

**MNI activity report
April- 18 June 2019**

20 June 2019

Topic	Objective	Update on recent developments and next steps
New temporary project: ENFit	<ul style="list-style-type: none"> Support ISO ENFit 20695 standard 	<p>DIS ISO 20695 – negative development: draft final standard provides for two orientations</p> <p>Following Paris 17 April meeting and 11 June teleconference, the CEN committee chair did not take MNI comments into account.</p> <p>The draft final international standard (DFIS) allows both orientation: female to male (recommended by MNI) and male to female. This de facto allows device manufacturers to market ENFit in the reverse orientation (male to female) without having to perform misconnection risk assessment or usability testing for this approach.</p> <p>The WG nevertheless supports the publication of the standard: the final draft standard is sub-optimal, but it is better than no standard.</p> <p><u>Next steps:</u></p> <ul style="list-style-type: none"> The text should be finalised by end of June and will go for translation until end August. Final vote for publication of the standard expected to start in September. Next opportunity to review the standard within a 3-year timeframe, with possibility to accelerate the process if major concerns arise from the market.
ONCA	<ul style="list-style-type: none"> Promote screening and nutritional care 	ONCA Spring meeting – Paris – 18 May

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	<p>strategies at the national level under the banner “Optimal Nutritional Care for All” (ONCA)</p>	<p>The ONCA ‘Spring meeting’ successfully took place in Paris on 18 May, co-hosted by ‘Collectif de lutte contre la Dénutrition’, French Federation for Nutrition (FFN) and the French PEN society (SFNCM). https://european-nutrition.org/good-practices/paris-spring-meeting/</p> <p><u>First take away:</u> Very good meeting: strong agenda, interesting discussions, good participation (almost 80 participants: carers, patients, local politicians and MoH representative). More communication than in the past: French speakers/delegates twitted via their organisation account. The hosts objective was to leverage the ONCA platform to boost ongoing efforts on nutritional care in France (e.g. Collectif Contre la Dénutrition) and to maintain the dialogue with health authorities.</p> <p><u>Second take away:</u> The French NIG (SFNS) was not involved in the decision to host the meeting in Paris, and in shaping the programme. It was mostly solicited for logistical and financial support.</p> <p>ONCA Conference confirmed in Cambridge – 19-20 November</p> <p>At ENHA’s proposal BAPEN & BSNA agreed to host the conference in the UK. However BAPEN could not allocate budget for the conference, leaving the total costs to ENHA and the BSNA.</p>

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		<p>MNI helped to find a cheap(er) venue -but nevertheless prestigious – with the support NNedPro (2017MNI Grant winner): Cambridge University.</p> <p>Conference objectives:</p> <ul style="list-style-type: none"> • BAPEN: leverage ONCA to resume advocacy/educational activities towards decision makers. • BSNA: re-establish close partnership with BAPEN and call for the establishment of a government coordinator on malnutrition, with responsibility to advance the nutritional care agenda in the UK. • Both BAPEN and BSNA perceive Brexit context as an opportunity to position good nutritional care as cost-effective therapy that cannot be ignored anymore. <p>Lessons learnt from Paris meeting and UK conference</p> <ul style="list-style-type: none"> • It appears both NIGs had surprises with the organisation of ONCA in their country. • MNI will ask FdM to establish a procedure to clarify country selection rules and funding repartition between PEN / NIGs. • MNI should identify priority geographies for ONCA, to guide ENHA in the choice of future ONCA countries. This will help to ensure NIGs are ready for ONCA and are able to fund and leverage. <p><u>Next steps:</u></p> <ul style="list-style-type: none"> • September: ONCA workshop to define EU outreach strategy • 19-20 Nov: ONCA conference in Cambridge – UK • Q2 2020: ONCA Spring meeting in Brussels – European Parliament • Q4 2020: ONCA conference in Copenhagen - Denmark

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Cooperation with patient groups and other stakeholders	<ul style="list-style-type: none"> Leverage patients voice on nutrition 	<p>EPF - action plan on nutrition – no progress so far in 2019</p> <ul style="list-style-type: none"> The development of the lay version of ESPEN guideline(s) is taking more time than expected, for a number of reasons ESPEN is currently developing the short version of the guidelines, which will be the basis for developing the lay version in cooperation with the EPF. The EPF will then have to decide which guideline(s) it wishes to focus on. (MNI recommended to start with the HEN or HPN guideline.) There has been important staff changes in the EPF secretariat (maternity leave, new Executive Director). Based on this, we don't expect substantial progress before the end of 2019 (tbc). <p>ECPC- cooperation with European Cancer Patient Coalition</p> <ul style="list-style-type: none"> MNI continues the discussion on potential cooperation with the ECPC for 2020. Interesting options are considered but it is still too early to share proposals at this stage. Czech ECPC member is involved in Czech Alliance for Nutritional Care (GROW project). AVKV (Czech NIG) is supporting the dissemination of the ECPC booklet 'Living well with cancer' Czech version. ECPC 8 June Congress featured a section on cancer and malnutrition: European and national cancer patients organisations acknowledged that malnutrition is an

