

# EPF/ONCA Kick-Off Webinar

## *Patient involvement in Nutritional Care*

### *-Policy and Practice-*

Kaisa Immonen

Director of Policy, European Patients' Forum

13 January 2022



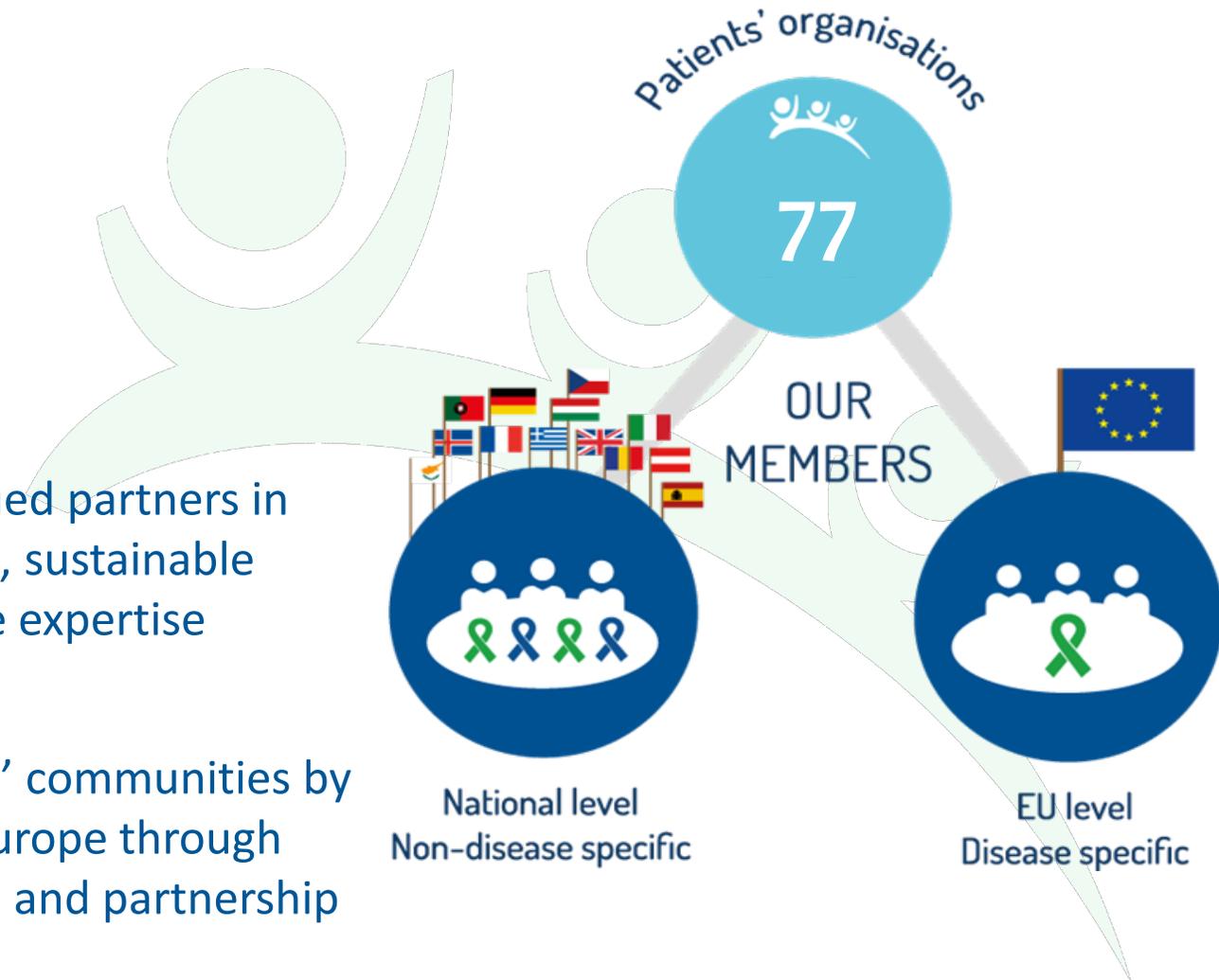
@eupatientsforum

“ A STRONG PATIENTS' VOICE TO  
DRIVE BETTER HEALTH IN EUROPE ”

