MINUTES

4TH MEETING OF THE EUPHORIC PROJECT

HELSINKI, *9 OCTOBER 2007*
10:00 – 13:00 and 14:00 – 16:00

STAKES
Lintulahdenkuja 4
Room Monitoimi A

Participants:

MB: Torre Marina − Istituto Superiore di Sanità (ISS), Rome (Italy)
AB: Bellocco Rino − Karolinska Institutet (KAR), Stockolm (Sweden)
AB: Häkkinen Unto and Mikko Peltola − Centre for Health Economics at Stakes (STAKES), Helsinki (Finland)
Douphi Persephone − Statistics and Registers, Stakes, Helsinki (Finland)
AB: Fusco Danilo − Department of Epidemiology ASL RM E (DEASL), Rome (Italy)
AB: Labek Gerold − EFORT-EAR Innsbruck Medical University (EAR), Innsbruck (Austria)
AB: Marrugat Jaume and Ferrer Yolanda − Institut Municipal d'Investigació Mèdica, Barcelona (Spain)
AB: Psaltopoulou Theodora – National and Kapodistrian University of Athens (NKUA), Athens (Greece)
CP: Mathys Stefan − Ludwig Boltzman Institute (LBI), Vienna (Austria)

Absentees:

CP: Alejandro Allepuz – Catalan Agency for Health Technology Assessment and Research (CAHTA) Barcelona (Spain)
CP: Karolina Lyubomirova − National Center of Public Health Protection (NHCPH), Sofia (Bulgaria)

Absent without informing of the reasons:

AB: Emanuela Taioli – Genetic Research Institute (GRI), Milan (Italy)

Note: MB: Main Beneficiary, AB: Associated Beneficiary, CP: Collaborating Partner

Invited:

ECHIM Project: Arpo Aromaa, Katri Kilpelainen (Public Health Instiurte), Helsinki (Finland)
OECD Health Care Quality Indicators Project: Päivi Hämäinen (STAKES), (Finland)
HDP Project: Olly Nylander (STAKES), Helsinki (Finland)

1. Welcome

Marina Torre (ISS) welcomes everybody to the 4th meeting of the EUPHORIC project. In particular, she welcomes the new associated beneficiaries (SAR, SOFCOT, TILAK and LBI). Marina Torre thanks Jaume Marrugat (IMIM – CV pilot leader) and Gerold Labek (EAR – orthopaedics pilot leader) for all the work done this semester, especially in the support given to the whole organization of the project, in the preparation of the revised First Interim Report, in the definition of the WPs and deliverables of the whole project, and for all the efforts put into the preparation of the pilots' protocols as well as the organization of all the activities and the involvement of the other partners.

Marina Torre introduces Dr Stefan Mathys from the Ludwig Boltzman Institute (LBI). Dr Stefan Mathis from the Ludwig Boltzman Institute introduces himself and describes the tasks of his institute which deals with the assessment of technology and medical activities.

2. Approval of the agenda

In order to have a structured way of reporting and discussing results and activities, the agenda has been structured following the organization in WPs as described in the First Interim Report. In order to have the possibility of meeting the representatives of the ECHIM and OECD projects (available at 11:00 and 11:15),

Unto Häkkinen suggests interrupting the discussion to await their arrival and to introduce the WP 3. All the participants agree and the agenda is formally approved.

3. Activities related to horizontal work packages

a. WP 1 Management of the project (Marina Torre)

i. Network among partners and contact with DG SANCO and HSWP

In these 6 months efforts have been put into strengthening the consortium and the contacts with DG SANCO and the HSWP. On June 11-12 , Marina Torre, Jaume Marrugat and Yolanda Ferrer participated in the 8th meeting of the HSWP held in Luxembourg. All the information related to the activities of the HSWP are available on the website http://www.nivel.eu/EC/WPHealthSystems/. Marina Torre invites all the partners to register at this site.
A summary report of the activities performed in the first semester of the year was sent to the HSWP and the EUPHORIC project was included in the last HSWP newsletter published in September 2007. A copy of the .PDF file was sent by ISS to all the partners (Newsletter).

