

MINUTES

SECOND MEETING OF THE EUPHORIC PROJECT

ROME, 9 JUNE 2006, 10:00 to 17:00

ISTITUTO SUPERIORE DI SANITÀ
VIA GIANO DELLA BELLA 34
ROOM 1, 2ND FLOOR, SIDE A

Participants:

Marina Torre - Istituto Superiore di Sanità, ISS
Fulvia Seccareccia - Istituto Superiore di Sanità, ISS
Paola D'Errigo - Istituto Superiore di Sanità, ISS
Gabriella Badoni - Istituto Superiore di Sanità, ISS
Stefano Rosato - Istituto Superiore di Sanità, ISS
Valerio Manno - Istituto Superiore di Sanità, ISS
Cristina Morciano - Istituto Superiore di Sanità, ISS
Danilo Fusco - Department of Epidemiology ASL RM E
Gerold Labek - EFORT-EAR Innsbruck Medical University
Weimin Ye - Karolinska Institutet
Fang Fang - Karolinska Institutet
Unto Häkkinen - Centre for Health Economics at Stakes
Roberto Elosua - Institut Municipal d'Investigació Mèdica
Emanuela Taioli - Genetics Research Institute ONLUS
Dora Psaltopoulou - University of Athens, School of Medicine
Karolina Lyubomirova - National Center of Public Health Protection

1) Welcome

Dr. Fulvia Seccareccia welcomed everybody to the meeting. She apologised for the delay in the organisation of the meeting, already scheduled in June 2005. The delay was due to some organisational problems (described at point 3) occurred at the beginning of the project and solved only at the end of 2005. As already notified to European Commission Dr. Seccareccia communicated that she has to resign as project leader because of internal rearrangement of her workload and her personal problems.

To assure the regular development and success of EUPHORIC, Eng. Marina Torre would take over definitively the scientific leadership of the EUPHORIC project and would be the reference point for all scientific questions.

Eng. Marina Torre invited all of the participants to the meeting to introduce themselves.

2) Approval of the Agenda

The agenda was formally approved.

3) Organisational issues

Eng. Marina Torre gave a brief overview of some problems occurred at the beginning of the project and she illustrated some organisational and administrative issues.

- a) **EAR as new partner.** At the beginning of the project the Austrian Heart Foundation partner withdrew from the project since he was not able to found the co-financing amount. As suggested by the EU Commission, ISS tried to find another partner in order to maintain the whole fund allocated in the Grant. On October 2005 European Arthroplasty Register (EAR) agreed to be part of the project and EAR was accepted by EU Commission as new partner.
- b) **Amendments to the grant.** On the 10th of April ISS sent the EU Commission a letter asking for several amendments. Currently the Commission is working on the contract to resolve the amendments question, a quite complicate process that will probably take some weeks. Anyway ISS hopes to receive the amended contract by the end of July. By then the EAR will be officially included in the project and will receive the pre-financing contribution. Bulgaria and Denmark, like other countries and Institutions willing to cooperate at the project without any financial contribution, will be included as Collaborating Partners a procedure that does not required amendments to the contract.
- c) **1st further pre-financing.** As stated in the grant, all beneficiaries will receive the first further contribution only if 70% of the pre-financing has been used. At that moment ISS can submit a table summarising all the expenses and EU Commission will prepare the payment. No justification of expenses is required by the Commission. Scientific report about the activities performed during the first year of activity was already sent to the Commission on April 10th.
- d) **Travel expenses.** The destination may be modified, but any changes shall be communicated to the operating unit at the DG SANCO, that has in charge the EUPHORIC project. In any case, at the end of the project, the total amount must not exceed the allocated amount with an allowance of 10%. About any changes the partners shall give notice contacting the following persons: Gabriella Badoni (gabriella.badoni@iss.it), Dr Cristina Morciano (cristina.morciano@iss.it)
- e) **Activities performed during the 1st year:** Survey, participation to the 4th meeting of the Health Systems Working Party (HSWP) held in Luxembourg on April 26th, 2005 (see slides available on the web http://ec.europa.eu/health/ph_information/implement/wp/systems/docs/ev_20050426_co02_en.pdf), questionnaire sent by NIVEL (Scientific Assistance Office of the Health Systems Working Party on) to monitor the progress of the project preparation of 1st year scientific interim report. From the analysis of Gantt chart presented by Eng. Torre it emerges that there is a delay of about eight months in respect of the planned activities. The partner coordinator has already asked EU Commission about the possibility to postpone the deadline of the project.