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		<p>underrecognized problem, the necessity to inform patients about the role of nutrition in cancer, and the need to involve ESMO to face cachexia.</p> <p>EONS – educational modules on nutrition for oncology nurses</p> <p>MNI is discussing the details of an educational module for oncology nurses on nutrition and clinical nutrition, including HEN and HPN, for 2020.</p> <p><u>Next steps:</u></p> <ul style="list-style-type: none"> • Sept: MNI will touch base the new EPF Secretary General on the guidelines • 3 Sept: Plan to have a final proposal from EONS
Global FSMP WG	<ul style="list-style-type: none"> • Raise awareness about malnutrition and value of medical nutrition beyond Europe • Link in with local medical nutrition decision-makers and key stakeholders 	No relevant developments to report.
Market Access WG	<ul style="list-style-type: none"> • Winning decision makers and HCPs awareness of nutritional therapies 	No relevant developments to report.

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Communication WG	<ul style="list-style-type: none"> • Raise MNI profile • Position malnutrition as a public health issue • Educate on the role of medical nutrition in disease management 	<p>Infographics (based on key messages extracted from the MNI dossier)</p> <ul style="list-style-type: none"> • Target audience reviewed to a general audience, including healthcare professionals (versus patients). • First draft to be circulated in the summer. <p>Review of MNI communication strategy</p> <p>In line with MNI objective to raise awareness, the MNI secretariat is organizing a review of its communication strategy: review of past activities since 2015 and development of a new strategy for 2020+.</p> <p>The exercise should also cover MNI public affairs credentials and needs.</p> <ol style="list-style-type: none"> 1. MNI webinar on 8 July to set the scene with company experts 2. Full-day F2F workshop in September-October once the expert group is fully staffed. 3. Communication strategy proposal by end 2019 <p><u>Next steps:</u></p> <ul style="list-style-type: none"> • June 2019: MNI Executive Committee Members to staff the communication expert group (communication, public affairs, media relations, digital media profiles welcome) • 8 July 2019: MNI communication strategy webinar • Q3 2019: MNI communication strategy workshop

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Relationship with ESPEN	<ul style="list-style-type: none"> Establish trust & ensure a good and sustainable relationship with ESPEN Strengthen MNI's influence on ESPEN priority setting and activities 	<p>Nutrition Education of Medical students (NEMS)</p> <ul style="list-style-type: none"> MNI confirmed its support to the NEMS project. ESPEN started communicating on the project at the ONCA Spring meeting in Paris & with a dedicated news alert for ESPEN members. <p><u>Next steps:</u> Presentation of NEMS at ESPEN Congress</p> <p>ESPEN guidelines dissemination</p> <p>Stephan Bischoff presented the process to transform ESPEN guidelines into '<i>short and practical</i>' versions to facilitate their implementation in clinical care via user-friendly apps.</p> <p>The MNI ESPEN WG recommends supporting this initiative as MNI starting with a pilot phase.</p> <p>Additional budget might be needed, as this activity was not planned for in the 2019 budget – tbc.</p> <p><u>Next steps:</u> Detailed proposal including pilot development, selection of (first) guidelines and exact budget to be confirmed shortly (+-8 K€ per guideline).</p> <p>MNI-ESPEN-ONCA Joint session '<i>Providing quality nutritional care at home for patients</i>' (ESPEN congress Krakow 2 Sep)</p>

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		<p>The session will take ESPEN HEN and HPN guidelines as starting point for a discussion on “<i>providing quality nutritional care at home for patients</i>”.</p> <p>Marek Lichota has confirmed his participation as ‘HPN’ patient. We are awaiting confirmation from a MoH representative and looking for a HEN patient (optional). As usual, MNI President will introduce the MNI Grant winner at the end of the session. MNI is encouraging ESPEN, ONCA to use the joint session as an advocacy platform at national level: to invite the media, local stakeholders & KOLs to listen to the discussions and take the messages back home.</p> <p>Support from local industry to identify high-level Government speaker would be appreciated.</p> <p>Draft programme attached.</p> <p><u>Next steps:</u> Finalise the programme by mid-July</p> <p>MNI-ESPEN Executive meeting – 13 May</p> <p>Rocco Barazzoni, Time Meyerhoff and Léa Coulet met on 13 May in Trieste to discuss ESPEN-MNI cooperation.</p> <ul style="list-style-type: none"> • MNI encouraged ESPEN to do more advocacy by leveraging existing tools (joint session, ONCA, GLIM, NEMS project, etc). <p>On the joint session in particular, MNI asked ESPEN to use the Joint Session as an advocacy tool in the countries where the ESPEN Congress takes place.</p>

