EPF Position Statement on Information to Patients on Food and Nutrition

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# Introduction

## Nutrition: From Bare Necessity to Essential Component of Disease Management

Links between nutrition and health have been known since ancient times.[[1]](#footnote-1) Evidence shows that nutritional foods are beneficial to good health outcomes, nevertheless, the burden of disease associated with poor nutrition continues to grow in Europe.

The prevalence of overweight and obesity is increasing in nearly all countries.[[2]](#footnote-2). **Unhealthy diets**, **overweight** and **obesity** contribute to a large proportion of noncommunicable diseases. National surveys in most European countries indicate excessive consumption of saturated fat, trans fats, sugar and salt, as well as low consumption of vegetables, fruits and whole grains, and increasing numbers of people with obesity, all of which not only shorten life expectancy, but also harm the quality of life.

Simultaneously, in some countries and among some vulnerable groups, **undernutrition** remains a concern.

Less well-known is the important role that nutrition plays in both **health and chronic disease management**. Indeed, for many people attaining good nutrition is not a simple question of having good eating habits. Some medical conditions mean that even when a person makes good nutritional and lifestyle choices, achieving good nutritional health remains challenging.

Research on the effects of nutrition on human health are still ongoing and very much needed.

## Background and policy context

Nutrition is a priority for many governments and international institutions. Most Member States have government-approved policies that aim to promote healthy diets, tackle the growing rates of obesity, and ensure nutrition and food security. Furthermore, policy developments from across Europe indicate that improvements to nutrition and diet require the engagement of many different government sectors and will need to involve action by both public and private sectors.

The EU is also tackling the area of nutrition from different angles (with activities and policies on obesity[[3]](#footnote-3), nutrition and ageing[[4]](#footnote-4)), with the work of the Directorate General on Health and Food Safety, including various areas connected to nutrition[[5]](#footnote-5) (labelling, food safety, food fraud, etc).

The recent WHO European Food and Nutrition Action Plan 2015–2020[[6]](#footnote-6) encourages action in a range of policy areas through a whole-of-government, health-in-all-policies approach. The goal of which is to improve the availability, affordability and attractiveness of healthy foods, with a view to improving the overall quality of the population’s diet and ultimately health and well-being.

At an international level, the WHO has for many years provided guidance to countries regarding the link between health and nutrition. In 2016, the United Nations General Assembly agreed on a resolution proclaiming the UN Decade of Action on Nutrition from 2016 to 2025.[[7]](#footnote-7) The main aims are to intensify action to end hunger and eradicate malnutrition, and ensure universal access to healthier and more sustainable diets. The resolution calls on governments to set national nutrition targets for 2025 and milestones based on internationally agreed indicators.

## EPF’s previous work

EPF initiated its work in the nutrition sphere in 2012/2013, with our contribution and endorsement of a book on patients and nutrition entitled ‘Patient Perspectives on Nutrition’[[8]](#footnote-8). The book includes an anthology of patients’ needs and experiences in relation to nutrition and its critical role in enhancing treatment and care of patients with serious chronic conditions. This book provided the stimulus for a Memorandum of Understanding between EPF, the European Nutrition and Health Alliance (ENHA), and the European Genetic Alliance Network (EGAN), and commitment to collaborative activities to raise awareness on the nexus between nutrition and an effective, integrated care continuum for patients.

This collaboration formed the basis of numerous initiatives at EU and national level to drive forward nutrition through the lens of patients, and collaboration with a major European campaign – ONCA - Optimal Nutritional Care for All.[[9]](#footnote-9)

A recent milestone was a European Patients’ Conference on Nutrition in June 2017, which aimed to explore the current state-of-play of various patient organisations in the field of nutrition in relation to prevention, treatment and management of disease, and discuss potential future steps in the area of nutrition. The resulting recommendations[[10]](#footnote-10) from this conference make the bridge between more generic awareness activities to more strategic focused work to drive nutrition as intrinsic to patient outcomes.

EPF, in line with its responsibilities as an agent for public health, for our specific constituency, has following this recent conference decided to elevate its strategy in the sphere of nutrition, with a particular accent on medical nutrition.

