



European
Reference
Network

MetabERN

European Reference Network
for Hereditary Metabolic Disorders

Workpackage 7: Education, Training and Capacity building

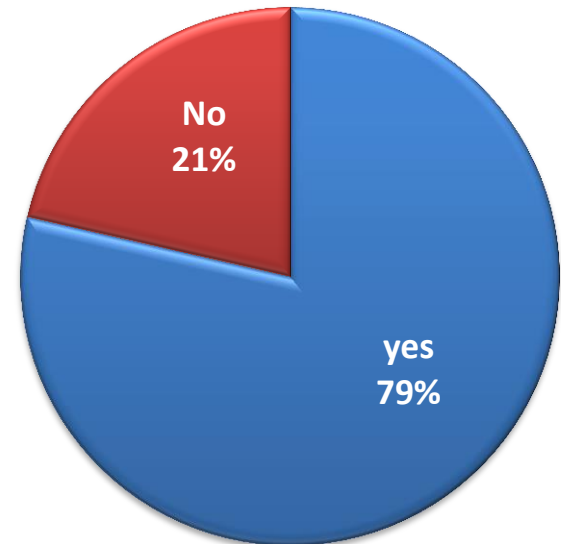
WP7: Education, training, and capacity building

Questionnaire about training and education in HCPs of MetaERN



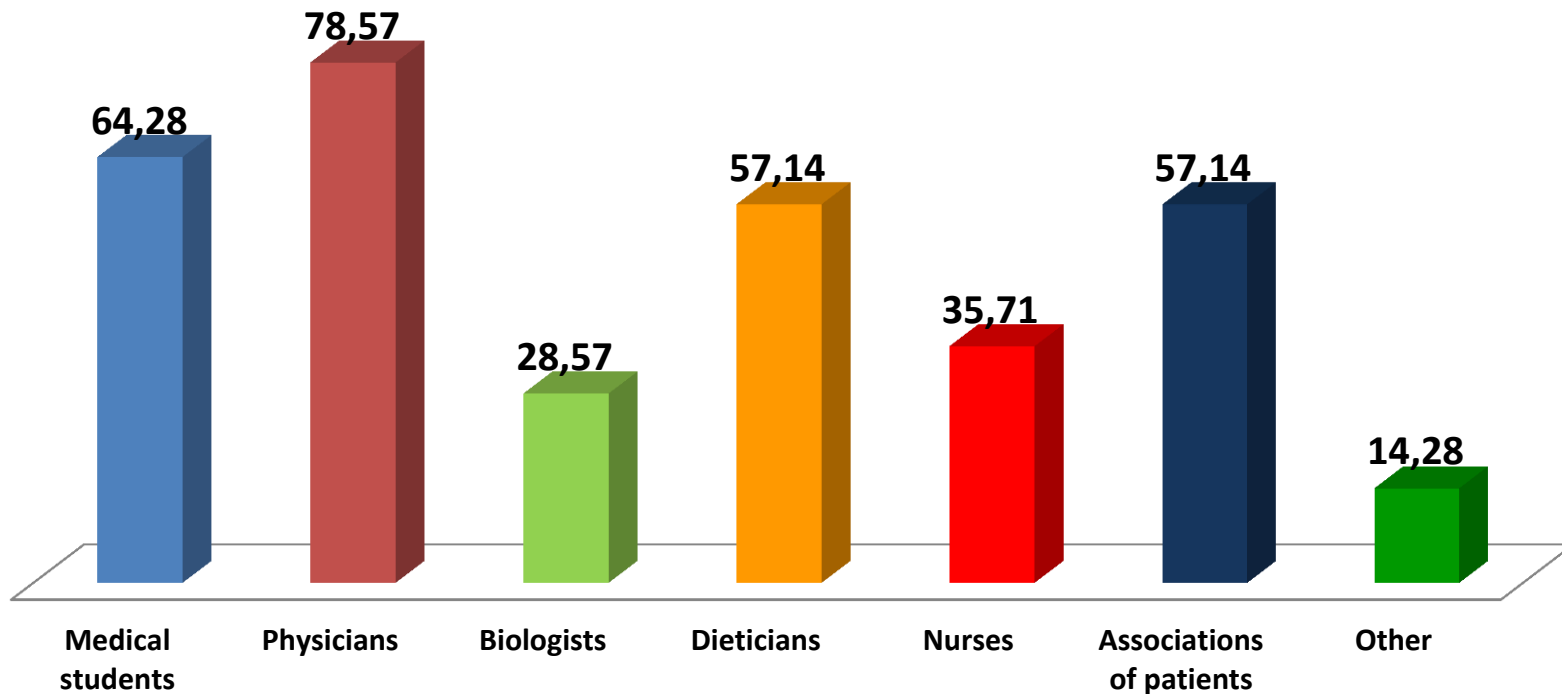
A/Training

1/ Do you have any training organized by your HCP/University involved in the field of Hereditary metabolic disorders?





2/ Intended for which stakeholders in the field of rare metabolic diseases?





Tables related to the text written
by the HCPs

- *Name of training:*
- *The characteristics of training*
- *The details about this training*

(Slide 5 and 6)

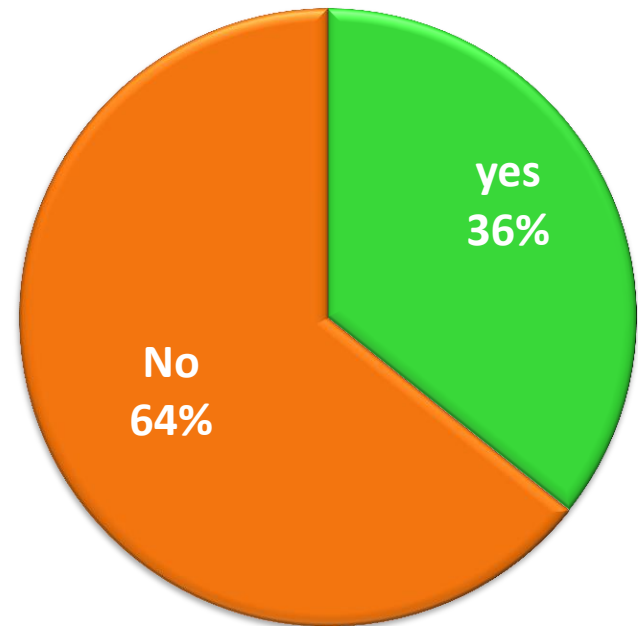
Members of MetabERN	Name	Characteristics
Belgium	All from the center of metabolic diseases, University hospitals Leuven, Leuven, Belgium	University diploma, master, PhD
Danmark	Different according to target group	Different, but mostly it concerns education during speciality training of physicians (e.g. paediatricians, geneticists, neurologists)
Germany	Hospitalization for dieticians Nurses participation in training regarding EET (emergency training, educational) Patients: cooking courses, weekend meeting with the whole family Physicians by invitation to annual CME In addition there is a project underway during 2018 to offer close cooperation for physicians by offering a co-operation as suggested by the National Plan for Rare diseases in Germany (NAMSE), training those who are interested in dealing with their patients according to guidelines etc.	No official training
Italy	University Diploma, Master	
Lille	DIU des Maladies Héréditaires du Métabolisme/Orphan Academy course 2009, Lille, IMDs with hepatic presentation/Orphan Academy course 2017, Lille, IMDs and transplantation/SFEIM 2x a year (2015 in Lille on UCDs)	
Netherlands	Besides the on site trainings, like participation's in Recordati and SSIEM Academy/Medical students and biologists -> integrated in the University of Groningen G2020 medical curriculum/Pediatric residents -> integrated in the Dutch Pediatric Association Top 2020 curriculum/Pediatric metabolic fellowship -> according to the Dutch Pediatric Association curriculum/Patient associations -> Dutch and foreign association in the fields of our specific expertises (PKU, TYR1, GSD, FAOD, movement disorders) as well as patient organizations at European and world wide level	All university diplomas (bachelor, master, PhD).
Poland		Classes with medical students (fifth year out of six year training) – seminars and bedside activity

