solely by the relevant National Authority

Glasgow Declaration

- Countries which do not have their own examination are encouraged to consider using the appropriate European Board Examination.

- The role of European Board Examinations is complementary to National Examinations where they exist.

Basics to an EU Exam

- European Training Requirement (ETR) with supplementary materials
- Approval by the UEMS Council

- Examination Steering Committee
- Description of the Exam structure & content
- CESMA Appraisal Group

European Training Requirements (ETR)

European Standards of Postgraduate Medical Specialist Training by UEMS (2012/29)

1., **ETR (UEMS 2017/06)**

General arrangement; 12 pages; special care on skills and competencies; Clinical and laboratory; 4/5 yrs of training

2., **Description of Clinical Genetics as a Medical Specialty in EU (UEMS 2017/06A)**

Revision of the 2009 yrs UEMS document; (6 pages)

3., **Syllabus (UEMS 2017/06/B)**

18 pages; 5 Domains: 1. Theoretical genetics / Basic science; 2. Clinical/Medical knowledge and specialist-level skills; 3. Genetic counselling and communication skills; 4. Laboratory skills; 5. Ancillary competences

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UEMS2017/06B

Syllabus for residents and trainees in Clinical Genetics

This syllabus is an outline and flexible summary of major and specific topics to be covered in some way in the training course of a resident. The basic goal of the syllabus is to help and ensure a fair and impartial understanding between the instructor and students such that there is minimal confusion in the topics, setting clear expectations of material to be learned. The syllabus provides neither a roadmap of course, nor organization/direction relaying the instructor's teaching philosophy to the trainees, as the syllabus is not a learning guide. Rather, the syllabus is a supporting reference material, content and priorities of training may vary in different training institutions.

Domain 1: Theoretical genetics / Basic science

1.1 Cellular and molecular mechanisms that underpin human inheritance

1.1.1 Basics
- 1.1.1.1 Nucleic acid structure, DNA and RNAs
- 1.1.1.2 Translation, protein structure
- 1.1.1.3 Chromosome structure and function (ploididty and cell cycle)
- 1.1.1.4 Monogenic vs. multifactorial inheritance
- 1.1.1.5 Mutations, variants, CNV
- 1.1.1.6 Cells, cell proliferation, cell specialization
- 1.1.1.7 Nuclear and mitochondrial genome
- 1.1.1.8 Gene editing, CRISPR

OSCE (Objective Structured Clinical Examination)


CERTIFICATE OF ATTENDANCE
European Diploma in Medical Genetics and Genomics

1st EU Exam in Medical Genetics and Genomics (EDMGG):

14 June, 2019, Gothenbourg, Sweden (before the ESHG meeting)

CERTIFICATE OF ATTENDANCE

In memoriam of participation at the trial exam of

European Diploma in Medical Genetics and Genomics

in Milan at the European Human Genetics Conference on June 16-19, 2018.

EBMG Chair	*Head of Board of Examiners*	*Head of Exam Committee*	*UEMS SMG President*

Date:

Certificate No.:

V. The ETR and Syllabus in Rare Adult Solid Cancers

info@uems.eu

MJC RUD Meeting
in association with the
UEMS Council Meeting
Saturday, 20th October, 2018.
12:00-13:00
Thon Brussels City Center
Avenue du Boulevard 17, 1210 Brussels,
Room "Sonja"

AGENDA

1. Welcome, approval of the Agenda
2. Annual report of the President
3. ENETS Proposal (Vassilios Papalois, UEMS Secretary General)
4. ETR for "Rare Diseases"
5. "European Board of Rare Diseases"
6. ETR for "Rare adult solid cancers"
7. "European Board of Rare adult solid cancers"

UNION EUROPÉENNE DES MÉDECINS SPÉCIALISTES
EUROPEAN UNION OF MEDICAL SPECIALISTS

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UEMS 2012/29

Training Requirements for the Specialty of ...

European Standards of Postgraduate Medical Specialist Training

(old chapter 6)

Preamble

I. TRAINING REQUIREMENTS FOR TRAINEES

I. TRAINING REQUIREMENTS FOR TRAINERS

II. TRAINING REQUIREMENTS FOR TRAINING INSTITUTIONS

I. TRAINING REQUIREMENTS FOR TRAINEES

1. Content of training and learning outcome
   a. Theoretical knowledge
   b. Practical and clinical skills
   c. Competences

2. Organisation of training
   a. Schedule of training
   b. Curriculum of training
   c. Assessment and evaluation
   d. Governance

II. TRAINING REQUIREMENTS FOR TRAINERS

1. Process for recognition as trainer
    a. Requested qualification and experience
    b. Core competencies for trainers

2. Quality management for trainers

III. TRAINING REQUIREMENTS FOR TRAINING INSTITUTIONS

1. Process for recognition as training center
   a. Requirement on staff and clinical activities
   b. Requirement on equipment, accommodation

2. Quality Management within Training institutions

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Training Requirements for the Specialty of

Rare Adult Solid Cancers

Preamble

The UEMS is a non-governmental organisation representing national associations of medical specialists at the European Level. With a current membership of 39 national associations and operating through 43 Specialist Sections and European Boards, the UEMS is committed to promote the free movement of medical specialists across Europe while ensuring the highest level of training which will pave the way to the improvement of 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.