ii. New collaborating partners

Thanks to Gerold Labek, four new collaborating partners were included in the project in this period (Slovak Arthroplasty Register (SAR), Societé Française de Chirurgie Orthopédique et Traumatologique (SO.F.C.O.T.), Tyrolian Arthroplasty Register (TILAK), and the Ludwig Boltzman Institute (LBI)). Gerold Labek will present them shortly. Dr Stefan Mathys from the Ludwig Boltzman Institute has recently performed a systematic review of the CV registers (87 found). LBI could contribute to both the CV and the arthroplasty pilots by offering the possibility of getting in touch with the European registers collected on the list. Jaume Marrugat aims to include as many as possible databases in the pilot, prioritizing those coming from the EUPHORIC partners and then the others. Therefore, he will send a letter to all the CV registers included on the list and undertaken after the year 2000 (for the homogeneity of the MI diagnosis) and inviting them to participate in the pilot.

iii. Meetings organization

Last semester, a meeting of the core group of the project was organized in Barcelona on 4-5 July 2007 in order to define the pilots' protocols and finalize the organization of the project. Minutes of the meeting will soon be put on the members area of the website.

iv. First Interim Report

The First Interim Report was submitted in the revised version on August 9. In this report, partner GRI was not included since they did not provide the requested documents. On the basis of the information received during the audit held in Rome at the ISS on October 2, the report was very appreciated by the EU and the next payment is ready. Marina Torre suggests using the first page of the Interim Report, prepared on the basis of the guidelines received and approved by the Commission, as the cover page for the forthcoming deliverables.

v. Evaluation of the project

As requested by the EU Commission, a deliverable related to the preparation of a protocol for internal and external evaluation was included in the First Interim Report. The document will be prepared by the end of 2007 and the related questionnaires will be put on the website. Marina Torre will send a draft evaluation plan to the partners by the end of November 2007.

vi. Use of the members area of the website

Within a week, all the partners will receive a user-id and password in order to access the members area of the website. In order to share the documents, the organization of the folders is discussed. All the EUPHORIC documents will be posted there to reduce e-mail traffic among partners. Marina Torre will check with CASPUR (technological partners) who will be authorized to upload the documents. The possibility of receiving an e-mail alert when a new document is uploaded on the website will be implemented.

b. WP 2 Dissemination strategy (Marina Torre)

i. Dissemination plan

As requested by the EU Commission, a dissemination plan has to be produced by December 2007. Marina Torre asks all the partners to provide information about events or publications they are planning to do for the next year.

ii. Diffusion policy

The document proposed by Jaume Marrugat during the Luxembourg meeting is discussed and approved.

iii. Organization of the final conference

Date and location of the final conference are proposed.
Marina Torre asks all the partners to prepare a proposal for and to contribute to the organization of the conference by inviting some speakers. The proposed date for the conference is October 2008 at an undecided location in southern Italy.

iv. Leaflets

At present, a leaflet is being translated into Spanish, Austrian, and Swedish. Marina Torre suggests that SO.F.C.O.T. translates the document into French. Gerold Labek is put in charge of following up on this item.
Marina Torre asks all the partners that have not yet submitted the translated version to send it to Gabriella Badoni as soon as possible. All the partners agree that if new collaborating partners are included in the EUPHORIC consortium, an update of the leaflets will be done by ISS.

v. EUPHORIC Bulletin: Marina Torre proposes developing an electronic bulletin that can be linked to the information collected on the website and disseminated by each partner through their own network. In order to prepare the bulletin, she will request the help of the partners when necessary.

c. WP 3 Liaison with other EU projects, EU programmes and health stakeholders

Unto Häkkinen (STAKES), responsible for this WP, introduces the invited representatives.

i. ECHIM (Arpo Aromaa, project coordinator, Katri Hakulinen, project coordinator) (leaflet). ….

