



**Minutes face-to-face meeting Advocacy WG
Friday 15 December 2017, 09.00 - 16.00 hrs
Oporto Oncology Portuguese Institute, Porto, Portugal**

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

Apologies received from: Patrick Crombez (PC) (Co-Chair)

*Emma Woodford (EW), EONS COO connected to the meeting via Skype
Daniel Kelly (DK), EONS Past President connected to the meeting via Skype*

1. RECaN Project

Daniel Kelly, the EONS Past President informs the group about the progress made on the RECaN project:

The main aim of the RECaN project is to raise the profile of the contribution of cancer nurses to cancer care. Two years of the RECaN project have now finished. The third year is coming up, which is when and where Advocacy Working Group will become (more) actively involved in the project. The project is built up in three phases:

1. Systematic literature review. Papers are currently being published.
2. Data collection of four case studies. In four different countries the status of cancer nursing in the country was examined: Estonia, Germany, the Netherlands and UK. In each of the countries, 100 questionnaires were completed about patient safety in their work place. In addition to the questionnaires, qualitative data from focus group discussions was obtained. A report with the findings will be produced. The report will include recommendations for each of the four EONS CARE Working Groups and the EONS Board. The full report will become available within the next six months. Early findings will be shared earlier, if possible.
3. Lobbying, using the results from phase 2 of the project. The Working Group will have to await the report of phase 2 to become available, before it can develop a strategic plan for lobbying.

It is likely that recommendations will need to be prioritised. It is suggested to perhaps focus on the impact of the findings on patients; Patient Advocacy. A programme to increase awareness could for example be developed. The Working Group is requested to consider the potential subject(s) / the main focus once recommendations become available.

The report and the future direction will be discussed at the Strategic Working Group Day of 17 May. It will be essential for the individual plans of the four Working Groups to complement one another. The members of the Advocacy Working Group RECaN Task Group (PC, SDH, HH, MvK, TT and HU) will need to remind themselves of this and have to look after this, once developing the plan. RECaN will be shaping the work of EONS and its WGs for the next few years. In the meantime DK is happy to be a point of contact for any RECaN related queries.

Daniel Kelly (DK), EONS Past President, disconnects from the meeting

2. Welcome and introduction

Apologies for the meeting were received from PC, the co-Chair of the Working Group.

All individual WG members introduce themselves to EW, the recently appointed new COO of EONS. EW started in September 2017 as COO, on a 3 days a week contract. She has a background as professional NGO coordinator and has been involved in EU health policy since 2008.

EW informs the Working Group members that at the November General Meeting in Ede, Lena Sharp was appointed as the new EONS President. Lena is based in Sweden and she will be EONS President for the next two years. At the same meeting Andreas Charalambous was appointed as President Elect. The EONS Board meets on a regular basis and it is the role of the Board to provide strategic guidance to the organisation. Team members relevant for the Working Group members to know, in addition to MM who is attending the meeting, are Rudi, the Membership Coordination Manager, Iveta, the Projects Manager and Helen, the Communications Manager.

EONS has 31 member organisations and a total of about 23.000 individual cancer nurses members.

The role of the Advocacy Working Group is to have an impact on policy, bringing together all the work of the other WGs.

EW has joined the Advocacy Working Group as an observer. In that role, the Working Group invites her to support their work by participating in meetings and discussions and to share ideas, thoughts and suggestions.

3. EONS Core Curriculum update = EONS Educational Cancer Nursing Framework

The project is nearly finished. At the November Board Meeting it was agreed to do a soft launch of the Framework in January 2018 and to have a big launch organised for on ECND 2018. EW suggests to attract European media attention at the May launch, at the press club in Brussels, and to include this in the communication plan of ECND 2018.

EW volunteers to review the list of MEPs and to provide the Working Group members with the contact details of the relevant MEPs, for inviting them. The Working Group members express the need for an official type of invitation, which they need for when contacting the MEPs.

This point is discussed further and in more detail, under item number 4.

4. European Cancer Nursing Day 2018

The group agrees that ECND 2017 was a great success. The 2017 event was prepared and executed by the Advocacy Working Group only. Included in the 2018 ECND Task Group are representatives of the other three Working Groups: Maria Dias (Communication), Jane Winter (Research) and Harald Titzer (Education).

