<u>MINUTES</u>

5TH MEETING OF THE *EUPHORIC* PROJECT
WORKING GROUP ON STATISTICS

INNSBRUCK, *26 MARCH 2008*
(16:30 – 19:00)

UNIVERSITY OF INNSBRUCK

Participants:

MB: Torre Marina – Istituto Superiore di Sanità (ISS), Rome (Italy)
AB: Weimin Ye – Karolinska Institutet (KAR), Stockholm (Sweden)
AB: Häkkinen Unto – Centre for Health Economics at Stakes (STAKES), Helsinki (Finland)
AB: Fusco Danilo and Carbone Anna Patrizia – Department of Epidemiology ASL RM E (DEASL), Rome (Italy)
AB: Labek Gerold and Fechter Renate – EFORT-EAR Innsbruck Medical University (EAR), Innsbruck (Austria)
AB: Marrugat Jaume and Ferrer Yolanda – Institut Municipal d'Investigació Mèdica (IMIM), Barcelona (Spain)
AB: Psaltopoulou Dora – National and Kapodistrian University of Athens (NKUA), Athens (Greece)

WEDNESDAY 26 MARCH

1. Welcome
 Marina Torre welcomes all participants and thanks Gerold Labek for hosting the meeting.

2. Approval of the agenda
 The agenda is approved.

3. WP 5.3   Validation of the datasets: discharge records, registers, surveys and clinical studies available in participant countries (Danilo Fusco)
 According to previous suggestions made by the partners, Danilo Fusco proposes changing the title of WP 5.3 to "Available sources of information in participant countries and development of a standardized methodology for comparative evaluation of outcomes".

 The following issues are presented and discussed:

 A) Register target group (WP 5.1, WP 5.2)
  Collected information must include:
  – Number of patients included;
  – Description of information and definition;
  – Computable indicators (according to indicators list);
  – Statistical methodology applied for each indicator;
  – Possible linking with health care information system datasets (e.g. discharge records, emergency room visits, mortality records, etc.).

  Discussion:
  – Track the case (revision or not? – excluded patients might run a high risk of dying);
  – General problem in discharge records: implant cannot be tracked (side of implant not stated in the records);
  – Problem: how to put the different databases together?

B) Health Care Information System target group

The following information must be provided:

- Description of information collected from health care information system and its definition;
- Used statistical methodology.

This should allow the comparison of the data collected in registers with the data collected in public health systems. The crucial point, however, is to find a way to link these two sources.

Discussion:

It is clear that currently the most important thing is to build up the system. Merging the data is impossible in practice. Realistically, they can only be extracted and compared.

Main problems: to get access to personalized data from other countries; no possibility in sharing data on a personalized level.

Therefore, the data used will either be:

a) Anonymous (excluding any possibility of going back to the patient); or

b) Acronymous (implying that finding or getting the key causes big problems)

It is clear that, at least for the orthopaedic pilot, only a few variables will be needed at an individual level.

It is finally agreed to entrust the leadership of the health care information system target group to Unto Häkkinen.

C) Further discussions refer to

Setting up a predictive model:

- allows different levels of analysis (long-term, short-term, etc. Remaining problem: tracing back to individual level).

The proposal to take copies of the original databases of about five to seven existing, functioning orthopaedic registers as a starting basis is rejected for the following reasons:

- Registers can only provide aggregated, i.e. de-personalized data. Access of raw data will be impossible;
- Registers are not paid for their help, and one cannot "simply rely on friendship";
- Time factor / staff resources: registers have to prepare their annual reports => the later in the year, the more difficult it will be for them to spend time on additional commitments.

Possible solutions:

- Include the registers concerned into some projects;
- Involve new arthroplasty register projects (pilots) into the process (i.e. tell them the variables they must collect so as to be able to set up an appropriate base).

Proposal for pilots:

Two more questionnaires must be filled in to gather the missing pieces of information.

The original suggestion of nine items is rejected, and it is agreed to incorporate the following three points:

1) Description (objectives, selection criteria, study period, number of patients included);

2) Methodology;

3) One or two questions on the main outcome.

It is made clear that this issue must be given top priority in order to be able to proceed according to schedule.

Pilots' partners agree to send to Danilo Fusco not more than three English peer-reviewed articles describing: pilot description, main results and statistical methods applied.

D) Indicators list

As a list of 54 indicators has already been decided upon, it is finally agreed upon to concentrate on the pilots.

Discussion:

According to Jaume Marrugat's suggestion, it is agreed to include unstable angina in the list of diseases under study.

E) Protocols of the individual indicators ("indicator sheets")

Information required:

- Definition;
- Rationale;
- Potential use.

The focus must be placed on definition; importantly, inclusion criteria, exclusion criteria, and definition of outcome.

List of potential risk factors. ICD-9-CM codes:

Danilo Fusco is asked to send the ICD-9-CM list he uses to Jaume Marrugat and Gerold Labek in order to be sure that the same list is used by all partners involved.

Discussion:

It is agreed that the indicators must be stable (according to the list); however, variables (e.g. length of hospital stay, etc.) must also be considered and still remain to be defined.

It is finally agreed that, after collecting information on potential risk factors used by partners, an extended protocol will be defined for each indicator that includes shared inclusion/exclusion criteria, variables to be used for risk adjustment and statistical methodology.

F) Risk adjustment procedures

Objective: to produce a predictive model for one country and use it for all other countries to calculate the expected outcome and to allow for the comparison of observed and expected outcome.

(e.g. mortality rate):   - per hospital;

                 - country average.

Suggestion: due to the existing difference in variables each country should use its own predictive model.

Required: calculation of the "Standardized Ratio" (SR)

Commitment: to benchmark hospitals (as benchmarking countries is impossible).

In conclusion, it is decided to organize another statistics meeting in September in order to clarify the open issues before the final meeting takes place in Rome in December. By the September meeting, the main documents, main steps, deadlines, etc. will be finalized.

Closing of the meeting

The meeting closed at 19:00.