Building on EPF’s work on health literacy and information to patients, and EPF’s involvement in the European Innovation Partnership on Active and Healthy Ageing Functional decline and frailty action group, EPF will work together with members to consider the outcomes and recommendations of the June 2017 European Patients’ Conference on Nutrition and raise awareness of the role of nutrition and diets in managing long-term conditions and maintaining optimal health and quality of life.

## Consultation process

This position statement was developed with input from EPF’s membership and expert patient representatives. Furthermore, the position statement has undergone consultation with the wider EPF membership, board and secretariat.

# The importance of food and nutrition in the prevention and management of chronic and long-term conditions

From a patient perspective, the following three-fold categorisation is helpful to understand the different needs and expectations of different groups of patients, and to plan policies accordingly.

## Nutrition in primary prevention and improved disease management

The first category relates to the importance of nutrition in **primary prevention** and improved disease management. This category encompasses nutrition as a preventative and health promotion measure, something that is relevant for all people and for public health. In this area, food and consumer legislation is most relevant, together with public health policies and health promotion and public awareness strategies to inform the public, including patients about healthy diets for example. Although this is very often the focus of consumer protection and public health organisations, patient organisations are also active in this area.

* For example, dietary supplementation with folic acid before and during pregnancy has been shown to be beneficial in reducing the incidence of spina bifida in new-borns.

## Nutrition in the managament of chronic conditions and better health outcomes

Making good choices about one’s diet is not just an important way to help prevent the onset of chronic conditions and maintain health.

This second category relates to where nutrition has a key part to play in the **management of a chronic condition and health outcome** as well as the importance of nutrition in secondary prevention and **prevention of multimorbidities**. Appropriate nutrition can prevent certain symptoms, delay the onset of complications, and improve health outcomes for certain patients. Certain foods will be more appropriate for some patients depending on their chronic condition(s).

* For example, people with type 2 diabetes or those with coeliac disease or lactose intolerance are in many cases able to stay well by avoiding certain types of foods. Proper nutritional counselling will enable them to maintain a healthy balanced diet. Appropriate food will ensure that their nutritional needs can be met despite their condition.

## Medical nutrition

For some types and phases of disease it is not possible to maintain a proper nutritional status and/or avoid disease symptoms with standard foods alone. In such cases **specialised nutritional products (medical nutrition)** are needed to supplement the diet, or to replace food. In these cases, patients are partially or entirely dependent on medical nutrition. This might be because of a (temporary) inability to intake food orally or because of the inability to process some parts of food (specific nutrients, or other substance).

Specialised dietary products may be needed temporarily because of an acute health threat. With such products the nutritional gap is closed until a person is able to return to their usual diet. In other cases, specialised products may be needed for the long term, sometimes even permanently, and will become an integral part of disease management throughout life.

Medical nutrition may be enteral (via the stomach) or parenteral (via the vein). Such nutritional formulas, often prepared in hospital pharmacies are given through a special feeding tube or intravenous catheter. Most often this can be done in one’s own surroundings, however it is sometimes given in hospitals, especially in more critical periods.

* For inflammatory bowel diseases such as crohn’s disease and ulcerative colitis, oral nutritional supplements, feeding via a tube or feeding intravenously may be necessary to ensure that nutritional needs can be met.

Such patients are potentially at risk of or may already be malnourished or more specifically undernourished. ‘Malnutrition’ in its broadest sense means poor nutrition and encompasses

both undernutrition and overnutrition. One definition for malnutrition that is commonly used is ‘a state of nutrition in which a deficiency, excess (or imbalance) of energy, protein, and other nutrients causes measurable adverse effects on tissue/body form (body shape, size and

composition) and function, and clinical outcome.[[11]](#footnote-11)

The above categorisation is not absolute and the limits between the identified areas may not always be clear. Many disease areas, such as cancer, may fall under all three categories at the same time because of the variety of affected body functions and the (increasingly often) identified causes of the disease.

**Questions relating to section 2 for EPF members:**

* Do you agree with the above categorisation?
* Is the above content clear?
* Is the above relevant to your organisation? And if so, in which way?
* Is there anything that you wish to add, change, remove or further clarify?

