



**Minutes face-to-face meeting Advocacy WG
Friday 24 March 2017, 09.00 - 16.00 hrs UK Time
National Council for Voluntary Organisations, London**

Participants: Patrick Crombez (PC) (Co-Chair), Aoife McNamara (AmcN) (Co-Chair), Graca Braz (GB), Halldóra Hálfánardóttir (HH), Sidsel Dragsbaek Holm (SDH), Merel van Klinken (MvK), Johan de Munter (JdeM), Theologia Tsitsi (TT) & Mariska Mooijekind (MM) (Working Groups Manager)

Apologies received from: Per Fessé (PF), Petra Riemer-Hommel (PRH), Paul Trevatt (PT)

09.00 hrs Start of meeting

1. Welcome

PC welcomes all Working Group members to the meeting, with a special welcome to new WG member MvK.

2. ESNO

ESNO stands for “European Specialist Nurse Organisation” and PC serves on their Board as EONS representative. ESNO has developed a common training framework, which is important in the recognition of specialised nursing. The diabetes association is a very active one. PC will contact their association to enquire if they have successfully obtained recognition and if so, to ask them about their approach. EONS could perhaps benefit from their experience.

On 30 November and 1 December 2017 ESNO is organising for a summit to take place in Brussels, in the part of the city area where the European Commission is situated, with the aim of having a number of European Commissioners participating in the summit.

The summit is built up as follows:

Thursday afternoon, 30 November, two leading experts will each give a 20 minute presentation, which is followed by a 20 minute panel discussion, followed by 5 x 10 minutes abstract presentations by ESNO members. PC has submitted an abstract on behalf of EONS and will hear by late April if the abstract has been accepted. On Friday morning, 1 December, there will be abstract presentations from ESNO members (5 presentations, 10 minutes each), followed by “the patient perspective” (5 presentations, 10 minutes each) for which patient associations will be contacted. The Friday afternoon programme addresses “Invest in the Health Workforce related to the Specialist

Nurse, Nurse in advanced level". Speakers from leading global and European Health and Nursing Organisations are being invited.

For EONS participating in the ESNO Summit means a great opportunity for networking with Commissionaires. The Working Group decides to participate in the Summit with all members and to hold a next face-to-face meeting in Brussels the following day, Saturday 2 December. It is suggested to contact Lena Sharp, who will by then be the EONS President, to see if she would be interested in attending the meeting also. Additionally a(nother) member of the Research Working Group could be invited to attend to answer any questions that may arise about the RECaN papers. MM will contact both Lena Sharp and Andreas Charalambous to check their availability and interest.

The registration fee for the Summit is EUR 135,-. PC will discuss with ESNO the possibility of offering EONS a discounted registration fee and the option of hosting a booth at the Summit. He will bring this up either in their Board meeting of 21 April, or earlier by email.

The main aim of participating is to have the opportunity to have a conversation with representatives of the European Commission and the European Parliament. It is suggested for the Working Group (WG) to make appointments with politicians once a list of the participating politicians is available and to have available promotional materials in the form of a toolkit and a laptop in the booth. The website of the European Cancer Nursing Day can be shown. The toolkit for the politicians could contain the RECaN papers prepared by the Research Working Group and general EONS promotional materials, amongst which the updated EONS Core Curriculum (see agenda item 5) and Position Statements. If needed Olga from ECCO can be asked for help.

All WG members will be offered two nights accommodation (on 30 November and on 1 December). MM will check availability of a meeting room at the EONS Secretariat for the face-to-face meeting and for a hotel for the two nights.

On the 5th of May the European Commission is holding a meeting on "biosimilars". ESNO has requested PC to participate in this meeting and JdeM is willing and available to join PC there. This is another opportunity for EONS to meet with representatives of the European Commission. PC will bring leaflets promoting the European Cancer Nursing Day, which will be prepared by GB and JdeM. PC will contact Ber Oomen, the Executive Secretary of ESNO, to see if he is willing and available to take some photos of the event, which can be used for the EONS website, Newsletter and Magazine. MM will inform Helen Oswald, EONS Communications Manager, copying in PC and JdeM.

3. **(Phase 2 of) RECaN Project**

Phase 2 of the RECaN Project will involve case studies of 4 countries, of which 2 are countries where cancer nursing as a specialism is well developed: the United Kingdom and the Netherlands and of which 2 are countries where cancer nursing as a specialty is less well developed: Germany and Estonia. These four countries will be compared in the case studies. A Steering Committee is being formed, in which a delegate of each of the EONS CARE Working Groups will participate and one delegate of the four relevant National Member Societies. The Committee Members have not yet been selected.

The Advocacy WG has been requested to indicate which data needs to be collected and how.

The Advocacy RECaN Task Group (TG) currently holds the following members: PC (chair), SDH, HH and TT. The WG members agree to strengthen this TG once we are passed the date of the European Cancer Nursing Day, which is Thursday 18 May. AMcN and MvK agree to join the RECaN TG.

As it is up to the TG to define which information is required from the four countries involved the Working Group has a brainstorm about the relevant questions to be asked / information to be gathered:

- Number of nurses in your country?
- Number of cancer patients and new diagnosis each year?
- Number of nurses working with cancer?
- Number of specialised nurses?
- Number of members of their oncology nursing society?
- Address, web link and social media accounts

The WG members agree that a number of questions about education will need to be included, such as:

- How do you define a cancer nurse?
- What level of education is required to become a nurse?
- What type of education is available in your country to specialise in cancer nursing?
- How much education is available to cancer nurses to compliment their job?
- Are nurses consulted for the planning and development of the national cancer programme?