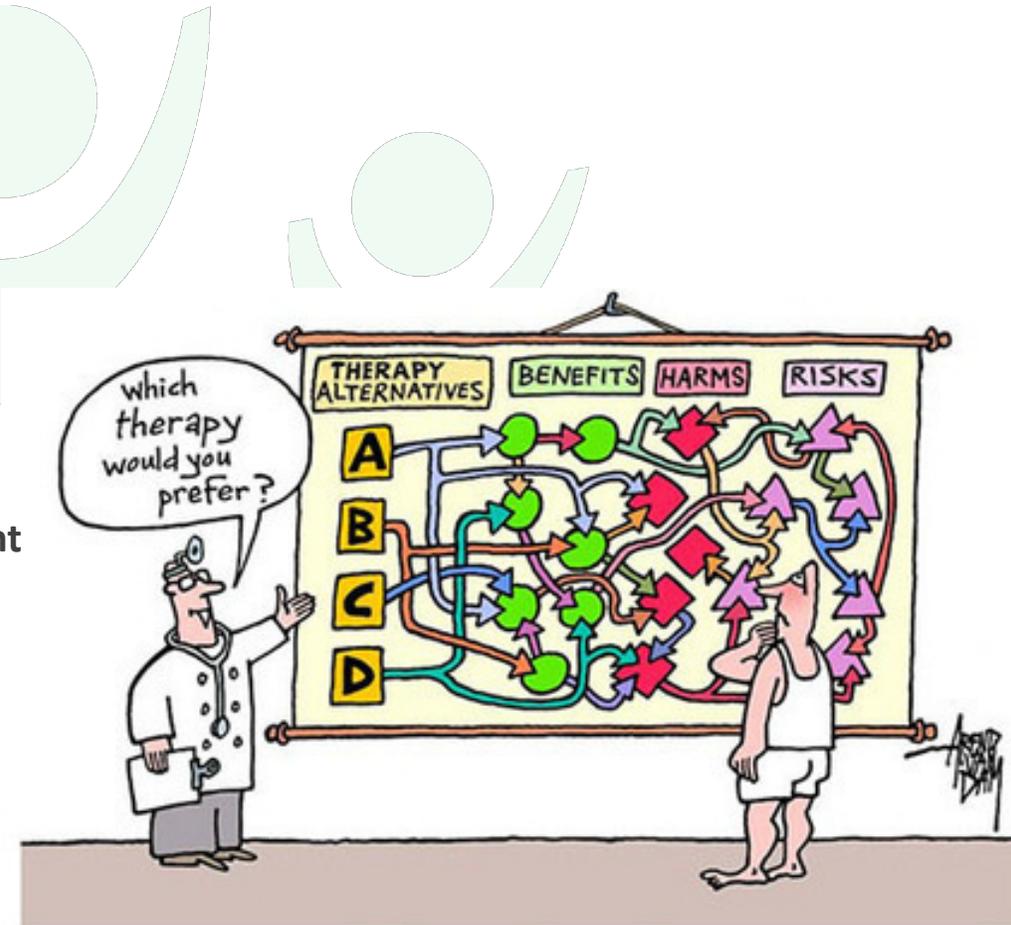
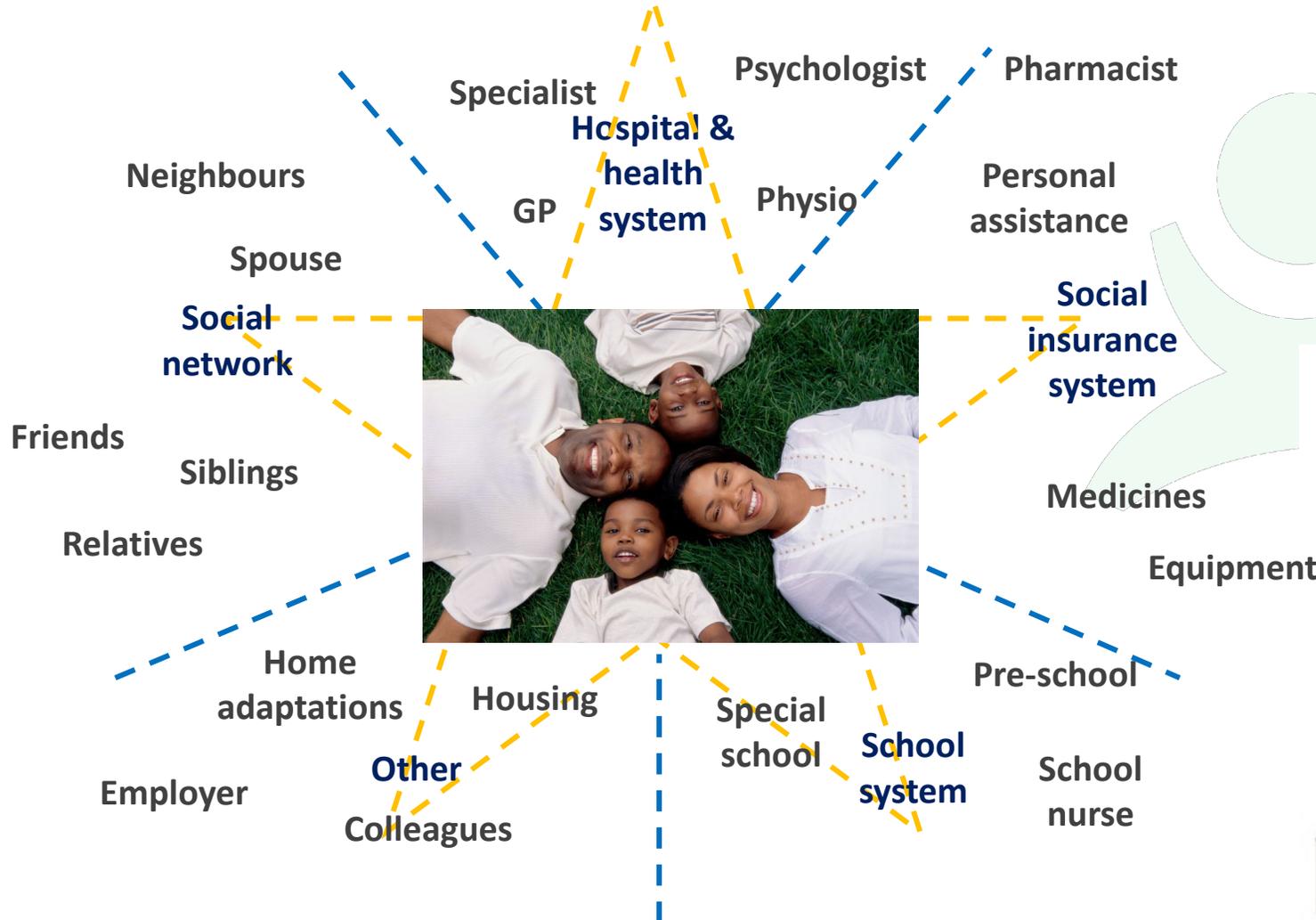


# What is EPF?

- The European Patients' Forum
  - Independent non-governmental organisation
  - Founded in 2003
- Our members
  - EU disease-specific & national coalitions
- Our vision
  - A Europe where patient organisations are valued partners in creating equitable, person-centred, accessible, sustainable healthcare systems, based on patients' unique expertise
- Our mission
  - Advance the interests of patients and patients' communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment, and partnership



