

Emerging PRC/EAPC RN study

The PRC and the EAPC RN are in the process of planning several new studies. The following note is a presentation of: **“A European symptom palliative care study, a prospective data collection in cancer patients during the palliative care disease trajectory”**

The EAPC RN has previously conducted two cross sectional studies, the cross sectional survey on pain and pain treatment (1,2) and the European Pharmacogenetic Opioid Study (EPOS) (3), and has also been involved in computerized assessment study by the European Palliative Care Research Collaborative, EPCRC (4).

Based on these and other studies (5, 6), it is generally agreed that there is a need to conduct an international prospective data collection in large representative patient samples, in order to:

- gain a better understanding of the symptom prevalence and symptoms variations over time in palliative cancer patients
- build on results from previous studies and further validate the assessment and classification systems for pain, cachexia, dyspnoea and other symptoms
- identify biomarkers and predictive factors for treatment selection and effect
- gain knowledge about the organization and delivery of palliative care and the variability across nations and institutions
- arrive at a basic set of indicators for assessment of patient characteristics and symptoms, endorsed by the EAPC RN, to be included in future palliative care studies
- ... reach other possible objectives

These are some of the issues discussed and considered as the basis in the planning and launching of a large European multicentre study. The upcoming study will probably have a “modular design” meaning that all centres need to include a minimum amount of data (the basic dataset), while other centres can collect more data, also supplemented with biobanking according to specific research objectives.

At present, the study protocol and research questions are being drafted. According to the timeline, the plan is to finalise the protocol and obtain ethical approval before the summer in order to include the first patients medio September 2010.

By this note we will like to inform you about the ongoing activities. We kindly ask you to sign up to take part in the study, give input and feedback about the study plan, design, as well as practical issues. Please contact Lotte Rogg (lotte.rogg@ntnu.no) or Stein Kaasa (stein.kaasa@ntnu.no). We would also like your participation in the inclusion at a later stage.

References:

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3. Klepstad P, Fladvad T, Skorpen F, Bjordal K, Caraceni A, Dale O, et al. The European Pharmacogenetic Opioid Study (EPOS): Influence from Genetic Variability on Opioid Use in 2209 Cancer Pain Patients. Abstract for the Research Congress of the EAPC, Glasgow 2010. In press. *Palliat Medicine*. [Abstract]. 2010.
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6. Borgsteede SD, Deliens L, Francke AL, et al. Defining the patient population: one of the problems for palliative care research. *Palliat Med* 2006; 20:63-68.