

# 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

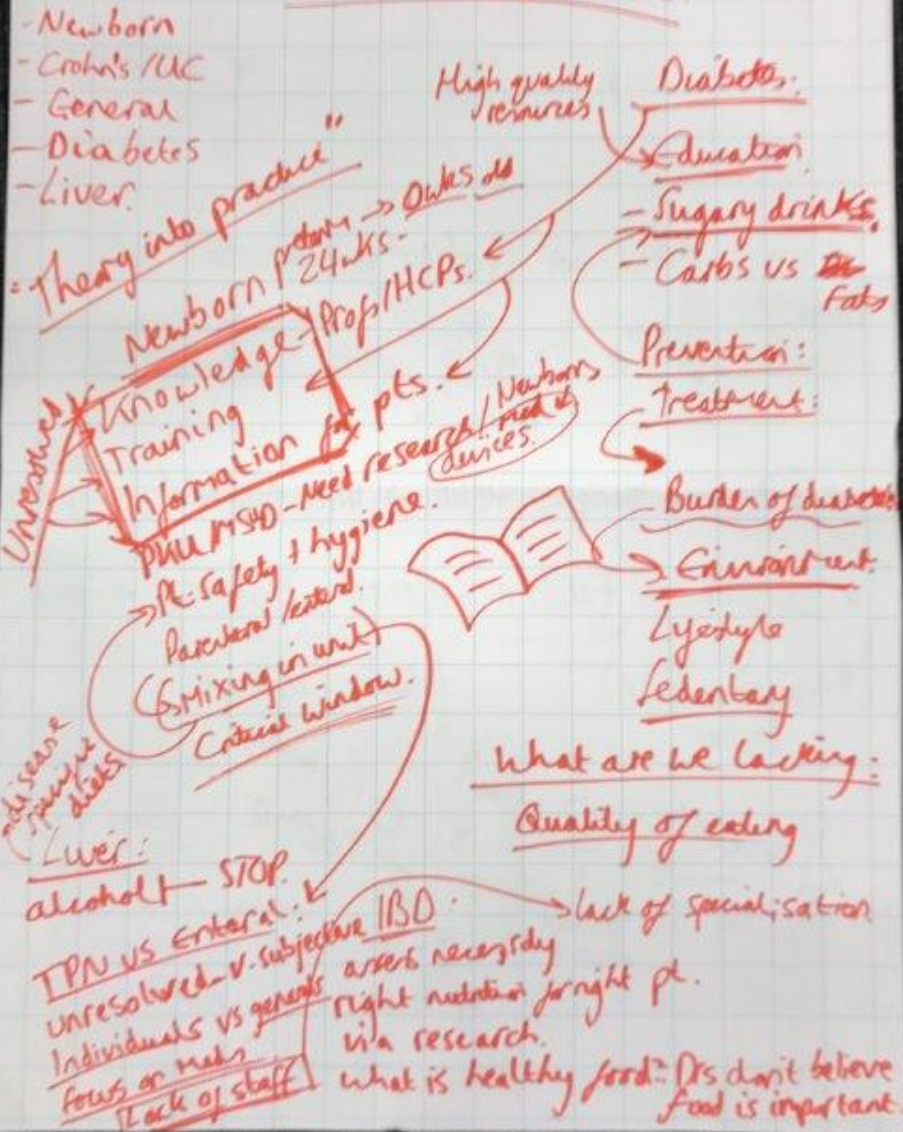
# Relevance of nutrition for patients

- 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  $\approx$  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

① MAIN UNRESOLVED CHALLENGES  
IN YOUR DISEASE.



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')

