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Editorial

Towards optimal nutritional care for all: A multi-disciplinary patient centred approach to a complex challenge



S U M M A R Y

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Ten years ago, European health care professional societies, health associations and members of the European Parliament convened in Brussels to discuss the necessary and urgent actions needed to improve access, initiation and follow up nutritional care for European citizens. As a response to this, in 2014 the Optimal Nutritional Care for All (ONCA) campaign was launched under the leadership of the European Nutritional for Health Alliance and its members. As of today this campaign has been rolled out in 18 European countries, whereby national multi-disciplinary platforms including patient groups work together to implement national nutritional care programs and develop good practices in care, research, education in order to increase awareness on malnutrition and improve nutritional care. This article describes the making of and evolution of the ONCA campaign, the outcomes and impact created, as well as opportunities to accelerate implementation of personalized nutritional care for all European citizens.

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Science, translation and implementation

The European Society for Clinical Nutrition and Metabolism (ESPEN) has led scientific research, innovation in nutritional care and initiatives to improve clinical implementation across Europe for over four decades. ESPEN has played a key role in bringing together European scientists in medical nutrition and metabolism to advance research and education in a multi-professional and multi-disciplinary fashion. Nevertheless, despite all the scientific evidence and progress that has been made, it has remained a challenge to ensure that patients across Europe get the nutritional treatment they require. This is at least in part due to the fact that nutritional care in patients as well as nutritional care as a preventive strategy have not been structurally implemented as an integrated part of patient care across Europe. So how to bridge this translational gap from scientific knowledge and expertise towards awareness and practical application by all health care professionals? Bringing together a variety of European stakeholders, all with a vested interest in nutritional care, such as the European Geriatric Medicine Society (EuGMS) and the European Federation of Associations of Dietitians (EFAD), was a logical first step (see Fig. 1).

The investigation: 2005

In 2005, leaders from ESPEN, EuGMS and other stakeholders, among them Professor Claude Pichard, Professor Jean-Pierre Baeyens and Dr. Pascal Daza-Ramirez started a working group and convened in Amsterdam to discuss this existential challenge: the

evidence is there, the solution is there, but how to make colleagues aware of the urgency and implement change?

An European-wide investigation was launched and presented in an internal report to the working group that delivered disturbing news:

- Apart from the professionals' societies, none of the key European associations in health care were aware of the prevalence of malnutrition [1] and nutritional care was not on their agendas;
- Health care professional societies talked about innovation mainly to each other and to individual companies;
- Nutrition and nutritional care related to malnutrition in patients as a result of disease was not included in key EU health care or disease specific programs;
- In summary: while nutrition related to obesity was a key policy area at EU and country levels, disease-related malnutrition, screening and nutritional care were largely unknown among key health care stakeholders.

The working group defined the following key recommendations:

- As health care is a multidisciplinary arena, stakeholders need to work together across disciplines to enhance outputs in health care, including nutritional care;
- Establish a multidisciplinary implementation platform including various disciplines e.g. physicians, dietitians, nurses and policymakers to drive the necessary change in political policies as well as daily health care practice;
- Organize the collaboration at European level to include nutritional care in European Union programs and at national levels,

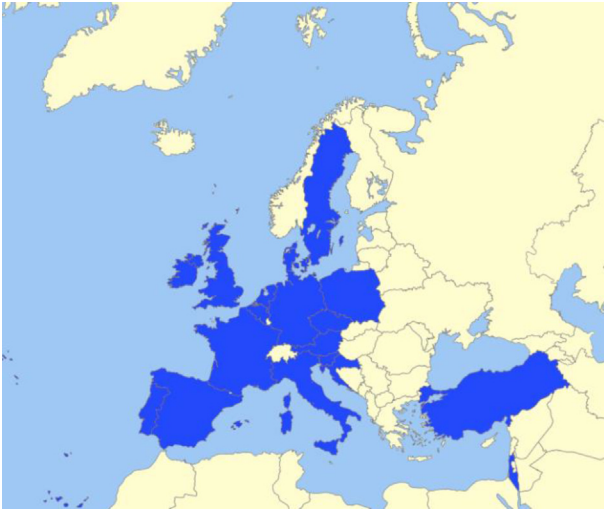


Fig. 1. At the start of 2020, 18 countries participate in the Optimal Nutritional Care for all campaign.

with the overarching aim to improve daily nutritional care practice.