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		<ul style="list-style-type: none"> • ESPEN invited MNI members to support ESPEN initiatives (Congress, workshops, fellowships) and shared initial ideas on an ESPEN foundation and establishing a professional secretariat. <p><u>Next steps:</u> Rocco Barazzoni might submit proposals for MNI companies consideration on workshops, fellowships.</p> <p>MNI Grant 2019</p> <ul style="list-style-type: none"> • MNI has received 9 excellent submissions from Belgium, Colombia, India, Portugal, Switzerland, The Netherlands (2), The United Kingdom and Turkey. • Portugal, Belgium, Switzerland and The Netherlands were shortlisted as top-4. • The number of submissions is smaller than in previous years, but the quality of submissions is increasing, which is a good signal. <p><u>Next step:</u> The joint ESPEN-MNI selection committee should suggest a ‘winner’ shortly.</p>
PN WG	Raise awareness on benefits of parenteral nutrition in the ambulatory sector	<p>Home Parenteral Nutrition awareness initiative</p> <ul style="list-style-type: none"> • Website almost finalised – launch planned before ESPEN Congress https://lds.wvd.mybluehost.me • Development of animated video explaining how HPN works

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		<ul style="list-style-type: none"> Rocco Barazzoni confirmed ESPEN HAN SIG cannot endorse MNI initiative, but gave blessing to launch the MNI HPN website, and showed willingness to use it to disseminate ESPEN upcoming HPN guideline. <p>PACIFHAN formally established</p> <p>PACIFHAN -the International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition- is formally established as an international not-for-profit organisation in Belgium. With members representing 10 countries (Australia & New Zealand, Czech Republic, Denmark, France, Italy, Poland, Sweden, United Kingdom, United States of America), PACIFHAN aims to represent patients and carers living with HAN in various countries.</p> <p>http://pacifhan.org</p> <p><u>Next steps:</u></p> <ul style="list-style-type: none"> Summer 2019: launch of HPN website End Aug 2019: Meeting ESPEN HAN SIG in course of ESPEN congress in Krakow End 2019: Development of animated video explaining how HPN works
National Industry groups / GROW project	Grow the medical nutrition market in Europe	<p>GROW 3</p> <p>GROW award to be split between the Slovakia and Brazil. Tbc on 25 June. CONFIDENTIAL</p> <p>MNI-NIGs annual meeting (ESPEN congress Krakow 2 Sep)</p>

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		<ul style="list-style-type: none"> • Invitation was sent to all NIGs and MNI Working groups. Please forward to your treams. • The agenda is still work in progress – all speakers invited – awaiting confirmation. <p><u>Next steps:</u> 2 July: MNI Executive Committee to approve GROW 2019 winner(s) and criteria for GROW 2020</p>
ESSD	<ul style="list-style-type: none"> • Define MNI position on ESSD proposal • Promote a single and practical classification system that secures patient safety 	<p>ESSD labelling proposal – new stalemate</p> <p>We have reached another stalemate with the ESSD:</p> <ul style="list-style-type: none"> • Viscosity measure: ESSD proposes fixed value +20% margin upwards. MNI WG confirms this is not realistic production-wise and requested the scientific rational for the 20% margin. • Labelling: ESSD showed no flexibility on its labelling requirements. MN WG confirms it cannot implement the suggested labelling without clear validation from the users. ESSD refused to consult healthcare professionals on their labelling scheme. <p>WG recommendations:</p> <ul style="list-style-type: none"> • Maintain dialogue with ESSD • Understand scientific rational (if any) behind fixed value +20% margin • Consult the users on the ESSD labelling proposal (dietitians, speech & language therapists, nurses, neurology specialists, GPs, etc) preferably with involvement of ESSD.

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		<p><u>Next step:</u></p> <ul style="list-style-type: none"> • MNI Executive Committee to advice on next steps.
Code of Conduct	<ul style="list-style-type: none"> • Develop a code of conduct to strengthen MNI reputation and credibility toward stakeholders 	<p>A draft is being discussed for MNI Executive Committee review on 2 September.</p> <p><u>Next steps:</u></p> <ul style="list-style-type: none"> • Review by anti-trust lawyers and MNI stakeholders planned in July-August • Delivery of the code postponed to Q3-Q4.
News from the MNI secretariat		<p>Potential new projects under consideration – for discussion on 2 July.</p> <ul style="list-style-type: none"> • PA working Group <p>Considering the ‘raise awareness’ objective, and the fact that a large number of extreme politicians will take office in the European parliament, it might be necessary to develop some Public Affairs expertise in order to be able to respond to potential threats/opportunities.</p> <ul style="list-style-type: none"> • Cooperation with stakeholders on home nutritional care – patient journey <p>MNI is exploring cooperation with patient groups and healthcare professionals. Depending on discussions/budget, this might materialize in a new project – still tbc.</p> <p>Important dates in 2019:</p> <ul style="list-style-type: none"> • 2 July: Executive Committee meeting – Frankfurt • 2 Sept: MNI-ESPEN-ONCA Joint Session and award of MNI Grant - Krakow

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		<ul style="list-style-type: none"> • 2 Sept: MNI-NIGs annual meeting & award of GROW – Krakow • 3 Sept: Executive Committee meeting – Krakow • 1 Oct: MNI WG workshop – Brussels • 19-20 Nov: ONCA conference in Cambridge • 29 Nov: Executive Committee meeting – Maidenhead - UK