I. TRAINING REQUIREMENTS FOR TRAINEES

1. Content of training and learning outcome

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 the possible genetic defect 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 specialty training is aimed at giving doctors qualifications in the field of rare adult solid cancers to enable them to treat patients with rare adult solid cancers 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 with a major social impact (malformations in general, familial cancers, inborn errors of metabolism, etc.).

Fileds 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

Rare Adult Solid Cancer Training Aims

The training requirements for the specialty of rare adult solid cancers aim to produce a competent rare adult solid cancer specialist. They need knowledge of not only the underlying disease processes, available diagnostic and therapeutic modalities but also an appreciation of the importance of the epidemiology and potential for prevention of rare adult solid cancer. Rare adult solid cancer specialists who generally work in hospital need to integrate their work with not only community based primary care colleagues but also other hospital based physicians and European Referemce Networks (ERN) as well.

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
4. The prevention of hereditary rare adult solid cancer, and serious disability, according to the choice made by those at risk of having affected offspring, based on full information and expert counselling
5. To contribute to the management of patients and families affected by rare adult solid cancers, in collaboration with other medical specialists, including treatment
6. To be advocates, where necessary, of those affected by rare adult solid cancers
7. To conduct and contribute to clinical and genomic research to enhance knowledge of the causation and natural history of rare adult solid cancers and conditions
8. To teach and instruct medical undergraduates and postgraduates in rare adult solid cancers, in order to raise the knowledge base across all medical specialties
9. To provide a knowledge and skills resource to all medical specialties, including through multidisciplinary meetings
10. To contribute to the public awareness for rare adult solid cancers

- 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

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 for 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 adults solid cancer speciality training is 5 years consisting of 1 year of common trunk and 4 years training in Rare Adult Solid Cancer Centre in an accredited program.

b. Curriculum of training

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

Countries will use assessment strategies appropriate to their needs. In due course there will be a move to a common approach to determining whether an individual is suitable to be recognized as a 'European medical specialist with additional clinical genetics competence'. Thus, there will need to be an assessment of knowledge, through a form of written examination, possibly online. 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). This assessment may take the form a 'best of five' (multiple choice) format, but has yet to be decided.

d. Governance

The governance of an individual's 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.

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 participations 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. 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 institution that participate in the program.

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. Act as a lecturer to a peer-audience on a regular basis, attend national meetings and able to demonstrate appropriate participation in continuing professional development
5. Able to recognize trainers whose professional behavior is unsatisfactory and initiate corrective and supportive measures as needed

2. Quality management for trainers

Trainers and Program Directors will have their job description 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 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.

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 teachers in a training center, and it is likely that non-medical healthcare professionals will also be engaged.

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 (e.g. 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 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 to a higher level of clinical responsibility and new assignments. To assist a European medical specialist with additional Clinical Genetics 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 he/she has 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.

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Syllabus for residents and trainees in Rare Adult Solid Cancers

This syllabus is an outline and flexible summary of major and specific topics to be covered in some way in the training course of a resident. The basic goal of the syllabus is to help and ensure a fair and impartial understanding between the instructor and students such that there is minimal confusion in the topics, setting clear expectations of material to be learned. The syllabus provides neither a roadmap of course, nor organization/direction relaying the instructor's teaching philosophy to the trainees, as the syllabus is not a learning guide. Rather, the syllabus is a supporting reference material, content and priorities of training may vary in different training institutions.

In this syllabus we inserted different review pubications to help the trainnes and trainers. There are several scientific publications, web pages, and conference materials available online that could be used for educational purposes in various types of rare cancers. There are significant differences in the relative amounts of available scientific publications (reviews): there are some (like sarcoma), which has very robust representation, while there are some others, that are hardly investigated and studied systematically, consequently the availability of supporting materials is often quite poor. The message of this imbalance that some specific areas needs an actual literature search, and the second message is that the more intensively investigated fields are the more frequent entries. During the future syllabus revisions special care should be devoted with inclusions of the ERNs, and/or by the UEMS, as possible recognised stakeholders in the medical education.

Launch & Maintainance of an EU Exam

- Participating healthcare & academic partners (Universities & Medical Ctrs)
- European Board?
  - European Board of Rare Adult Solid Cancers?
  - EJP-RD?

Glasgow Declaration

- Candidates for the final part of a European Board Examination must be medical graduates and should be
  either
- Certified specialists in any country (eligibility to be determined by the relevant Section or Multidisciplinary Joint Committee)

  or
- Trainees in the final year of specialist training in a UEMS member country.

Glasgow Declaration

- Candidates who pass a European Board Examination and who are certified specialists may call themselves “Fellow of the European Board of …..” and will receive a certificate.
- Trade sponsorship should not be used to subsidise the examination.
- It was established a UEMS Council for European Specialist Medical Assessments (UEMS-CESMA) as a part of the ECAMSQ™ (European Council for Accreditation for Medical Specialty Qualification)