



Optimal Nutritional Care for All

A European Health Innovation Initiative

Report of the mid-year ONCA meeting
20th May 2016, Warsaw, Poland

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On behalf of the European Nutrition for Health
Alliance

Introduction

Our vision: a world with optimal nutritional care for all

Every patient who is malnourished or at risk of undernutrition is systematically screened and has access to appropriate, equitable, high quality nutritional care.

The 20th May 2016 saw the second mid-year meeting of the Optimal Nutrition for All initiative held in Warsaw, Poland. Another lively and informative event showcased the work of national delegations which was varied and continually inspiring. This workshop meeting allowed delegates to share progress, ideas, challenges and new opportunities. Once again there was an engaged and dynamic group, supportive of each other's ventures and open to new perspectives, solutions and process. The inclusion of Ireland as a new partner in the initiative brings the number of organisations involved in ONCA to 14, a truly European initiative. The main outcomes and discussion of the meeting are presented below and all presentations as well as specific country updates and further information on the meeting can be found at:

http://www.european-nutrition.org/index.php/events/optimal_nutritional_care_for_all_annual_workshop_20_may_2016_warsaw

**Optimal Nutritional Care for All
Implementation Workshop Warsaw, May 20, 2016**

Agenda

Chairs: Anne de Looy & Olle Ljungqvist

- 9.00 - 9.30: Arrival and registration**
- 9.30 - 9.35: Welcome and adoption of agenda**
- 9.35 -10.45: Achievements last half year and measuring progress, key topics**
10.45 – 11.00: Edyta Grabowska – Wozniak: Medical Nutrition in the Polish Health care system
- 11.00 - 11.30: *Coffee break***
- 11.30 - 12.20: Co-funding Action Plan 2016 – 2020**
- 12.20 - 13.00: Communications: How to create more visibility nationally and Europe-wide**
- 13.00 – 14.45: *Lunch***
- 13.45 - 14.30: Status activities European patient organisations: Marek Lichota**
- 14.30 - 15.00: Health economics: status and new initiatives in countries, presentation animated video**
- 15.00 - 15.30: Agenda Nov conference Spain: discussion on key topics and format**

Adjourn

Current Achievements and Challenges– Country Reports

The discussion of current activities focused on the specific aspects of developing nutritional plans which were common to many of the countries.

Three main areas of interest were outlined by countries prior to the meeting: *the challenge of measuring nutritional status in clinical settings, Public/Private Partnerships and Involvement of Patient Organisations.*

Measuring Nutrition and recording data

Several attendees highlighted the challenge of recording nutritional status, collecting data and applying codes in diagnosis, due to the inconsistencies in computer systems between regions and indeed hospitals.

Israel reported on the development of a unified file for nutrition for all computer programmes in hospitals across the country in the last six months. A change in management of the Health Ministry released funds to enable more effective data collection and Israel's involvement in the Nutritionday project means that effective data collection methods already exist in some hospitals and can be replicated elsewhere.

In Germany, meetings with the organisation responsible for ICD10 codes have been a priority in developing the criteria to code malnutrition. Criteria are needed which can be reliably measured using easy to perform bedside techniques. The definitions of malnutrition (published in Clinical Nutrition¹) have begun to address this lack of robust definitions.

It was reported that the Joint Programming Initiative have launched their Malnutrition Knowledge Hub and recently the MaNuEI (malnutrition in older persons) project was awarded. MaNuEI 's first priority is to define malnutrition in older people, which should help address the gap. <http://jointprogramming.nl/news/manuel/>

Public Private Partnership – Ministries of Health and industry

The group discussed the challenge of establishing a stakeholder group with parameters appropriate for a wide range of partners and managing budgets, expectations and differing agendas. The need for transparency was key especially when aiming to work with both industry and government.