# Why is nutrition so important to patients?

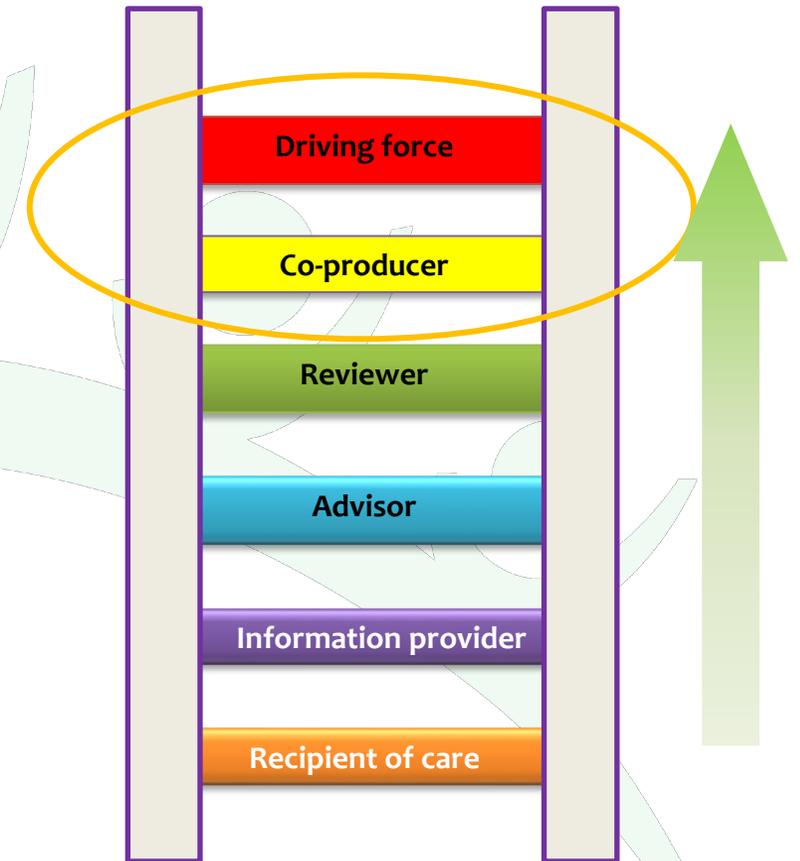
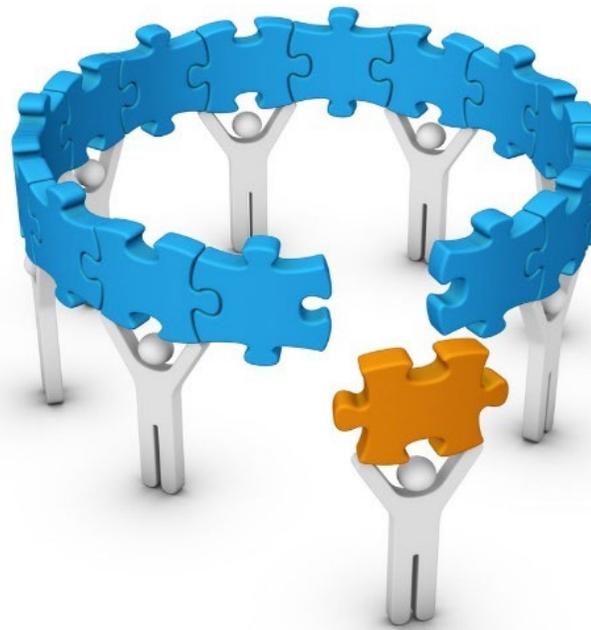


*informed consent*

# Meaningful patient involvement in (nutritional) care



“From working *for* patients...  
to working *with* patients”



Adapted from PatientPartner FP7 Project (2010),  
[www.patientpartner-europe.eu](http://www.patientpartner-europe.eu)

# Additional readings

- EPF fact-sheet on clinical nutrition guidelines - [https://european-nutrition.org/wp-content/uploads/2020/02/EPF Clinical nutrition infographic FINAL.pdf](https://european-nutrition.org/wp-content/uploads/2020/02/EPF_Clinical_nutrition_infographic_FINAL.pdf)
- EPF Position Statement on Information to Patients on Food and Nutrition (March 2018) - <https://www.eu-patient.eu/globalassets/policy/nutrition/epf-position-statement---nutrition.pdf>

# THANK YOU FOR YOUR ATTENTION!

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# What is Optimal Nutritional Care?





# Where are we?

- In the EU 33 M people are at risk of becoming malnourished
- 1 in 4 hospitalised patients is malnourished
- 10-20% of cancer deaths can be attributed to malnutrition rather than the malignancy itself and 1 in 2 cancer patients experience involuntary weight loss
- Malnutrition impairs quality of life and can reduce survival time
- Malnutrition costs an estimated 170B annually due to complications and longer hospital stays



# What do we need?

“If you are serious about health,  
you should be serious about nutrition”

- Nutritional care should be an integral part of high quality care
- Every patient should have access
- A patient-centred approach





# Personalised nutrition

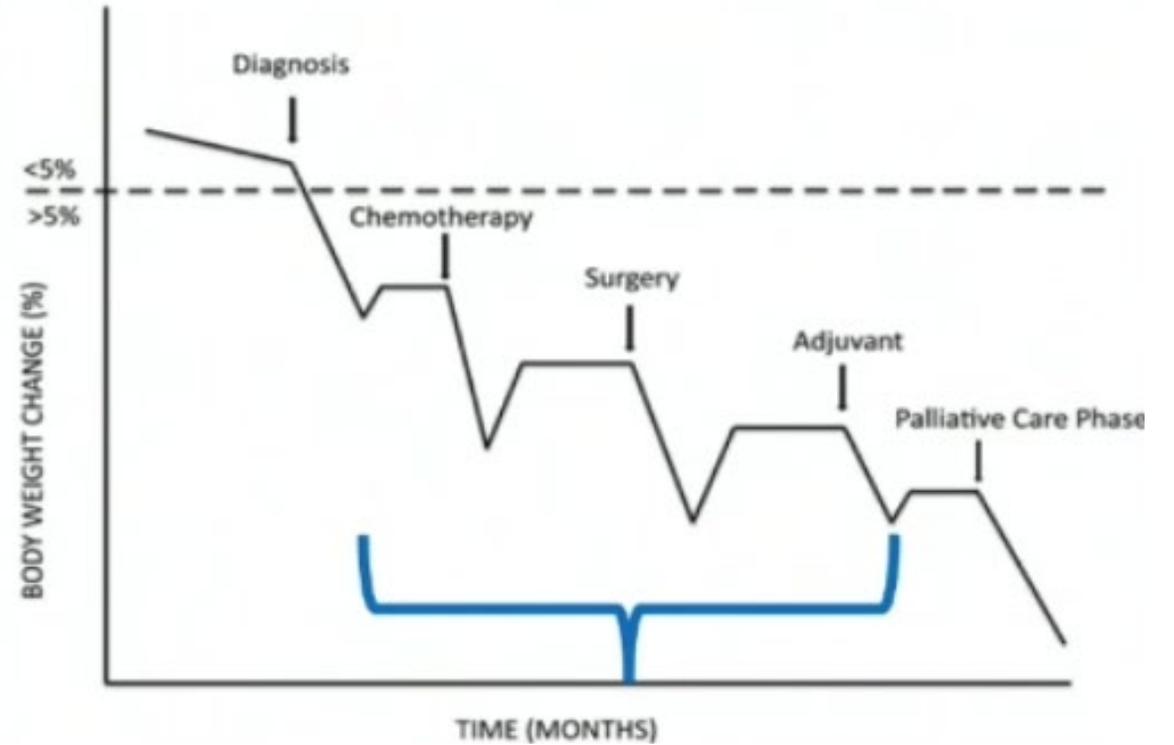
- Each person is different and has different nutritional needs
- Treating the patient, not just the disease, improves outcome





# Early intervention

Early intervention is critical to prevent malnutrition!