4) Results of Survey

Despite the project came across many difficulties during its first year of activity, the first phase (survey) can be considered concluded. During the meeting held on December 16th, 2004 a draft list of outcome indicators was presented as well as a draft of the questionnaires. During the first semester of the 2005 these two documents, circulated among the partners, have been finalised on the basis of the partners suggestions. The questionnaires completed by all of the partners have been collected in the deliverable, available as draft (see the file in attachment *Deliverable EUPHORIC.doc*).

5) 1st Deliverable preparation

During the meeting all of the partners received a copy of the first deliverable as draft, containing the protocol of the project, the description of each country, a list of web sites and/or reports focussing on the objectives of the project (collection and validation of outcome indicators), the list of indicators and the questionnaires filled in by all of the partners (1st version). All the collected material will be used to be published in the web site.

Attached to these minutes all of the partners would receive the electronic form of the deliverable. They are requested to verify, amend and complete (where necessary) their part. Also it would be appreciated a contribute to complete the following sections:

- web sites, reports, documents of interest;
- results of survey (description).

Furthermore the deliverable completed should be sent back to Gabriella Badoni (gabriella.badoni@iss.it) or to Dr Cristina Morciano (cristina.morciano@iss.it) no later than the 5th of July, 2006.

6) Planning of future activities

a) Questionnaires In order to fit the collected information for the web site, Dr. Paola D'Errigo explained to the partners how to reorganise the information. To this purpose she illustrated the excel table where the information would be coded, according to the definitions agreed during the meeting. The coordinator would send all of the partners that excel table. Partners GRI and EAR Dr E. Taioli and Dr G. Labek raised a question: *how is it possible to track the patient in datasets available from the partners?* Thus they suggested the development of a questionnaire, addressed to all of the partners, to ascertain the following questions:

- Is the admission date available in your data source?
- Is the discharge date available in your data source?
- Are life or death status at the discharge available in your data source?
- Is the admission diagnosis available in your data source?
- Is the discharge diagnosis available in your data source?
- In your country is it possible to track the patient?
- Are you aware of EU projects based on individual data?
- In your country is it permitted by law to get the personal information of patient?

Once approved the minutes of the meeting, ISS would send this questionnaire to all of the partners.

b) Web site. Eng. Marina Torre introduced CASPUR, Inter-University Consortium for the Application of Super-Computing for Universities and Research, an inter-university computing Consortium established in 1992 in Rome.

The Consortium is a non-profit organization, financed by MIUR the Ministry for Education Universities and Research (Ministero dell'Istruzione, dell'Università e Ricerca) and by other associated Universities. Its purposes are to manage a centre capable of assuring a high quality and high-powered processing service; to promote the use of the most advanced information processing systems, to support public and private scientific and technological research; to develop research programs aiming at a more effective and innovative usage of information and communication technology, in collaboration with other organizations and enterprises.

He cooperates with the National Institute of Nuclear Physics (Istituto Nazionale di Fisica Nucleare - INFN), the Italian National Agency for New Technologies, Energy and the Environment (Ente per le Nuove Tecnologie, l'Energia e l'Ambiente - ENEA), the National Institute for Geophysics and Volcanology (Istituto Nazionale di Geofisica e Vulcanologia – INGV), the Institute for Applied Computing (Istituto per le Applicazioni del Calcolo - IAC-CNR), the Institute for the study of Nanostructured Materials (Istituto per lo Studio dei Materiali Nanostrutturati - ISMN-CNR), the National Institute for the Study and Application

of Naval Architecture (Istituto Nazionale di Studi ed Esperienze di Architettura Navale (INSEAN), and several other Universities.

