



Report of the 3rd Optimal Nutritional Care for All Conference 2016

November 21 & 22, Madrid

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Executive summary

Our vision: a world with optimal nutritional care for all

‘Every citizen needs good nutrition and if malnourished or at risk of undernutrition is systematically screened and has access to appropriate, equitable, high quality nutritional care’.

Launched in 2014, the Optimal Nutritional Care for All (ONCA) campaign is a multi-stakeholder initiative, which aims to ensure optimal nutritional care for all European citizens.

Now in its third year the ONCA conference is organised and run by the European Nutrition for Health Alliance (ENHA) and was held in Madrid on the 21st-22nd November 2016.

The conference was hosted by the Spanish delegation and chaired by Professor Olle Ljungqvist (ENHA Co-Chair, ESPEN representative) and Professor Anne de Looy (President of the European Federation of the Associations of Dietitians, ENHA Trustee). Over 130 delegates representing 15 countries attended the conference including speakers representing the Spanish Ministry of Health, the European Association for Homes and Services for the Ageing, and the European patient groups EPF and EGAN.

An additional pre-meeting led by Cees Smit (EGAN) was held for the patient group representatives attending the ONCA conference; patient groups also addressed delegates during a dedicated patient advocacy session on the first day of the conference, entitled *‘How patients drive public health and better care: best practices and proposals for the future’*.

At past conferences, country delegates were asked to deliver presentations on their progress in advancing the aims of the ONCA campaign, via the ONCA dashboard system. However, at the 3rd ONCA conference, delegates were asked to send their completed dashboards to ENHA prior to arriving in Madrid, so that these could be circulated and reviewed before conference proceeding; these can be downloaded from the ENHA website at: <http://www.european-nutrition.org/index.php>

The 3rd ONCA conference dedicated more time to discussions on the priorities of each ONCA member country for 2017. During each of these discussions and questions and answer sessions, members were also invited to share the approaches and tools they would use to meet their objectives, and to consider how these might be applied in different ONCA member countries.

Members also highlighted perceived challenges that they might have to overcome, and how best these could be addressed by ENHA.

Discussion within and between countries revealed several key themes about their experience at the conference and what they had learned; these in turn informed the next steps for each national multi-stakeholder team:

- A multi-disciplinary and multi-stakeholder national platform is essential for the success of ONCA.
- Every country emphasised the importance of including the patient voice in their activities, and the need to engage with patient groups to maximise the impact and sustainability of ONCA.
- The involvement and commitment of the Ministry of Health/politicians is vital in driving national change.
- Quality indicators for good nutritional care are seen as an important tool to drive sustainability.
- Educating healthcare professionals at every stage of their careers is key.

Plenary sessions also focused on how patients drive public health and better care, best practice across Europe, opportunities for international collaboration, and ONCA applied research projects.

Presentations from the conference are available at:

http://www.european-nutrition.org/index.php/events/optimal_nutritional_care_for_all_annual_conference_21st_22nd_november_2016

Our vision: a world with optimal nutritional care for all

‘Every citizen needs good nutrition and if malnourished or at risk of undernutrition is systematically screened and has access to appropriate, equitable, high quality nutritional care’.

Launched in 2014, the Optimal Nutritional Care for All (ONCA) campaign is a multi-stakeholder initiative which aims to ensure optimal nutritional care for all European citizens through nutritional screening and follow up on a national level.

Now in its third year the ONCA conference is organised and run by the European Nutrition for Health Alliance (ENHA) and was held in Madrid on the 21st/22nd November 2016. It provides an opportunity for countries working on developing nutrition plans to come together to share best practice, ideas, gain inspiration and access contacts and expertise. This involves building and strengthening functional national stakeholder groups, creating momentum, trust and energy through a multi-country approach. As the driving force behind the campaign, ENHA works with its members and partners to engage with countries looking to develop national nutritional care plans and actively supports them to:

- Strengthen national alliances
- Assess national needs and drive development of Key Performance Indicators
- Connect to national governments and European Organisations
- Tailor communication
- Engage and involve National Industry Groups

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[http://www.european-nutrition.org/index.php/events/optimal nutritional care for all annual conference 21st 22nd november 2016](http://www.european-nutrition.org/index.php/events/optimal_nutritional_care_for_all_annual_conference_21st_22nd_november_2016)

Who is involved?

Eight countries comprised of multi-disciplinary and multi-stakeholder groups have been involved in ONCA since its inception in 2014: Croatia, France, Germany, Israel, Slovenia, Spain and Turkey. A further five countries joined in 2015: Belgium, the Czech Republic, Denmark, Netherlands and the UK. Ireland joined in 2016.

Working with Patient Groups

ENHA has a long standing collaboration with the European patient groups EPF (European Patients' Forum) and EGAN (Patients Network for Medical Research and Health), who are able to help countries to develop relationships with their national patient organisations. An additional pre-meeting led by Cees Smit (EGAN) was held for the patient group representatives attending the ONCA conference. The objectives were to introduce the ONCA concept and to discuss the importance of effective engagement with country stakeholders in order to provide the vital patient perspective to the development of national nutritional care strategy and plans.

Conference Programme and reporting

The two day conference included presentations on a range of topics linked to the ONCA campaign. Presentations from the conference are available at:

http://www.european-nutrition.org/index.php/events/optimal_nutritional_care_for_all_annual_conference_21st_22nd_november_2016

Day 1 – Conference session summaries and key points

ONCA Spain and the Regions

To begin the conference, delegates heard from members of the Spanish contingent and their invited guests on their efforts to improve nutritional care, and the impact of the ONCA campaign on regional and national efforts to ensure optimal nutrition for all.

Elena Andradas, Director of Public Health, Quality and Innovation at the Spanish Ministry of Health, Social Services and Equality began the session, welcoming delegates and expressing her desire for the Ministry to Health to work more closely with ONCA Spain to achieve optimal nutritional care for all.

Miguel León Sanz, President of SENPE (the Spanish Society of Parenteral and Enteral Nutrition) began his presentation by highlighting the costs of malnutrition to Spanish society, before outlining SENPE's short and long-term objectives. Short-term, the organisation hopes to raise awareness of the importance of malnutrition prevention among politicians and civil servants.



Long-term objectives include building a national action plan against malnutrition; promoting regional initiatives that consider malnutrition screening, and ensuring equity of access to malnutrition care across regions, without bias due to health status or disease. Miguel described how the ONCA campaign was helping SENPE to achieve its objectives through sharing ideas as to how best to communicate, plan, implement and audit its recommendations and initiatives.