Portugal	Lysosomal Storage Disorders - Primary Care Involvement; Lysosomal Storage Disorders – Updates on Diagnosis and Treatment	We organize clinical sessions targeted for disease awareness, red flags and early referral of suspected patients with lysosomal storage disorders from Primary Care to our Reference Center /We organize clinical sessions targeted for healthcare professionals of the Reference Center on updates on diagnosis and treatment of Lysosomal Storage Disorders/We also have had or collaborated in master or PhD degrees on Lysosomal Storage Disorders.
Portugal	Introdução às Doenças Hereditárias do Metabolismo (for medical Students, in Pediatrics) Curso Básico de Doenças Hereditárias do Metabolismo (annual, 21h course, disorders or syndromes review by seniors and clinical cases presented by young MD)	The course is with assiduity registry and optative final exam; only a local diploma
Slovenia	Not a formal self-standing training program.	Training is a part of medical school and pediatric residency curricula and also part of BSc and MSc curricula for dietitians.
Slovenia		Partially is a regular education for the medical diploma at Medical Faculty, but it is a part of master degree at the education for the dietiticians
Sweden	: Yearly training program with different aspects on IEMs, A three-day course on Neurometabolic diseases, Mitochondrial diseases on a regular basis. Every year week-long gatherings of families of children with rare diseases including IEMS including medical information and education. Ongoing PhD projects in IFMs.	



B/ Internship

Do you have an internship in the field of rare metabolic diseases in your HCP or university?





Text written by HCPs concerning :

- *Name of intership*
- *Characteristics*
- *The details about this training*

(Slide 9)

Members of MetabERN	Yes	No	Name	Characteristics
Belgium	Yes		fellowship IEM	2 year training (clinical)
Italy		no		Only during the course of resident in Paediatric Specialization the doctor receive a specific training in metabolic disorders
Italy	yes			Before to be retired, I was a Biochemist and I spent my time in studying some IMD as a researcher
Lille	Yes		DES de Pédiatrie	Yes, but integrated in the pediatric internship
Netherlands	yes		Integrated in the NVK Top 2020 curriculum for Dutch pediatric residents. For foreign applicants we provide internships -on request- based on their (and our) interest and expertise.	
Poland	yes			only bedside with students



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Workpackage 7: Education, Training and Capacity building

C/Opinion concerning organization of training in the field of rare metabolic diseases

- For you, what is the priority topics of training in MetabERN?

✓ 1st Priorities topic

Examples of stakeholders:

- Students and physicians
- Young doctors and GPs- early diagnostic, they should know where to send patient with atypical symptoms (adult patients)

Subjects

- Guideline book
- Develop courses such as and supplementing SSIEM Academy and Recordati courses with mostly a clinical focus
- Clinical approach to patients, homogenous management at national and EU level
- To approach medical student to metabolic disorders
- Study Biochemistry in depth
- Update of the current situation
- Open access E-learning modules of cases representing the 7 subnetworks
- Lysosomal Storage Disorders
- Awareness
- Early diagnoses of IEMs
- The metabolic emergencies
- Diagnoses for primary pediatricians, improvement of knowledge in adult medicine

✓ 2nd Priorities topic

Examples of stakeholders

- Courses directed toward laboratory scientists
- Specialist like hematologists, rheumatologists – to remind them about rare
- Beginning metabolic colleagues

Subjects

- Increasing awareness for metabolic diseases
- How to produce shared guidelines
- To increase knowledge on inborn metabolic disorders
- Identify the symptoms
- Basic clinical and biochemistry learning for beginning metabolic colleagues
- Case/topic discussions in expert groups using CPMS (enabling experts from outside the ERN, if applicable)
- Metabolic diseases (such LSDs)
- Continuity of care (Pediatric to Adult Transition)
- Emergency therapy
- Standards of care for IEMs
- Diagnostic approach in metabolic