ECHIM first developed a long list of health indicators. From among those indicators them, a short list has been defined. ECHIM is working with all the MS to develop and implement the short list indicators. They are also discussing and drawing the implementation guidelines. The contribution of EUPHORIC to ECHIM is considered very interesting since it is related to outcome indicators. Marina Torre was contacted by ECHI in order to suggest five indicators to be included on the ECHI short list. The EUPHORIC consortium will select

them on the basis of the ECHIM inclusion criteria. The selected indicators will be included in the section on health care quality. Katri Hakulinen is the reference person for further contacts.

ii. OECD (Päivi Hämäläinen, Finnish coordinator of the OECD quality indicator project). The HCQI project is a subproject of the OECD health care project. Twenty-three to thirty-two countries are participating in the project that was developed from the previous work done on a project of the Commonwealth Fund NY and the Nordic Council. A set of 10 indicators was developed from the previous work done that identified priority areas for additional indicator development. Six areas were selected: cardiac care, diabetes mellitus, mental health, patient safety, primary care and prevention/health promotion. The first set of indicators has been included in the OECD systematic data collection and will be collected yearly. In-patient safety and mental health fields were included in 2005. The HCQI project still does not have any new indicator lists available. Arpo Aromaa highlights the need to develop indicators on outcome after procedure.

iii. eHID (Marina Torre). The First Interim Report of the project (available on internet) was distributed. eHID focuses on information collected by GPs for four specific indicators: incidence and prevalence of diabetes, burden of mental illness, and prevalence of ischaemic heart disease. Jaume Marrugat will check the usability of the data collected by the eHID project in the CV project since the analysis refers to British local prevalences.

iv. EUnetHTA (Gerold Labek). The EUnetHTA project will end in December 2008 and the structure of the project has already been defined so cooperation is not possible. They are now preparing the final report, but are willing to cooperate with new projects in the future. .

v. EUGLOREH (Marina Torre). Marina Torre contacted Luciano Vittozzi, the project leader of the EUGLOREH project. The aim of this project is to produce a report about health in Europe by the summer 2008. Luciano Vittozzi agreed to establish cooperation with EUPHORIC, therefore, he proposed considering a section dedicated to EUPHORIC in the report or to report the results of both EUPHORIC pilots in the specific sections (2.3.1; 2.3.11). Marina Torre asks the leaders of both pilots to evaluate if EUPHORIC could contribute to the report with the results achieved in both pilots.

vi. Eurocare: Emanuela Taioli (Associated Beneficiary GRI) did not attend the meeting and could not present this point.

4. Activities related to project objectives (core work packages)

d. WP 4 Indicators development (Marina Torre)

i. List of indicators (first result).

The list of indicators was defined and included in the last version of the Deliverable N. 1 submitted to the EU Commission.

ii. ***Deliverable N.1 "Survey: the first phase of the project":*** The final version of the first deliverable was sent to the EU Commission in July. It was also distributed to all the ECHIM participants.

iii. ***Deliverable "Detailed sheets of the collected outcome indicators (long list)":*** A draft version of the deliverable, which gathers all the sheets describing the indicators, is distributed. The deliverable will be released in its final version by the end of the year. All the information collected will be used to feed the indicators web-based database. Theodora Psaltopoulou (NKUA) will help in preparing the sheets that Emanuela Taioli has not sent.

iv. ***Glossary:*** During the HSWP meeting held on December 5 2006 it was decided to build up a glossary of the terms used by the project in order to adopt a common language. In June 2007, the EUPHORIC project was requested to contribute to the glossary by sending about 5-10 items related to best practice and benchmarking. Marina Torre thanks Rino Bellocco (KAR), Danilo Fusco (DEASL), Gerold Labek (EAR) and Sergio Mariotti (ISS) who actively contributed in producing this document. This activity also resulted in the idea of preparing a glossary which would be useful for the EUPHORIC project. Jaume Marrugat proposed to refer to the latest edition of the "Last's Dictionary of Epidemiology" for the most common terms. Marina Torre proposes to include additional terms in the list submitted to the HSWP in order to build a specific glossary for outcome research to be put on the website. Each partner is asked to integrate the existing glossary. "Last's Dictionary of Epidemiology" could be considered as a reference.

e. WP 5 Development of an adverse outcome risk indicator in real clinical and register databases, and its possible use in administrative systematic databases (Gerold Labek and Jaume Marrugat).

i. WP 5.1 Cardiovascular pilot (Jaume Marrugat)

1. Description of CV pilot protocol.

   A two-step approach will be applied:

   1st step: Data from population-based hospital MI registers will be used to fit predictive models of events at 28 days and perhaps 6 or 12 months only in patients with acute myocardial infarction undergoing the following procedures:
   CABG, PTCA and coronary angiography.
   This must be done in order to prevent heterogeneity in patient characteristics that could stem from taking all patients who undergo these procedures (since some of them are patients with stable coronary heart disease).

