



## **Minutes - EONS Research Working Group Face-to-face meeting, Thursday 26 October 2017 NCVO, London, United Kingdom**

### **Participating:**

Andreas Charalambous (AC) (co-Chair), Mary Wells (MW) (co-Chair), Nuria Domenech Climent (NDC), Iveta Nohavova (IN), Wendy Oldenmenger (WO), Ulrika Östlund (UO), Lena Sharp (LS), Mariska Mooijekind (MM) (Working Groups Manager)

### **Unable to attend:**

Daniel Kelly (DK), Greg Kotronoulas (GK), Elizabeth Patiraki (EP), Jane Winter (JW), Theresa Wiseman (TW)

### **Guest to the meeting:**

Emma Woodford, EONS Chief Operating Officer

### **Thursday 26 October**

#### **1. Lunch, opening and information on Board decisions**

LS informed the Working Group (WG) on the plans of the EONS Board for a number of linked events in Brussels or the Brussels area, for May 2018:

- Wednesday 16 May – meeting with MEPs in Brussels, presenting the RECaN results
- Thursday 17 May – Strategic meeting of all four CARE Working Groups (funding will be made available; does not have to come from the WG's budgets)
- Friday 18 May – Celebration of European Cancer Nursing Day

**ACTION:** All WG members were asked to please mark these dates in their calendars to ensure availability.

The group was informed about conversations taking place between EONS and ESMO, about the possibility for EONS to organise a nursing track during the 2018 October ESMO congress, in Munich. This would replace a separately organised EONS 11 congress. EONS would have available one large meeting room for this track. DK, LS and EW have drafted a nursing track outline, for review by ESMO. The group suggested to try and obtain accreditation of such track, if possible, to make it even more attractive for nurses to attend. Pending confirmation, the meeting / nursing track would be announced at the November Leadership Summit in Ede.

#### **2. Research Travel Grant**

The WG agreed that preferably a grant winner should not receive another EONS Grant within 12 months after winning. When awarding a Grant, geographical spread would also

be taken into consideration. Wording will be as follows: "People that have not received funding over the past 12 months, have priority or preference."

**ACTION:** Task Group to amend wording of call for applications.

### **3. EONS Research Grant**

The WG discussed the experiences in obtaining outside funding for the EONS Research Grant. When IN contacted pharma companies about possible funding for the grant, she was informed that companies are not willing or able to supply such a substantial amount of money for a project they have not any involvement in the selection process of.

It was suggested to, in the future, obtain funding for and make available two Grants, for a smaller amount of money (EUR 10.000,-), for a "stepping stone project". The group agreed that research from outside the already wealthy countries should be encouraged. It was agreed for IN to speak to pharma companies to see what it is they would be interested in and willing to support. Furthermore, it was suggested to combine funding requests to pharma of the Research Workshop and the Research Grant. The evaluation of the Workshop could be used when contacting pharma.

**ACTION:** EM to explore the possibility of combined funding from pharma for both the Research Workshop and the Research Grant.

**ACTION:** AC put forward the idea that one of the future EONS Summits to have a Research focus.

### **4. Working Group composition (Chairs, Board Member representation)**

In January 2019, the following WG members have served (the maximum of) 3 terms of 2 years: AC, MW, DK, IN, UO, LS & TW. The group agreed to the following:

- LS, IN & NDC to leave the group by the end of 2017
- AC to leave the Research WG by June 2018.
- From June 2018, WO will be the new co-Chair, replacing AC.

Earlier this year, the group appointed two new Working Group members, rather than one. Therefore the Working Group now holds 12 people, which means only 3 vacancies become available.

LS informed MM she would like to become an observer in the Communication WG.

AC suggested he could perhaps move from the Research WG to the Advocacy WG by June 2018.

It was agreed that the WG members who will have served their terms: DK, MW, TW & UO would leave the group by December 2018.

**ACTION:** MM and WO agreed setting up the application process, with a closing date of end December. The application text should state that another call for applications would follow in a year's time, for four new members. AC, MW and WO agreed to hold a conference call to discuss the applications received and to undertake Skype interviews with shortlisted applicants.

### **5. Update on the previous Research Workshop held in Sweden**

The 5<sup>th</sup> EONS Research Proposal Workshop took place from 10 to 12 May 2017 at the Regionalt Cancercentrum, Stockholm, Sweden. In total 12 delegates took part in the Workshop, coming from 7 countries. The facilitators agreed there was a mixed level of knowledge amongst the participants. The participants provided positive feedback about the workshop, particularly appreciating the critical evaluations of their research proposal and the safe and highly learning environment in which the workshop took place.

**6. Plan for the next Research Workshop (venue, participants)**

The 2018 Research Workshop will feature a PhD theme. AC volunteered to host the event in Cyprus and AC, MW, WO agreed to be involved. MW agreed to contact GK, to see if he would like to join the Task Group.

Potential dates for the three day event are 6-7-8 June or 13-14-15 June. A maximum of 10-15 delegates can be accommodated, which includes 2 local delegates.