# EU legislation related to information to patients on food and nutrition

There is a large body of EU law that deals with food law or other aspects of nutrition. A part of this legislation concerns food production. Plant health and biosecurity, plant reproductive material, pesticides and GMOs are all (partly) regulated under EU law.[[12]](#footnote-12) Another part of the legal framework is concerned with animals[[13]](#footnote-13) and issues such as: meat production, milk and milk products, as well as animal feed.

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. The European Union's food safety policy aims to protect consumers, while guaranteeing the smooth operation of the single market. The EU has agreed standards to ensure food hygiene, and to control contamination from external substances, such as pesticides. Rigorous checks are carried out at every stage, and imports (e.g. meat) from outside the EU are required to meet the same standards and go through the same checks as food produced within the EU.

The Commission's coherent and comprehensive Community Strategy to address the issues of **overweight and obesity**, by adopting the White Paper ‘A Strategy on Nutrition, Overweight, and Obesity-related health issues’ focuses on action that can be taken at local, regional, national and European levels to reduce the risks associated with poor nutrition and limited physical exercise, while addressing the issue of inequalities across member states. This strategy encompasses a range of Commission policies including **food labelling** and **health and nutrition claims** related policies with the purpose of improving nutrition and preventing overweight and obesity.

The **common agricultural policy** (CAP), ensures the provision of safe, affordable, high quality food, produced sustainably and respecting strict standards (environmental, animal welfare, food safety, etc).

The first two sections below, are not of specific focus on patients, but affect the general population. The last sections are focused on food-law that affects patient in particular.

## The General Food Law Regulation

When it comes to the regulation of food itself, the most comprehensive legislative act is the General Food Law Regulation. This is a horizontal framework, on which all EU and national food legislation is based. The general principles of this Regulation cover all stages of the **food-cycle** (production, processing and distribution). The main aim of the Regulation is to ban the sale of foods dangerous to health or unfit for consumption. Factors such as normal conditions under which food is used by the consumer; **information provided to the consumer**; the effect on health, in the short and long term; cumulative toxic effects; and specific sensitivities of certain consumer groups, for example children, are taken into account.

The Regulation also sets up the **European Food Safety Authority**[[14]](#footnote-14), which provides scientific and technical support to the European Commission and EU countries in all areas impacting on food safety. It is also responsible for coordinating risk assessments, identifying emerging risks and advising on crisis management.

## Biological and Chemical Safety

European food law also deals with specific aspects such as the **biological and chemical safety of food**.

When it comes to biological protection, legislation is concerned with eliminating or minimising risks related to bacteria, viruses, parasites, prions and biotoxins. Some of these hazards have posed serious risks to public health, such as Salmonella, Listeria monocytogenes, biotoxins in live molluscs or BSE. In this context, the legislation deals with aspects like **food and feed hygiene**.

**Chemical safety** concerns chemical substances that are used in food production and distribution. Such chemicals might be food additives, flavourings, contaminants, residues of veterinary medical products, and food contact materials. Most of those substances play an important role but can have negative effects. For example, in order to keep food hygienic and attractive it needs to be kept in containers that are made of chemical substances such as plastics. These clear benefits of the use of chemicals in food production and distribution have, on the other hand, to be balanced with potential risks for the health of the food consumer due to side effects and residues of these chemicals. That is exactly what this part of the legislation deals with.

## food information to consumers

### General labeling

A new **EU Regulation on the provision of food information to consumers[[15]](#footnote-15)** was adopted in December 2014. The new law combines 2 Directives into one legislation: 2000/13/EC - Labelling, presentation and advertising of foodstuffs and 90/496/EEC - Nutrition labelling for foodstuffs.

These new EU food labelling rules aim to ensure that consumers receive clearer, more comprehensive and accurate information on food content, helping them make informed choices about what they eat. The obligation to provide nutrition information under these new rules has applied since 13 December 2016.

The legislation has brought some major changes that affect the food products that are sold around Europe:

* Compulsory nutrition labelling
* Referring to the energy value or energy value and fat, saturates, sugars and salt
* Although not compulsory, other nutrients such as vitamins, fibres, or minerals may also be referred to
* Allergens (e.g. soy, nuts, gluten, lactose) must be clearly presented

Although this labelling is not directed to the needs of patients in particular, it can have a great impact on the life of people with chronic conditions, as explained above.