Website:

For ECND 2017, a separate website was built:

www.europecancernursingday.com. EW recently suggested the Working Group to consider integrating this site in the regular EONS website: www.cancernurse.eu. The rationale for hosting a separate website was that ECND is to support and promote cancer nursing in Europe in general, and is not intended to (just) promote EONS. Hosting costs for this separate domain name are not high. The Working Group agrees to continue the separate website. Sponsor logos can be included in the website, following the EONS Branding Guidelines that have been recently finalised, following a suggestion made by the Advocacy Working Group.

EW informs the WG that due to the financial position of EONS it has been agreed for all website maintenance to be done by Steve Rowett (EONS Website Manager), in his regular working hours. No external consultants can be hired for this type of work. Access to the ECND website has been transferred from Jason Harris to EW. EW informs the group that should Steve Rowett have to work many hours in addition to his regular hours on this specific project, funding for these extra hours will come from sponsorship funding. The Task Group will not have to include a post on website maintenance costs in the project's budget.

Three day programme:

In 2018, the celebration of ECND will be part of a three day programme:
16 May = MAC meeting, presenting preliminary results of the RECaN report to MEPs. PC and EW will meet the MEPs who are hosting, in January. EW will co-ordinate this day.

17 May = Working Groups Strategic Meeting, co-ordinated by the Board.

18 May = ECND, including a meeting at the Brussels press club
Advocacy WG members are invited to participate in the MEP meeting of 16 May, which is a lunch meeting. WG members can fly in, in the morning of 16 May and can travel back on Thursday evening, after the WG Strategy Meeting. EW suggests the Friday press meeting to be organised by the Education Working Group, should it be agreed to have a focus on the Framework. ECND will be coordinated by the ECND task group.

The Working Group agrees to meet again face-to-face, possibly at the September ECCO Summit, with a 2-hour conference call on Tuesday 22 May, starting at 10.00 hrs CET = 09.00 hrs UK Time.

ECND Artwork:

The ECND banner was recently updated by an EONS contact from the Brussels office, by kind gesture.

ACTION: AMcN will check all files used for promotion of ECND 2017 and will contact EW, should any additional files require updating. Jason Harris has given permission for all ECND artwork to be used again and edited accordingly for ECND 2018.

JdeM informs all that an advert, announcing ECND 2018, was placed in Ede Leadership Summit programme booklet.

Core Curriculum launch:

The Working Group had an extensive discussion about whether or not the group agrees with the Board decision to have a major launch of the EONS Educational Cancer Nursing Framework on ECND 2018. The WG prefers to have a focus on ECND itself, not having attention distracted by the launch of the Framework and not having two separate press releases. The WG is happy to refer to the Framework in the ECND press release, but prefers to have a main focus on ECND. Therefore, the WG suggests to organise the major launch of the Framework prior to ECND 2018. EW suggests the group to consider coming up with something concrete, to enhance the political impact for ECND and ensure a clear call to action for MEP's.

Belgium Societies event:

Earlier, EW had suggested organising a Belgian event on 18 May 2018, bringing together all three Belgian oncology nursing societies. Discussions between two of the three Belgian oncology-nursing societies took place at the Leadership Summit in Ede. In follow up to this meeting, further discussions have taken place and JdeM informs the WG that the two organisations have had to conclude that it is a plan, which is difficult to realise as one of the two societies has already made plans for the celebration of the day and the third society is not available for contact.

Press release:

The WG members agree for the ECND Task Group to discuss in their next conference call if the ECND press release should focus on ECND only, or if it should also include launch of the EONS Educational Cancer Nursing Framework, preliminary RECaN results and other subjects.

ACTION: MM to ensure that Rebecca Verity, co-Chair of the Education Working Group and Task Group Chair of the Framework update, is invited to the conference call of the ECND Task Group, where this will be further discussed.

Competition for members:

The WG members support the idea to organise a contest for two ECND 2018 Awards; one for "most creative" and one for "biggest impact", to stimulate creativity of the EONS members on Social Media. Two grants of EUR 500,- each will be made available for the next EONS congress. This will be budgeted for in the ECND budget. An award will be handed over at the event. The Task Group is to further discuss and develop this plan. Competition guidelines will be created by the ECND task group.

