

optimal

nutritional care

for all

Final version

**Report and recommendations of the
EU Patient Group Conference on Nutrition**

Brussels, June 29, 2017

organized by



'Thank you for including me in a great event'

'Such an inspiring meeting'

*'Great opportunity to participate in the conference!
It gave me a lot of new information, as well as
direct contact with participants from different countries'*

*'The meeting - I did not know what to expect
and the meeting was really a surprise'*

'I was impressed by the open spirit and atmosphere'

*'It is an important step and great opportunity to
work together as patients on the new agenda for the upcoming years'*

*'I can only repeat myself - that I enjoyed
very much participating in the meeting'*

*"I was moved by the open atmosphere during the World Café, everyone was
willing to share ideas and build upon those of others"*

(Additional feedback as heard from participants after the meeting)

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1. Introduction

1.1 Aim of the conference

In light of the European Nutrition for Health Alliance's (ENHA) Optimal nutritional care for all (ONCA) campaign, the Patients Network for Medical Research and Health (EGAN) together with the European Patients Forum (EPF) and the Platform Patients and Food Netherlands, organized a conference for EU patients' groups to discuss the topic of nutrition.

The main aim of the conference was to explore the level of interest among these groups for the issue of nutrition in relation to prevention, treatment and management of disease, and to gather and test the level of support to work on a renewed patient agenda on nutrition for the period 2018 – 2021. The first patient agenda on nutrition was made in 2012 and published in 2013 in the book 'Patient Perspectives on Nutrition', presented at the Annual Meeting of EPF in Dublin.



The meeting itself was a great success with thirty representatives from EU Patient Groups. The day started with a number of introductory presentations to update everyone's knowledge on the topic of nutrition, including medical nutrition, and the patients' perspective. Also, the institutional background of the work of the European Nutrition for Health Alliance (ENHA) and the 'Optimal Nutritional Care for All' (ONCA) campaign was explained in more detail. After that, a number of EU Patient Groups presented their main concerns, challenges and solutions for nutritional issues within their communities in short pitches. In the afternoon, and guided by the interactive World Café methodology, all participants discussed four central questions in order to yield answers and building blocks for the renewed patient agenda on food and nutrition for the period 2018 – 2021.

The preconference paper of this conference, the list of participants and the presentations are all available in annexes to this conference report. For some further background information on the topic, please see the video 'The challenge of personalized food in a nutshell' at the following link: <https://www.youtube.com/watch?v=Vt3PS5NW96g>.

Overall chairman of the conference was Cees Smit (EGAN, Platform Patients and Food Netherlands). The afternoon interactive brainstorm was facilitated by Gaston Remmers (Platform Patients and Food Netherlands).

1.2 What is ENHA and ONCA?

During this conference, Frank de Man, secretary-general of ENHA explained what is behind these acronyms. The European Nutrition for Health Alliance (ENHA) driven ONCA campaign is a multi-stakeholder initiative to foster that 'Every citizen who is malnourished or at risk of undernutrition is systematically screened and has access to appropriate, equitable, high quality nutritional care.' Key to the ONCA campaign's effectiveness is aligning national stakeholders, such as healthcare professionals, patient groups, industry associations and public authorities behind agreed objectives. Priorities are to establish a national alliance, develop a nutritional care-plan to facilitate malnutrition screening, nutritional care implementation, as well as actively promote public awareness, appropriate reimbursement policies and medical education.

In 2012, ENHA started to talk with European patient organizations EPF and EGAN, to work together on the issue of nutrition. Therefore, a 'Memorandum of Understanding' (MoU) was signed during the 2013 EPF Annual General Meeting in Dublin. As a result of all this work, the Platform Patients and Food Netherlands was started in 2015 as a first national working platform focusing on the needs and wishes of patient groups on food and nutrition. The main aim of this Platform is to get nutrition recognized as a medical prevention and intervention strategy.

Because of this cooperation a first patient conference on nutrition was held in 2012 with a first patient agenda and as a result the book 'Patient Perspectives on Nutrition' was published.