Dr. Andrea Paladin showed some websites of other Institutions designed by CASPUR, just to give an example of the ways the architecture of Euphoric website could be. As for the language of the Euphoric website, Eng. Marina Torre suggested that only the section specific for the description of each country-partner as well as the explanation of the broad aims of the projects needs to be translated in the mother-tongue of each partners' country, whereas the other parts of the website should be in English. The sections dedicated to each country should include links to some relevant national institutional websites.

- c) **Pilot** On the basis of the information collected during the survey two major area of action can be highlighted: cardiovascular and orthopaedics.
- i) **Cardiovascular.** In the cardiovascular area the project has the possibility to cooperate with Dr Anselm Gitt, who expressed his interest in the project during the HSWP on April 26th 2005 and stated that he is very interested in finding a way of joining the efforts. Dr. Fulvia Seccareccia gave a presentation about the Euro Hearth Survey Programme coordinated by Dr. Gitt, showing some slides explaining the Euro Heart Survey rationale and structure (<http://www.escardio.org/initiatives/ehs/>). Dr. G. Labek would be interested in contacting Dr. Anselm Gitt to receive some explanations about the methods have been used in the Survey Euro Hearth Programme.
 - ii) **Orthopaedics.** All of the partners agreed that Dr G. Labek, who is the EFORT-EAR (European Arthroplasty Register) coordinator, would be the pilot study coordinator for the orthopaedic issue (collection of standardised information through the different registers already running in Europe). In this phase, since outcome parameters in arthroplasty have been already determined, it would be interesting to validate them on large cohorts of patients. The main aim of this part of the project is to evaluate the different instruments in quality control of medical products (Clinical studies, Manufacturer, Public Health Authorities, Registers) and to set up detailed basic information about Register Organisations and the historical development. A result of the pilot could be a negotiations with politicians to include Arthroplasty Registers as regular instruments (<http://www.ear.efort.org/>).
 - iii) **Indicators Sheets.** Detailed sheets of indicators (as shown during the meeting on December 16th 2004) will be prepared for a set of indicators selected for the pilot phase. These sheets will be used as an operating manual for the selected indicators calculation and validation. The form will be sent by the coordinator to be completed by all of the partners.
 - iv) **Cooperation with OECD Health Quality Indicators Project (HCQI).** Cancer is a pathology that cannot be neglected in an outcome project. There are already several projects working on this topic, but the OECD Health Quality Indicators Project (HCQI), besides proposing indicators concerning the cancer pathology (for example “cancer screening rates and survival”) has been working on topics overlapping with those of the EUPHORIC project. Dr. Edward Kelley, the scientific responsible of the HCQI, was contacted during the HSWP on April 26th. ISS proposed to share EUPHORIC experience and knowledge with HCQI project.
All of the participants to the meeting agreed to consider Unto Hakkinen and Emanuela Taioli as potentially candidate to participate in possible OECD meetings. ISS will contact Dr Edward Kelley to arrange the cooperation.

7) Any other business

- a) **Request of ÖBIG and BQS to become Collaborating Partner.** The Health Institutes ÖBIG and BQS, the public health institutions responsible for outcome measurement in medicine in Austria and in Germany, have given statements of interest to be included in the EUPHORIC-procedures. They have not requested financial resources, but they aim to be

included in consultations as to give feedback that might be strategic to maximize the research impact in public health. Partners agreed to invite them to join in.

- b) Euphoric publications.** As for the dissemination of the aims of EUPHORIC project, all of the partners accepted the proposal to publish an article about the EUPHORIC protocol and Survey results in a public health journal (European Journal of Public Health, Health Quality and Management, etc...).
- c) Euphoric Logo.** A preliminary of the logo had been presented. It is a hand-painted faun, a mythological symbol of wild passions (such as euphoria, that could be the link with Euphoric). As suggested a crescent moon, made up of yellow stars to remind of the EU logo, could be put under the faun, to simulate a sort of smile.

8) Next meeting

The next meeting will take place in Rome in December 2006. The coordinator will send the possible date by the end of September.

The meeting ended at 04:00 p.m.