# Healthcare organisation – a challenge

In care pathways, the patient is travelling through the different silos of the healthcare system while in need of optimal nutrition.

This requires screening, follow up care and alignment between healthcare professionals through a multidisciplinary approach.





# The ONCA Campaign

**optimal**  
**nutritional care**  
**for all**



# The European Nutrition for Health Alliance

Our aim is to ensure that the protection of a person's nutritional status is an integral part of care in aging and disease.





# The European Nutrition for Health Alliance

Translating nutritional care science into policy.



## Spain

16 stakeholders and covers 75% of all health care professionals in Spain

[View country page](#)



## Portugal

Mandatory screening and access for high quality nutritional care

[View country page](#)



## The Netherlands

Reduce the occurrence and burden of malnutrition in the Netherlands

[View country page](#)



## Italy

Reduce malnutrition burden and ensure quality nutritional care sharing

[View country page](#)



## Austria

Country Dashboard & Good Practices

[View country page](#)



## Czech Republic

Country information & Good Practices

[View country page](#)



## Denmark

Reducing the incidence of disease-related malnutrition

[View country page](#)



## Belgium

A broad platform of competencies and forces of Belgian partners

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## Israel

Implementing better nutritional care

[View country page](#)



# Shaping policy through multistakeholder collaboration



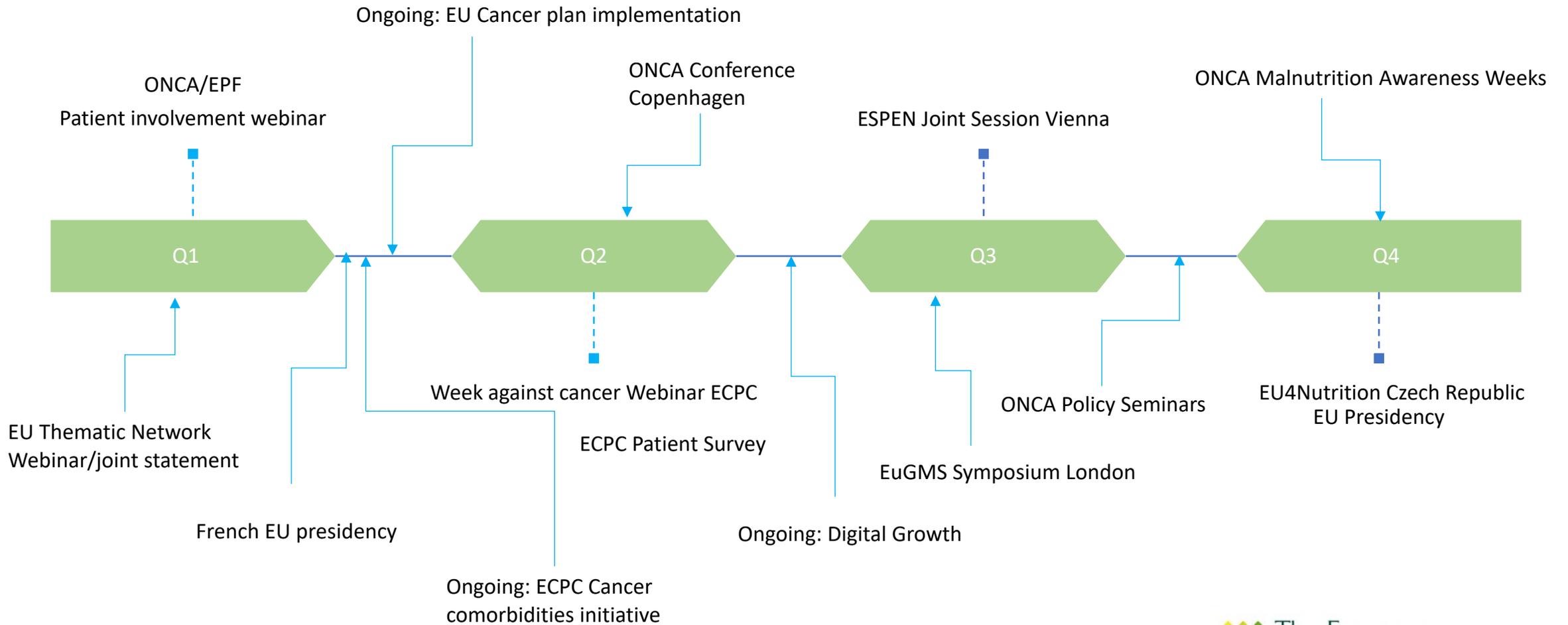


# How do we do this?

- ✓ Creating new opportunities
- ✓ Building the relevant platforms
- ✓ Forging and leveraging multi-stakeholder alliances
- ✓ Crafting and delivering strong messaging