1.3 Evaluation of the first patient agenda on nutrition of 2012

The first agenda of 2012 (see Annexe 1) was set up with the aim of increasing awareness among EU Patient Groups on the importance of nutrition in the prevention, treatment and management of disease. At the same time, European patient umbrella groups such as the European Patients' Forum (EPF) and the Patients Network for Medical Research and Health (EGAN) wanted to work more closely together with the European Nutrition for Health Alliance (ENHA) to establish a mutual cooperation and to be more closely linked to European networks that are relevant for a more active involvement in nutrition related policy work in Europe. After five years, the organizations concluded that indeed awareness has risen over the years and that patient groups became more active and involved in the EU wide 'Optimal Nutritional Care for All' (ONCA) campaigns as well as their respective national steering committees. It also became clear that the 2012 agenda contained important notions, but lacked a strategy and an action-plan to follow up and implement the agenda priorities. Hence, a re-evaluation and analysis of the needs and gaps of individual EU Patient Groups in 2017 would be beneficial. That is also the background to organize the conference on nutrition for EU Patient Groups in Brussels on June 29, 2017.

2. From ‘malnutrition’ in the elderly to ‘nutrition throughout the life-cycle’

Over the past five years, the character of the ONCA campaign has changed from a focus on malnutrition in older age groups, disease related malnutrition (DRM) and mandatory screening to a broader life-course approach that includes every EU citizen.

This change has certainly emerged from the cooperation with EU Patient Groups that reaffirmed that nutrition should play a much bigger role in the prevention, treatment and management of many diseases. For EU Patient Groups, nutrition plays a key role throughout the life-cycle, from pre-conception care to care for older people.

Another issue that played a role in these years was the increasing importance of prevention to avoid the impact and occurrence of several chronic diseases, especially with regard to food – Malnutrition Related Diseases or MRD. It is recognized that the consumption of especially processed foods containing high levels of sugar, salt and bad fats should be strongly reduced, whereas the consumption of fresh and preferably vegetable products should be increased.

2.1 Three categories of patient groups

Three groups of patients attended the conference; those looking at nutrition for prevention and improved disease management purposes, those where nutrition has a key part to play in the management of their condition and health outcome, and those entirely dependent on medical nutrition, day and night.

2.2 Medical nutrition

The last group mentioned above, refers to a group of patients, who can't eat normal meals and are exclusively dependent on liquid nutrients being pumped or infused into their body through a tube. This maybe enteral (via the stomach) or parenteral (via the vein) - this is their lifeline. Most often this can be done in one's own surroundings and sometimes it is given in hospitals, especially in more critical periods. Marco Greco, President of EPF, living with Crohn's disease is a typical representative of this group of patients and shared his experience during the opening of the conference. He clearly pointed out what it means for a patient to be for 24 hours per day, dependent on medical nutrition. He made quite clear that peer support plays an important role in the specific patient groups for medical nutrition supporting each other in sometimes starting the therapy and to continue with it in terms of compliance. This can pay off in terms like increase of body weight, that can be a vital sign for patients who are below ideal body weight. Also, Carolyn Wheatley from Patients on Intravenous and Nasogastric Nutrition (PINNT) UK mentioned the importance of peer support and long-term friendships within these organizations. Marco also showed a slide from Marek Lichota from the Polish medical nutrition group 'Appetite for Life' showing a placemat with normal healthy food and a plate with a plastic bag with medical nutrition (see image). This slide shows the contrast of two different food regimes, often within one family. The example also illustrates that where daily meals are a social and mostly pleasant event, some family members can't fully participate in these meals and sometimes may feel isolated.

This happens not only in family situations, but also in societal events with friends, at work or in sport (if possible) events.



Dear Donator,
Our lives' rhythm is determined by the drops of nutritional formulas that are prepared in hospital pharmacies.

Some of us will never taste strawberries or dumplings because we have to take all the nutritional substances through a special feeding tube or intravenous catheter.

Such way of nutritional values delivery is for the ill people the only chance of survival and simultaneously their greatest limit. Enteral and parenteral nutrition binds us to an I.V. pole even for 18 hours a day.

A special pump is the chance for normal life. It delivers needed substances to an organism, irrespective of the position and whereabouts.

Association „Appetite for Life“ improves quality of life of children and adults on parenteral and enteral nutrition.