   The Mascara Study (57 randomly selected Spanish hospitals) meets these characteristics and will be used to determine the role of individual and hospital characteristics on the described outcome. This will allow the CV pilot to come up with a model with a number of significant variables that will benchmark hospitals. This information will permit the CV pilot to determine a set of important variables that should be ideally collected from administrative discharge records to achieve a standardized hospital benchmark for these procedures in Europe. At hospital level, a minimum number of easily collectible characteristics should allow proper classification. Country (simple) characteristics will be taken from existing or completed European projects (EUROCISS, ECHIM…).

   2nd step: The fitted model for 30-day mortality should be validated in other registers from different countries in Europe and the hospital discharge records themselves. If the Beta estimates for each variable are similar among countries, the model could be used to benchmark hospitals. Expected 30-day mortality rate can then be calculated with individual, hospital, and country characteristics if average patient characteristics, together with the country and hospital characteristics, are known. This theoretical rate can thereby be compared to the actual rate and the hospital benchmarked from among the remaining available hospitals previously benchmarked in Europe. This result could be considered as a basis to develop a web application set up.

2. First results of Mascara database analysis. A set of bivariate tables are presented together with the first models for individual and hospital characteristic levels. Jaume Marrugat undertook the analyses in a two-step way: firstly, fitting models with individual patient characteristics , and secondly, including hospital and country characteristics in the multilevel analysis. In order to measure the variability among countries, Jaume Marrugat asks all the partners to contribute to the analysis by providing data extracted from their own databases (about 300 patients). The following years will be considered: 2002 for all the partners, the most recent year that each partner has available.

CV questionnaires on the necessary variables from hospital characteristics, hospital registers and discharge records will be distributed among the partners as soon as possible to explore the consistency of data collected in the participant countries. Since Danilo Fusco is preparing a survey about the information collected through the discharge records in the EUPHORIC participating countries, he will send his comments on the questionnaire on discharge records and will coordinate its distribution to the partners with Jaume Marrugat. Anselm Gitt has not answered the three contact attempts made in the last three months: collaboration with Euro Heart Survey is thereby unlikely. Unto Häkkinen suggests using the Finnish register of MI patients based on admission records which is complete and contains many individual variables. A meeting or a conference call between Jaume Marrugat and Unto Häkkinen is needed to make an agreement on data utilization before March 2008. Jaume Marrugat will send what he needs and the steps to follow.

ii. WP 5.2 Orthopaedics pilot (Gerold Labek)

1. Description of orthopaedics pilot
   The orthopaedics pilot was structured in subpackages.
   5.2.1: Assessment and summary of the arthroplasty registers in Europe.
   It will be based on the questionaire mentioned at 2. waiting for appoval., A personal visit is recommended to allow a detailed analysis.
   5.2.2: Comparison of clinical literature and register data concerning outcome measurement. The implants to be studied are defined, and some preliminary results are presented. There seems to be a significant bias in metaanalyses of clinical studies which might reduce the validity of this major source for implant assessment.
   5.2.3: Quality control mechanisms and quality control procedures by manufacturers.
   G.L. will ask manufacturers to deliver their internal procedures for quality management. M.T. will give support with her personal expertise in the evaluation of the material.
   5.2.4: Significance of the indicators proposed from a medical expert's point of view.
   The indicators identified in phase 1 of the EUPHORIC project do not seem to be of high importance from an orthopaedic surgeon's point of view. A scientific statement concerning all indicators, originally identified and now proposed, will be done.
   5.2.5: Public health related data sources and their linkage.
   This dataset is structured in three parts.
   1) A summary of public health related outcome-focused registers in Finland and Sweden: SF and S have long term experience and a mature system in outcome measurement by registers. STAKES and KAR will prepare a summary report including all relevant projects, their parameters and indicators as well as their function and activity in the network of registers and the public health system.
   2) A summary of public health related datasets concerning implant safety: The data sources will be summarized and a comparison of some major incidents (implant fracture) will be made in order to evaluate the differences between countries, literature and registers
   3) Discharge records: To assess the validity of discharge records for outcome measurement. Since this WP will be influenced by potential budget relocations, the detailed definition was postponed after the decision.
   5.2.6: Summary of the basic data concerning indicators from international databases.
   Will try to calculate the proposed indicators based on the databases available now.