EW agreed to look at possibilities to obtain funding for the event. As discussed earlier, the group would look at combined funding between the Research Workshop and the Research Grant. Quotes from previous Workshop participants could be used, when contacting pharma. And state the aims and objectives, the rationale, the expected outcomes and the link with the EONS strategy. The event would not be advertised until funding has been secured.

**ACTION:** WO and MM agreed to work together on putting together information, for EW to use, when contacting pharma.

**ACTION:** AC would contact his university to explore the possibilities of having a flyer produced there, hopefully free of charge.

**7. Pending from previous meeting - website flyer “EONS is a potential professional research partner”,**

The WG members agreed that the website flyer, which was developed as a result of feedback received through the EONS Membership Survey, should be advertised on social media.

**ACTION:** AC had prepared a draft flyer and MW and EW agreed to review this draft flyer.

**8. Update on Change Champions Grant**

This Grant was set up in collaboration with the Royal Marsden Hospital (RMH). EONS is awaiting a payment from the RMH for giving out a next Grant. Rudi Briké has contacted the RMH in relation to this and is awaiting a response in follow up at the time of this meeting. When funding is received, a Grant will be given out in 2018. In total RMH will have paid EUR 10.000,- for the 2016 and 2018 Grants. EONS will be responsible for funding for the 2020 and 2022 Grants.

**9. Working Group representative for Task Group 2018 ECND**

**ACTION:** AC agreed to write to JW to see if she is willing to be the WG representative on this Advocacy Task Group.

**10. Planning next face-to-face meeting**

The group will meet on 17 May 2018. Furthermore, a next “regular” face-to-face meeting will be planned to take place in November 2018.

**ACTION:** MM to contact Working Group chairs about the November 2018 planning.



## **Minutes - EONS Research Working Group RECaN meeting, Friday 27 October 2017 NCVO, London, United Kingdom**

### **Participating:**

Andreas Charalambous (AC) (co-Chair), Mary Wells (MW) (co-Chair), Nuria Domenech Climent (NDC), Iveta Nohavova (IN), Wendy Oldenmenger (WO), Ulrika Östlund (UO), Elizabeth Patiraki (EP), Lena Sharp (LS)

### **Unable to attend:**

Daniel Kelly (DK), Greg Kotronoulas (GK), Jane Winter (JW), Theresa Wiseman (TW)

### **Agenda:**

#### **Friday 27 October**

#### **09.00 – 16.00 hrs RECaN Meeting**

The members of the group agreed to that the next version of Paper 1 is drafted as soon as possible and the final paper is submitted to the IJNS by the end of 2017.

### **Discussion of Paper 1**

Andreas has received comments from most co-authors and will work on these.

Key points:

Size and scale of review

Evidence base growing for interventions led by and involving cancer nurses – illustrates range and scope of cancer nursing across all stages of the care continuum and highlights the need for training and support for such interventions

Evidence base for cancer nursing covers all areas of the ICN definition of nursing – at all stages, in all settings, different levels of nursing.

Use the data in tables to pull out points for the discussion – evidence gaps etc.

### **Discussion of Paper 2 – meta-analysis**

Mary presented the slides used at ESMO, with updated forest plots from the meta-analysis.

Using Nurse-led vs usual care trials, n=119. Standard mean differences for anxiety, depression, QoL.

Aim for JAMA. Limited word count of 3000, plus 5 tables/figs.

Core message – cancer specific QoL scales show positive benefit of nurse-led interventions.

Cost effectiveness meta-analysis not possible as reporting poor and huge variety in 'measurement'. Narrative summary planned, with table of +ve and -ve 'costs'.

Key points:

Anxiety and depression – CES-D and HADS blunt instruments, not showing anything much.

QoL data not reported properly in many cases. General measures of QoL (e.g. SF36) not showing much difference in nurse-led vs usual care. Cancer specific measures showing differences in most domains.

Symptoms – this is difficult because so many different scales are used.

Discussed whether, for example, SDS and DT could be combined – decision was that we should not do this. Wendy and Ulrika to advise Pauline on whether and how fatigue scales might be combined. Decided that we could legitimately combine EORTC elements for pain and symptoms with other symptom scales.

How should we look at sustained benefit of interventions? So far, we have just looked at first 6 months after intervention. Decision to group as 6-12 months (intermediate) and >12 months (long-term).

*The members of the group agreed that authorship on the other papers will be offered to all members.*

### **OMAHA paper** (Elisabeth to lead)

We have 4 hours of transcripts on discussions and decisions. Could these be analysed as part of this paper? Maybe someone from the wider OMAHA group could do this? (?Cecilia and Maria)

### **Education paper**

Short communication probably most appropriate. Need to go back to individual trials and see what countries they are from, so that we can look at whether specialist nurses exist in those countries. Use column of who delivered intervention from the supplementary tables in Paper 1.

Think of questions related to education to ask Pauline to sub-group.

## **Trial design paper**

Lessons for future trials.

688 different measures across 119 trials – how are these used and reported.

Need for core outcome set, agreed measures.

What makes a nurse-led trial useful? Clear description of intervention, interventionist etc. Use of TiDiER framework.

Possibility of further analysis of dataset for other papers.