STOWARZYSZENIE
„Apetyt na Życie“
www.ApetytNaZycie.org

We invite you to support children as well as adults which use enteral and parenteral nutrition by making a donation of 1% of the tax for 2014 just by filling in the PIT form accordingly and the means will serve the persons under our care.

1%

- Nr KRS: 0000 409 039
- Requested amount: calculated according to the instruction
- **Specific objective: Appetite for Life**
- Please point out 'I agree to the processing of my data'

Both Marco and Carolyn came up with a large number of practical obstacles (lack of understanding and facilities at emergency hospital units, ignorance and mistrust while traveling through customs and reimbursement issues) and particular needs from these specific patient and user groups in relation to new technology and new products. In one of her slides, Carolyn showed the Patients' Charter they developed in the tender processes of buying medical nutrition supplies and equipment in the UK. A model, certainly of value in the negotiation process of other patient and disease groups with governments and or insurance companies. Finally, Carolyn reported on the progress to start with PACIFHAN, the International Alliance of Patient Groups for Chronic Intestinal Failure and Home Artificial Nutrition.

From a medical perspective, Jean-Charles Preiser from the Erasme University Hospital in Brussels explained the role of the physician in medical nutrition. Especially when patients are on the Intensive Care Unit (ICU), knowledge about their nutritional state and needs and wishes could be helpful. Therefore, he made a strong plea to include this information in electronic patient record systems. He also discussed available Evidence-Based Knowledge versus the many unknowns with regard to food and nutrition and the importance of patient

groups' input in the development of scientific guidelines and care-standards within the European Society for Clinical Nutrition and Metabolism (ESPEN).

2.3 Nutrition in primary prevention and improved disease management

For these groups, several concrete examples of preconception care were mentioned, like the addition of folic acid to avoid the birth of children with spina bifida as well as the importance of nutrition in the first '1.000 days' of babies. The so-called '1.000 days', is the influence before birth till the second birthday on the long-term health from people. As well as for babies as for adults, the lack of standards of care and guidelines for parenteral situation on 'patient safety and hygiene (institution kitchens) was mentioned as a topic here.

In a number of presentations, it was mentioned that a more prominent role of nutrition in daily medical practice would improve outcome. And also that more attention for prevention in the long-term would lead to less costs through the long-term decrease of people with life-style-related diseases and a better participation of people with chronic diseases in society.

2.4 Nutrition in the management of chronic conditions and better health outcomes

Disease specific groups

In short pitches, EU Patient Groups explained their specific nutritional needs and demands. Issues like better access to information on food products (labelling, reading product information) was one of the central themes in many of these pitches. Other issues were collection of data from individual experiences of patients with nutrition and to translate these into data that are useful for a more Practice-Based Evidence or Evidence-Based Medicine Approach. Ownership of these data, electronic patient records and privacy of these data were also addressed. A remarkable input came from one of the participants, who spontaneously mentioned – caused by the meeting content itself – that we should not forget the nutritional status of our caregivers. Important contributions were on the specific needs of people with coeliac, liver and kidney disease. A remarkable contribution during these pitches came from Isabelle Manneh from ECPC about Cancer Cachexia and the lack of knowledge on that within the cancer patient community (see text box).

Cachexia in cancer

Urgency and relevance of nutrition for patients, were clearly demonstrated by a presentation from Isabelle Manneh from the European Cancer Patient Coalition (ECPC). ECPC performed a study among 907 people with cancer, of which more than 90% did not receive any information about cachexia from their health professionals. Whereas, almost 70% reported that they lost weight after the cancer diagnosis. More than 70% of the respondents didn't know the meaning of the term 'cachexia'. So, for ECPC there is a need to empower individual patients and patient associations by producing more information on cancer patients' nutritional needs. They will do this also by drafting a 'Cancer Patients' Bill of Rights for appropriate and prompt nutritional support.

3. World Café,

In the afternoon session of this conference, Gaston Remmers from the Dutch Platform Patients and Food, introduced participants to the World Café Method in which four questions were to be answered by all participants in small discussion groups. Groups had 20 minutes to discuss one question before moving onto the next question in a group composed of different participants. In this way, participants, also had the opportunity to know each other better, participating in an active exercise where all could contribute. In a lively, interactive session the following questions were discussed:

- a. What are the main unresolved challenges regarding nutrition and prevention with regard to 'your' disease?
- b. What are the main unresolved challenges regarding nutrition and prevention in general?
- c. In what way could the patients' voice on nutrition and prevention become more influential, for instance with regard to research, policy and clinical practice?
- d. What should we do to have an update of the EU Patient Agenda ready by August 2017? And what is the first step that we need to take now?