As of the beginning it was clear that the vision and mission of the working group could be successful provided that the issue of malnutrition would be considered not just as a medical issue, relevant for medical professionals only. To attract the attention of policymakers and political decision makers with the aim to change health policy as well as daily health care practice, multi-stakeholder engagement was required as well as an issue defined in terms of interest for society at large. These observations and recommendations resulted in the establishment of the European Nutrition for Health Alliance (ENHA) [2], a multi-stakeholder collaboration whose goal was to include nutritional care in key EU programs and support national platforms to implement (mandatory) screening for all patients at risk of malnutrition and personalized follow up care. The project was initiated under the branding of ‘The fight against malnutrition’.

Building trust: 2006–2010

In the years 2006–2010, ENHA organized a number of conferences under the umbrella of various EU Presidencies among others Belgium [3], Czech Republic and Poland [4] to build trust among key stakeholders and explore commitment for ENHA's objectives.

In the UK, ENHA together with the British Association for Parenteral and Enteral Nutrition (BAPEN) and the International Longevity Center (ILC) published a policy report on malnutrition among older people in collaboration with the Associate Parliamentary Food and Health Forum of the British Parliament [5]. In parallel, ENHA and members worked with Members of the European Parliament to include disease-related malnutrition into a number of key EU health programs until 2010 and beyond:

- The White Paper Nutrition, Overweight and Obesity (2008);
- ‘Together for Health 2008–2013’;
- The European Action Program Against Cancer (2011–) for which ESPEN experts developed the nutritional guidelines;
- European Innovation Platform on Active and Healthy Ageing, EIP AHA (2012–) in which ENHA was the first chair of the Nutrition Working Group.

In summary, these policy changes and directives from the EU served to place undernutrition and disease-related malnutrition on the map at various levels of the political arena.

In December 2010, Members of the European Parliament (MEP), the Belgium EU Presidency and ENHA organized a conference at the Parliament at which European policy makers and experts called for mandatory nutritional risk screening for all European citizens. Around this time the cost of malnutrition was beginning to surface from studies mainly from the UK showing that this was even more costly for society [6,7] than obesity. UK data projected to the European level suggested that 33 million adults in Europe were at risk of malnutrition [8], which amounted to an estimated cost of €170 billion each year to European healthcare systems [9].

Former Slovenian Prime Minister Alojz Peterle, Co-Chair of the Parliament's Environment, Public Health & Food Safety (ENVI) Committee's Working Group on Health, and host of the Nutrition Day Conference, stated: “*Malnutrition is associated with a whole host of current public health concerns and chronic conditions – including obesity, cardiovascular disease, musculoskeletal disorders, some cancers and certain rare diseases all of which place a considerable economic burden on healthcare systems, particularly as our society continues to age. Malnutrition requires a cross-cutting solution; a good first step would be mandatory nutrition risk screening across Europe, on which I will encourage my colleagues to adopt a Parliamentary Resolution.*”

ESPEN/ENHA delegates Professors Cornel Sieber, Alessandro Laviano and André van Gossum warned that: “*EU Member States still lack effective systems to address malnutrition, and the condition remains under-recognised and under-treated in Europe. We are measuring the health and economic impact of malnutrition in Europe, and the statistics are bleak. 20 million people in the EU suffer from malnutrition, 33 million are at risk. In hospitals malnutrition affects up to 40% of all patients and in care homes it is even higher - up to 60%.*

We therefore call on the European Union to recognise the serious impact of malnutrition on patients, professionals and healthcare systems, and to ask Member States to prioritise nutrition in their public health policies.”

Frank de Man, ENHA Executive Director commented that “*Nutrition is a basic need, let's treat it like one.*”

Policy makers and experts unanimously agreed that influencing EU programs and boosting research still remained necessary, however the key priority was that across Europe, patients at risk should undergo (mandatory) screening and have access to personalized nutritional care.