Additionally questions about how cancer care is organised in the relevant country will need to be included, such as:

- Does your country have a national cancer plan?
- Is cancer nursing specifically acknowledged in the plan?
- Are there specialised cancer centres?
- Are there specialised centres within a general hospital?
- Are cancer patients mixed with other patients?
- Is there cancer nursing provided within home care?
- Is there a competence framework within your country?

Furthermore the Working Group members suggest it would be helpful and relevant to ask nurses to describe “a day in the life of...”

- A community nurse
- A hospital based nurse

To find out what is included in their normal working day.

Also, questions on “outcome” are to be included.

The RECaN Task Group will plan for a conference call to discuss and further develop the questionnaire. TG members will check if the ESNO Common Training Framework document is relevant for use.

The TG acknowledges that active lobbying with politicians is required and that it is important to keep politicians involved on the longer term. The RECaN project will be discussed in the May Board Meeting, following which PC will update the WG members.

4. European Cancer Nursing Day

GB updates the WG members on the progress made on the preparations of the European Cancer Nursing Day. A number of changes were made to the briefing document, after which the document was shared with the heads of the National Member Societies and their communication representatives, by Rudi Briké. In the document and accompanying email the National Member Societies were asked to provide EONS with specific data. In total (only) 14 members responded to the request by providing numbers, which is not a sufficient number to be representative for Europe. The WG therefore agrees to prepare only one press release – and not the national press releases as was initially aimed for. It is agreed to send the press release to the National Member Societies by individual emails, via the Communication WG. The National Member Societies will be requested to forward the press release to their Ministries of Health and to further cascade nationally.

The ECCO Position Statement has been shared with the WG members by MM and a draft website celebrating the event has been created, currently available at www.europecancernursingday.com. AMcN will email all WG coming Monday with the request to provide feedback on the website within one week. After the feedback of the WG members has been processed by Jason Harris, the link will be provided to the EONS Board Members, also with an invitation for providing feedback.

All Working Groups and Working Group members and Board Members have been asked to provide quotes and photos for the European Cancer Nursing Website and to ask people in their networks to do the same. Not all Board Members have submitted their quotes. MM and AMcN will ensure to remind the Board Members of this request when providing the web link for review. GB has provided the three EONS Presidents, Daniel Kelly, Lena Sharp and Erik van Muilekom, with a draft press release. Up to now, feedback to the document has not yet been provided. GB will send a reminder.

AMcN has been in contact with Olga from ECCO. AMcN has fully informed Olga on the activities EONS has planned for the European Cancer Nursing Day and she has invited ECCO to provide feedback.

JdeM volunteers to prepare a draft communication plan that will be shared with all WG members on 3 April. Once the plan has been agreed upon by all WG members, JdeM will liaise with Jason Harris, Helen Oswald and the Communication WG in preparation of the day.

A (simple) promotional flyer will need to be prepared and JdeM and GB volunteer to work on this. MM will contact Jason Harris with the request to develop an electronic signature, promoting the event.

The to do list of European Cancer Nursing Day TG is discussed and updated. AMcN presents www.europecancernursingday.com to the WG members. All WG members are invited to review the web pages and to provide AMcN on any feedback they may have.

During the discussions the WG members conclude that it would be useful if EONS had branding guidelines. The group agrees that this would be a task for the Communication WG, rather. AMcN will share the Irish Association for Nurses in Oncology (IANO) guidelines with MM, following which MM will write to the Communication WG with the request to establish EONS branding guidelines.

5. EONS Core Curriculum update (15 mins)

PF has provided a written update in his absence at the meeting: *“The task group for the update of the Core Curriculum are now on our 4th draft. We are doing major revisions for example in the structure as there were repetition in some of the different sections, adding new section and update the core curriculum to where we are today. It has taken longer time that we accepted when we planned the work because of the major revisions and fit the doc today’s standards and where we are heading. If all goes well we will have a final draft for review end of April beginning of May.”*

The WG members agree that the Updated Core Curriculum, a European guideline, is a useful tool for advocating. It could be used for the (promotion of the) RECaN project also. The WG agrees to bring a number hard copies to the ESNO meeting of November.

6. Advocacy web pages (15 mins)

JdeM presents the updated web pages to the WG members, which he has been working on together with PF. Some feedback is directly shared. JdeM will discuss the feedback with PF and will incorporate this into the web pages.

Position statements are being discussed. The WG agrees to remove all Position Statements, except for the “UK referendum result: Leave” and “Nurses in cancer care”. Two new Position Statements will be added to the website: one on “Education” and one on “Cross Cultural Oncology & Nursing”. Furthermore Katarina Lokar’s document will be uploaded to the website, which is a form by which anyone can suggest or request EONS to consider preparing a new Position Statement. The WG agrees that at the moment there is no need or urge for developing new PSs.

An extra web page should be developed in the main Advocacy menu, promoting the European Cancer Nursing Day, linking directly to the website of European Cancer Nursing Day. JdeM will liaise with Helen Oswald.

It is agreed to combine the two pages on “EU and EONS” and “EU Directives”. The new title will be “EONS active at EU level”. PC will check the relevance of the content of the two pages.

It is suggested to add two statements of non-nursing organisations on the “Networking” page. MM to provide JdeM with the files of the Inclusive Communications Survey.

7. AOB (15 mins)

EONS representation (within collaborating organisations)

MM will liaise with Rudi Briké on building a list of EONS representatives in collaborating organisations, such as:

- PC represents EONS in the ESNO Board, MASCC and European Commission Meetings
- Danny Kelly serves on the ECCO Board

- Andreas Charalambous participates in the ECCO Oncopolicy Committee
 - JdeM represents EONS at the EMA
- MM to contact Rudi to further build on maintain this list.

EONS Link

All Working Group members are encouraged to use EONS Link for sharing files.