

MINUTES

3RD MEETING OF THE EUPHORIC PROJECT

LUXEMBOURG, 24 APRIL 2007

9:00 – 13:00 and 14:00 – 15:30

EUROPEAN COMMISSION

HITEC BUILDING

RUE EUGÈNE RUPPERT 11, L-LUXEMBOURG - GASPERICH

ROOM HTC 02/280

Participants:

- MB: Torre Marina – Istituto Superiore di Sanità (ISS), Rome (Italy)
AB: Bellocco Rino - Karolinska Institutet (KAR), Stockholm (Sweden)
AB: Labek Gerold – EFORT-EAR Innsbruck Medical University (EAR), Innsbruck (Austria)
AB: Häkkinen Unto – Centre for Health Economics at Stakes (STAKES), Helsinki (Finland)
Kontio Niina - Statistic and Registers, Stakes, Helsinki (Finland)
AB: Marrugat Jaume – Institut Municipal d’Investigació Mèdica (IMIM), Barcelona (Spain)
AB: Psaltopoulou Theodora – National and Kapodistrian University of Athens (NKUA), Athens (Greece)
CP: Allepuz Alejandro – Catalan Agency for Health Technology Assessment and Research (CAHTA),
Barcelona (Spain)
EC: Artur Furtado – DG SANCO, Luxembourg (until 11:30)

Absentees:

- AB: Fusco Danilo – Department of Epidemiology ASL RM E (DEASL), Rome (Italy)
AB: Taioli Emanuela – Genetic Institute of Research (GIR), Milan (Italy)
CP: Lyubomirova Karolina – National Center of Public Health Protection (NHCPH), Sofia (Bulgaria)

Note: MB: Main Beneficiary, AB: Associated Beneficiary, CP: Collaborating Partner, EC: European Commission

1. Welcome

Marina Torre welcomed everybody to the 3rd meeting of the EUPHORIC project, the first after the approval of the amendment of the contract. In particular, she welcomed the new partner EFORT-EAR (Gerold Labek) who was officially recognized as Associated Beneficiary of the project after the approval of the amendment.

A special welcome was addressed to Alejandro Allepuz of the Catalan Agency for Health Technology Assessment and Research (CAHTA), included in the project as a collaborating partner since March 27. CAHTA is cooperating within the European Arthroplasty Register (EAR) and expressed its interest in joining EUPHORIC.

Marina Torre thanked Jaume Marrugat for having accepted the leadership of the cardiovascular pilot.

Partners DEASL and GRI did not attend the meeting, however, they sent a proposal of their involvement in the future activities (Attachments 1 and 2).

2. Approval of the agenda

Following the suggestion received from the EU Commission, point 5.e Dissemination of the results was added to the agenda that was formally approved.

3. Organizational issues

Marina Torre gave a brief overview of the events that occurred after the last EUPHORIC meeting held in Rome in June 2006 and she illustrated some organizational and administrative issues.

On 29 January 2007, the amendment to the contract was officially approved by the Commission. The amendment stated the inclusion of EAR, the change in the leadership of the project since Fulvia Seccareccia resigned, and the change in the deadline (postponed by one year) (14 December 2008). Unfortunately, formalizing all these changes required a long time, considering that the request for the amendments started in April 2006. Consequently, the project came to a standstill and the milestones envisaged in the initial work plan were delayed. For this reason, the overall schedule was reorganized (as described in the EUPHORIC First Interim Report sent to the EU Commission on February 22 2007).

Despite the difficulties raised by the administrative problems, the project completed its first phase (survey) and started the organization of the second phase (the pilot). Marina Torre asked every partner (present and not) to give a more active contribution in the remaining 20 months so as to fulfil the project's goals. On the basis of the survey's results, the pilot phase will focus on cardiovascular and orthopaedics, confirming the initial hypothesis stated in the agreement. Gerold Labek and Jaume Marrugat were designated project leaders of the orthopaedics and cardiovascular pilots respectively.

Marina Torre referred to some comments received by the EU after submitting the First Interim Report. They mainly focussed on the importance of working as a network and disseminating the results. Therefore, interaction with other projects relevant to the definition of indicators (i.e. ECHIM, eHID) was emphasised in order to share documents, results and methodologies and to define the strategies that EUPHORIC will implement to disseminate the results. The Main Beneficiary (MB) will accomplish such requests as soon as possible.

4. Results of the first phase of the project

The results of the first phase of the project were presented in the first deliverable "EUPHORIC Project: results of the first phase of the project" submitted to the EU Commission in its final form on April 23 2007. The deliverable includes the outcome indicators list and other collected information. During the first phase of the project, the website (www.euphoric-project.eu) was set up. The website was illustrated by Marina Torre (see point 5.c).

M. Torre handed out copies (CD) of the documents to the meeting participants which have been produced in the project up to now (first deliverable, First Interim Report with all the attachments, leaflet).