Redesign: 2011–2013

The European Parliament conference conclusions required thorough evaluation and analysis: was ENHA in the upcoming years going to continue influencing health policies in Brussels or change focus and develop an action plan to support mandatory risk screening for malnutrition and further better nutritional care for patients in daily practice? In this regard, ENHA trustees and members acknowledged and took into consideration a number of key concepts:

- To effectively implement a paradigm shift in nutritional care, participation of patient groups both at the European and national levels is a *conditio sine qua non*;
- In European policy terms, health care policy and finance are ‘subsidiary issues’ meaning that national governments are responsible, not the EU;
- Consequently, change and innovation of nutritional care practice cannot be achieved at central EU level but needs to be implemented nationally, country by country.

Therefore, after achieving the support by Brussels policymakers, it was now time for ENHA to take the next step and redesign its strategy and transform its functionality into an 'implementation support engine'. ENHA would encourage and support professional healthcare societies, patient groups and other stakeholders to establish multidisciplinary national platforms, and thus transfer ENHA's model from Brussels to the national level. National platforms should aim at driving national reforms and, with ENHA's support, work with national health authorities.

European Patient Forum

A key step was to get European patient groups strongly involved, contribute and together 'bring nutrition back' into daily health care practice. Through the indispensable support and perseverance by patients' rights leaders Cees Smit and Nicola Bedlington, the European Patient Forum (EPF), the European Genetic Alliances Network (EGAN) and ENHA signed a Memorandum of Understanding in 2012 which sealed their joint commitment to selected key priorities:

- Support the goals of nutritional risk screening and follow-up with patient-tailored care;
- Raise awareness of the importance of nutrition among European patient groups;
- Support participation of patient groups in national implementation activities.

This mutual commitment was supported by a number of events and activities: the 2012 ENHA, EPF and EGAN invitational conference in Brussels [10], the 2013 ENHA, IrSPEN and EPF conference in Dublin [11], and the publication of the book 'Patients Perspectives on Nutrition'[12].

Implementation engine

The challenge was how to define and design 'an implementation engine'? What were the key drivers and conditions that bring patients, health care professionals and other stakeholders together to establish the national collaboration and translate their good will into an effective implementation program? Another unknown factor was whether country delegations were willing to work along the lines of a mutually agreed European approach.

In collaboration with the members, ENHA designed a toolkit including recommendations for the national alliances:

- To build on the national societies already existing within ESPEN, EFAD and other professional society networks;
- To take the multidisciplinary composition of ENHA as an example and include key professional societies and patient groups in the national platform;
- To design a national nutritional care plan;
- To use a template benchmark and dashboard, consisting of 13 indicators to measure progress over time.

With agreement and support of its members, ENHA connected with a number of countries that showed interest to check whether the toolkit was workable for their teams and whether they were willing to work along the proposed indicative lines. As the toolkit was based on commonly understood principles and internationally accepted good practices, the country teams agreed with this approach.

Moreover, country teams and ENHA acknowledged that whilst working according to the templates was a key objective, each

country had its specific cultural, professional and political environment that should allow national variations.

In summary, key conditions required for countries to participate were and remain their commitment to:

- establish a multidisciplinary national platform including patient groups;
- implement a national nutritional care plan and promote good nutritional care practices;
- work together with other countries for mutual learning and create Pan-European impact.

Launch of the Optimal Nutritional Care for All campaign

With the commitment of ENHA members, the buy-in of selected countries for a European wide approach and the toolkit in hand, the next step was to brand the European umbrella such that it would positively drive change and innovation.

In particular, it was acknowledged that it was time to move away from phrases such as 'The fight against malnutrition', towards a more positive phrasing which was felt to be needed to encourage key stakeholders and colleagues to join the initiative. Acknowledging that health care delivery is never perfect, there is always room for improvement and with a positive connotation to encourage all parties to join the campaign, ENHA branded its campaign 'Optimal Nutritional Care for All', ONCA.

In 2014, the 'Optimal Nutritional Care for All campaign was launched at a conference in Brussels [13], organized in collaboration with our Belgian colleagues, one of the eight starting countries and chaired by ENHA co-chairs and trustees Professor Olle Ljungqvist and Professor Anne de Looy. One of the key themes was the need to work in multi-disciplinary teams in which all relevant partners would be represented.