After these questions were addressed, all answers were collected, assembled and clustered into one document, which was sent to all participants within one month after the conference for their additional comments and approval.

This synthesis was further condensed by the organizers into 7 sets of recommendations. These 7 recommendations will serve to kick-start the structure of the forthcoming renewed EU Patient Agenda on Nutrition for the period 2018 – 2021.

3.1 Key recommendations

The preliminary 7 sets of **recommendations** as well as proposed actions from the patient groups are:

1. **Strengthen European Patient collaboration on Food and Nutrition**

The European patient's voice on food and nutrition has been too fragmented in the past. This conference shows the need to further professionalise this voice, and hence develop a proper actionable agenda. This would e.g. include the following options:

- Organize an appropriate network for EU Patient Groups to work on Food and Nutrition

- Create National Platforms of patient groups around food/nutrition and with national ONCA Steering Committees and therefore their stakeholder networks
- Capacity building for Patient Groups on food and nutrition
- Involve also consumers as 'pre-patients' in the collaboration
- Capitalize on existing initiatives and efforts and support existing work of other organizations.
- Develop a strategic and actionable agenda, including lobbying and communication

2. EU-wide Education and Dissemination of existing information and materials

There is, on the one hand, abundant material and experiences to be shared among stakeholders, and on the other hand limited access to it, sometimes even ignorance about it – not only among patients but painfully enough frequently also among specialised doctors. The specific actions should be tailor-made according to the diverse audiences:

- For Patients/Citizens and caregivers: collecting/dissemination of disease-specific nutrition practices, like the dementia-guide from Israel, etc.
- For Medical Professionals: Improve Disease-specific nutrition information in curricula of physicians, dieticians, etc.
- For Guideline Developers(e.g. ESPEN, EFAD) Create lay-versions of guidelines and care standards to empower individuals. As an example of a best practice in this respect: PINNT UK together with BAPEN
- For 'healthy' citizens: general information about the gradual development of chronic disease. To this extent, between EU patient and citizen groups working on food and nutrition is valuable
- In general: put patient 'Best Practices' with regard to food/nutrition on new ONCA website (european-nutrition.org)
- General remark: avoid duplicating work existing organizations already do, but use each other potential to network and cooperate!

3. Food Labelling and Consumer Safety

Appropriate and trustworthy information on ingredients when purchasing food is crucial to patients and citizens. This should be done in close connection to already existing initiatives within the EU.

- Involvement of patients/citizens with the food and nutrition regulatory environment (analogy: European Medicines Agency and their patient and consumer involvement policy, see: http://www.ema.europa.eu/ema/index.jsp?curl=pages/partners_and_networks/general/general_content_000708.jsp&mid=WC0b01ac05809e2d8c)
- Clear Labelling, product and safety information and guide how to read labels for specific diseases.
- Accuracy regarding the completeness of all ingredients

4. Enhance Innovative Scientific Research Practices that support Patients drive for Self-Care

Patients have a strong drive for Self Care through food and nutrition and devise numerous strategies to that extent. They also claim that food can't be researched as medical drugs are researched, and that innovative research practices are needed. These include:

- Focus more on the potential gains that can be reached in medical outcome through more attention for food and nutrition as prevention and treatment tools in medical day-to-day treatment
- Prioritise the personalisation of food approaches over the indiscriminating application of generic general public food pyramids
- Devise strategies to upgrade valuable individual experiences with food and nutrition to a) disease-specific or subgroup specific knowledge and to b) Evidence Based Practice/Medicine
- Develop Citizen Science approaches that uncover contextualized and highly fitting food and nutritional approaches (see e.g. www.BeyondRCT.net)
- Develop new approaches to Data-stewardship on health and nutrition that place citizens in the control, guarantee their privacy, and stimulate research (see e.g. www.midata.coop)
- Focus on innovative research areas, e.g. the role of gut microbiota and probiotics, body-mind interactions, the functionality of placebo's, relationships between food patterns, low-grade inflammatory processes and the immune system, the interaction of food and drugs etcetera.