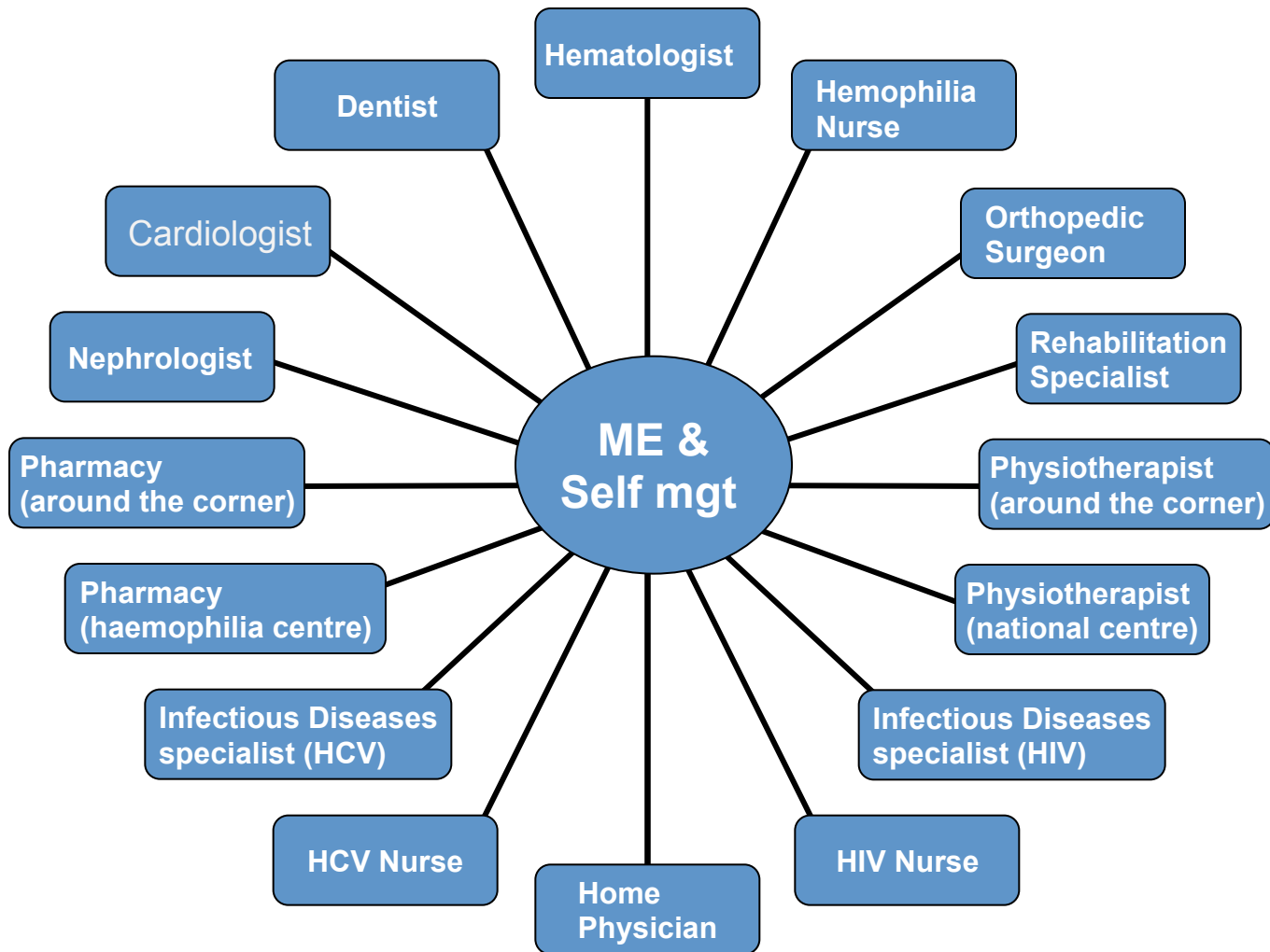




# Patients depending on medical nutrition: key issues

- 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



# 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 ?

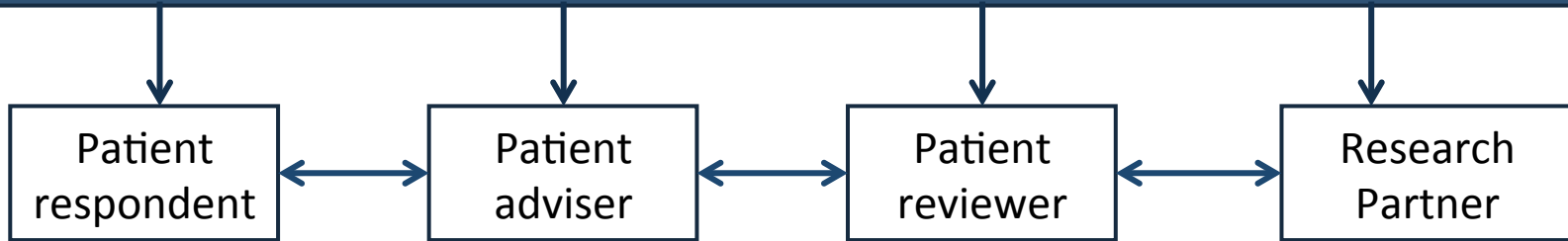
# European survey of 907 people with cancer about the importance of nutrition

- 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



Giving information

Not time consuming

Requires first hand experience with the condition or disease

Giving advise

Two-way communication

Often single involvement

Making an assessment

Direct influence on the aims and design of the study

Often single involvement

Collaboration throughtout the life cycle of the research

Partnership based on equality

Time consuming

May require substaintial education and/or support

optimal  
nutritional care  
for all

Share  
Good  
Practices

Share in your network ↗

20 shares

The collage contains the following posts:

- Event:** Education of patient groups on nutrition. Croatia. Education. 5 shares.
- Event:** Raising awareness on optimal nutritional care. Croatia. Awareness. 2 shares.
- News:** Management of malnutrition in complex chronic patients. Spain. Screening. 4 shares.
- Study:** Prevalence of malnutrition in subjects over 65. Spain. Malnutrition. 20 shares.
- News:** APNEP: Political aspects of undernutrition awareness. Portugal. Awareness. 9 shares.
- News:** APNEP: nutritional evaluation in internal... Portugal. Research. 4 shares.

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