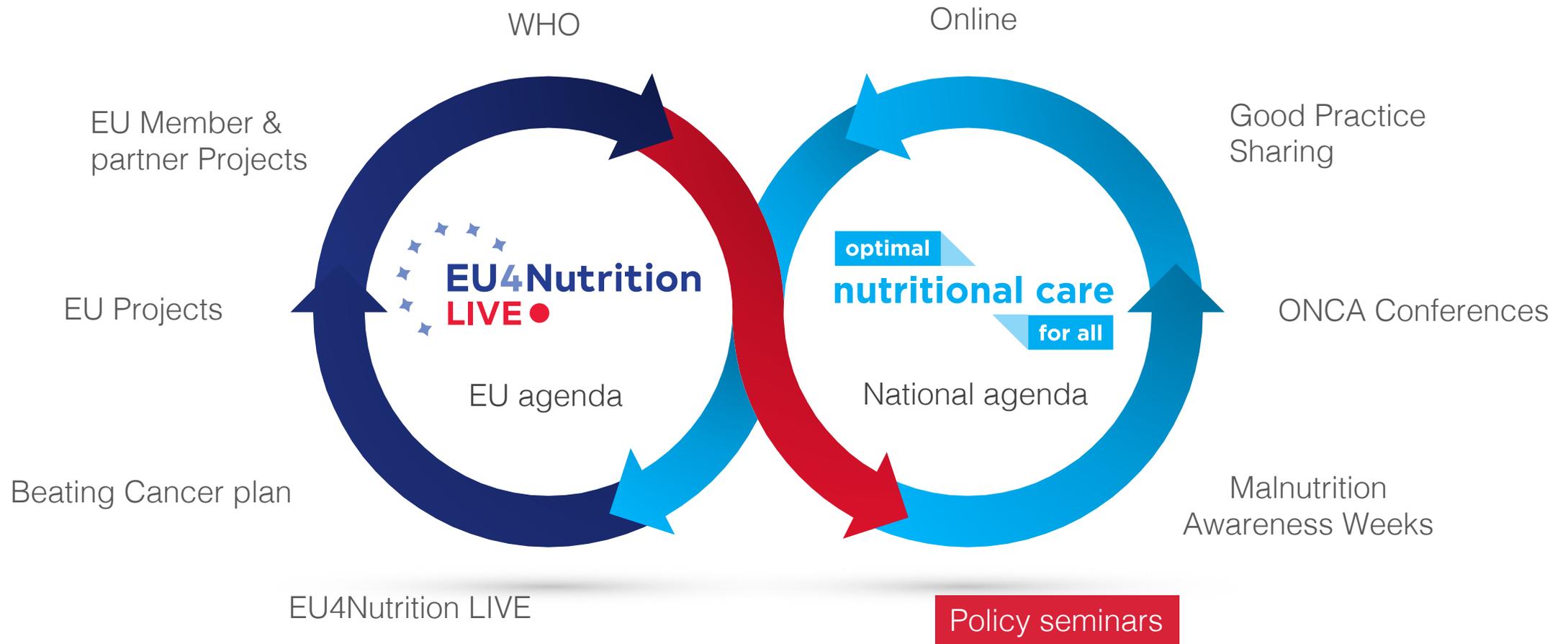


# ENHA activity overview





# Policy shaping: think Europe, act local





# The EU4Nutrition platform



**“If you are serious about health, you should be serious about nutrition”**



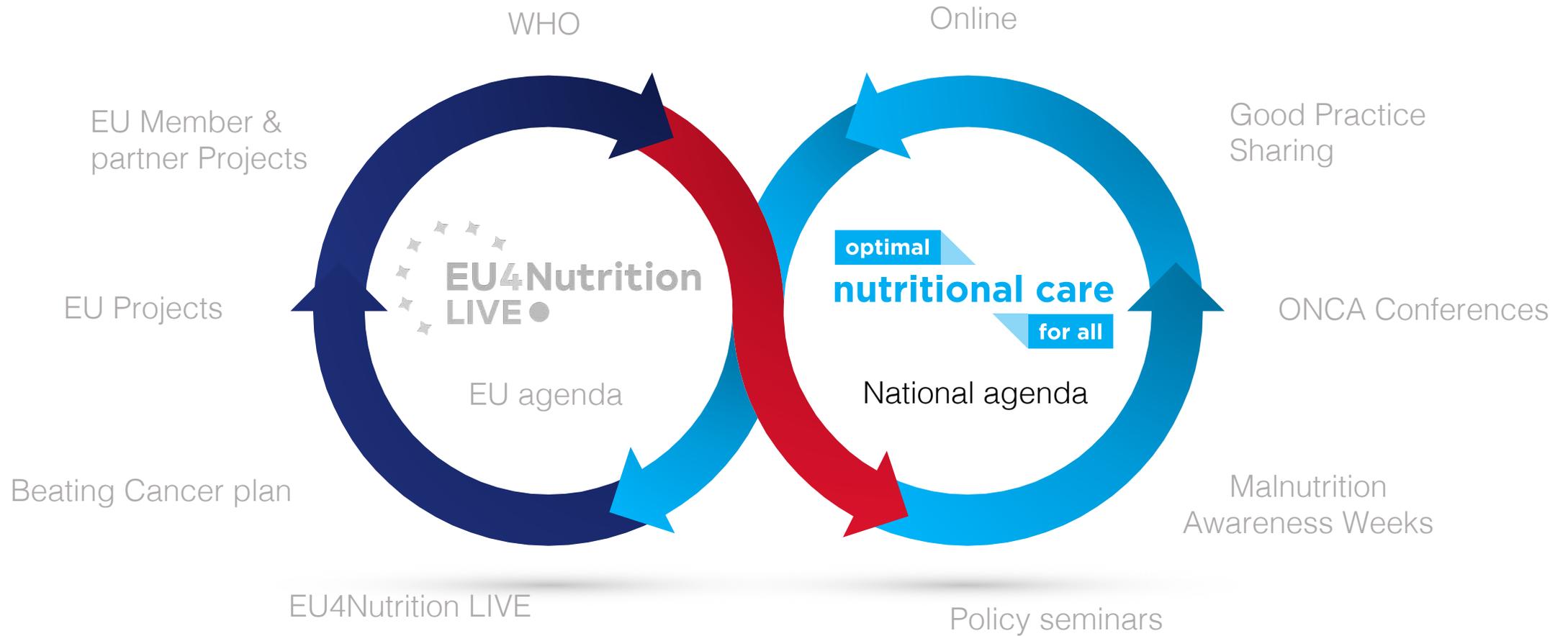
# The European (Health) Union

- ✓ The European Health Union
- ✓ EU4Health
- ✓ Europe's Beating Cancer plan
- ✓ Horizon Europe





# Policy shaping: think Europe, act local





optimal  
**nutritional care**  
for all





# The ONCA teams

- ✓ Patients
- ✓ Professionals
- ✓ Decision makers



**Mette Holst** ORCID in

Main contact Denmark

Head of Clinical Nutrition Research, Aalborg University Hospital, editor for this homepage and spokesperson for the collaboration between DSKE, ONCA-Denmark and ONCA.

[Contact](#) [View country page](#)

## THE DANISH TEAM



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**Jonathan Emil Andreasen**  
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**Jeppe Rønnebæk Kongsbak**

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**Jørgen Wiis**  
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**Mie Lauwers**  
Danish Diet & Nutrition Association

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**Tatjana Hejgaard**  
Observer  
Danish Health Authority

ORCID in



# A Pan European Coalition





MAW

#MAW2020



**MALNUTRITION**

**AWARENESS**

**WEEK**

- ✓ Israel
- ✓ Greece
- ✓ Portugal
- ✓ UK
- ✓ Italy
- ✓ Czech Republic
- ✓ France
- ✓ Denmark
- ✓ Spain
- ✓ Austria...



