

Minutes face-to-face meeting Advocacy WG
Thursday 4 June 2015, 09.00 – 15.30 hrs
Dansk Sygeplejråd, Copenhagen, Denmark

Participants: Patrick Crombez (Co-Chair), Birgitte Grube (Co-Chair), Sidsel Dragsbaek Holm, Per Fessé, Katarina Lokar, Mariska Mooijekind (Projects Manager)
Apologies received from: Françoise Charnay-Sonnek, Petra Riemer-Hommel, Ineke Lokker, Paul Trevatt

1. Welcome

All WG members briefly introduce themselves. For each of the (active) Working Group members EONS would like to register when they joined the Working Group. The information is as follows: KL: May 2012; PC: September 2013; BG: September 2013; PF: May 2012; SDH: June 2014.

2. EONS Strategy 2015 - 2016:

“Strengthening our political voice and impact across Europe”

Incl. Recognition of cancer nurses (was agenda point number 5)

At the Strategic Meeting of the EONS Board of last February the above strategy was agreed upon.

BG informed the Working Group members present on the work of the European Alliance for Personalised Medicine (EAPM). The alliance was originally initiated by the European Cancer Patient Coalition (ECPC) to advocate that the patient should be at the base of the treatment - not the targeted medicine. EAPM promotes the holistic approach. In the past EONS has led their Education Group: “How can we educate healthcare professionals?” EAPM is now a stand alone alliance, no longer part of ECPC. EAPM charges an annual membership fee of EUR 10.000,- per organisation, per year. BG suggested the EONS Board might consider joining EAPM however this was declined as the value to EONS was felt not to be clear. BG still strongly feels that EONS should become a member, especially as nurses are currently not represented at EAPM. Participation of EONS would mean advocating for patients and a way into networking on European level. A reduced membership fee has been offered to EONS, which alternatively could be paid for from the annual Working Group budget. The Working Group agrees for BG to contact EAPM with the request to be updated on their developments and asking to perhaps sit in on one of their meetings to experience how relevant it would be for EONS to participate. BG will update the WG on her findings.

3. Representation of EONS on EU level

Paul Trevatt's (PT) participation in the EU Task Force “Expert Group on Cancer Control” and Andreas Charalambous' (AC) participation in the ECCO Task Force on “Cancer Care Quality”

The WG agrees to ask PT and AC to collaborate with the WG more intensively. The Working Group would appreciate receiving regular updates, to

be consulted on the agenda(s) for next meetings etc. PC will contact both PT and AC with this request.

EONS Strategy 2015 - 2016:

“Strengthening our political voice and impact across Europe”

Incl. Recognition of cancer nurses (was agenda point number 5)

Suggestion I of how to strengthen the political voice and impact of EONS across Europe: Education

SDH believes EONS should be known for courses, translation and education. E-learning is considered to be an important feature within education. However developing and keeping e-learning modules is very time and money consuming and the EONS Education Working Group has had to conclude that it is not possible for EONS to develop and maintain its own modules. Therefore a list of recommended e-learning sites has been prepared by the Working Group and made available on the Education web pages. SDH stresses that industry should be included in the networking of EONS, not just politicians, and that nurses should be offered the opportunity too to participate in courses of pharmaceutical companies.

PF points out a valuable website on guidelines: www.nccn.org and KL informs the WG on www.uptodate.com, a website providing good and practical information which is evidence based. MM will forward these suggestions to the Education Working Group. The WG can decide if they wish to include them in their web pages.

Suggestion II of how to strengthen the political voice and impact of EONS across Europe: Knowledge sharing

The EONS congresses and website are regarded as knowledge sharing opportunities.

KL stresses however that the 2015-2016 strategy should be part of a larger, strategic plan. EONS should define concrete aims for the longer term. The WG chairs will take this comment to the EONS Board.

4. Position statements

A procedure for development of (new) Position Statements (PS) is being defined by the Working Group:

- A suggestion for a new PS or for review of an existing PS is sent in by the Working Group / a Working Group member; the EONS Board; an EONS National Member Society or an Individual member. The suggestion should include a motivation and concrete data supporting the request.
- Any requests for development or review of a position statement will need to be brought to the Advocacy WG
- The Advocacy WG will prioritise topics for Board consideration
- The EONS Board will decide if they find the development relevant to the current EONS strategy

- When the list is agreed, new PS's will be developed by the WG (or a new TG assigned by the WG) in consultation with all relevant parties. The draft will be shared with the individual or organisation that made the suggestion and after review will be shared with the membership for comment.
- The near to final version will be provided to the EONS Board for discussion and sign off.
- A communication plan will be prepared, defining how the information will be shared widely e.g. website, newsletter, press-releases, social media etc). A review of the effectiveness of the PS and its communication plan will be made.
- A review date will be defined.

KL, with the support of the rest of the WG members, will be responsible for defining criteria for incoming requests and for the development of a web form. MM and the WG chairs will inform the Board on this procedure at the next EONS Board Meeting.

Position Statement (PS): Role of nurses in cancer care

This PS has been updated during the f-t-f meeting. This will now be distributed to the (other) WG members for feedback. BG and PC would like to provide a draft version to the EONS Board in the August Board Meeting.

Position Statement: Education for health care professionals in personalised medicine

A hard copy of the draft is shared with the WG and discussed. BG will update the PS once she has spoken to Dennis Hogan of ECPC. Furthermore the Working Group agrees to prepare an additional PS on "Education and qualification". BG will contact FCS with the request to work on this together.

Position Statement: Culturally competent cancer care

PC will share a draft of the PS with the WG before the end of August

It is agreed that the above mentioned will be followed up on before making a start on the development of any additional PSs. Possible subjects would however be:

- Nursing research
- Teenage cancer care
- Care of patients with co-morbidities
- Rare cancers
- The importance of holistic approaches to cancer care

5. Inclusive Communications

The Task Group exists out of PC & PF (chairs) and SDH, KL & PRH (members). Furthermore Graca Braz has volunteered to participate in this Task Group on behalf of the Communication Working Group.

The WG agrees to develop a survey and to distribute this to non-oncology nurses through the EONS National Member Societies. The purpose of the survey is to identify if there is a need for European non-oncology societies to establish a collaboration with EONS, especially regarding (basic) education programs in oncology. This could be facilitated through the national oncology nursing societies. It is clear that the role of the national oncology nursing societies will be paramount in this project and will need to be clarified in a second phase. A draft of the introductory text and the on-line survey will be prepared by PF and shared with the other Task Group members in August.

6. Advocacy web pages

The Advocacy web pages have recently been updated by the WG chairs. It is agreed that a quarterly check of the pages would be helpful. BG will ask IL if she would be willing to do a quarterly review of the website.

The following changes are agreed:

- “EU directives” should be under “EU and EONS”
- To discuss the possibility of placing the Position Statements on the Home Page with Kate Griffin, Website Editor.
- Including a paper explaining what a Position Statement is on the page. BG has a paper and will share this with the WG.
- FCS will be asked to review the page “EU and EONS”
- To include updates on the work of PT and AC in the website
- To include links on the relevant pages, rather than on a separate page

7. AOB

The WG currently has two seats available for new WG members. BG will arrange for a call for applications to be included in the next Newsletter.