



# CONTINUITY OF NUTRITION CARE

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## THE POWER OF CONCERTED EFFORTS AGAINST MALNUTRITION





International Conference Amsterdam 15 & 16 June



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# The role of patient advocacy in the European debate

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## Plataforma de Organizaciones de Pacientes (POP) (Spanish Platform for the Patients' Organization)



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## Achieving nutritional care policy justice for patients

Early detection and nutritional assessment

Access and adaptation

Health and food education

Digital transformation

Measuring health outcomes

Patient participation

Information accessibility

Multi-stakeholder approach





## Ensuring safety: Early detection and nutritional assessment

Patients **properly identified** and assessed in terms of their nutritional status.

**Incorporation of specific assessment tools** and criteria for different chronic diseases.

Importance of nutrition in **primary prevention** and improved disease management.

Prevention of multimorbidities. Appropriate nutrition can prevent certain symptoms, delay the onset of complications, and improve health outcomes for certain patients.



## Ensuring safety: Prevention VS cure



## Ensuring safety: Health and food education

We must **identify and segment** people with food risks

It is necessary to address nutrition problems from the **beginning of the diagnosis** of the chronic disease.

**Training and informing professionals and patients** of the importance of nutrition in chronic disease is a priority.

Adequate **feeding guidelines** should be offered to each person's vital moment and disease process.





## Ensuring safety: Co responsibility



## Ensuring safety: Measuring health outcomes with PROMS and PREMS

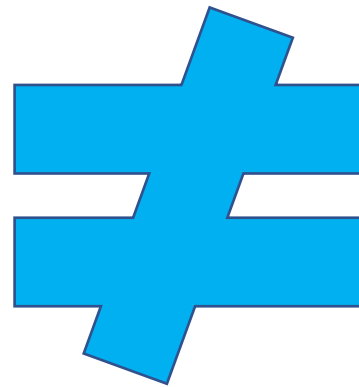


The **clinical effectiveness** of healthcare services is a key component of patient safety. The integration of evidence in the provision of services, through processes of clinical effectiveness, promotes updated, effective and consistent medical care.

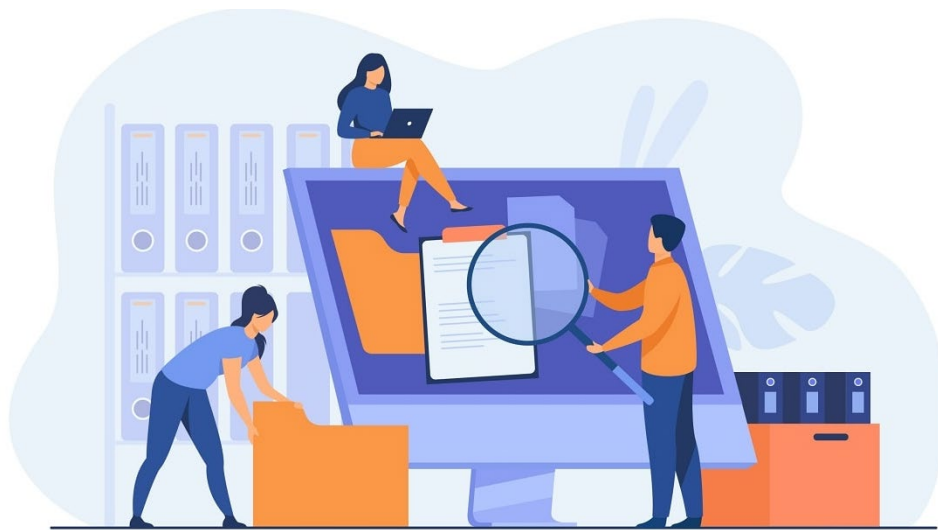
To ensure effectiveness and efficacy, an **evidence-based practice** must be adopted, improving **transparency about data and results**, reducing side effects or complications, as well as incorporating feedback from patients about their **quality of life**.



## Ensuring safety: Measuring VS impact QOL



## Ensuring safety: Information accessibility



We need to be able to fight against the **information gap**, to ensure that all people, regardless of their ability or abilities, can receive this information, also including **caregivers**.