2. Questionnaire about registers
   The questionnaire has been sent for review. Since Rino Bellocco has replied with comments the day before the meeting, it was agreed to modify the questionnaire according to the proposals and to circulate it for final agreement by e-mail. Deadline for final approval will be 31 December 2007.

iii. WP 5.3 Validation of the datasets: discharge records, registers, surveys and clinical studies available in the participant countries (Gerold Labek). Already discussed in detail during the meeting of 8 October 2007 (see minutes of the meeting).

1. Risk adjustment and statistical analyses (Gerold Labek).

2. Deliverable "discharge records" (Danilo Fusco). Already discussed (see WP 5.1, point 3) since the collection of information related to the discharge records is also presented in the CV pilot.

3. Cooperation with HDP (Olli Nylander, Finnish coordinator of the Hospital Data Project). HDP 1 Metadata from 1999, focus on diagnoses. Results are also used outside the project. It is considered a good start and foundation for EU data collection and analyses. Objectives HDP 2: improve comparability of statistics. Increase scope of data collected. Extend the work to new member states. Identify ways of extending data (outpatients, cross border, patient mobility). Focus on diagnosis and procedures.

   Improve access and use of the data by (inter)national organizations. Progress. Familiarization for new states. Metadata and methods ready. Cooperation with the OECD/WHO is setup. Data collection for time series 1999-2005 for old and new member states. Expert group on procedures nearly ready. New data collection with scope extension and coverage of EU starts in autumn 2007. Objectives: improving comparability, use of data, extension of analyses, cooperation with other agents 2007-2008. Medio 2008 project will be finalized within time frame and budget.

f. WP 6 Setting up and maintaining an indicators database (Marina Torre)

i. Updating of the EUPHORIC website.

Marina Torre asks all the partners to check their own page and to send all the integrations and suggestions to Gabriella Badoni. Marina Torre asks the leaders to provide a short description of their respective pilots. Strategies about the publications of the prepared documents were discussed.

ii. Preparation of the database and validation of data.

Marina Torre shows all the partners how the web-based database has been filled in using the information collected from the questionnaire during the survey. The starting point is the indicators list. Only the data sources that could be used to calculate the 54 indicators included in the EUPHORIC long list have been considered. A guideline for the completion of the questionnaire is distributed. All the partners are asked to check the information and validate their own record. It is also possible to add new records and to add other information if available.

iii. Browsing the database

The next step is the implementation of the browsing strategies. Marina Torre asks all the partners to propose how to organize the browsing (keyword, subject, country?).

5. Any other business

Marina Torre indicates that the project has to present a Second Interim Report by February 15. In order to be ready by the deadline, Marina Torre invites all the partners to finalize the deliverables that were planned for the period 15 December 2006 to 14 December 2007. Jaume Marrugat mentions that both cardiovascular and orthopaedics protocols as well as the sheets with the preliminary statistical analyses are deliverables that could be presented as technical reports.

Partner KAR, informed about the GRI issue, agrees on initiating the necessary steps to achieve the objectives of recycling this partner's funds.

6. Next work-in-progress meetings

a) Athens: 3-5 December 2007 (core working group)
b) Innsbruck: 13 and 14 March 2008 (to be confirmed)
c) Final conference: October 2008 at an undecided location in southern Italy.

The meeting ended at 17:00.