The European  
Nutrition for Health Alliance



Event



**Education of patient groups on nutrition**

Croatia  
Education

Share in your network ↗ 5 shares

Study



**Prevalence of malnutrition in subjects over 65**

Spain  
Malnutrition

Share in your network ↗

Study



**Prevalence of malnutrition in subjects over 65**

Spain  
Malnutrition

Share in your network ↗

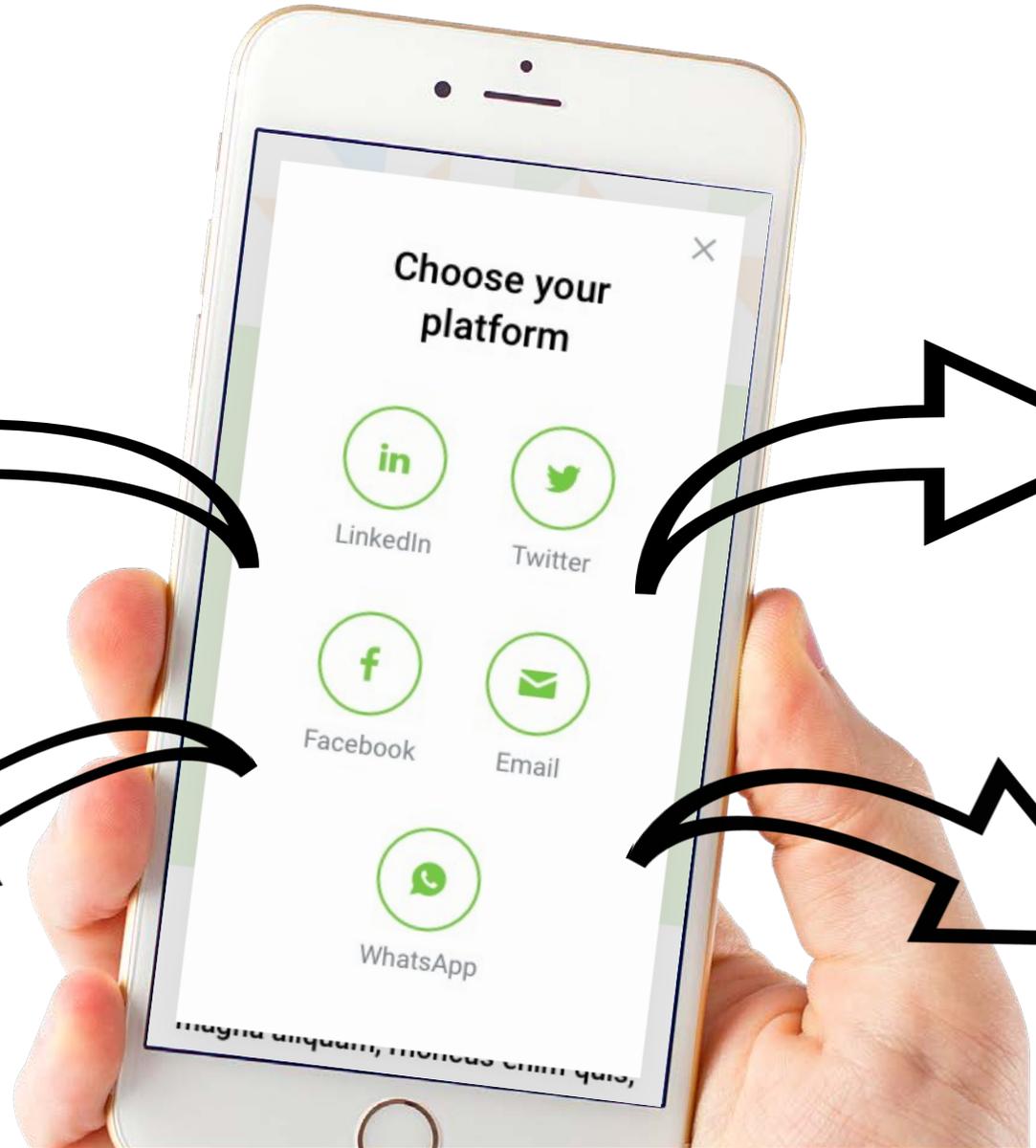
Event



**Education of patient groups on nutrition**

Croatia  
Education

Share in your network ↗ 5 shares







# 16 & 17 May Copenhagen

optimal  
**nutritional care**  
for all  
International Conference

## Creating Equality in Nutritional Care

 The European  
Nutrition for Health Alliance

 EU4Nutrition  
LIVE

 DSKE  
DANSK SELSKAB FOR KLINISK ERNÆRING

 KOST  
ERNÆRINGS  
FORBUNDET  
SUNDHED ER EN RET



Get involved!

[joost@european-nutrition.org](mailto:joost@european-nutrition.org)