5. Focus on Prevention throughout the life-cycle

Prevention is key, the distinction between a patient and a healthy citizen is not absolute but gradual. To some extent, we are all on our way to become patients or even co-morbid patients; one third of kidney patients first suffered from diabetes. Prevention is much more cost-effective in the long run, and lifestyle and food habits play a great role in this. We insist that we need to move from cure (treatment of symptoms of lifestyle-diseases) to prevention. Likely topics to be addressed:

- Smoke free first generation, with adequate lifestyles (1-20 years)
- Strong focus on adults 'programming', through good food practices, the health of their children in the first 1000 days of their lives, including the importance of own mother-milk for the reduction of certain chronic diseases
- Improve early diagnostic methods, also early in life, regarding the nutritional status and needs, including DNA-testing
- Integration of people with chronic diseases in society
- Personalised life-cycle approach, insisting on the value of eating well throughout all life cycles

6. **Develop a health promoting and healthy food environment**

Our social and physical environments determine a great deal of our daily decisions. These should become more *salutogenic*, in order to make the easy and tasty choice the healthy choice. This includes, a.o.:

- Public insistence on the use of unprocessed and fresh foods over processed foods
- Better quality of (fresh) food products in shops and stores
- Better quality of food in institutional care environments
- Disease-specific food offerings in care-environments
- More creativity in care environments to face limited food budgets in institutional care settings
- Create financial incentives for healthy choices
- Personalised food approaches
- Sensitise care professionals regarding the value of food habits for health
- Develop proper support for caregivers of patients (including adequate food and lifestyle habits); if they fall sick because of their strenuous tasks, we create more patients instead of less
- Showcase global socio-economic gains through health food regimes

7. **Strengthen collaboration between key stakeholders: patients/citizens, agrofood & health care system**

The development of novel food and nutritional approaches depends crucially on the collaboration of key-stakeholders: in the agrofood sector, the health care sector and among patients and citizens. They all have something to gain and to lose, they all face a level of uncertainty. Hence, collaborative processes should be designed that allow for:

- An acceleration of the learning curves in all sectors involved
- The development of appealing projects that showcases a win-win-win: good for the citizens and patients, good for the food sector, and good for health sector

Annexe 1 - The first patient agenda on nutrition from 2012

Recommendations of the first invitational conference for EU patient groups on nutrition, held on July 4, 2012 in Brussels

Nutrition and patient associations

1. Patients and their associations must be seen as key players to drive quality and equity of care.
2. Find a collective agenda and increase the engagement and interaction between patients, industry and other stakeholders.
3. Knowledge on nutrition must be integrated into patient peer support and management.

Nutrition and awareness

Dietitians must be part of a multi-disciplinary health providing team adopting a holistic view on health and it is the responsibility of patients to take the lead in their health.

Nutrition and medical education

1. There is a need to improve medical education so that it includes nutrition.
2. Nutrition education must start at an early age.

Nutrition and health

1. Treatment and management of disease as well as identification of need and nutritional care must be considered individually.
2. Nutritional equivalency in substitute products is vital in ensuring good overall nutrition.
3. It is important to keep a holistic view of disease; nutrition is a part of that view and can have a positive impact on patient health.

Nutrition and requirements

1. Clear labelling of food is fundamental in supporting patients to manage their condition
2. Guaranteed access to safe and nutritional food is a right and essential in preventing malnutrition among patients.

Nutrition and disease specific information

1. It is essential that the importance of dental care in nutrition and its role in ensuring good health, especially in older age is not forgotten.
2. Routine nutritional screening of at risk groups is essential in preventing malnutrition among patients.

3. The area of nutrition in pregnancy must be highlighted as key, influencing health and disease prevention.

Nutrition and research

1. There is a need for further research on the impact of nutrition in retinal disease patients.
2. Vitamin D supplementation should be routine for those over 60. It is a cheap, effective intervention and can prevent deficiency and disease as well as presenting an achievable target.
3. Any further research carried out must be supported by patient groups and driven by their needs.