'Over the years of advocating on the issue of malnutrition, we've learnt that working across multi-disciplinary teams is the best way we'll be able to turn the vision of optimal nutritional care for all patients into a reality,' explained Olle Ljungqvist. Anne de Looy said *'This campaign has the potential to not only raise awareness of the need of effective monitoring and diagnosis but also to bring together and target effective teams for patient care.'*

Delegates acknowledged the crucial role that patient groups can play in improving nutritional care delivery and enthusiastically welcomed support by EPF and EGAN.

"Patients can have very specific nutritional needs, particularly when chronic diseases are involved. Empowering patients will enable professionals to better identify and address these needs," said Nicola Bedlington, EPF General Secretary. There was also wide consensus that getting support from policy makers would be an essential step in the campaign.

Government's nutrition dilemma

To engage national authorities such as the Ministry of Health or other policy makers, is a challenge for every national platform. Ministries of Health typically have national nutrition programs primarily focusing on public health: food safety, obesity and prevention.

Medical nutrition or nutritional care are often not part of such programs but are dealt with as part of health care delivery. Budget-wise, nutritional care is a minor part of health care expenditure, hardly visible as a health care budget line item. Combined with the lack of awareness that many health care professionals still have, inclusion of nutritional care into the national health agenda is not a self-evident priority, despite growing evidence of its relevance and effectiveness. However, over the last 6 years the efforts by the national platforms driven by 'Optimal Nutritional Care for

All have shown considerable progress. Many of the national platforms succeeded to connect with and work together with their Ministries of Health and make nutritional care a pillar of the national nutrition and/or health innovation programs.

Consolidation and expansion: building critical mass

Since the start in 2014, ONCA has grown and currently 18 countries participate in the campaign and more new candidate countries are in the process of applying to join. Campaign growth and progress per country are eminent, whilst at the same time feasibility and manageability remain points for attention.

As the campaign has become ENHA's key activity and taking the finite capacity of the Charity into account, there are limitations to further expansion, both in terms of new countries and activities.

Around 65% of ENHA/the campaign's budget is indeed composed of in-kind contributions invested by delegates of patient groups, professional societies and other stakeholders across Europe.

In 2018, Optimal Nutritional Care for All evolved into an interactive, 'always on' campaign to maximize impact [14]. Aligning content of the online platform, the yearly Spring Meeting and Conference and seamlessly connecting all offline and online activities provided a base for further growth.

Content tracks and good practices

The full integration of on- and offline activities was supported by two strategic decisions:

- To segment the campaign into 4 clearly identifiable content tracks that emerged from the country dashboard: Measure, Educate, Implement and Influence;
- To start collecting implementation good practices from the 18 countries and ENHA members, publish them on the campaign's online platform and encourage patients, professionals and students to use them for learning and implementation purposes.

Sharing good practices has now become one of the focus points of the campaign. Health professionals share innovative

implementation, effective communication channels and research outcomes. Patients share their stories and experiences Fig. 2.

Years to come: maximizing impact nationally

Is the Optimal Nutritional Care for All campaign successful? Does it support improving health care outcomes for patients? If we perform a cross-check among the countries that already had or under the umbrella of Optimal Nutritional Care for All started to innovate their national activities over the last 6 years, we can measure considerable progress and outputs, for example:

- implementation of nutrition guidelines and the nutritional care process, including screening (mal)nutrition diagnosis, dietary treatment and monitoring
- patient versions of nutrition guidelines
- sharing good practices of national implementation of screening and follow up care
- nutritional care and/or education programs in many of the ONCA countries
- substantial increase of government involvement
- improved reimbursement for medical nutrition and dietetic care OR
- enable patients to get access to nutritional or dietetic advice by a professional.

For a number of countries, for example Spain, Portugal, Slovenia and France, to co-host one of the yearly ONCA events with ENHA, provided concrete results in terms of support by national politicians and/or government to improve nutritional care for patients.