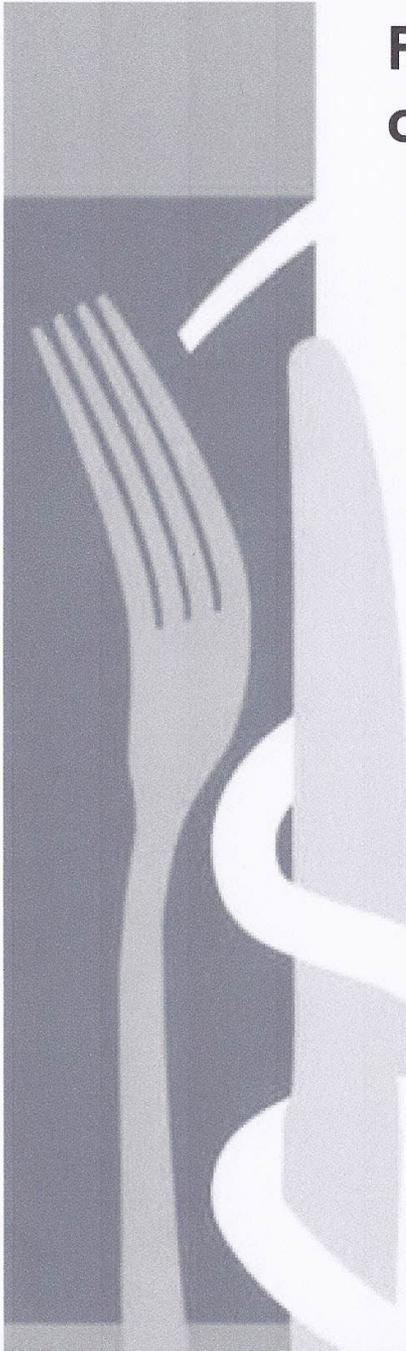
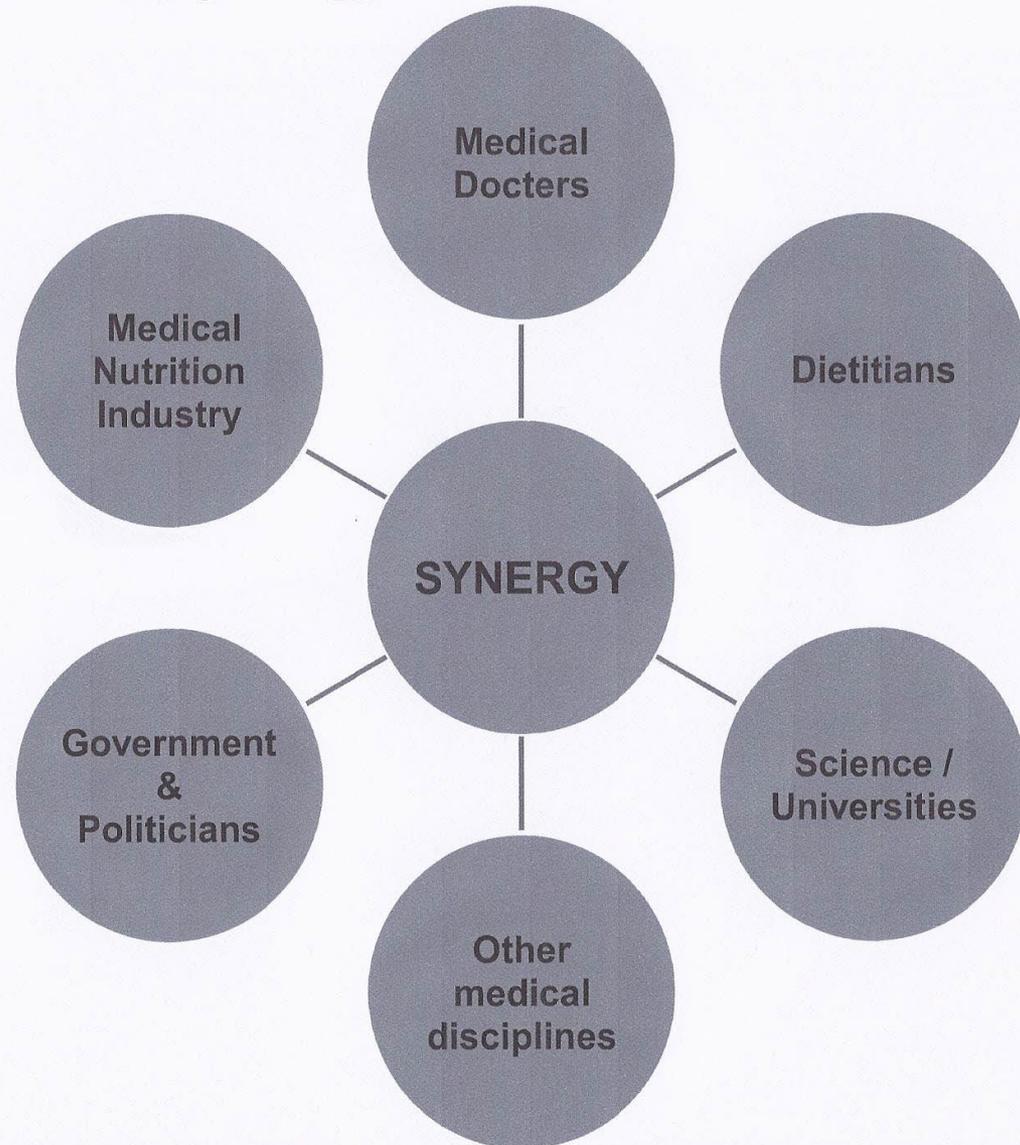
# Nutrition as a priority for European Patient Groups



Dr. Cees Smit, European Patients Forum (EPF)  
Platform Patients and Food, The Netherlands

ENHA/EPF, Webinar, January 13, 2022

# Fighting malnutrition together: finding the optimal synergy



# The missing link ?



# **Why should nutrition be so important for European Patient Groups?**

- **A lot of patients have all kind of questions about their medical treatment and prevention in relation to their nutrition and personal lifestyle. In many cases there is not enough time for these Q&A in the medical environment & it's not always a priority topic for patient groups, politicians and policy makers**
- **But also in personal life, there is not enough time for cooking and healthy food, enough rest and (adapted forms of) sports**
- **Nutrition and lifestyle should be an integral part of medical treatment and public prevention strategies**
- **COVID-19 has shown that nutrition and lifestyle were important factors that contributed to hospital and ICU-admissions**

# Connection European and National Nutrition Policies

- ENHA – Optimal Nutrition Care for All Campaign
- ± 20 National Steering Committees (NSC)
- In each NSC we would like to see 2 – 3 patient representatives that could bring the patient perspective in these practice & policy teams
- These patient representatives could also serve as a group that could formulate EU nutrition policies for patients & carers and assist EPF in bringing this agenda to the EU Comm & Parl.

# What can we offer?

- To NSC's to look for patient representatives (disease-specific or more general) to participate in NSC activities
- To NSC's: materials on meaningful patient involvement
- To Patient Groups: Background material on nutrition, guidelines, lay-versions, etc.

# For more information:

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Cees Smit, Dutch Platform Patients & Food  
[info@smitvisch.nl](mailto:info@smitvisch.nl)

# What should healthcare professionals learn from patients?

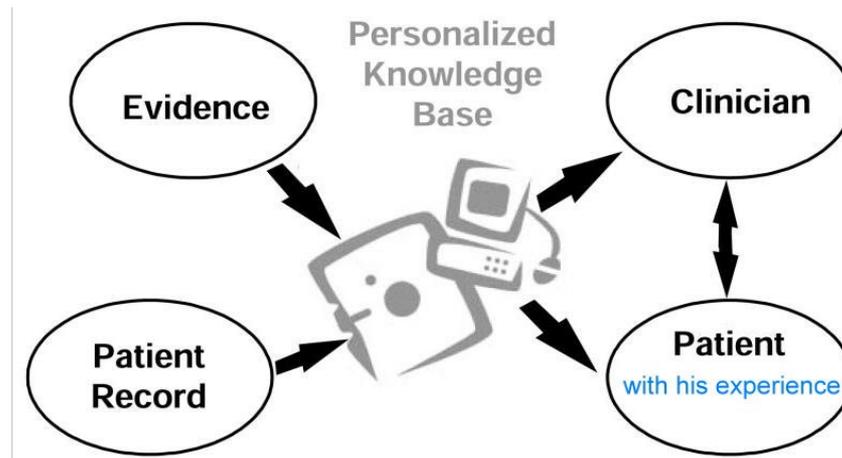
Dušan Baraga



## What should healthcare professionals learn from patients?

-Certainly, this is the experience that every patient has in overcoming illness and living with a chronic illness.