5. Planning of future activities

Marina Torre showed a draft list of the work packages outlined for the organization of the project (Attachment 3). The list contains five WPs:

- WP 1 Coordination of the project (ISS)
- WP 2 Liaison with other EU projects (STAKES and GRI)
- WP 3 Indicators development and implementation (EAR, IMIM)
- WP 4 Setting up and maintaining the indicators database (ISS)
- WP 5 Promotion of EUPHORIC, dissemination of results (ISS).

All the WPs were discussed following the approved agenda of the meeting.

As for the indicators development and implementation (WP 3), complementary to the activities performed in the first phase of the project, Marina Torre proposed to prepare a deliverable by collecting detailed information for the selected indicators (WP 3_1). Each indicator will be described in a sheet containing: the indicator's definition and description, and source of information (bibliography). Marina Torre offered the availability of ISS to coordinate this activity. The partners were invited to submit the requested information for the indicators that they had added to the first list.

In benchmarking, it is important to know how data are adjusted, therefore, the importance of knowing what kind of confounders would be considered for both pilots and where the data are produced were underlined. In some cases, discharge records might be considered and validated. It was proposed to check the discharge records as a database for outcome measurement. A final product of this activity could also be a guideline to decide if a selected database can accomplish the objectives since it contains all the necessary information. Therefore, considering that there are different contexts in the participant countries, it would be useful to produce a summary on what information is routinely collected, how it is organized and managed (WP 3_2) and also to organize a deliverable about risk adjustment methods (WP 3_3). On the basis of the experience of partner DEASL in managing discharge records and implementing risk adjustment methods and since they did not have other reasonable WPs, it was proposed to ask them to be responsible for both of these WPs.

Data available in project EPIC might help in defining possible confounders. Partner NKUA will let all of the partners know what kind of information is collected in the EPIC project and how it can be useful for EUPHORIC.

a) Orthopaedics pilot (WP 3_4)

Gerold Labek illustrated the organization of the orthopaedic pilot (see PP presentation Attachment 4). Information about the organization of a register and potential problems related to it will be a result of the orthopaedics pilot. To do this, an in depth analysis of the tools and procedures adopted in the existing orthopaedic registers in Europe will be performed. All the participating registers in the European Arthroplasty Register (EAR), (24 registers in 19 European countries: two of which are Finland and Sweden who are also participating in EUPHORIC), will be included in the study and will cooperate with all of the institutions participating in EUPHORIC. Gerold Labek proposed to Theodora Psaltopoulou to be included in the orthopaedics pilot for the activities related to the statistical and risk adjustment procedures. Theodora Psaltopoulou will check the availability with her head of department and will send a description of NKUA's contribution.

Partner EFORT-EAR will visit Finnish and Swedish arthroplasty registers by the end of June 2007 and will organize a joint meeting with EUPHORIC partners STAKES and Karolinska Institut. Gerold Labek asked Unto Häkkinen (STAKES) and Rino Bellocco (Karolinska Institut) to send a detailed list of which registers their institutions have available.

b) Approach to cardiovascular (CV) management assessment (WP 3_5)

Jaume Marrugat illustrated the organization of the cardiovascular pilot (see PP presentation Attachment 5). The aim of this activity is to investigate the validity of routinely collected data on admission- and procedure-related outcomes, focussing on the best representative disease samples that are accessible. The designed procedure will consist of: 1. Choosing diseases, 2. Selecting procedures to assess, 3. Selecting suitable outcomes, 4. Selecting potential confounders at country level and at hospital level, 5. Undertaking appropriate population register data analyses, 6. Assessing administrative data collection and linkage, and 7. the comparison of results from 5 and 6.

We agreed on selecting acute coronary syndrome (ACS) with or without ECG ST segment elevation for the analyses, an admission categorization that leads to a discharge diagnosis of non-q wave, or q-wave MI. The analysis of potential confounders would be a key point in the CV pilot (country level, hospital level). We also agreed on selecting the following three procedures to be tested :

1. angiography
2. early revascularization within the acute phase of an ACS (i.e., thrombolysis or angioplasty with or without stenting, with or without eluting drugs)
3. CABG undertaken at any time after the ACS.

This information could be collected from other European projects, wherever available, or from the EUPHORIC participant countries by means of a questionnaire. The CV pilot will take advantage of what already exists (MASCARA project in Spain) and from possible contacts with other projects such as the ACS-European Heart Survey from the European Society of Cardiology. The considered outcomes will be: in-hospital mortality, infarction, angina, infarction extension, and 6-month (maybe one-year) readmission for unstable angina, reinfarction, heart failure, severe arrhythmias, cardiovascular death, and death by other causes.

Administrative data will be taken into account and data linkage with other registers will be considered. The comparison of population registers and administrative data will be useful in making recommendations to public health systems and to citizens.

A glossary to identify ACS was defined by STAKES in cooperation with the Stanford University. Unto Häkkinen will send documents to Jaume Marrugat about the information collected in 30 countries.