¹ Cederholm, T., Bosaeus, I., Barazzoni, R., Bauer, J., Van Gossum, A., Klek, S., Muscaritoli, M., Nyulasi, I., Ockenga, J., Schneider, S.M., de van der Schueren, M.A., Singer, P. (2015) **.Diagnostic criteria for malnutrition - An ESPEN Consensus Statement.** Clinical Nutrition. Jun;34(3):335-40. doi: 10.1016/j.clnu.2015.03.001. Epub 2015 Mar 9

Denmark shared their experience of successful engagement, having developed a forum for malnutrition which now has 19 stakeholder groups. The forum is among others sponsored by industry; stakeholders range from nurses to an older people's union, representing 60% of population. By creating a forum (which is seen as neutral), all partners have equal input and leave their individual agendas to one side. As a result they have had six of their recommendations met by the government to date. This neutral format reflects the aims of the ONCA initiative and the work that ENHA and its members are doing to stimulate the creation of such groups in each member country.

ENHA delegates reported that the Alliance works as a public/private partnership; bridging the gap between science and treatment through the development of messages and innovation through mutual collaboration. Transparency is maintained by having a group of independent trustees who make decisions for ENHA as well as members who follow their own mandate. ENHA offered to circulate their model of governance for countries who are interested to use as a template for developing this type of model of working.

Slovenia reported that by working with health insurers and broadening their funding base they have been able to focus in community health centres including projects on older chronic disease in older people. Implementing MUST has given uniformity and they now very rarely take a step without Ministry of Health backing.

Patient Group Participation

Delegates reported that working with patient groups is now vital to developing nutrition plans in their countries. Nutrition cuts across the disease specific nature of groups as a key consideration for all patients in ensuring continued good health. In summary:

- There are still some challenges in engaging patient groups, often because there is no specific group which links to nutrition.
- In most cases the groups are established based on disease type as opposed to nutrition.
- Increasing public awareness and engaging with disease specific groups where nutrition is a major consideration e.g. cancer or short bowel conditions could be a route to working with patient groups more widely.
- In Turkey contact with cancer groups has led to a project increasing knowledge and understanding. As a result, Turkey have produced leaflets for outpatients and cancer departments. There is also a multicentre project to be launched at the end of 2016, run by the nutrition department in hospitals and involving oncology, neurology and gerontology units.

- ENHA emphasised the importance of persevering in this area and the benefits of patient group participation. The European patient groups EPF and EGAN offered to broker introductions where possible

It was agreed that one of the strategic aims of ONCA should be to offer expertise in nutrition for patients; supporting them to better understand nutrition both as a part of a healthy lifestyle and a mechanism to manage their condition. A report by the patient groups and ENHA on patient perspectives is available for download.

[http://www.european-](http://www.european-nutrition.org/index.php/publications/details/patient_perspectives_on_nutrition)

[nutrition.org/index.php/publications/details/patient_perspectives_on_nutrition](http://www.european-nutrition.org/index.php/publications/details/patient_perspectives_on_nutrition)),

Co-funding discussion and opportunities

The possibilities for co-funding ONCA in the future were discussed among the group. ENHA delegates reported on progress of meetings to develop co-funding opportunities with the EC, European societies and industry groups with an interest in ONCA's activities. The following key points emerged from the discussion:

- There are two routes to consider future funding options; on a European and a national level.
- It was emphasised that there are no plans to grow ENHA as an organisation.
- The focus of all fundraising activities is on the ONCA initiative.
- The European part of ONCA (run through ENHA) seeks to continue to support national delegations and develop new tools for communications and dissemination.
- In addition to other funding options being considered, delegates were asked to consider the feasibility of each national country to offer support of €1500-2000 a year to support the European ONCA initiative.
- The focus of co-funding is about supporting countries to continue with the successful meetings and interactions held to date.

Communications

Turkish delegates reported the outcomes of their first Clinical nutrition congress for students in April 2016 attended by >400 students and organised by the Turkish ONCA group. The conference covered malnutrition, good nutrition and the meaning of health economics. The focus was on different topics and cases (e.g. surgery or oncology), demonstrating that nutrition was a multidisciplinary concern. The conference had positive feedback and a huge number of applications, meaning it may now be run twice a year.

Similarly in Slovenia, students organised their own nutrition conference and approached the Slovenian Clinical Nutrition Society for support and involvement. This conference has now run for three years and resulted in forcing the faculty to include nutrition in the curriculum.

