

**Minutes conference call Advocacy WG
Tuesday 17 March 2015, 14.00 hrs CET**

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

1. Welcome

PC welcomes all participating Working Group members to the call.

2. Position statement on “Role of nurses in cancer care”

The current version of this statement is available on the EONS website: <http://www.cancernurse.eu/advocacy/positionstatement.html>. PC will work on an update of the statement, mainly by including a bullet pointed item on cultural competent care. PF suggests addressing “cancer rehabilitation” in the Position Statement. He will provide a suggestion to the other WG members within two weeks, for approval. The updated version will be shared with the Working Group members, for review.

3. Future position statements

The Working Group members were invited to provide suggestions for relevant subjects for future statements. BG has suggested preparing a statement on “Education”, for which a draft version already exists. BG will be asked to further develop the draft and to share the final draft with the Working Group members, for their review. PC suggests preparing a statement on “culturally competent cancer care” that he is willing to prepare. PRH suggests creating a statement on “Nursing Research”. PC will contact the Research Working Group chairs with this proposal. (The Advocacy WG is aware that the Research WG has created a Position Statement (available at: <http://www.cancernurse.eu/research/workinggroup.html>).

Position statements will be uploaded to the EONS website and highlighted through the EONS Newsletter. They can be used for discussions with policy makers and regulators.

Absent Working Group members are invited to provide suggestions for any topics they may think relevant.

4. Inclusive Communications

The paper prepared earlier by KL and PRH has been merged with the feedback received at the Advisory Council Meeting of last November. The draft paper on “Inclusive Communications” is shared with the Working Group members for feedback. All participants to the call are in agreement with the document and with the proposal to establish a dedicated Task Group to focus on this subject. BG or PC will co-chair the Task Group, together with Per Fessé. PRH, KL and SDH are willing to be on the group as Task Group members. It is agreed that MM will contact Paul Trevatt, Chair of the

Communication Working Group, to invite one of the Communication Working Group members to participate in the Task Group.

PC will contact PF by early April to further establish and to action the Task Group.

PC informs the Working Group members that one of the future issues of the EONS Magazine will have a focus on Advocacy and this subject should certainly be included in the edition.

5. Recognition of cancer nurses

PC provides a verbal update on the future planning of the work on this subject. BG and PC are preparing a paper, which will be published on the website and used for policy maker and regulatory engagement. BG and PC will contact Martine Piccart, President of ECCO, to schedule a meeting to discuss the document and to define further, more concrete actions for the recognition of oncology nursing at an EU-level.

BG and PC will also ask FCS to share the ESNO document on the “Common Training Framework”. This document could also be helpful and will be shared with the Working Group members, once received.

6. Representation of EONS on EU level

Update on Paul Trevatt’s participation in the EU Task Force “Expert Group on Cancer Control”:

EONS attended the second meeting of the EU Expert Group on Cancer control in Luxemburg in March.

During the two day meeting a variety of topic areas were discussed including:

- *Towards a cancer information system for Europe: update on cancer registration*
- *Quality in healthcare: the European commission initiative on Breast Cancer*
- *Reflection on previous activity at EU level, including dissemination of the European Code against Cancer*
- *CANCON joint Actions*
- *Developing a roadmap of items to be discussed by the expert Group*
- *Consultation for the proposal for future actions on Rare cancers*
- *Palliative care*

During the meeting and in the evenings EONS developed stronger partnerships with a number of the lay members / patient advocate and the groups International Brain Tumour Alliance, European organisation for rarer diseases, EUROPA DONNA and EUROPA UOMO.

Actions

PT will give a fuller oral update and take questions from board members at the next board meeting.

Update on Andreas Charalambous' participation in the ECCO Task Force on "Cancer Care Quality":

A second meeting of the Taskforce was unfortunately cancelled. This meeting will possibly be replaced by a virtual meeting towards the end of April. In the mean time a questionnaire was circulated to the Taskforce members in relation to oncopolicy and how members' needs in this field could be best served through ECCO.

7. Advocacy web pages

PC informed the WG members that the "Advocacy" pages of the EONS website have been reviewed and updated. It is the intention to include the "EU Directives" page in the "EU and EONS" web page. FCS will be asked to review the page(s) related to EU-level work. Working Group members are requested to provide suggestions to be included in the web page "useful links".

8. AOB

The Working Group members will be consulted in relation to a proposal of EAHP, the COST initiative. Further information will follow shortly, by email.