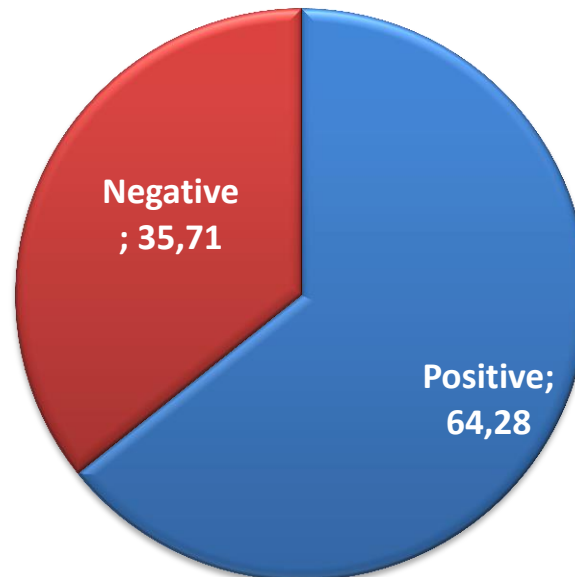
✓ 3rd Priorities topic

Subjects

- Offer of cooperation
- How to organize age transition
- To increase the suspicious in metabolic disorders
- Correct use of internet referee sites
- Close connection with SSIEM Academy
- Knowledge of expert centers, networks and contacts
- Use of IT resources to facilitate care for IEMs
- The basic knowledge about screening and the main groups of metabolic diseases



-What's your opinion about training organized by e-learning?



Opinion concerning training by e-learning

Comments

- Is always good to reach a large public
- (No) Always face-to-face education in Denmark until now

- We are setting up an eLearning program (Lectora) that will be available via our website and addresses students and interested physicians teaching the most prevalent hereditary metabolic diseases

- e-learning is a good way but it's necessary also to create vis a vis meetings or master courses

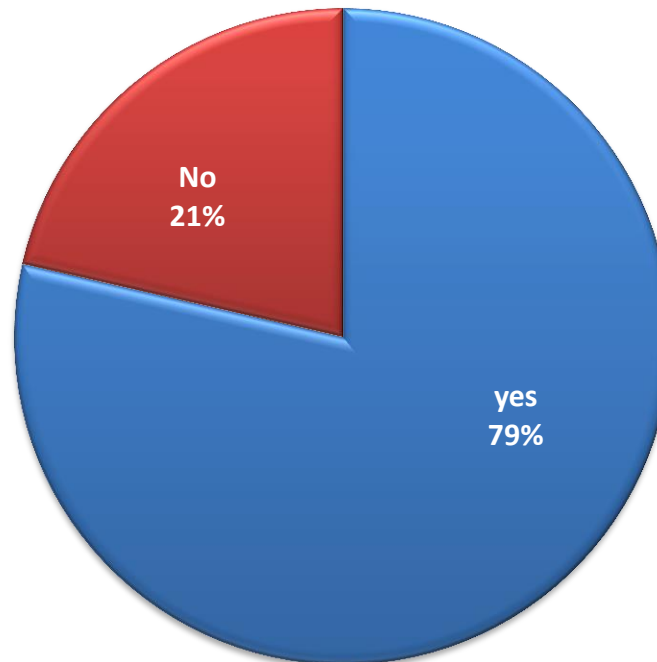
- I do not think that physicians, with their lack of time would sit at the computer and do the e-learning training in this very narrow and specialist field, I think that more resendable would be to organize additional sessions dedicated to rare metabolic diseases during their specialist, regional or national conferences

- But also other types are needed (e.g. intensive courses, ...).

- But a course at hospital is probably a better option/ regarding the EU language policy – should we proceed with English only?"



- Do you prefer training organized by HCP/University compare to e-learning?



Opinion concerning training organized in HCP/University

Comments

- Not sure whether our current training would fit in with EU.
There is no recognized subspeciality of IEM in Belgium.
- We are the only center for IEM

- We are doing this on our own. The faculty is not interested. There is no support by the HCP. All work load and costs are covered by the center

- We are working to promote a master class for adults clinicians in cooperation with SSIEM

- At the moment in my University, which is also HCP, a course is building for medical students regarding rare diseases in general, but I don't know when and if it will start

- We have e-learning in progress in collaboration with our faculty team, but additional support would be essential to speed up.

- Slovenia has a small population and the education in IEM is limited to a selected number of student and physicians