Communication plan:

JdeM, Task Group Chair, handed out a draft communication plan for ECND 2018. The document will be reviewed and discussed in the next conference call of the Task Group. Additionally the Task Group will discuss with Helen Oswald if a separate Facebook page will be developed for the event, or to create the event on the current EONS Facebook page. JdeM is eager to commence social media promotion as soon as possible in 2018. Generic messages will be used until ECND plans are finalised.

The hashtag has agreed to be updated to: #ECND2018

ACTION: MM to invite the Task Group members to participate in a conference call on Thursday 4 January at 20.00 hrs CET = 19.00 hrs UK time and to extend the invitation to Rebecca Verity.

EW updates the WG members on ongoing conversations between EONS and ESMO. EONS will hopefully organise a three-day nursing track and symposia at the ESMO congress, which is to be held 19-23 October in Munich. Hopefully, EONS and ESMO will reach an agreement prior to the end of this year.

On 7-9 September 2018 an ECCO Summit on oncopolicy will take place in Vienna. The meeting programme should become available within the coming weeks. EONS is hoping and aiming to have a dedicated session on RECaN included.

5. Position statements

EW informs the WG members on the Proportionality Test Directive, which has been proposed by the European Commission. This Directive could require member states to conduct a test on any new professions before they are officially recognised in that country to see if they are really needed in relation to other existing qualifications. The directive as it stands is being opposed by health professions because it would limit the recognition of specialist professions across the EU, which could have direct consequences for getting cancer nurses recognised in our member countries. This is a concern to numerous groups, who have responded by preparing Position Statements, not asking to stop the directive, but to ask for an exemption for health professions. The WG agrees to engage and to prepare a Position Statement on this subject. EW stresses that action within the coming six months is necessary. For building a strong Position Statement on this subject, the RECaN results are considered to be very relevant and useful. EW recommends the Task Group to speak with Daniel Kelly and Lena Sharp about the input they have received from the RECaN focused group discussions. HU will join the Position Statement Task Group (which up till now consisted of PC, MvK and TT). EW agrees to be involved in the development of this new statement also.

ACTION: EW to share the Position Statements of the dentists, doctors and pharmacists with the WG members.

EW will speak with the head of policy of ESMO to find out if they plan to act on this.

The Position Statement task group will follow up on this work in a separate conference call.

Once the Position Statement on the Proportionality Test Directive has been finalized, the Task Group will look at developing a Position Statement on Leadership, following Ede Leadership Summit

6. ESNO update

AMN reads out the briefing PC has provided on the developments within ESNO, in writing:

The Brussels event, scheduled for early December, did not take place. The President of the organisation has stepped down. The Vice President will remain on the Board, but does not have the ambition to continue as Vice President or to become the new President. A call for the various Board positions will be advertised over the next few weeks for the roles of President, Vice President, Secretary and Treasurer. Other current Board Members agreed to continue as Standing Committee, until a new Board is in place. Formation and future direction of three ESNO Working Groups, Governance, Education and External Relations, describing their domain, will also need to be defined.

7. Advocacy web pages

JdeM and Per Fessé (previous Working Group member) updated the Advocacy web pages, ahead of ECND 2017. All WG members are invited to review the pages. HP will assist JdeM with updating the pages.

ACTION: MM to remind all WG members to review the pages and to provide feedback prior to the end of January 2018.

8. AOB

ACTION: It is agreed for SDH and HH to send occasional requests to Helen Oswald, the EONS Communications Manager, to tweet about the Advocacy web pages / Working Group.

ACTION: Furthermore it is agreed that it would be useful if the EONS Newsletter regularly highlights features of the Advocacy web pages and WG activities. MM to remind WG members on a monthly basis to provide input.

ACTION: All WG members to more actively engage in promoting the WG and its activities on Social Media. The individual WG members are free to select media of their own preference to become active on.

MvK attended CODE meeting earlier this year, on the request of PC. Through MvK, EONS has been invited to continue working on this group. The WG members agree that it is up to the EONS Board to decide if the organisation wishes to engage.

ACTION: MvK will share the information with PC, who will take it to the Board for a decision.

EW offers to give training or an update session on the work processes of the European Commission and Parliament at the next face-to-face meeting. This offer is accepted by the WG.

JdeM informs the WG on the work he has done for EONS in relation to biosimilars. He will start preparing information materials for cancer nurses, working with biosimilars. He kindly requests WG members who have national guides for nurses working with biosimilars available, to share these with him (with a cc to PC).