

IMPROVING PATIENT CARE ACROSS EUROPE: THE NEED FOR PATIENT-CENTRED GUIDELINES AND PATIENT INVOLVEMENT

Katie Gallagher, Policy Adviser,
European Patients' Forum

12 November 2018

Opening Ceremony

ONCA Conference, Sintra



@eupatientsforum

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



About EPF



European Patients' Forum

- Independent, non-governmental advocacy umbrella organisation set up in 2003
- Represents the collective patients' voice at EU level



Our members

- 70+ EU disease specific organisations & national patient coalitions

Our vision

- “All patients with chronic conditions in Europe have **access to high-quality, patient-centred** health and related care”

Our mission

- “To be the collective influential patient voice in European health and related policies and a driving force to advance **patient empowerment** and **equitable patient access** to care in Europe”



- ✓ **Raise awareness** of the role of nutrition and diet in managing long-term conditions, maintaining optimal health and quality of life;
- ✓ **Coordinate the patient perspective** on the topic of information to patients on nutrition – EU patient task force on nutrition;
- ✓ Underline the understanding and importance of **meaningful patient involvement**;
- ✓ Emphasise the importance of **health literacy** and **informed decision-making** concerning nutrition;
- ✓ Encourage the **patient-professional partnership** and shared decision-making;
- ✓ Highlight the **need for summaries of clinical nutrition guidelines for patients**;
- ✓ Outline **shortcomings** in **existing European policy and legislation** from the patient perspective



Nutrition: From bare necessity to an essential component of disease management

- **Lifecycle approach** to nutrition from pre-conception care to care of older people
- Nutrition: adapted according to the **patient's needs**
- Food and nutrition in the **prevention, treatment and management of chronic and long-term conditions:**
 - Nutrition in primary prevention and improved disease management
 - Nutrition in the management of chronic conditions and better health outcomes and
 - Medical nutrition
- **EU legislation** related to information to patients on food and nutrition



EPF Position on Information to patients on food and nutrition – March 2018

Key recommendations

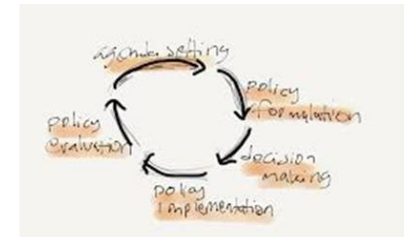
- Meaningful **Patient Involvement** in any area of policy that affects them;
- **Reimbursement and Access** to appropriate and timely nutritional care for all;
- **Research** for the development and improvement of policies and legislation;
- **Regulatory requirements** relating to food production and labelling,
- **Lay-friendly information and awareness** - research, guidelines, and good practices concerning nutrition need to reach patients



Clinical Nutrition Guidelines and Summaries for Patients - Nov 2018

WHAT is the paper about?

- Underlines the importance of **information to patients** on food and diet choices;
- Provides an overview of existing **nutrition guideline development processes**;
- Highlights evidence based **scientific nutrition guidance** available for specific disease areas, while giving examples of existing examples of patient friendly summaries of this information and **nutrition guidance developed by patient organisations for patients**;
- Explains why **patient summaries** of clinical nutrition guidelines are needed and aims to **inspire scientific societies** and guideline developers;
- Provides recommendations for **improving existing guideline development processes**, improving **patient involvement** and the **development of patient summaries**.



Involve patients throughout the design cycle



"You have to learn about thousands of diseases, but I only have to focus on fixing what's wrong with ME! Now which one of us do you think is the expert?"

Nutrition Guideline Development and Lay Person Summaries (Nov 2018)

WHO is the document intended for?

- **Scientific societies and organisations developing clinical nutrition guidelines**
- **Patients' and carer organisations**
- **Healthcare professionals and their organisations**



Existing nutrition guidance for patients by patients

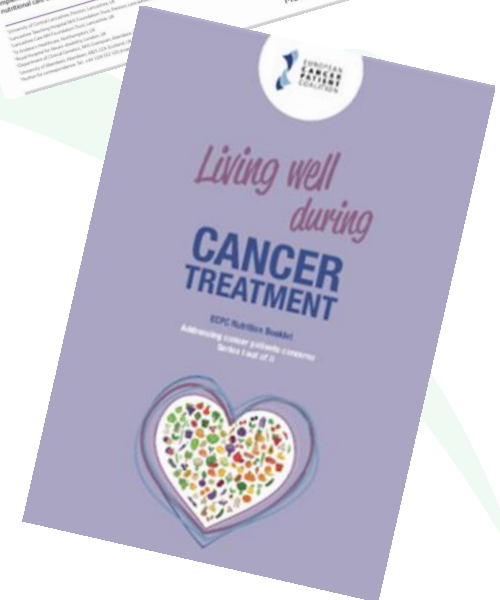


SPECIAL REPORT
For reprint orders please contact: reprint@futuremedicine.com
Nutritional management of individuals with Huntington's disease: nutritional guidelines

- Alba Trovati, Lilian Campos, Arlen Russell, Vanessa Zlot, Shila A Simpson, & Daniela Bui
- Purpose points**
- Good nutritional care is a fundamental element of the management of individuals with Huntington's disease.
 - Nutritional assessment and care planning for individuals with Huntington's disease must take account of the stage of the disease and feeding difficulties individuals may experience.
 - Patient's weight must be monitored regularly and blockages should be altered in a way that is acceptable to the individual, with an agreed target weight is advised.
 - Due to the variability in energy requirements and the potential for rapid weight loss, early individual assessment and regular reviewing of nutritional care plans are vital.
 - Many individuals have very increased energy requirements and it is essential to provide adequate macro and micro nutrients.