Delegates then heard from Paloma Casado, Deputy Director of Public Health, Quality and Innovation at the Spanish Ministry of Health, Social Services and Equality. Paloma explained that disease-related malnutrition (DRM) was a priority, not just due to its socio-economic costs, but also because of its impact on quality of life, and quality of care.

Paloma introduced the Ministry's strategic DRM goals: to prioritise prevention and early detection; to expand training for healthcare professionals on DRM and its management; to raise awareness of DRM amongst patients and families; and to instil a bio-psycho-social approach to the issue.

To conclude the Spanish delegation's session, Carles Blay, Deputy Director Chair of Palliative Care, Professor of Health Sciences, University of Vic. Central University of Catalonia and Rosa Burgos, Secretary of SENPE, Nutrition Unit, Hospital Vall d'Hebron, Barcelona introduced their study, 'Malnutrition beyond diseases: A cohort study about the impact of clinical complexity and social factors'.

This Catalonia-based cohort study focused on the needs of complex patients, i.e. the 5% of the Catalonian population who use health services in a hugely intensive manner. Carles and Rosa partnered with SENPE, the Catalonian health authority and primary care nurses to design an epidemiological study, aimed to build a community strategy to fight malnutrition amongst this vulnerable cohort.

Complexity is a health and social issue:
additional data about them from a study cohort

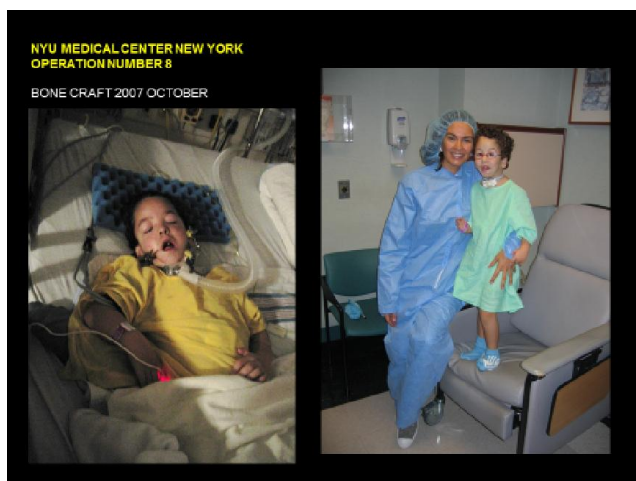


- **Objectives:** To establish an integrated and a collaborative health and social strategy for the screening and management of nutritional care, mainly from a community-based as well as a patient-centered approach.
- **Observational and multicenter randomized study** performed in Osona, representative of the Catalan society (80% Urban, 20 % rural)
- **Sample size: 384 patients. 404 CPCHN recruited.**
- **Age: 79 ± 13 y (60 % women), 95 % multimorbidity.**
- **37% are under home care programmes**
- **Only 54 % living independently, 10 % severely handicapped and 34 % never leave home**
- **40% cognitive impairment (dementia or depression)**
- **61% need a caregiver (50 % parentive, 10 % caregiving another person)**
- **Only 30 % have devices for remote warning/alert**
- **60 % handicapped in basic daily activities (Barthel).**
- **85% problems in instrumental autonomy (Lawton-Brody)**



How patients drive public health and better care: Best practices and proposals for the future

The next plenary session was moderated by Cees Smit (European Genetic Alliance Network) and Laurène Souchet (European Patients Forum), and invited patients and patient advocates to share their visions for how patient and healthcare workers can work in partnership in achieving good nutrition and nutritional care for citizens including patients.



Ozlem Kaymaz, a member of the Turkish delegation shared the challenges faced by her son Daniel, who required specialist medical nutrition via enteral tube feeding. A former beauty model, Ozlem described how for patients with specialist nutritional needs 'there is no road, let alone a red carpet' in Turkey. Ozlem also described her work offering what was initially emotional

support, and is now more practical advice on medical nutrition, and lobbying at governmental level to raise awareness.

Orna Resisi (Israel) delivered an equally powerful presentation entitled 'Food is much more than nutrition', in which was recounted her experiences of having multiple medical and nutritional problems, describing how 'No-one could see me as a whole person... I was constantly hungry. Not just undernourished, but constantly hungry, mentally and physically'.



Orna emphasised how difficult living with a condition requiring parenteral or enteral feeding can be, and that whilst the Israeli health service's feeding pump was suitable for bed bound people, it was not so for those who 'want to keep on living'. She concluded by stressing that 'patients need to be looked at as a whole, as a person', and their needs and aspirations accounted for in their treatment.



Next, Monika Malíčková (Czech delegation), speaking on behalf of Život bez střeva (the Life without Intestine' group) also spoke about the need to include patients in service provision, particularly with regards to ambulatory pumps; Monika's presentation included how until 2014, pumps were not transportable, meaning patients were

confined to their homes for 16 hours a day.

Conference then heard from Marek Lichota, representing Apetyt na Życie (Appetite for Life), a Polish-based patient support group for patients requiring parenteral or enteral feeding at home (Home Artificial Nutrition – HAN). Marek showcased the work of Apetyt na Życie, which includes offering advice on the practical aspects of life living with HAN; the organisation of HAN conferences for medical students; workshops for non-



governmental organisations (NGOs), and charity fundraising events.

Jorge Hinojosa, Director of the General Patients Alliance (AGP), a multidisciplinary organisation comprised of: patients associations, healthcare professionals, the pharmaceutical industry and public administration then introduced AGP's manifesto for DRM. The manifesto begins to consider the steps necessary to implement a communications plan in conjunction with wider stakeholders, to meet the AGP's

DRM objectives:



- Train health professionals, patients and family members on DRM
 - Implement measures that allow an early diagnosis and prevention: screening and nutritional assessment
 - Patient monitoring and Registries for evaluating patient outcomes
 - Develop a plan to evaluate health outcomes
 - Foster the development of a framework document for the approach of the DRM in the Spanish national health service
- Raise awareness among policy makers

Finally, Josefa Kachal from the Department of Nutrition in the Israeli Ministry of Health introduced '*Eating and Living with Dignity: A practical guide for caregivers and family members of persons with dementia*'.

Her presentation demonstrated that multidisciplinary approach had been taken to produce the booklet, encompassing nurses,

occupational therapists and dietitians, and focuses on advice for how to manage nutrition in those with dementia, as well as how changes in nutritional behaviour can indicate the onset of dementia.