Patients affected by specific nutrients or allergens can take those into consideration when making their nutritional choices. Clear and harmonised labelling is clearly a considerable advantage for patients.

* What is your organisation’s position with regards to the new food labelling regulation? Has your organisation publicly reacted to this new legislation?

### Regulation on foods for specific groups

Parallel to the general labelling Regulation, another **EU Regulation on foods for specific groups**[[16]](#footnote-16) was adopted in 2013 (and is applicable since 2016). This regulation sets the rules for foods intended for infants and young children, food for special medical purposes, and total diet replacement for weight control. The content and marketing of food products specifically created for and marketed for these groups, is regulated more strictly under this piece of legislation.

#### Dietary Foods for Special Medical Purposes

When it comes to patients whose dietary management is under medical supervision, the legislation is in a transitional phase. For the time being, an **EU Directive on dietary foods for special medical purposes**[[17]](#footnote-17) dating from 1999 is still applicable. The legislation applies to foods intended for patients living with a disease, disorder or medical condition who are unable to meet their nutritional requirements with normal food. The current legislation lays down essential requirements in the composition of the food, as well as the minimum and maximum levels of vitamins and minerals that they may contain.

In 2015, a new delegated EU Regulation[[18]](#footnote-18) supplementing the EU Regulation on foods for specific groups as regards the **specific compositional and information requirements** for food for special medical purposes was adopted, and which will only be applicable as of 22 February 2019. The changes envisaged are not major (with some exceptions), and the existing rules for a big part will be maintained. The main need for this new legislation was to bring the labelling aspects in line with the General Labelling Regulation (see section 4.3.1).

One of the main changes that has introduced, is the prohibition to make nutrition and health claims on foods for special medical purposes, in order to ensure legal clarity and avoid inappropriate promotion of products.

#### Gluten-free Food

A series of legislations[[19]](#footnote-19) harmonise the requirements when it comes to food that may be labelled “gluten-free” or “very-low gluten”. This labelling is compulsory for all foods containing gluten-free ingredients. Since the latest rules are applicable (since 20 July 2016), the requirement does not only apply to pre-packed food, but also to (for example) foods that are served in restaurants.

### Food for people with diabetes

On basis of a repealed Directive on foodstuffs intended for particular nutritional uses[[20]](#footnote-20) no longer in force, the Commission was required to conduct a study on the aptness of special legislation for people with diabetes. The report[[21]](#footnote-21) that was produced by the Commission in 2008, concluded that “people with diabetes should choose a healthy diet and should be able to do so from normal foods. In the light of these reviews there are no grounds for developing specific compositional requirements for foods intended for people with diabetes”.

## Parenteral nutrition

Contrary to enteral nutrition (via the stomach), parenteral nutrition (via the vein) is considered to be a “medicinal product”, and is therefore regulated under one of the three possible procedures for marketisation of medicinal products.[[22]](#footnote-22)

**Questions relating to section 3 for EPF members:**

* Is the above information clear?
* Are there any clarifications to be made?
* Are there other areas, which are not mentioned that should be explored or explained?

# EPF statement and recommendations

The topic of nutrition is very broad and multi-faceted, affecting patients and consumers in diverse ways. Listed below are some recommended key actions and aspects that should be considered in order to take patients’ needs further into account, and to provide improved information on food and nutrition to patients.

## fundamental Role of Patient organisations

The involvement of patient organisations in any area of policy that affects them is key.

In this context of nutrition, the role of patient organisations is vital. As highlighted above, patients are affected by all aspects of nutrition and based on experience have valuable insight to how policies can be improved or better applied. Whether it is about clear labelling and better consumer protection, or food that fits the needs of patients with specific conditions, nutrition affects both the health and quality of life of patients and so patients’ needs, and perspectives need to be considered.

Furthermore, the ways in which nutrition affects certain disease areas is very often still unknown and even when it is, limited attention is often drawn to it. Patient organisations have an equally important role in advocating for further research and involvement of patients in such research.

## Information and awareness

Information and awareness are essential to improving public health and patients’ quality of life. Literacy influences health and disease as does other factors such as genetics and social determinants.

