

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

Nicola Bedlington, Secretary General, European  
Patients' Forum

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 @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



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## EPF funding sources



### Principles of Transparency and Good Governance

Commitment to independence, transparency and diversification of funding – not relying on any one source [Transparency and independence in all aspects of our work: Code of Ethics and Framework for working with funding partners](#)

Full details of EPF's funding available at our website:

<http://www.eu-patient.eu/About-EPF/Transparency/>

EPF is a registered NGO on the European Commission's Transparency Registry

### Percentages of the total EPF budget for 2018

Unrestricted grants from commercial sector - 61.8% - contribution to operations and engagement, capacity building programme

European Commission – 24.4% - direct contribution to EPF's project portfolio (PHP, FP7, H2020, IMI-JU)

Restricted grants from commercial sector - 13.0% - contribution to specific project (EUPATI)

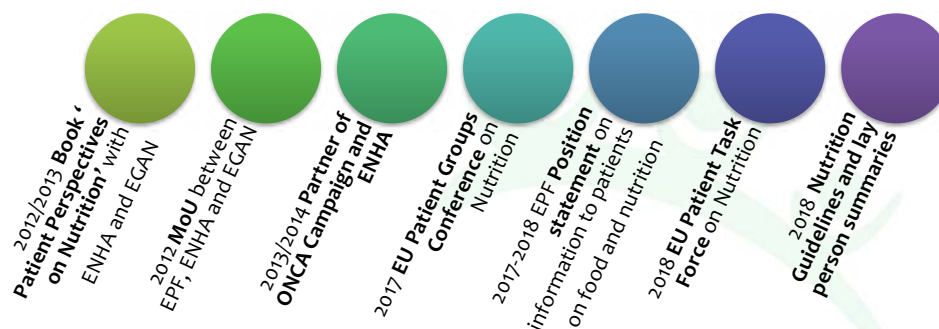
Membership fees – 0.8% - annual fee structure ranging from 100€ - 1,000€ based on an organisation's annual turnover.

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## EPF and Nutrition



### EPF activities to date



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## EPF's Objectives



- ✓ **Coordinate the patient perspective** on the topic of information to patients on nutrition;
- ✓ Underline the importance of **meaningful patient involvement**;
- ✓ **Raise awareness** of the role of nutrition and diet in managing long-term conditions, maintaining optimal health and quality of life;
- ✓ Emphasise the importance of **health literacy** and **informed decision-making** concerning nutrition;
- ✓ Highlight the **need for lay person summaries of clinical nutrition guidelines** and inspire learned societies;
- ✓ The **patient-professional partnership**;
- ✓ Outline **shortcomings** in **existing policy and legislation** from the patient perspective



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## Preliminary Position on Information to patients on food and nutrition (March 2018)



### Highlights

- Nutrition as a bare necessity and an **essential component of disease management**:

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
- **Lifecycle approach** to nutritional care

- **Key recommendations** on the fundamental role of patient organisations in:

**Nutrition-related policy-making; information and awareness; regulatory requirements; research; access to appropriate nutrition and reimbursement**



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## Nutrition Guideline Development and Lay Person Summaries (Nov 2018)



### WHAT is the document about?

- Development of **clinical nutrition guidelines**;
- the importance of **lay-person summaries** of these;
- and the importance of **patient involvement** in the development processes of guidelines and lay person summaries alike

### Recommendations:

- **improving guideline development processes**;
- **developing lay person summaries and**
- **improving patient involvement**



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

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## Nutrition Guideline Development and Lay Person Summaries (Nov 2018)



### WHO is the document intended for?

- **Learned societies and guideline developers**, informing of the importance of patient involvement in these processes with recommendations and inspiration on how lay-person summaries of these guidelines should be developed
- **Patient and carer organisations**, providing information on clinical nutrition guidelines available for specific disease areas, their development processes as well as examples of lay-person summaries of this information.



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## Lay person summaries



### Cancer and Nutrition

- 2017: **European Cancer Patient Coalition (ECPC)** + Sapienza Università di Roma **European Survey** of 907 people with cancer about the importance of nutrition: **90%** of respondents **did not receive any information about weight loss because of cancer (cachexia)** from their health professionals
- Need to **empower** individual patients and patient associations by producing **more information** on cancer patients' nutritional needs
- 2018: **ECPC booklet 'Living well during cancer treatment'** addressing cancer patients concerns, based on the **ESPEN guidelines on nutrition in cancer patients** and the **ESMO handbook of Nutrition and Cancer**



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## Why patient involvement



- 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)

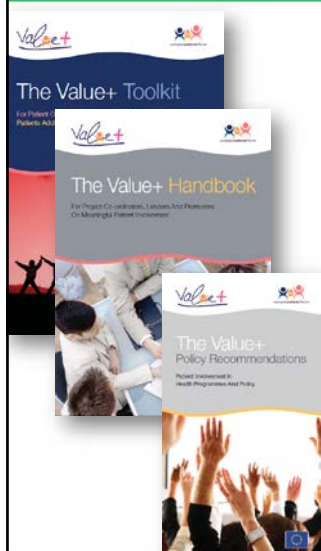
- It brings benefits – instrumental and intrinsic value → key to developing healthcare in a way that benefits patients (and society)
- Patient Involvement is a common operating principle of EU health systems:

“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

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## The Value+ model



- **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:
  - The participating patients or patient organisations
  - Other participating organisations and funding bodies
  - The quality of their experiences during the involvement process
- The opposite of tokenism
- **Value+ Toolkit and Handbook** offer guidance how to realise this

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## Added Value of Patient Organisations

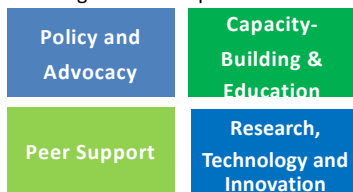


Patient organisations: the untapped potential of healthcare systems!

### 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:



### Challenges:

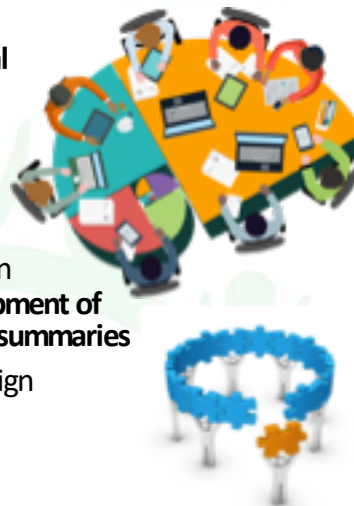
- Overcoming the culture of tokenism;
- Professionalisation vs. representativeness;
- Lack of resources & funding
- Credibility & alleged lack of independence;
- Lack of performance measurement – or rather lack of knowledge on how to measure the impact of patient organisations?

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## Take Away Messages

- ✓ **Nutrition** is a bare necessity and an **essential component of disease management**
- ✓ **Patient** as 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**

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THANK YOU



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## More information?



- [EPF Position statement on information to patients on food and nutrition;](#)
- [2018 EU Patient Task Force on Nutrition](#)
- [EPF Report on the Added Value of Patient Organisations](#)
- [Book 'Patient Perspectives on Nutrition'](#)



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