PATIENT INVOLVEMENT IN THE DEVELOPMENT OF CLINICAL NUTRITION GUIDELINES AND LAY SUMMARIES

GASTON REMMERS, CEES SMIT
TANJA EL-NEMR, KATIE GALLAGHER

19 November 2019
ONCA Conference, Cambridge

"A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE"
EPF and Nutrition

EPF activities to date

2012/2013
- Book 'Patient Perspectives on Nutrition' with ENHA and EGAN

2012
- MoU between EPF, ENHA and EGAN

2013/2014
- Partner of ONCA Campaign and ENHA

2017
- EU Patient Groups Conference on Nutrition

2017/2018
- EU Patient Task Force on Nutrition

2018
- EU Patient Task Force on Nutrition

2018
- Nutrition Guidelines and lay person summaries

2019
- Formal collaboration with ESPEN on patient involvement in guideline development and summaries

2019
- EPF Cluster on Nutrition

“A STRONG PATIENTS’ VOICE TO DRIVE BETTER HEALTH IN EUROPE”
Development of lay summaries and clinical nutrition guidelines – Patient involvement

- Lay version format of existing clinical nutrition guidelines for patients and caregivers are considered by both patients and ESPEN to be a high priority for future work.

- EPF and ESPEN established formal collaboration in 2018 in the context of this project. The project is developing patient versions of existing guidelines and ensuring strong patient involvement in the review of new guidelines.

- EPF works closely with its membership and the wider patient community to facilitate patient involvement in ESPEN’s guideline related activities.

- EPF also hopes to work closely with EFAD and dietitians who can use their expertise and people centred skills to ensure guidance is relevant and easily applied.
In summer 2019, EPF hosted a webinar on patient involvement in the development of clinical nutrition guidelines and lay summaries, and published a call for patient representatives on 14 disease and care areas.

- Disease and care areas: **10 new lay summaries and 4 new guidelines** are being developed.
- Currently, ESPEN is contacting interested patient representatives and forming working groups.
EPF Collaboration with ESPEN

Development of lay summaries – Patient representatives identified

1. Chronic intestinal failure
2. Oncology
3. IBD
4. Surgery
5. Polymorbidity
6. Neurology
7. Geriatrics
8. ICU
9. Hepatology
10. Home enteral nutrition
EPF Collaboration with ESPEN

Development of new guidelines – Patient representatives identified

1. Nephrology
2. Hospital Food
3. Micronutrients
4. Pulmonary diseases
CLINICAL NUTRITION GUIDELINES

WHAT IS CLINICAL NUTRITION?
Clinical nutrition is a discipline which deals with the prevention, diagnosis and management of nutritional and metabolic changes related to acute and chronic diseases and conditions caused by a lack or excess of energy and nutrients. Any nutritional measure, preventive or curative, targeting individual patients is clinical nutrition.

HOW TO PREVENT AND MANAGE CHRONIC CONDITIONS

1. When patients are unable to eat normally, they may need specialised nutrition administered via the stomach, intestine, or via the vein.
2. Healthcare professionals should use evidence-based guidelines when selecting the most appropriate method of nutritional support.

EATING IS NOT A LUXURY AND FOOD IS MUCH MORE THAN NUTRITION

AN EXAMPLE OF PATIENT INVOLVEMENT IN GUIDELINES AND LAY SUMMARIES DEVELOPMENT

EPF and ESPEN, the European Society for Clinical Nutrition and Metabolism, are collaborating on:
- developing patient versions of guidelines and
- ensuring strong patient involvement in the review of new guidelines.

This collaboration began in 2013, and currently addresses 14 disease and care areas. EPF is working closely with its membership and the wider patient community to facilitate patient involvement in these activities.

PATIENT INFORMATION ABOUT FOOD: WHAT IS EPF ADVOCATING FOR?

LESS FAT = MORE CARBS + FAT 9% = Optimization of the EU "Food Labelling Regulation"

More transparency from food manufacturers, mandatory colour-coded front-of-pack labelling across food products and European harmonisation.
Medical Curriculum with 4 patient contributions
THANK YOU FOR YOUR ATTENTION!

Follow us on Social Media!

/europeanpatientsforum
/eupatient
/eupatientsforum
/eu-patient.eu/blog

More information
www.eu-patient.eu
info@eu-patient.eu