The booklet can be downloaded from the following link:

A photograph showing a caregiver in blue scrubs feeding an elderly woman with a spoon. The woman is wearing a colorful patterned scarf and a white bowl is visible.

https://www.health.gov.il/PublicationsFiles/Dementia_Nutrition_en.pdf

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More information about the involvement of patients and patient advocates in the ONCA campaign can be found in the Patient's report (Appendix 1); this

report includes more information about all of the presentations delivered, and the patient meeting which was conducted before the first conference plenary.

Impact of ONCA: New best practices from the countries

This session, designed to allow countries to share best practice in terms of maximising the impact of the ONCA campaign on public attitudes and policy decisions, began with a presentation from Prof. Sadık Kılıçturgay of Turkey, entitled ‘Seeding fertile land: the role of Education and Training of Students for the fight against malnutrition in Turkey’.



Malnutrition: team approach, basis of EN & PN were presented by the MD's, dentists & pharmacists.

Sadık explained how the Turkish Society for Parenteral and Enteral Nutrition (KEPAN) has developed a highly focused strategy to increase the awareness of malnutrition and its management and prevention students in medical, nutrition and dietetics, nursing and pharmacy faculties. The approach sees KEPAN delivering workshops to different medical faculties in Turkey, drawing students' attention to malnutrition and nutritional

support which is available.

These workshops also encourage the health authorities to add more lessons to the pre-graduate medical curriculum about clinical nutrition.

Next, Rian van Schaik, Manager of the Dietetic Department of St Lucas Hospital, Brugge, presented a study of staff attitudes towards the use of enteral nutrition (EN) and parenteral nutrition (PN) in patients, and the associated usage and costs. The study identified a series of barriers to effective EN and TPN usage, including:

- Dietitians not being members of treatment teams
- Dietitians not being experienced in EN/PN

az sint-lucas		Problems and actions taken 3	
Problem	Action taken		
Reluctance nursing staff to provide EN: tube bothers patients	Training nurses in EN (and TPN) support		
Physicians: intention to treat with TPN	EN/TPN according guidelines by dietitians		
Not following TPN guidelines > malnutrition/hypernutrition	Focus: EB based/best practice TPN guidelines ESPEN/ASPEN		
No malnutrition and clinical nutrition treatment by dietitians	Mandate signed by each physician for dietitians to treat patients without referral		

21/11/2016 Cost-effectiveness and improvement of nutritional care by dietitians in nutrition teams 119

- Reluctance of nursing staff to provide EN for fear of bothering patients

Rian outlined the measures taken in each instance to address the problems identified, and emphasised that ‘doctors and dietitians must work together in dietary management teams, including kitchen and medical directors’.



Spanish delegation member Dr Cristina Cuerda, Chair of the Scientific Committee of SENPE, and member of the Nutrition Unit, Hospital General Universitario Gregorio Marañón, Madrid then shared the communications and dissemination plans of the Alianza másnutridos.

Cristina went through the initial planning stages, including creating the brand and logo, and considering the necessary aspects of a successful public affairs and communications plan. Public affairs elements include:

- Creating a network of project ambassadors at national and regional level
- Arranging one-to-one meetings with health social authorities across Spain
- Organising an annual debate forum and inviting politicians, civil servants and healthcare workers

Alianza másnutridos means of communicating their message also include:

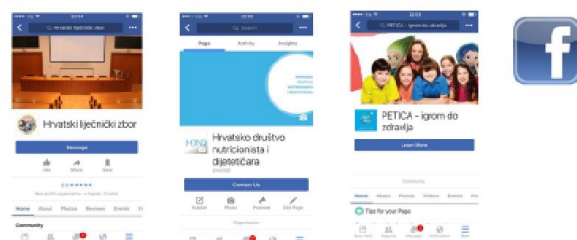
- A website, available in Spanish, and English
- Notebooks containing information tailored for different stakeholder groups
- Quarterly e-newsletters detailing all publications and activities
- Forums, included bi-annual debates, and press conferences

Staying with the theme of health communications, Asst. Prof. Darija Vranešić Bender, Croatian Society of Clinical Nutrition, Croatian Medical Association University Hospital Zagreb showcased Croatia's approach to communications and dissemination.

Darija listed the communications channels utilised:

- Live events (Congresses, Conferences, LLL modules)

Do not underestimate the power of Facebook



- Classes & events at Universities (Zagreb, Rijeka, Split)
- Media – print, TV and online (websites, newsletter)
- Online media: websites, newsletters
- Social media: Facebook pages

And included some guidelines for how to effectively attract journalists to stories around DRM, including:

- Always include numbers, figures and infographics in press releases
- Have a clear message
- Include statistics and predictions

Finally, Dr Ruth McKee (UK), Consultant Colorectal Surgeon at Glasgow Royal Infirmary talked about BAPEN's (British Association of Parenteral and Enteral Nutrition) approach to achieving systems wide improvements in nutritional care in the UK.

Ruth outlined the activities that BAPEN had undertaken to promote an integrated approach to nutritional care across different care settings in partnership with different stakeholders, including:



- Producing and promoting National Health Service commissioning guidance
- Producing video material to raise awareness of parenteral and enteral nutrition amongst healthcare workers
- Hosting regional meetings
- Training thousands of healthcare workers, both face-to-face, and online

Ruth also described BAPEN's plans to continue their regional activities; introduce a malnutrition self-screening tool, and a series of nutritional care tools for use by healthcare workers.

Day 2 – Conference session summaries and key points

Eating Well and Nutritional Care: Best practices across Europe

To begin the second day of the conference and to open the session on best practice across Europe, Arnt Steffensen, Chair of the Norwegian Diet and Nutrition Association discussed how country groups can achieve their objectives through political lobbying.

He outlined the challenges faced in Norwegian residential care settings, e.g. a shortage of clinical dietitians, and more older people needing care. He also described the challenges in residential care food service, e.g. staff time restraints, and kitchen capabilities.

Solution: Political lobbying



When the system is wrong, you must talk to the people who has the power to change the system.

The politicians.



To address these challenges, NDNA, in conjunction with the Norwegian Consumer Council, wrote a report on food care in residential care communities. NDNA then organised meetings with all the main political parties in the Norwegian Parliament; and arranged debates between them, and secured the backing of 20 national health organisations for a political declaration on the issue.



