

MINUTES

MEETING OF THE EUPHORIC PROJECT CORE WORKING GROUP (Coordinators of the project and pilots)

BARCELONA, 4 JULY 2007

IMIM

PARC DE RECERCA BIOMÈDICA DE BARCELONA

Participants:

MB: Torre Marina – Istituto Superiore di Sanità (ISS), Rome (Italy)

AB: Labek Gerold – EFORT-EAR Innsbruck Medical University (EAR), Innsbruck (Austria)

AB: Marrugat Jaume and Ferrer Yolanda – Institut Municipal d'Investigació Mèdica (IMIM), Barcelona (Spain)

Note: MB: Main Beneficiary, AB: Associated Beneficiary

1. Preliminary agreements

Aim of the meeting: to finalize the pilots' protocols, to discuss the detailed WPs and work plan organization in order to have a general overview about the partners' participation, and to do some fine tuning in the overlapping regions.

Deadline for the protocol of the pilots' studies is August 15 2007.

2. Cardiovascular pilot

Jaume Marrugat presents the outlines of the pilot study for the selected cardiovascular diseases.

The questionnaire will be forwarded to the participant countries (the questionnaire is discussed in detail and amendments introduced).

The questionnaire will consider basic country characteristics and basic hospital characteristics. Basic country characteristics can be taken from existing data bases [e.g., EU ISARE project at <http://www.isare.org/> HCQI (OECD Health Care Quality Indicators Project) www.oecd.org, ECHIM (European Community Health Indicators Monitoring) www.echim.org, <http://www.healthindicators.org/ICHI/general/startmenu.aspx>, WHO, etc] but also requested from the partners for validity assessment.

Comments about the Administrative / discharge / admission data requested from each EUPHORIC participant country

Gerold Labek will obtain some more e-mail addresses in order to send the questionnaires.

IMIM will contact Lars Wallentin via Rino Bellocco (Karolinska). IMIM will request Anselm Gitt to participate in a paper and offer acknowledgement in the project.

IMIM insists on the fact that all databases have to be anonymous at individual levels. As well, country and region codes will be numbered (at least at the end) and the participants will be informed of this procedure. Jaume Marrugat suggests including only the Mascara data and the EHS data in the analysis to avoid wasting time and disagreement if confidentiality becomes an issue. It is important to underline the protocols used for confidentiality and data protection (in IMIM internal procedures).

IMIM will have a clear deadline for sending the data.

In the discharge administrative databases: IMIM s to create an algorithm for diagnosis (one of the most important results of EUPHORIC) in order to give a prospective position of AMI. Is there any standard procedure?

Gerold Labek suggests that discharge records cannot be used for everything.

IMIM should clarify if they will use a register or a survey. All the participants agree on the need to define a common glossary which is useful for the project. The glossary will be put on the website.

For each (or as many as possible) hospital(s) admitting myocardial infarction patients in their country, a list of data to be requested regarding at least patients with main discharge diagnosis of myocardial infarction (see ICD codes below) admitted during 2002, and the latest year available was agreed.

3. Orthopaedics pilot

The preparation of the orthopaedics pilot protocol is ongoing. A draft version of the protocol will be circulated before the Helsinki meeting in order to get a final agreement.

Apart from the methodology, other aspects will be addressed such as, how administrators, manufacturers or physicians solve orthopaedic implant problems and how they can be detected as soon as possible.

Gerold Labek has identified a CV register in Austria led by Prof. F. Weidinger. He will contact him and organize contact with Jaume Marrugat.

We will emphasise strict project management, including milestones, deliverables and deadlines for all activities for all partners.

This will be more important for the WP 5.2 since there are more partners involved in the orthopaedics pilot.

Access to physical data from registers or similar datasets is problematic from a legal point of view since these data are generally personalized.

In most cases, getting permission would require a longer time frame than is acceptable to the EUPHORIC timetable. Furthermore, contribution from the registries to re-arrange data (i.e. depersonalization) is rarely offered without financial coverage of the expenses. EAR has been working for several years on a procedure and will not succeed in establishing such a system until 2009.

We will render the contents anonymous for supranational comparisons of hospital characteristics, regions,.....

4. Conclusions

- Everything (people, hospital, region) has to be anonymized.
- Questionnaires will be sent to the partners once corrected.
- IMIM has to contact Anselm Gitt and the Greek partner.
- Danilo Fusco (Partner DEASL) will collect the information about discharge records for comparison among countries (Italy, Sweden, Finland and Spain).
- The core group will establish milestones, reports, deliverables and deadlines for the overall project. Marina Torre will make a proposal based on what she already has before July 20.
- Jaume Marrugat will send a list of potential partners involved in the CV pilot.
- Every partner will know what he has to do before the end of September.
- Marina Torre will provide us with the final budget for everybody: the initial sum and the remaining sum.
- IMIM will ask the EUPHORIC Coordinator, Marina Torre, to seek Arthur Furtado's approval in mobilizing the collaborating partners actively involved in the pilots (e.g., Anselm Gitt) and in authorizing the participation of IMIM investigators in EUPHORIC missions or meetings which were not scheduled in the initial protocol (e.g., Health Systems Working Party meeting attendance, or the visit to the Greek partners in November 2007).
- Partner GRI has not yet sent the requested planning of their future activities, therefore, it is not clear how they will contribute to the continuation of the project. Gerold Labek will ask them to cooperate with the orthopaedics pilot.