The relevance of nutrition for EU patient groups

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How it all started
Memorandum of Understanding 2012
EPF – EGAN - ENHA

• Conferences in Brussels (2012) and in Dublin (2013) to define and start implementing an European patient agenda

• Publication “Patient Perspectives on Nutrition”, 2013

• Partner in the ‘Optimal Nutritional Care for All’ campaign conferences in Brussels (2014), Berlin (2015) and Madrid (2016) with also a plenary patient session

• An European patient nutrition brainstorm conference, June 29, 2017 in Brussels
PATIENT PERSPECTIVES ON NUTRITION
Relevance of nutrition for patients

• The relevance of nutrition and nutritional care for patient groups can differ significantly throughout life

• Its importance depends on the value nutrition or nutritional care can add to the prevention, treatment and management of the specific disease or disability

• Affected families are looking for information

• Interest in common food as well as personalized food

• Nutrition, who is responsible in the health care environment?
EU Patient Groups June 29, 2017

- Brussels brainstorm conference with ≈ 30 participants from a wide range of European, disease specific patient groups

- They see the urgency of the issue

- Also in relation to prevention
  (instead of curing life-style diseases)

- Outcome: recommendations for all stakeholders
  & a renewed patient agenda on nutrition 2018 - 2021
European Patient Forum Conference, June 29

Marco Greco, EPF chair

“Nutrition, nutritional care and the collaboration with ONCA are one of EPF’s key priorities for the upcoming years”
Three types of patient groups

- Those depending on medical nutrition day and night
- Those for whom nutrition plays a key role in the management of the disease and health outcome (kidney, cancer, coeliac, liver)
- Those who need nutrition for prevention (spina bifida, ‘first 1.000 days’)

Patients depending on medical nutrition: key issues

- The relevance of peer support (compliance and earlier intervention)
- Practical issues (ICU, EPR, Tenders, Emergency issues at hospitals and customs)
- Nutritional information in EPR
- PACIFHAN
Comorbidity and A Circle Full of Health Care Contacts

- Dentist
- Hematologist
- Orthopedic Surgeon
- Rehabilitation Specialist
- Physiotherapist
- Physiotherapist (around the corner)
- Physiotherapist (national centre)
- ME & Self mgt
- Home Physician
- HIV Nurse
- HCV Nurse
- Infectious Diseases specialist (HIV)
- Infectious Diseases specialist (HCV)
- Pharmacy (haemophilia centre)
- Pharmacy (around the corner)
- Nephrologist
- Cardiologist
- Hemophilia Nurse
The ‘fear factor’

Three problems:

Comorbidity & the use of multiple medication (polypharmacy)

Lack of coordination between physicians and other staff, which needs self-coordination

Appropriate nutrition & support

Who can and lead coordination when self-care is difficult or no longer possible?
European survey of 907 people with cancer about the importance of nutrition

- A structured questionnaire was designed to analyse the importance of nutrition for people with cancer.
- The study was conducted by the European Cancer Patient Coalition (ECPC), Sapienza University of Rome, and Healthware International.
- **72.9%** (n=603) of the respondents *didn’t know* the meaning of the term “cachexia”
- **92.4%** (n=764) *did not receive* any information about cachexia from their health professionals.
- **69.7%** (n=586) of respondents reported that they *lost weight* after the cancer diagnosis.
- There is a need to **empower individual patients** and patient associations by *producing more information* on cancer patients’ nutritional needs.
Scientific & Educational issues

- Nutrition in curricula universities etc.
- Evidence-based medicine vs evidence-based practice
- Data collection and ownership
- ESPEN Scientific guidelines & care standards
  - There is a need for lay-versions
  - Best practice: PINNT UK & BAPEN
  - (NHS Involve): Patient/citizen involvement in research
Patient panel

Patient respondent
- Giving information
- Not time consuming
- Requires first-hand experience with the condition or disease

Patient adviser
- Giving advice
- Two-way communication
- Often single involvement

Patient reviewer
- Making an assessment
- Direct influence on the aims and design of the study
- Often single involvement

Research Partner
- Collaboration throughout the life cycle of the research
- Partnership based on equality
- Time consuming
- May require substantial education and/or support

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