Monitoring progress

Each participating country is encouraged to measure its national progress along the lines of 13 key performance indicators (Fig. 3). A key contribution to monitoring success and highlighting progress in achieving the campaign's ambitions has been the use of the dashboard.

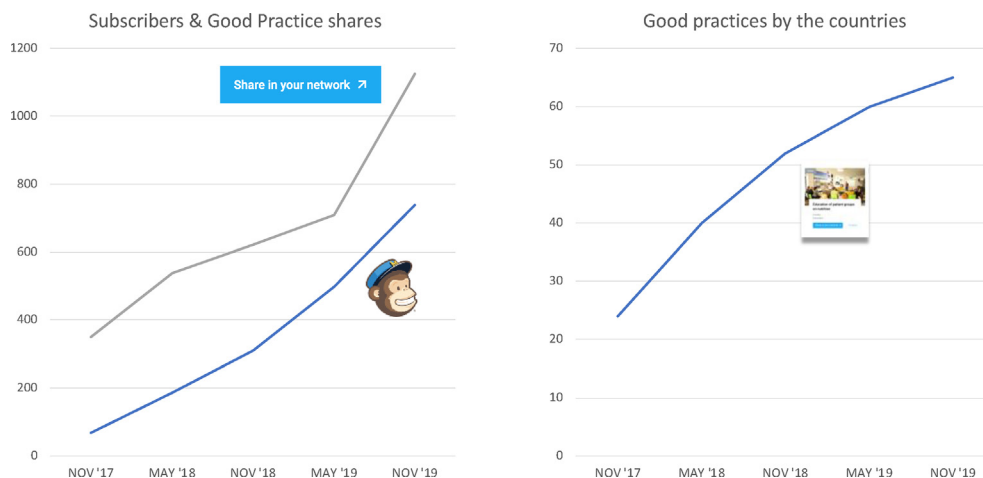


Fig. 2. Two years progress of generating good practices by the countries and sharing good practices online.



Fig. 3. Example of a country (Belgium) dashboard that is updated annually. Green: optimal situation, Orange: improvement underway, Red: improvements/corrections needed.

These outcomes demonstrate the importance of comprehensive national plans including the support of or delegated by the government which is in various stages of development in the 18 ONCA countries.

Future strategy and scope

In the near future, the campaign's strategy will be updated to capitalize on its strengths and take optimal advantage of new opportunities. Country dashboards show room for improvement and also if country programs are successful, continuous evaluation and innovation are prerequisites to remaining successful in the future. Therefore, it is recommended to maintain the current focus on the innovative activities and together with the countries and ENHA members continue to develop the campaign to improve outcomes and increase impact for patients. As a relevant template for collaboration among stakeholders, extra efforts are being undertaken to accelerate patient participation.

For example, patient collaboration with healthcare professionals like physicians, dietitians and nurses as well as clinical scientists is underway to produce patient-oriented versions of treatment guidelines, which will enhance patient empowerment and improve the potential for active guideline implementation and effectiveness of dietary management.

Working at EU level will remain relevant to leverage the results of the campaign and convince EU policymakers to include mandatory screening and nutritional care in European public health and research programs. However, influencing EU health policy and the legislative process with the aim to improve health care daily practice will have limited impact as health care is not a core competence of the EU.

If we don't hang in there together [15]

At the heart of the future campaign strategy will be the full scope of patient care pathway from prevention and mandatory screening to follow up care and all steps in between. Building on the success of the online campaign to drive awareness and share good practices, ONCA will explore whether the implementation toolkit can be extended for example with practical digital decision support applications for patients.

The key will be to continue to strengthen and grow the collaboration among key stakeholders including health care professionals, scientific societies, patient groups, and policymakers. The challenge is to keep the shared vision and keep the focus on creating impact for patients. The ONCA campaign proves that in effective, personalized health care and prevention, all interested parties care together.

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Conflicts of interest

Frank de Man is the ENHA Executive Director, Cornel Sieber is the former co-chair of ENHA, Rocco Barrazonni is the chair of ESPEN, Ceri Green works for Nutricia Specialized Nutrition, a company supplying medical nutrition products and services, the other co-authors are ENHA Trustees.

Statement of authorship

All authors have contributed to the writing and critical review of this manuscript.

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