Good practice I
FINGER-FOOD
"Eating is no longer a fight"



Good practice II
Zorg met Sterren
"A Michelin Guide for care"

Next, Aad Koster, Chair of the European Association for Health and Services for ageing (EAHSA) introduced 'Zorg met Sterren', or 'Hospitality Care with Stars', a rating system to measure hospitality in care institutions. He explained that the audit system, similar to a Michelin guide for care homes, worked through:

- Conducting a 360 degree internal evaluation of hospitality on site via online questionnaire
- Conducting an external audit of hospitality policies, accommodation and facilities, customer service, treatment, food and beverages and ambiance
- Arranging face-to-face interviews with care home management, and residents on the basis of questionnaires

- Organising a national award ceremony for top performers

To conclude the session, Ronit Endevelt of the Israeli Ministry of Health's Department of Nutrition delivered a presentation entitled '*Innovative policies to create a better nutrition environment for all*', which detailed a methodological approach to measuring optimal nutrition through collating data on body weight documentation at the community level.

Ronit also compared the Department of Nutrition's findings with comparable international data, to demonstrate the extent of the socio-economic impact of sub-optimal nutrition, and illustrated how to engage members of the public when designing interventions to combat poor nutrition.



Opportunities for International Collaboration

What will be the outcome of the economics component?

Benefits to NutritionDay Participants

- Improved unit/hospital reports
- Improved country reports
- **Wider Benefits (countries, NDay participants, non-participants)**
 - Evidence on cost of malnutrition and nutrition care
 - Improved evidence to facilitate comparison of nutrition care, inputs, outcomes between countries
 - Expanded evidence on what inputs yield to different (potentially desirable) outcomes and which inputs are most worth the money
 - Expanded evidence on what potential process or input changes could be brought about at minimum cost with maximum return on investment

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To begin the plenary session on opportunities for ONCA countries to participate in international projects and research, Karin Schindler from Wien University talked through the features of Nutrition Day, on behalf of the Nutrition Day team.

Karin explained that Nutrition Day is an annual event, designed to:

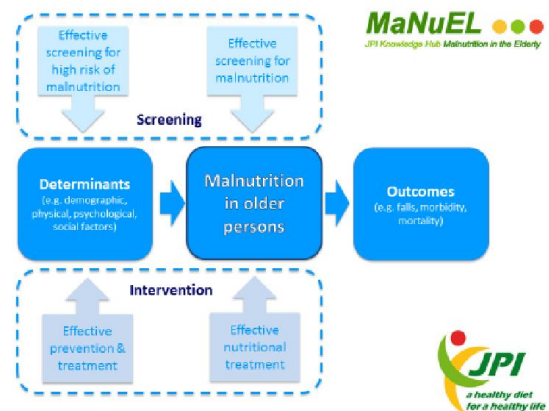
- Increase awareness of nutrition issues
- Improve quality of nutrition care
- Share best practice in costs and uses of resources
- Improve stakeholder commitment
- Promote good nutrition care structures
- Stimulate changes on political levels
- Compare nutrition situations of health care institutions and patients
- Improve the nutrition situations of patients and nursing home residents

It achieves these objectives through issuing questionnaires which participant groups can use to provide details on quality of care indicators and the costs of nutrition care.

From these data, the Nutrition Day team are able to produce stakeholder reports which compare standards with other participants, and develop stakeholder specific benchmarking and feedback reports using the Delphi method.

Karin also introduced the MaNuEL project, a European funded project, designed to support transnational networking activities on the definition of malnutrition amongst older people, and the integration and harmonisation of currently available screening instruments. Its various work packages seek to:

- Define treatable malnutrition
- Identify means of screening malnutrition
- Identify the determinants of malnutrition
- Consider means of prevention and treatment of malnutrition
- Develop policies and education regarding malnutrition screening and treatment in older persons across Europe
- Consider how best to manage malnutrition



The projects series of surveys are currently being used by partner countries in Austria, Belgium, France, Germany, Ireland, The Netherlands and Spain; Karin invited all interested ONCA members to get in touch.

Co-funding and allocation for applied research ONCA projects



The next session witnessed ENHA General Secretary Frank de Man outline the aims of the future co-fundraising strategy between ENHA and ONCA members, including:

- Managed growth of ONCA towards 2020
- Secure sustainability
- Risk sharing by extending the funding base
- Driving innovation by initiating applied research projects

Frank then presented a number of potential co-funding opportunities which could be explored in the period 2017-2020, namely:

- Developing contributions from country delegations, whether cash, or in-kind support

- Seeking additional support from ENHA members
- Exploring additional industry funding
- Partnering in EU projects through ONCA members, and country delegations

Frank concluded by proposing a timetable for the next steps to be taken in 2017, encompassing a survey of all ONCA members, a brainstorming workshop in Italy 30 March- 1 April, and the ONCA workshop and Conferences in May and November, respectively.

Finally, to conclude the conference's plenary presentations, Dr Katja Povhe Jemec officially invited all ONCA members to the 2017 ONCA Conference, to be held in Slovenia on the 13th-14th November 2017.



Conference discussions and debates

Throughout the conference, ONCA delegations were regularly asked to pose their questions to plenary speakers, ENHA Trustees and their fellow ONCA members, and to consider general topics for discussion.



Following the reflection of ONCA members during these country break-out discussion sessions, it emerged that the most pressing issues for discussions were:

- Improving political engagement
- Improving education around nutrition
- Co-funding approaches

Political engagement

This discussion began with ENHA Co-Chair Olle Ljungqvist asking if any ONCA countries had been successful in approaching their governments. The French delegation described how at the 2015 ONCA conference in Berlin, they had laid the groundwork for a revolution.

France then published a manifesto, including a series of interviews with patients, physicians, politicians and many others, about nutrition. They made 10 simple policy

recommendations, and issued a call to action, utilising the petition website change.org. Whilst the petition has only garnered 4000 signatures as of yet, they hope to increase this figure as they meet politicians during the year of France's Presidential election.

Conference Co-Chair Anne de Looy then asked the Israeli delegation, which included several members of the Israeli Ministry of Health, how best France and all other member states could take such actions forward in 2017. Israel stressed that the process of political engagement is very complicated, and ongoing. They all emphasised the necessity of a multidisciplinary approach encompassing a wide range of stakeholders engaging in dialogue. They concluded that as they are in a state of crisis with younger generations, Nutrition Day is an ideal opportunity to gain the endorsement of a Minister to engage medical students in nutrition issues.



Olle Ljungqvist then asked Robert Johnstone, a UK patients' representative, how patient groups can help ONCA members to approach their Ministries of Health. Robert used his experience of sitting on the board of the EPF to explain that politicians and civil servants are much more interested in what the patient has to say than healthcare workers, because patients are the voters.



He claimed that if a patient contacts the politicians representing their constituency, tells a story about their condition and needs in a structured manner, with information provided by medical experts in conjunction with an organisation run by professionals, then the politician becomes interested.

