



**Draft minutes face-to-face meeting Advocacy WG
Friday 25 November 2016, 09.00 - 16.00 hrs UK Time
“Room 4c”, 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), Per Fessé (PF), Katarina Lokar (KL), Johan de Munter (JdeM), Petra Riemer-Hommel (PRH), Theologia Tsitsi (TT) & Mariska Mooijekind (MM) (Working Groups Manager)

Apologies received from: Per Fesse (PF), Paul Trevatt (PT)

1. Welcome

Apologies received from PF and PT.

Agenda will be rearranged to address some of the topics before PRH has to leave the meeting. Also Andreas Charalambous will dial-in to the meeting to discuss the RECaN project and Jason Harris (designer)

2. Representation of EONS on EU level

- JdeM to report on EMA meetings
Was the only nurse attending the meeting. Cancer nurses should be involved in the meeting, clinical trials. Input from cancer nurses is important. Made a statement during the meeting on this and suggests that EONS writes to the EMA to this effect. Meeting dates should be communicated as early as possible. JdeM asks the group if someone else would be interested in attending some of the meetings, him not always being the one attending, also depending on the subjects which are being discussed. Also members of the other CARE Working Groups could be invited to participate, depending on the subject. This will need to be discussed in the next EONS Board Meeting.
PC will write to Ber Oomen (ESNO) to ask for a list of future meeting dates and the subjects. PC will ask Ber on how to get in contact with EMA directly to ensure direct communication, also for EMA to be aware of EONS' participation.
Good discussions between regulators, doctors, pharma.

PC on the Board of ESNO. November 2017 ESNO Summit 30 November (afternoon) & 1 December (full day), PC participates in scientific committee to develop the programme. First draft agenda has been prepared. Title: ask PC. Politicians will be invited to participate in the Summit. Good

opportunity for EONS for networking. Perhaps EONS to present on RECaN? PC will try to get this included in the programme; there are still some time slots open. Perhaps EONS can host a booth. PC will try and get that, free of charge. PC to inform the Board and ask for further input. Plan f-t-f mtng WG around the dates of the summit? To enable all WG members to attend + Rudi to host the booth + Lena to represent the society, as President. F-t-f mtng: afternoon 29 and morning of 30 November?
Next f-t-f mtng on Friday 24 March in Limasol, Cyprus, hosted by Theologia. Larnaka airport. All WG members to inform MM on costs of flight within one week after the meeting.

3. EONS Core Curriculum update

MM will email Per to ask him to briefly update the group on the progress made in this Education Task Group.

4. RECaN Project

- Andreas Charalambous, co-Chair of the Research Working Group, to join the discussions by telephone

PC provides the group with a brief update on his participation in the Research Working Group meeting of last Monday. Five papers will be written.

ECCO and EONS made a Position Statement on ... Advocacy Working Group was not invited to assist in writing the Position Statement. Daniel Kelly and Andreas Charalambous wrote the statement. There is a need for clear communications between the different Working Groups on the RECaN.

MM to set up EONS Link for the Advocacy Working Group.

Brief update on RECaN project by AC.

Based on the research questions systematic review: 5 potentially identified papers, primary and secondary outcome. Papers 1: identifying the role and types of interventions. Will be presented at ECCO as late breaking abstract. 2: cost effectiveness = main paper related to primary outcome. Will need to be submitted to high ranked paper lancet of oncology, perhaps. Paper 3: education and training and patient experience. Probably most challenging paper. Paper 4: design of future cancer nursing trials. Poor methodological quality of studies found. Result of initial screening of the papers. Paper 5: identifying the populations. Define and clear relationship in cancer care in ???
ECCO PART – ECPC related.

Papers are planned to be produced by May 2017.

PC will share the email received from AC with the Working Group members, which describes the above.

AC & DK members of ECCO oncopolicy committee and AC oncopolicy Position Statement ECCO patient advisory committee & EONS Position Statement signed by all 24 ECCO member organisations. DK and AC made a draft, ECCO office has added to it. Now: 5 page Position Paper. Has been reviewed by ECCO patient advisory committee. Four pillars to illustrate why cancer nursing speciality is needed in Europe. Define what a specialist

cancer nurse is and what she does. PC will share the Position Statement with the WG members. Not in small detail; it is a “setting the scene” document. Position Statement will hopefully be released next month.
MM: use this Position Statement for the paper on the European Cancer Nursing Day?

KL: EONS needs to inform the various WGs and the society membership in general on the RECaN project continuously to stay updated and aware.

5. EU Cancer Nursing Day

GB has provided all WG members with an updated version of the document. The document is approved by all WG members. One point of discussion is the definition of cancer nursing. PC to discuss with Daniel Kelly which definition to use and include.

Aim is the recognition of cancer nursing.

Toolkit to be prepared and shared with the society members.

Jason Harris advises EONS to get EONS stated on the promotional materials of the European Cancer Nursing Day, taking the credit for the day. Not just the RECaN logo.

Involve other societies in the promotion thereof.

Social Media. Twitter, Facebook, hashtags.

Memes. Both photo and video.

Individuals can write up their own message, giving their own reason and rationale

Separate website. RECaN and/or European Cancer Nursing Day?

Combine SoMe campaign RECaN and European Cancer Nursing Day? Jason to prepare a proposal for the next business meeting. JH suggests to invite donations through the website.

- Cards / memes
- Video
- Website

GB, PC, JH & MM to work on a proposal for the Presidents. JH will start working on the proposal. JH and PC to join the business meeting of 13/12?
MM to ask DK. For the evening part perhaps?

The progress made on the to do list of the TG is discussed.

MM will contact Daniel Kelly about the (draft) press release for European Cancer Nursing Day. TG to provide a draft for the review by the TG? Or will DK provide the text?

MM to make further arrangements for the photo shoot at the Amsterdam ECCO congress.

MM to make preparations for the advert for Cancer World.

6. Terms of Reference

Terms of Reference document is discussed. AMcN has made some suggestions for change. The suggestions are being discussed and AMcN will update the document accordingly. MM will ensure for the new document to be uploaded to the website.

7. Advocacy web pages

JdeM updates the WG members on the work he has done together with PF. Together they have worked on updating the Advocacy web pages. Steve Rowett has indicated that most suggested changes can be made relatively easily. The WG discusses the suggested changes. JdeM will follow up with PF and with Steve Rowett. SR will send a link to a draft updated website.

8. Position statements

Under review by Theresa Wiseman, EONS Secretary, also for a check of the English language. Board comments will be integrated. Expected to receive the Position Statements within a few weeks. Then uploaded to the website.

Brief article for EONS Newsletter, when web pages have been updated also = PC. Plus an article in a different Newsletter on the European Cancer Nursing Day (AMcN).

ISNCC had suggested for EONS and ISNCC to prepare a Position Statement together. The group agrees to use the Position Statement on Cross Cultural Oncology Nursing and Cultural Competent Cancer Care. PC will write to ISNCC.

9. AOB

Advocacy representative on the Communication WG: GB

KL shares with the WG that sadly she has to leave the group. HH to take over KL's position in the RECaN TG.