Partner IMAS-IMIM will design a questionnaire to gather information about specific data that can be collected in each country. Jaume Marrugat asked each partner to send (in a week's time) what databases are available for the CV pilot and to summarize how each partner can contribute to the CV pilot by May 2. Detailed WPs of the CV pilot will be defined by the end of June.

c) Website (WP 4)

The website has been online since the beginning of March. At present, it contains the presentation of each institution and a general description of the activities performed by the project. Marina Torre asked all of the partners to check all the information that has been put on the web and to send any integrations and/or amendments to Cristina Morciano (cristina.morciano@iss.it). Marina Torre showed the web-based application in the members area for the indicators list that is now only accessible with a password. As well, the web application was developed by CASPUR to gather the information collected during the survey by means of the questionnaire onto a database. The input on the database will be performed by ISS. A retrieval system is being studied. As soon as the pilot starts, there will be a forum in the members area that can be used by all of the partners. Marina Torre proposed to set up a section on the web dedicated to the public where the outcome research, indicators and the overall aim of the project is explained simply and clearly.

d) Cooperation with other projects (WP 2)

This activity has been included in WP 2 and Marina Torre asked Unto Häkkinen to be jointly responsible for this WP along with Emanuela Taioli.

The projects being considered are:

- *ECHIM*: ECHIM is now coordinated by a Finnish partner (Arpo Aromaa, KTL). ISS is one of the associated beneficiaries of the ECHIM project (Emanuele Scafato). EUPHORIC will interact with ECHIM both through the EU Commission (HSWP) and personal contacts by Marina Torre with Emanuele Scafato, and Unto Häkkinen with Arpo Aromaa.
- *OECD*: Unto Häkkinen got in touch with Niek Klazinga of the OECD Health Care Quality Indicators Project. It was proposed to share the methodology and results of EUPHORIC with them and to invite a representative of the OECD Health Care Quality Indicators Project to the next EUPHORIC meetings. Unto Häkkinen will be responsible for the liaisons with the OECD Health Care Quality Indicators Project.
- *eHID*: As suggested by the EU Commission, EUPHORIC will keep in touch with the eHID project (Douglas Fleming). Gerold Labek (EFORT-EAR), who is also interested in e-health, will be responsible for this liaison.
- *EUnetHTA*: CAHTA is a partner of the EUnetHTA project. Outcome assessment in joint arthroplasty is closely related to health technology assessment. Partner EFORT-EAR will be responsible for this liaison.

- *EUGLOREH*: The project leader is Luciano Vittozzi of the Italian Ministry of Health. Marina Torre will contact him in order to evaluate possible cooperation. The pilots will focus on some specific pathologies and/or procedures of both the orthopaedic and cardiovascular areas. Regarding other high impact subjects on health systems which were previously considered in the survey in both the questionnaire and indicators list, all of the participants agreed to analyze them by cooperating with other existing projects and to produce specific reports.
- *Cancer*: Emanuela Taioli (GRI) sent a proposal about the cooperation with Eurocare (Attachment 2).
- *Transplantation*: Emanuela Taioli (GRI) will send a proposal to all of the partners.
- *Stroke*: Unto Häkkinen suggested getting in touch with a Finnish group who is working on it (more information will be sent to all of the partners).

e) Dissemination of the results (WP 5)

It has been highlighted that one of the most important results of the project is to make recommendations to public health systems by giving policy makers indications on how to interpret the information and also how to inform the public.

The main language of the website will be English. However, to spread the information widely in the participating countries, the publication of some documents and some web pages will also be considered in other languages. As a first step, Marina Torre asked all of the partners to translate the leaflet in their own mother tongue.

Jaume Marrugat presented a document about the exploitation and dissemination of the results that is approved by all of the partners (Attachment 6). Marina Torre reported that ISS is preparing a paper describing the project protocol and the results of the first phase and using the article about ECHI (EUPHA) and the article about the OECD Health Care Quality Indicators Project, International Journal for Quality in Health Care as examples. Marina Torre asked Jaume Marrugat to prepare a draft about the publication policies within EUPHORIC.

As requested by the EU Commission, Marina Torre asked all of the partners to periodically send a list of events/congresses where they plan to present EUPHORIC and on every occasion to state that EUPHORIC is a project funded by the EU Commission DG SANCO.

An abstract presenting the project and the results of the first phase will be sent to the EUPHA Congress (deadline 1 May 2007). As it was the first time the project had been presented, the project coordinator was asked to do the presentation.

6. Any other business

As a general consideration, in order to stimulate partner participation, it was suggested linking the financial contribution to the actual involvement and, if necessary, to redesign the budget. The project coordinator will check with the European Commission about this possibility.

Since EUPHORIC's activities will require access to datasets in various fields of interest and cooperation with various institutions, this might lead to a situation where stakeholders, which are not included in the network, will try to influence the reports and activities in favour of particular interests. Therefore, it was decided to define a "Transparency agreement" (Attachment 7).

7. Next meetings

The following general meetings were planned:

- October 9 2007, Helsinki (before the EUPHA Congress)
- April 2008, Innsbruck
- October 2008, Final workshop, Rome

Those responsible for each WP and pilot will organize specific meetings.

The meeting closed at 15:30.