On the direct involvement of Ministries of Health, the Spanish delegation reiterated that members need to be prepared to contact a lot of officials before receiving a reply, perhaps in partnership with a public relations agency. Cees Smit (EGAN) also highlighted that where Ministries may be unresponsive, changing the focus on an approach, e.g. to illustrating the economic benefits of tackling malnutrition, could provide a means of engaging civil servants.

Cees also raised the issue of political engagement around reimbursement challenges, i.e. difficulty in securing reimbursement for rare nutritional needs, and suggested that more European-level policy support would be welcome. Karin Schindler highlighted the UN's Sustainability Goals as an opportunity for ONCA members to lobby their governments and engage with their Health Ministries, as 'all ONCA countries are signatories of the WHO's Food and Nutrition Action Plan, so hold them to that!'.

Education



Anne de Looy began a discussion on education by approaching ONCA delegations and asking what their activities, and future plans in this area were. Portugal stated that they needed to improve education as 'most people don't care about nutrition', with the result that patients with complex conditions in intensive care can't be removed from ventilators as they are malnourished. Their future approach will be to approach universities and make the case that nutrition should be included in medical curricula.

Slovenia also emphasised the need to improve nutrition education, stating that whilst they are trying to have nutrition included in medical curricula, it is difficult as there is no specialism in clinical nutrition, at any level. Thus, Slovenia will work towards establishing a certification for medical nutrition, covering evaluation and nutritional concepts, to provide certified, qualified nutritional knowledge in Slovenia.

Anne de Looy and Olle Ljungqvist then focused on Belgium, which has had successes in raising public awareness of issues around nutrition, including the social/psychological aspects of malnutrition. They stated that their efforts began after the 2015 ONCA conference when they decided to reactivate the Belgian branch of ONCA. Asked how they manage to work across their country's different regions, they noted the importance of compromise 'Working across 11 million inhabitants, 3 communities, 3 official languages.... we work closely together, and that is the Belgian solution'.



Spain also commented on the integration of the medical and social aspects of nutrition in education efforts, noting that adopting a patient centred approach was crucial, and the need to capture more best practice from around Europe to increase public engagement with the issue of nutrition.

Co-Funding

Following Frank de Man's presentation on the various co-funding opportunities ENHA and ONCA members could pursue between 2017-2020, ONCA members asked a series of questions to clarify the role of national organisations and ENHA.

On the role of the medical nutrition industry within ENHA, Frank explained how ENHA is a UK registered charity, operating under British law. Whilst industry organisations are ENHA members and contributors, all strategic decisions are made by the Board of Trustees, a board composed of independent individuals not representing external interests. Finally, Frank emphasised that there is never a mandate that a majority of Trustees can force a decision: instead, such decisions require a consensus.



The Israeli delegation highlighted each ONCA member's government and Ministry of Health may have funds which could be utilised to further the objectives of the ONCA campaign. Olle Ljungqvist asked how many ONCA members had formed registered nutritional charities, and found that the Czech delegation are the only to do so thus far.

Other delegates asked for further information about how any additional funds would be spent. Frank de Man clarified that funds would be used for additional activities which further the objectives of the ONCA campaign, such as conducting applied research, and enhancing outreach and communications. Finally, Niamh Rice, representing Ireland, underscored that by enhancing ONCA's capacity to create forums to share best practice, and generate new data and international comparisons, ONCA members would be well equipped to approach policymakers and demonstrate the value of promoting proper nutrition policies.

Country priorities, approaches and challenges

During one of the country breakout discussions held during the conference, ONCA members were asked to list their priorities for 2017; the approaches and tools they utilise to achieve those objectives, and any potential challenges which they may face when trying to achieve these objectives.

Common priorities were to increase the number and range of stakeholders member groups interact with, to improve public awareness of the issues surrounding malnutrition, and to actively engage politicians and policymakers. The approaches listed provide a variety of ideas for how best to achieve these objectives, and potential challenges range from ensuring healthcare workers have access to the necessary training and resources to implement nutritional policies, to how to navigate restricted national and regional fiscal climates.

Country	Priorities	Approach	Challenges
Belgium	<ul style="list-style-type: none"> • Increase public awareness of the Belgian alliance • Improve nutrition policies and standards • Work on reimbursement policies • Work on policy implementation • Improve education 	<ul style="list-style-type: none"> • Create a logo for the alliance • Create quality indicators • Establish a hospital accreditation system • Engage with care communities, and hospitals • Engage physicians, dietitians, nurses and pharmacists throughout their careers 	
Croatia	<ul style="list-style-type: none"> • Increase awareness of malnutrition issues amongst: authorities; institutions; medical associations; community GPs; patient organisations, and the general public • Work to improve reimbursement and protection • Develop new nutritional 	<ul style="list-style-type: none"> • Collaborate with a PR agency • Develop engagement strategies for each stakeholder group • Present research findings • Define projects with realistic timescales and KPIs 	<ul style="list-style-type: none"> • Develop a communications platform, with a visual identity, i.e. a logo

	<p>standards and meal plans for institutions</p> <ul style="list-style-type: none"> • Implement nutritional screening at primary care level • Develop home care approaches 		
Czech Republic	<ul style="list-style-type: none"> • Identification of different nutrition related heterogeneities amongst different regions, and different healthcare providers 	<ul style="list-style-type: none"> • Establish an APNP (charitable trust), the 'Alliance for Nutritional Care' 	
Denmark	<ul style="list-style-type: none"> • Ensuring sustainability of the country group • Creating a communications and dissemination strategy 	<ul style="list-style-type: none"> • Establishing both short and long-term goals and funding structures • Strengthening their strategy of creating 'Forums for Malnutrition' 	<ul style="list-style-type: none"> • Establishing comprehensive success criteria
France	<ul style="list-style-type: none"> • Engage patients' associations • Engage politicians • Increase public awareness of nutrition issues 	<ul style="list-style-type: none"> • Further promote the French nutrition manifesto • Issue press releases, making recommendations on nutritional support teams, dietitians and the price of food in hospitals • Issue a call for action • Create a website 	<ul style="list-style-type: none"> • Determine how best to approach patients' associations, and communicate the importance of nutrition to them • Determine how best to engage politicians
Israel	<ul style="list-style-type: none"> • Educate medical students in nutrition • Improve communications efforts • Create self-screening tools 	<ul style="list-style-type: none"> • Add cases involving nutrition in the exams of medical students • To include the Deans of Israeli medical schools in planning • Create videos on nutrition issues to upload to YouTube 	<ul style="list-style-type: none"> • Determine the essential features, e.g. questions, of a self-screening tool • Establish quality indicators, e.g. questionnaires
Netherlands	<ul style="list-style-type: none"> • Enlarging the stakeholder partnership group • Develop a 	<ul style="list-style-type: none"> • Approach patient representatives • Learn from best practice of other 	<ul style="list-style-type: none"> • Knowing how ONCA can facilitate collaboration between national groups and EU-wide organisations and