SUMMARY The delivery of good nutritional care is a fundamental element of the management of individuals with Huntington's disease and all patients with Huntington's disease will, at some point, need dietary intervention because of the sequelae of the disease. The European Huntington's Disease Nutritional Guidelines have been developed to improve the nutritional management of individuals with Huntington's disease. The guidelines were developed through a series of workshops across Europe to produce nutritional guidelines to improve the nutritional management of individuals with Huntington's disease. The guidelines were developed through a series of workshops across Europe to produce nutritional guidelines to improve the nutritional management of individuals with Huntington's disease. The guidelines were developed through a series of workshops across Europe to produce nutritional guidelines to improve the nutritional management of individuals with Huntington's disease.

Future Medicine

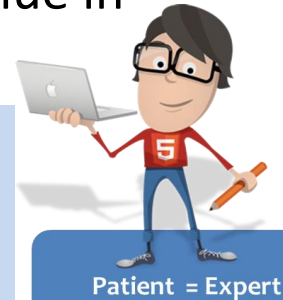


Why do we need patient involvement?

- i. It is a right (“nothing about me, without me”) – an intrinsic value in itself

“The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare.”

Alma Ata Declaration – Principle IV (1978, WHO)



- ii. Unique expertise and experience brings benefits – instrumental and intrinsic value → key to developing healthcare in a way that benefits patients (and society)
- iii. Patient Involvement is a common operating principle of EU health

“All EU health systems ... aim to involve patients in their treatment, to be transparent with them, and to offer them choices where this is possible... to offer individuals information about their health status, and the right to be fully informed about the treatment being offered to them, and to consent to such treatment. All systems should also be publicly accountable and ensure good governance and transparency.”

Council Conclusions on common values and principles in European Union Health Systems, 2006

What does meaningful PI look like?

Meaningful
patient
involvement

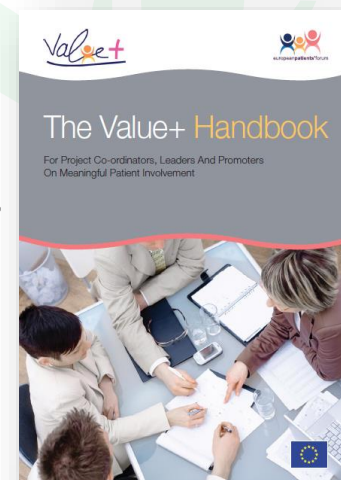


Appropriately resourced



Patient Experience ≠
patient satisfaction surveys

- **Meaningful Patient Involvement** = patients take an active role in activities or decisions *that will have consequences for the patient community, because of their specific knowledge and relevant experience as patients.*
- The involvement must be **planned**, appropriately **resourced**, carried out, and evaluated from the perspectives of participating patients or patient organisations
- The opposite of tokenism
- **Value+ Toolkit and Handbook** offers guidance how to realise this



Added Value of Patient Organisations

Patient organisations: the untapped potential of healthcare systems!

Report on the Added Value of Patient Organisations

Objective: to highlight the value of patient organisations as legitimate stakeholders in health-related policies.

The report identifies 4 main areas where patient organisations provide added value:

**Policy and
Advocacy**

**Capacity-
Building &
Education**

Peer Support

**Research,
Technology and
Innovation**



Challenges:

- Overcoming the culture of tokenism;
- Professionalisation vs. representativeness;
- Lack of resources & funding
- Credibility & alleged lack of independence;
- Lack of performance measurement – or rather lack of knowledge on how to measure the impact of patient organisations?

For improving guideline development processes, developing patient summaries of guidelines for patients and patient involvement

Guideline developers

- To develop **lay summaries of guidelines for patients** in a systematic and transparent way, through co-design, together with patients organisations with formal cooperation agreements and appropriate compensation;
- To **involve patients** and their organisations throughout the development of **evidence based clinical nutrition guidelines**; in the scoping, prioritisation, drafting and patient summary development stages, with appropriate compensation, in accordance with the Value+ project principles;
- To ensure that the outcome of the process (patient summaries and clinical nutrition guidelines) be **easily available**, in plain language and available **in as many languages** as possible



For improving guideline development processes, developing patient summaries of guidelines for patients and patient involvement



Patient Organisations

- To **develop strategies** on how their involvement in the development of clinical guidelines, care standards and patient versions of these materials could be enhanced;
- To **cooperate** with professional societies in the development of nutrition guidance for patients, in the format and content of patient summaries of guidelines for example;
- To **disseminate** this document widely to their networks, raising awareness and to inform their members of existing clinical nutrition guidance, summaries for patients and patient-led initiatives highlighted throughout

EPF Collaboration with ESPEN

- 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 are currently in the process of formalising a collaboration in the context of this project with respect to the **development of patient versions of guidelines** and to **ensure strong patient involvement in the review of new guidelines**
- **EPF** will work 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.

Take Away Messages

- ✓ **Nutrition** is a bare necessity and an **essential component of disease management**
- ✓ **Patient** as an active and equal partner
- ✓ **Early and meaningful patient involvement** in **nutritional care** and throughout the **development of clinical nutrition guidelines** and **lay version summaries** of these in a systematic way, through co-design
- ✓ **Meaningful Patient involvement** has to be appropriately **planned and resourced**
- **Patient involvement in guideline development** will render **more patient-centred health care provision**, **more democratic health care policy-making** and **quality improvement of care and policy**.



More information?

- [EPF Clinical Nutrition Guidelines and Summaries for Patients](#)
- [EPF Position statement on information to patients on food and nutrition](#)
- [EPF Report on the Added Value of Patient Organisations](#)
- [Book 'Patient Perspectives on Nutrition'](#)
- [EU Patient Task Force on Nutrition](#)



THANK YOU



www.eu-patient.eu

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