Germany reported working to influence the national educational curriculum for medical students. In the last year they have had the opportunity to provide input on the curriculum and almost all the recommendations put forward were accepted.

Examples of best practice in Communications

Spain

- Press releases of all regional achievements
- Articles and news in lay and professional media.

Croatia

- Communicate in national press, but lack funding for a full communications strategy.
- Numbers are a quick sell to newspapers and get the message out.
- Are collaborating with those media who are covering other activities, not just ONCA, so have a well-established relationship with media which can use to get out messages on malnutrition.

Ireland

- Have a PR company.
- Make sure there is a fact and a figure with any release as this is helpful to get stories into news. 'Numbers drive news'.
- Producing a film of patients sharing their experiences to be used for advocacy and in press.
- Cancer expert report from a round table due for publication.

It was suggested that ENHA/ONCA Europe consider having a Facebook page/twitter account for ONCA.

Patient perspectives – Marek Lichota

Marek presented a Polish and European perspective of the status of patient groups emphasising the importance of nutrition to patient groups.

Marek has not only established Appetite for Life; the association for home enteral and parenteral patients in Poland, but has also been instrumental in founding PACIFHAN in 2014. PACIFHAN is an International Alliance of Patient organisations for Chronic Intestinal Failure and Home Artificial Nutrition (Australia, NZ, Italy, Poland, Czech Republic & USA among members) who work together to promote international work on Home Artificial Nutrition.

Marek also reported on recent EPF/EGAN activities and outlined plans for the next ONCA conference to be held in Spain, November 2016. These include:

- Inviting a delegate from every national ONCA committee.
- A plenary patient group meeting on the first day of the conference.
- A plenary patient group session at the conference.
- A break out session on patient perspectives.
- Involvement of PACIFHAN and contributions from older people/representatives.

Health Economics Update

Delegates from MNI shared an animation on the theme of Disease Related Malnutrition which outlines the cost savings and benefits of using Oral Nutritional Supplements to treat malnutrition. The video is being translated into several languages (including Czech and Turkish) and MNI can put country delegates in touch with the producers to arrange further translation if needed.

The video can be accessed at: <http://www.medicalnutritionindustry.com/>

Countries updates on health economic research

Switzerland

- Research through a government sponsored intervention trial involving 2500 people in internal medicine who will be screened and followed up at 6 months (results are expected in next 12 months).
- Outcomes include medical intervention and cost effectiveness, length of stay, how long can work and how much money was spent on care.

Croatia

- Conducting a study looking at clinical nutrition and associated outcomes, specifically the connection between diagnosis and re-hospitalization with NRS status and nutrition.
- Focus groups with general practitioners (GPs) and nurses to identify barriers and solutions regarding the availability of nutrition support to discharged patients in community.
- The project will be rolled out through 2017 and will also include the Czech Republic, Slovenia and Cyprus.

UK

- BAPEN produced an updated economic report in November 2015².

Ireland

- Have submitted a research paper applying the Elia & Norman et al method of calculating costs for the Irish situation.

Turkey

- Completed a study looking at the meaning of hospital malnutrition in the health care system in economic terms from a Turkish perspective.
- Almost all malnourished patients have double the costs, across all disease settings.

Spain

- Conducting a study looking at prevalence of patients with chronic conditions in hospitals, looked at length of stay, hospitalisation in community, follow up and prevalence of malnutrition (50%).

Planning 3rd ONCA conference, November, Madrid, Spain

Delegates suggested topics for the forthcoming ONCA conference to be held in Madrid in November 2016. The aim is to make the event as interactive as possible; building an agenda based on relevant topics for national delegates. The conference will be co-branded by the Spanish Ministry of Health.

²<http://www.bapen.org.uk/pdfs/economic-report-full.pdf>

Topics requested include:

Content

- A discussion of Spanish experience and regional pilot studies
- Health Economic updates
- A special session on Patient groups
- Press agency presentation/involvement
- Education/training of students e.g. from Slovenia and Turkey
- EC & JPI to be invited
- Nutrition Day involved
- Food based nutrition – EFAD present on food based models from other countries.
- EU MaNuEI - project

Format

- More focus on smaller 'break out' groups and interactions, mix up countries and groups.