	communications strategy	ONCA members	institutions
Portugal	<ul style="list-style-type: none"> Join efforts at EU level Increase awareness of malnutrition risk Improve legal framework for access to clinical nutrition for outpatients Secure reimbursement for clinical nutrition: ensure access for outpatients 	<ul style="list-style-type: none"> Gather local data via nutritional screening, e.g. risk, prevalence and HE 	<ul style="list-style-type: none"> Ensuring the necessary protocols are in place and training/skills available to perform such screenings, and gather such data
Slovenia	<ul style="list-style-type: none"> Educate all stakeholders on nutrition issues Work towards the implementation of clinical pathways for nutritional disorders Build alliances 	<ul style="list-style-type: none"> Establish a nutrition certification, with follow-up educational materials for continuous professional development, e.g. online courses Continue work on the 'Nutritional and health enhancing physical activity' programme, 2015-2025 strategy Approach Ministry of Health for partnership/collaboration 	<ul style="list-style-type: none"> Standardising terminology, nutritional concepts, standards of treatment and documentation nationally
Spain	<ul style="list-style-type: none"> Patient-centred strategy Approval and implementation of the framework document on DRM Educate healthcare workers Media awareness and engagement Refocusing on paediatrics Dietitians in the national health service Sharing best practices 	<ul style="list-style-type: none"> Spanish network of health schools for citizens Connect Alianza másnutridos with regional policymakers Pre and post-graduate professional organisations Create a professional communications plan Alignment of all stakeholders in paediatrics Development of professional regulations 	<ul style="list-style-type: none"> Empowerment of the patient Decentralised national health service and social support infrastructure Financial support, and topic competition Competing topics Broad scope of the project Financial support Financial support Keeping these updated

	<ul style="list-style-type: none"> • Sharing best practices 	<ul style="list-style-type: none"> • Engaging national/European platforms • Utilising national/European platforms 	
Turkey	<ul style="list-style-type: none"> • Increase the awareness of issues around malnutrition for health authorities and healthcare workers • Implement mandatory nutritional screening tools across care settings 	<ul style="list-style-type: none"> • Continue to offer student training programmes in universities • Engage stakeholders, particularly those involved with long-term care facilities 	<ul style="list-style-type: none"> • Lack of nutrition teams in some hospitals and universities
UK	<ul style="list-style-type: none"> • Establish commissioning guidance for Clinical Commissioning Groups (CCGs) • Raise awareness of burden of DRM to CCGs • Increase awareness of DRM and self-screening amongst public 	<ul style="list-style-type: none"> • Empower healthcare workers through DRM education • Lobby Government to train more dietitians, via patients' association • Seek services of a PR agency 	<ul style="list-style-type: none"> • Clinical Commissioning Groups budget restrictions

Acknowledgements

The European Nutrition for Health Alliance would like to thank all speakers and delegates for their continuing work and congratulate all countries on their progress in making the ONCA initiative a success. ENHA would also like to express its gratitude to its members (including ESPEN, EFAD, EUGMS, MNI, HOPE and PGEU) and patient group partners (EGAN & EPF) for their support. We are grateful to MNI for sponsoring the ONCA programme and conference.

Appendix 1: Patients' groups report

*'I got strength from knowing I am not alone
and I hope that being part of a group of
complex patients will empower each and
every one of us'*

(Orna Resisi)

Report from the patient representatives sessions at the ONCA Conference on 'Optimal Nutritional Care for All' in Madrid, November 20-22, 2016

Compared to the two earlier ONCA conferences in Brussels (2014) and Berlin (2015), this Madrid conference certainly brought in a new and more personal element in the ONCA community, namely the strong patients' and parents' voices reflected in a number of very touching personal experiences on how it is to deal as a person or a parent with long and difficult periods of dependency on medical nutrition.

In addition, there were presentations on scaling up individual patient experiences to lobbying by specific nutritional patient groups and a short reflection on the complexity of care models for patients with comorbidity issues. This all came together in a one-hour plenary session at the beginning of this 130 participants counting conference. On the second day, the concept of 'citizen science' was discussed as a tool to get more information from these individual 'experience based' stories instead of waiting for the results of carefully designed 'evidence based' studies which rarely can be realized in 'real life' settings.

In total, 12 patient representatives came to Madrid to participate in the ONCA-conference as members of National Steering Committees (NSC's) or as member of the joint EPF/EGAN/ENHA Working Party on Nutrition.

Preconference session

For them, a special preconference session was designed just as in Berlin 2015. Cees Smit (EGAN) welcomed everyone and that was the start of an informal' get to know each other, followed by an overview of patient participation and cooperation of European Patient Groups: EPF (European Patients' Forum, eu-patient.eu) and EGAN, (European Patients Network for Medical Research and Health, egan.eu) within the European Nutrition for Health Alliance (ENHA).



Illustration 1: The preconference session for patients (photo: Meike Engfer)

Ceri Green introduced the central theme and the issues at stake for the conference with involvement from all stakeholder groups within ONCA. Gaston Remmers, one of the co-founders of the Dutch Platform Patients and Food (patientENvoeding.nl) discussed more in-depth the use of individual and citizen-collected data in research and the accompanying ICT and patient-driven governance structures needed to facilitate that. Finally, Laurene Souchet from EPF ended with a reflection on the importance of patient involvement and empowerment. From this very first session on, it became evident that for many representatives it is important to know that many people deal with severe nutritional complications and needs. Many more than they ever expected before they came to this conference.

Plenary Patients' Session

This 'I am not alone' experience was reinforced at the first ever, patient-led plenary session of these three ONCA-conferences so far with the personal testimony by Ozlem Kaymaz, the mother of nine-year old Daniel from Turkey. Daniel was born with a very rare disease: Nager syndrome and from his birth it was impossible for him to drink and eat by himself. Not only a large number of operations was necessary in his early years, but also several complicated tube-feeding mechanisms and types of medical nutrition were needed to guide him through these difficult years. At present, the Kaymaz family, including Daniel's older sister and his younger brother (without genetic Nager syndrome), is now rather happy and adapted to the situation, which at the beginning of Daniel's life seemed to become so troublesome, (for more information, see www.daniels-life.com).