-If every healthcare professional could taste at least 1% of everything a patient experiences, this would be a major contribution to treating patients.



## What should healthcare professionals learn from patients?



### Experiences about:

- drugs (side effects, regime, form...)
- every day life (family, nutrition, work, social life, ...)
- dealing with health system (sick leave, insurance, waiting lists...)

### Problem:

- lot of different experiences

## What should healthcare professionals learn from patients?

Solution:

education  
cooperation

**We need educated patients and very good educate health care providers**

Example:

- IBD patient association
  - school and workshops for patients
  - seminars for health workers and patients
- cooperation with other associations (common goals)



## What should healthcare professionals learn from patients?



### Example:

- IBD patient association
  - school and workshops for patients
  - seminars for health workers and patients
- cooperation with other associations (common goals - nutrition)
- appeal for realization of the Resolution on the National Program on Nutrition and Physical Activity for Health 2015–2025, which was approved by the National Assembly of the Republic of Slovenia
  - joining ONCA
  - cooperating with health care providers
  - cooperation with institutions (Ministry of Health, National Institute of Public Health (NIJZ))

## What should healthcare professionals learn from patients?



### Purpose:

- get well educated health providers who could understand diversity of patients problems and needs
- get patients who could understand instructions
- acquire a system that could cover costs and provide funding

### Results:

- elective subject clinical nutrition in undergraduate study of medicine
- Department of Clinical Nutrition at the Faculty of Medicine (all set for subspecialization for clinical nutrition)
- the clinical pathway of nutritional treatment in primary health care is set
- clinical pathway of nutrition treatment is tested in two primary care centers.

**Objective:** Better access to clinical dietitians in primary care centres.

## What should healthcare professionals learn from patients?

Patients are different, their diseases and needs are different, even if they have the same disease. For proper treatment we all need knowledge and cooperation.



**Hvala!**

# Patient advocacy on nutrition

Marzena Nelken

“ A STRONG PATIENTS’ VOICE TO  
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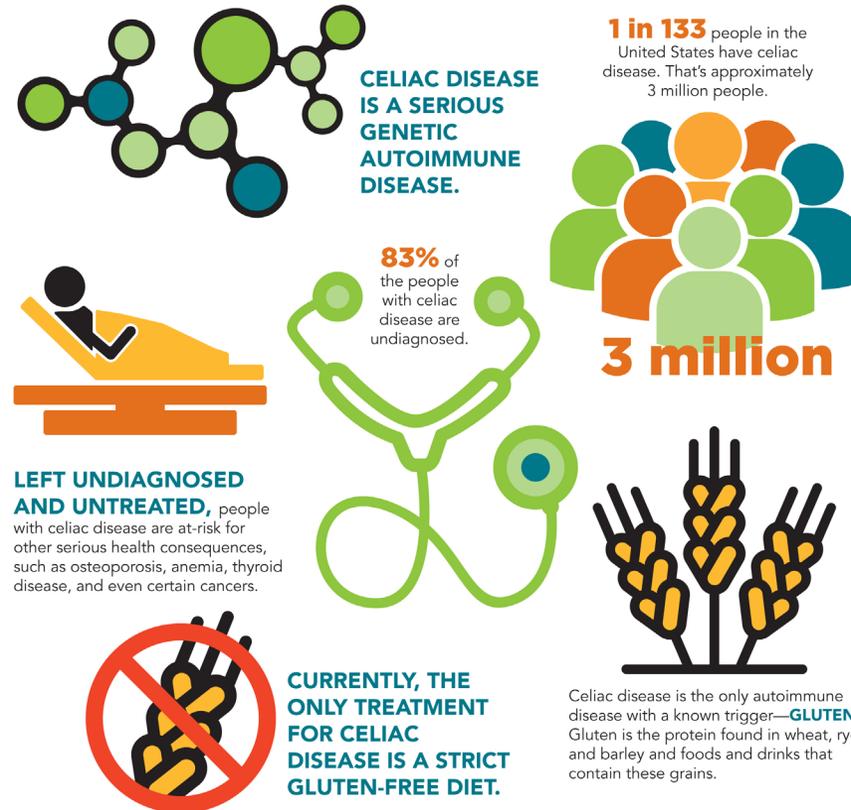
 Federacja  
Pacjentów  
Polskich

**EPF** European  
Patients  
Forum

# Patient advocacy on nutrition

- Nutrition is not only food
- Diagnosis - more inclusive research that mirrors citizens and patients experiences is needed
- „It’s JUST a diet” - Attitude change needed
- Diet as prevention of other chronic diseases
- Health professionals’ support

## CELIAC DISEASE AT A GLANCE



# Healthy food challenge



- Education

„read food labels”

*Ingredients: pork meat (74%), potato starch, salt, soy protein isolate, stabilizers (E 451, E 450, E 452), thickener (E 407), wheat fiber, flavor enhancer (E 621), pork animal protein, glucose, antioxidants (E 316, E 301), acidity regulators (E 326, E 261, E 262), aromas, whey (from milk), yeast extract, preservative (E 250)*

# Patients involvement

- National coeliac societies provide **advice and support** to people with the condition particularly advising them on safe products to eat.
- societies produce a **directory** of safe products to eat and **guidance** on how to read food labels
- particular concern for patients where there is *no choice in food available and little information* about its content: hospitals, care homes, schools, nurseries and workplace canteen
- campaigned for **better labelling** on both packaged foods sold in shops and over the internet, and for foods that are served in catering

# Success and challenges

- In 2012 a new European law became mandatory which sets clear standards for the **labelling of gluten-free packaged foods**
- Further changes in labelling law are needed to provide standards around the use of '**may contain**' labelling which is being used indiscriminately by some manufacturers
- debate about the nutritional value of gluten-free substitute foods with suggestions that they may be higher in fats and sugars and lower in nutrients such as iron and calcium.
- promote the need for **healthier options** and nutritional quality equivalent to the products that are replaced.



Thank you!

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