From a health literacy perspective, it is important that research, guidelines, recommendations and good practices concerning nutrition, reach the intended audience; patients and citizens. This might mean that research should be explained and disseminated in a lay-friendly way, but also that communication and dissemination techniques should be improved. Patient organisations, healthcare professionals and governments, all have their specific roles to play in this area. Furthermore, being health literate empowers patients to understand information about their health and make more informed decisions.

On the other hand, it is important that research and good practices reach policy-makers in appropriate ways. Information and awareness are an imperative for policy making. Especially when it comes to disease-specific research, there are vast amounts of information that policy-makers working in the area of food regulation are not aware of for example, but once communicated correctly can improve decisions regarding various policies.

## Regulatory requirements

Regulatory requirements are of clear importance, as explained in more detail above. Food production is a process with many interests and with various interests that need to be taken into account. Nevertheless, food and nutrition’s impact on human health is the most important variable in this equation. Many of the problems faced by patients can be tackled with the right regulatory adjustments. Whether the focus is the production of food, the packaging of it, or the allergens and nutrients it contains, regulatory requirements can assist patients in making the decision that is right for them based on their specific conditions.

## Research

The critical role of nutrition in improving quality of care has been shown. However, as in all areas, continuous research is very important for the development and improvement of policies and legislation. Nutrition is no exemption and in many areas, especially in research relating to the effects of nutrition on specific chronic conditions, research is underdeveloped.

## Access to appropriate nutrition and reimbursement

Even though regulatory requirements might be in place, patients can still face issues regarding access to the appropriate nutrition if reimbursement is not planned correctly. A common example is that of gluten-free products which are most of the time more costly than alternative products. Patients with conditions preventing them from tolerating gluten are not reimbursed for the extra expenses they need to cover.

## Disease-specific needs

Much of the information on nutrition is very much linked to a specific condition. Very often what can be very beneficial for one person can be a major obstacle for the other. Disease-specific needs are a cross-cutting issue affecting all identified categories of major importance; whether it comes to research, awareness, regulatory requirements or reimbursements, the asks of each patient group might differ. At the same time, consolidating this information, while still being able to take into account the needs and sensitivities of each group is of great importance.

Recommendations resulting from the recent European Patients’ Conference on Nutrition provide further, more specific recommendations and proposed actions with regards to strengthened European collaboration on food and nutrition; EU-wide education and dissemination of existing information and materials, food labelling and consumer safety, enhanced innovative scientific research practices that support patients drive for self-care; prevention throughout the life-cycle; the development of a health promoting and healthy food environment and strengthened collaboration between key stakeholders.[[23]](#footnote-23)

**Questions relating to section 4 for EPF members:**

* Do you agree with the above aspects and key actions proposed?
* Are there any positions or recommendations that in your view are missing? If so, what should be added?
* Is there anything that you wish to add, change, remove or further clarify?

# Conclusion

This position statement builds on our previous work on the area of nutrition and will be a stepping-stone towards a closer focus in 2018.

EPF will in future years further explore the role of nutrition and diet in managing chronic conditions, maintaining optimal health and quality of life. EPF will work together with our members to raise awareness of the role of nutrition in managing long-term conditions, through the dissemination of this position statement, the resulting recommendations from the recent European Patients’ Conference on Nutrition on nutrition, referred to above, and future information materials on nutrition.

There is growing recognition of the burden to healthcare systems caused by malnutrition,

both due to poor identification of nutritional risk in patients and because of a lack of inclusion of nutritional care plans when it comes to disease management. In this respect, EPF will continue to explore access to secondary and tertiary prevention, promoting early intervention and diagnosis.

We will also continue to support the work of other health NGOs driving primary prevention and health promotion by providing a patient’s perspective where appropriate.

With this position statement, EPF advocates for a lifecycle approach to nutrition, affirming that nutrition has a significant role to play in the prevention, treatment and management of many chronic and long-term conditions, from pre-conception care to care of older people.

**General Questions for EPF members:**

* Do you agree / disagree with the overall structure of this position statement?
* Is all the content relevant to you? Are their specific points that are more relevant to you/ your organisation? and if so which ones?
* Any other comments or suggestions?
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