Illustration 2: Ozlem Kaymaz during her presentation (Photo: Meike Engfer)

The same type of positive thinking was delivered by Orna Resisi from Israel, married and mother of three children. Orna suffers from diabetes type 1 which has effected the digestive system and caused inability to eat. Orna has been on TPN (Total Parenteral Nutrition) feeding for 5 years and on tube enteral nutrition since 2014. The topics, she addressed were medical, emotional, social, and economic issues associated with not being able to eat. Orna came on the stage together with her backpack, filled with 2,5 kg. of enteral nutrition, a load she has to carry with her 24/7. For more information, see Orna's presentation on [youtube.com/watch?v=w1qkT8F-br4](https://www.youtube.com/watch?v=w1qkT8F-br4).

After these two very personal presentations, the central group issues of persons living on Home Artificial Nutrition (HAN) were addressed by Monika Malickova from the Czech Republic and Marek Lichota from Poland. Both are leading specific-disease groups for patients with strong medical nutritional needs. Monika explained that her organisation 'Život bez střeva' (Life without Intestine, zivotbezstreva.cz) supports patients on HAN and tries to improve their quality of life. One of the topics is also to raise public awareness during the world Home Artificial Nutrition (HAN) weeks, which will take place next year on October, 15, 2017 World HAN Day. Marek's organisation in Poland 'Stowarzyszenie Apetyt na Życie' (Appetite for Life, apetytnazycie.org) is doing similar activities since its start in 2012 and with strong inspiration from similar organisations elsewhere like the Oley Foundation in the USA (oley.org) and PINNT in the United Kingdom (pinnt.com). Both organisations avoid to give medical advice, but focus on practical aspects of life with HAN and how to adapt to the therapy.

In this part, Jorge Hinojosa of the Spanish General Patients Alliance (GPA, Alianza General de Pacientes, alianzadepacientes.org) described the Alliance's special manifest on disease related malnutrition (DRM) and the way they cooperate with the Spanish National Steering Committee, the host also of the Madrid Conference in 2016. The main issues of the manifest are:

- Train health professionals, patients and family members on DRM
- Implement measures that allow an early diagnosis and prevention: screening and nutritional assessment
- Patient monitoring and registries for evaluating patient outcomes
- Develop a plan to evaluate health outcomes
- Foster the development of a framework document for the approach of DRM in the Spanish NHS
- Raise awareness among policy makers

Josefa Kachal from the Ministry of Health of Israel closed this session with a short presentation of a practical guide for caregivers and family members of people with dementia 'Eating and Living with Dignity'. The purpose of this booklet is to provide families with tools and methods at all stages of the disease. In the early stages 'what are the signs that can indicate problems with buying and storing food, preparing the meal, organizing the eating environment, eating the food', etc. And in advanced stages of dementia, practical advice on what to eat when a person has functional problems. This booklet can be downloaded from:

www.health.gov.il/PublicationsFiles/Dementia_Nutrition_en.pdf

The plenary session from the patient groups in Madrid was jointly chaired by Laurène Souchet from EPF and Cees Smit from EGAN. Cees closed the session with a couple of more general remarks with regard to the treatment of complex patients, namely that it is important for professionals to understand that most patients come to you with a long personal and medical history, that they are most often experts in self-management and coping with their disease but at the same time there is also a 'fear factor' that somewhere in the medical process something goes wrong through a combination of lack of coordination, polypharmacy or a temporary/permanent inability to manage the disease by themselves or their caregivers.

On the second day of the conference, Gaston Remmers (Platform Patients and Food Netherlands) addressed the plenary with the need for a learning-based attitude in a number of domains. Gaston kicked off his presentation proposing a broadening of the debate on nutrition and disease from Disease Related Malnutrition (DRM) to Malnutrition Related Disease (MRD), and from a focus on disease remediation to health promotion through nutrition and food. He illustrated the shift by a short video on the challenge of personalized food (see www.youtube.com/watch?v=Vt3PS5NW96g).

This challenge can be addressed by a much broader cooperation among stakeholders in biomedical research, patients/citizens and food producers, aiming to deliver a repertoire of personalised food systems.

A second theme Gaston addressed was the urgency to go beyond RCT's and look more carefully to the potential of 'citizen science' as a tool to get more and more

information available from all individual 'experience based' stories instead of waiting for the results of carefully designed 'evidence based' studies which rarely can be realized in 'real life' settings (see www.BeyondRCT.net). The data gathered from these individual experiences could and should also be collected in a bottom-up designed and citizen-controlled governance model, that allows from new types of Big Data research. He advanced the Health Data Cooperative model as developed in Switzerland as a very promising governance model (www.midata.org)

Gaston's third topic was his proposal for 'European Learning Journeys', that ENHA/ONCA could organize for interested ENHA-members: two to three day-visits to a specific country or region, getting in-depth and first-hand understanding of 4 to 5 cases, practices, enterprises or policies addressing specific aspects of nutrition and health. All this, to facilitate and accelerate learning throughout Europe on the value of food and nutrition for health, through the organization of hands-on field trips to best practices.

Closing patients' session

At the end of the second day of the conference another closed session for patients representatives ended the patients part of the ONCA conference. It was here that Dusan Baraga (Slovenia) and Ivica Belina (Croatia) mentioned that they would be glad to take up the challenge to give attention to the patient and citizen input in the follow-up ONCA meetings in 2017 (Prague, May 19, 2017 and Slovenia, November 13/14, 2017) as both were impressed by the input the patients' experience already had for them in the meetings in Berlin, but certainly here in Madrid.

Karl Haberstig (Germany) mentioned more in general the resistance from stakeholder groups in Germany to involve patients in policy issues and research. Something he experienced in particular because of his own personal change from being a specialist in general medicine and psychotherapist treating 'psychosomatic' patients, to a patient not being able to find adequate treatment. He suggests to be aware of the wider context of 'body, mind and spirit' or 'nutrition' for our biology, our psychology (e.g. empathic Patient-therapist- relationship, the 'Fear factor') and our ontology (including dignity, intuition, higher awareness etc.). From his double perspective, he can easily see through doctors' insensitiveness and incapacity, which is not always appreciated.

Robert Johnstone responded that in his view this is certainly a specific topic related to Germany, well-known from other experiences as well, like with the public perception of EUPATI, the European Patient Academy. This EUPATI is a public-private partnership project from the Innovative Medicine Initiative (IMI) initiated by the European Commission but nevertheless perceived most often in Germany as ethically wrong and influencing patients by industry. For the patient participation in nutritional issues this is certainly a topic of attention and in 2017 from EPF an initiative can be expected to address these relationship and governance issues with various groups of stakeholders, like pharma, medical devices, diagnostics, etc.