Inequality in access to information about treatment, services or benefits aggravates the situation of **discrimination** of the people affected, at the same time that it can imply a danger to Public Health.



## Ensuring safety: Information accessibility



## Ensuring safety: Access and adaptation

Patient requires **access to specialized nutritional care services**. This involves ensuring that trained nutrition professionals are available and accessible to provide advice and support to patients, both in hospital and primary care settings. Each chronic disease may have specific nutritional needs

Stress the importance of tailoring diets and nutritional therapies to address the individual needs of chronically ill and malnourished patients. This may include **adjustments** in nutrient intake, food textures, and specific therapies, such as oral nutritional supplements or enteral nutrition.





**It's easy not to see  
something you're not  
looking for**

## Ensuring safety: Digital transformation

We need a difference approach towards hoaxes and fake news with quality, didactic and accessible information. A fight against a **digital divide** is crucial to ensure that all people regardless of their ability or abilities can receive that information.

We must prioritize the protection of privacy and confidential information patients and developing adequate organizational systems to improve safety and quality of care





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## Ensuring safety: Digital competences



## Ensuring safety: Active patient participation and empowerment

**Active participation** implies that patients are protagonists, that their voice is heard and they actively participate in the areas that affect them, improving decision-making and the care process.

The experience of patients as a key element: Our experience are a vital measure of **healthcare quality**.

We have to participate in **evaluating and co-designing healthcare services** so they work better for everyone.

We must not lose focus that patients are the final beneficiaries.





## Ensuring safety: Coordination and communication





## Ensuring safety: Crucial involvement of EPF and local patient organizations

Patient organizations play a fundamental role in the dissemination of information of interest to the groups they represent, becoming an essential channel as mediators between patients and health agents, who can:



- Participate in the measurement of **health results**, indicating which values matter to patients.
- Give greater **visibility** to the disease.
- Represent and promote the **rights of patients**.
- Promote **access to therapies**.
- Promote care for **caregivers**.
- Create **community** and support networks.



## Ensuring safety: Patient-centered care



## Ensuring safety: A multi-stakeholder approach

Patients and health professional must have a **correct communication** (active listening) which allows prioritizing biopsychosocial well-being of the person, informing **of all the existing therapeutics alternatives**.

**Communication between different patients** is essential and serve to improve collaboration and the development of effective strategies adapted to the needs of the patients.





## Ensuring safety: A multi-stakeholder approach



## Ensuring safety: EU legislation

### The International Declaration on the Human Right to Nutritional Care. “Vienna Declaration”

The EU's **food safety policy** covers food, from farm to fork. It is designed to guarantee safe, nutritious food, as well as clear information on the origin, content, labelling and use of food

**Overweight and obesity**, by adopting the White Paper ‘A Strategy on Nutrition, Overweight, and Obesity-related health issues’

Patients recalls *article 35 of the EU Charter of Fundamental Rights* and recommends that the EU should support patients’ access to nutrition appropriate to their condition as part of the fundamental right of access to preventive health care and to medical treatment

Patients calls on the EU and Member States *to guarantee equity and justice* in terms of access and reimbursement of nutritional care among the different territories and pathologies



## Ensuring safety: EU legislation

**UK.** Nutrition law. *Brexit Issue*. NICE, directives to face nutrition and malnutrition Chr. Pat.

**France.** Programme National Nutrition Santé 2019-2022

**German.** Federal Institute for Risk Assessment (BfR) specific rules for chronic conditions

**Spain.** Health Ministry (MINSALUD) prevention.

**The Netherlands.** National nutrition guideline (Richtlijnen Goede Voeding). Case of success

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## Summary

**Patient and patient organization should be involvement in developing legislation**

**Accessible and equity legislation**

**Prevention and early detection**

**Unmet needs of patient**

**Collaboration between professional and patient organizations**

**Nutritional screening**

**Capacity building and education**

**Multi disciplinary and holistic approach**



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Thank you for your time

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