Karl also mentioned the need for a broader attention for integrative medicine.

Other suggestions at the end were to look more into health insurance challenges around nutrition, a possible revision of the 2013 book 'Patient perspectives on nutrition' and of course at the next conference, more time for personal exchange of experiences.

It became already clear from the contacts during the conference that there is a need for a large pool of experienced patients' speakers on the use of medical nutrition and new fresh food approaches to health, that could represent this group at other conferences, like the one on Mediterranean Food in Ostuni (Italy) in March-April 2017 and in The Hague at the ESPEN Congress in September 2017.

It was also mentioned as a possibility to meet in between this and the next ONCA conference with a larger group of patient representatives in Brussels. Most probably this meeting will be held at the end of June 2017.

All presentations from the patient representatives during this conference are downloadable from european-nutrition.org through a dropbox download programme.

List of patient representatives present during the ONCA Conference Madrid 2016



Illustration 3: Patients' group picture (photo: Meike Engfer)

(From left to right: Monika Malickova, Marek Lichota, Laurène Souchet, Karl Haberstig, Ozlem Kaymaz, Cees Smit, Gaston Remmers, Robert Johnstone, Dusan Baraga, Orna Resisi and Ivica Belina (Jorge Hinojosa is missing))

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Cees Smit (The Netherlands, EGAN)	info@smitvisch.nl
Laurene Souchet (Belgium, EPF)	laurene.souchet@eu-patient.eu

Appendix 2: Conference agenda

Monday, 21st November

10:30 – 11:00: Coffee Reception

11:00 – 11:20: Opening & Welcome, Agenda Why ONCA

Conference co-chairs: Anne de Looy & Olle Ljungqvist

Welcome by the Spanish delegation: *Miguel Leon Sanz, Cristina Cuerda Compes*

‘ONCA Spain, call for MoH ONCA support in Europe, WHO-EURO’: *Elena Andradas, Director of Public Health, Quality and Innovation: Spanish Ministry of Health, Social Services and Equality*

11:20 – 12:00: ONCA Spain and the Regions

‘+Nutridos Alliance: What has ONCA brought Spain so far?’

Miguel León Sanz, President of Spanish PEN society (SENPE), Nutrition Unit, Hospital 12 de Octubre, Madrid

‘Spanish strategy on DRM within the Chronic Patient Plan’

Paloma Casado, Dep Director of Public Health, Quality and Innovation: Spanish Ministry of Health, Social Services and Equality

‘Malnutrition beyond diseases: a cohort study about the impact of clinical complexity and social factors’

Carles Blay, Dep. Director Chair of Palliative Care, Professor of Health Sciences, University of Vic. Central University of Catalonia and Rosa Burgos, Secretary of SENPE, Nutrition Unit, Hospital, Vall d’Hebron, Barcelona

Plenary Questions & Debate

12:00 – 13:15: How patients drive public health and better care: best practices and proposals for the future

Moderators: Cees Smit (EGAN) & Laurene Souchet (EPF)

Introduction

12:05 – 12:20: ‘Experiences from a mother with a son on tube feeding’

Ozlem Kaymaz, Turkey

12:20 – 12:35: ‘Experiences from a patient with medical nutrition’

Orna Resisi, Israel

12:35 – 12:45: ‘Appetite for Life’

Monika Malickova, Czech Republic and Marek Lichota, Poland

12:45 – 12:50: ‘Spanish Patients Manifesto’

Jorge Hinojosa, Spain

12:50 – 13:00: ‘Living well nutritionally with dementia’

Josefa Kachal

13:00 – 13:15: Discussion ‘Future of patient involvement in ONCA campaign

13:15 – 14:15: Lunch dining

14:15 – 15:30: Impact of ONCA: new best practices from the countries

‘Seeding fertile land: the role of Education and Training of Students for the fight against malnutrition in Turkey’

Prof. Sadık Kılıçturgay

‘Cost-effectiveness and nutrition teams’

Rian van Schaik, AZ St Lucas hospital Brugge

Plenary Questions & Debate

Health communications in Spain’ & Croatia

Cristina Cuerda, Chair of the Scientific Committee of SENPE, Nutrition Unit, Hospital General Universitario Gregorio Marañón, Madrid.

Darija Vranešić Bender, University Hospital Zagreb

‘Regional Meetings Improve Nutritional Care’

Dr Ruth Mckee, Consultant Colorectal Surgeon, Glasgow Royal Infirmary

15:30 – 16:00: Break

16:00 – 16:45: Break out brainstorm country delegations: key issues for 2017

Country priorities, approach, challenges

What tools and support are needed for 2017

16:45 – 17:15: Plenary Questions & Debate

17:15: Group Photo

19:15: Meet in hotel foyer to walk (5 minutes) to Conference Dinner

Tuesday, 22nd November

08:30 – 09:30: Eating Well and Nutritional Care: best practices across Europe

‘Healthy food and clinical nutrition in care homes’

Arnt Steffensen, chair Norwegian Dietetic and Nutrition Association

‘Eating Well and Nutrition Management’

Aad Koster, chair European Association Health and Services for the Ageing

‘Innovative policies to create a better nutrition environment for all’

Prof. Ronit Endevelt, Ministry of Health Israel

Plenary questions & debate

09:30 – 10:30: Opportunities international collaboration

Nutrition Day: Status and participating ONCA countries

Karin Schindler, Wien University

‘MaNuEl project’ - JPI Healthy Diet for a Healthy Living

Karin Schindler, Wien University

Learning for food and nutrition: Beyond RCT’s’, data governance and

learning journeys’

Gaston Remmers, the Netherlands

Plenary questions & debate

10:30 – 11:00: Break

11:00 – 11:30: Co-funding and allocation for applied research ONCA projects

Dr. Frank de Man, ENHA

Prof. Cornel Sieber, Co-Chair ENHA, Professor for Internal Medicine and Geriatric Medicine at the Friedrich Alexander-Universität Erlangen-Nürnberg, Director Institute for Biomedicine of Aging, Nürnberg

Plenary questions & debate

11:30 – 12:45: Brainstorm sessions countries & plenary debate

Key priorities 2017

Co-funding ONCA 2017 and feasibility country contributions to ONCA

Plenary Questions & Debate

12:45 – 13:15: Policy Innovation and ONCA Events 2017

'The National Nutrition and Physical Activity Strategy 2015 – 2025 & welcome conference 2017 in Slovenia'

Dr. Katja Povhe Jemec, Ministry of Health Slovenia

Workshop 2017: Czech Republic

Candidates 2018

13:15 – 14:00: Lunch & Departure