MINUTES

EUPHORIC PROJECT – WP5.2 MEETING

HELSINKI, 16 JUNE 2008

(14:00 – 17:45)

STAKES, MEETING ROOM: PORKKANA

PARTICIPANTS:

AB: **Unto HÄKKINEN** and **Persephone DOUPI**,
Centre for Health Economics at Stakes, Stakes Unit for eHealth and eWelfare (STAKES), Helsinki (Finland)

AB: **Weimin YE** and **Christina PERSSON**,
Karolinska Institutet (KAR), Stockholm (Sweden)

AB: **Gerold LABEK** and **Renate FECHTER**,
EFORT-EAR Medical University Innsbruck (EAR), Innsbruck (Austria)

MEETING AGENDA:

1. **WELCOME**
   Persephone Doupi welcomes the participants of the meeting.

2. **APPROVAL OF THE AGENDA**
   The agenda is approved.

3. **QUALITY REGISTERS: DATA COLLECTION AND REPORTING – SWEDEN**
   Presentations by Weimin Ye and Christina Persson.

   Weimin and Christina report on the methodology applied, the work progress achieved, the problems emerging in the course of their work, and give an overview of the present status of their report and on the preliminary results obtained.

   Weimin's presentation focuses on providing general information. He distinguishes between nationwide registers and quality registers, and lists the most important examples of each category, also indicating the respective year of foundation (slides pages 2-4). Moreover, he points out the three main differences between the two groups (pages 5-6), and gives an overview of the problematic issues associated with each category (pages 7-8). He finally presents four main criteria to be considered in the selection of a quality register (p. 9) and the schedule of activities envisaged for the next three months (p. 10).

   One of the most remarkable features about nationwide registers in Sweden is that they can be linked electronically, which is not possible in other countries. However, this is sometimes associated with considerable time lags due to the transformations of data collection formats necessary. On an average, national level register data are available in Sweden about two years after collection, the first year being used for data clearing on a regional level; the data from 2006, for instance, are becoming available right now. A major problem particularly smaller 'quality registers' suffer from in Sweden is their dependence on multiple funding, which implies that they are discontinued or have to limit their activities if funds are cut down.

However, this does not affect the Swedish Arthroplasty Registers.

Christina's presentation is headlined '7 Swedish registers' and provides an overview of the registers that have been dealt with in more detail. Work on two registers (the Swedish Inpatient Register and the Swedish National Hip Arthroplasty Register) has already been completed while five registers (the Swedish Medical Birth Register, the Causes of Death Register, the Swedish Birth Defect Registry, the Register on prescribed pharmaceuticals in Sweden, and the Swedish cancer register) are still being worked on (web-based data extraction completed, phone contact ongoing).

Apart from the main problem areas described (structuring of registers in the report; getting in contact is sometimes time-consuming; registers often change over the years: name, organisational structure, activities, objectives, etc.), special attention is given to the following issues:
- staff;
- legal status;
- publications; and
- budget.

Among other things, these topics are largely discussed by the participants (see Point 5 of the minutes).

Copies of both PowerPoint presentations have been annexed to these minutes.

4. QUALITY REGISTERS: DATA COLLECTION AND REPORTING – FINLAND

Presentation by Persephone Doupi.

Also Persephone explains her method of work, the progress of work and status of her report including the mention of problem areas with the questionnaire, particular gaps identified in the data collection, a summary of her preliminary findings, as well as a proposal of how to structure the final report.

Persephone has prepared a draft version of her report, which she hands out to the participants for reference.

Based on an extensive national review from 1997, the Finnish health care registers were divided into four categories:
a. Statutory nationwide registers (specified by law)
b. Research registers
c. Patient registers of healthcare units
d. Other (special) registers (usually local)

A total of 48 Finnish registers were examined in detail during that review.

Quality registers do not exist as such in Finland, but rather registers established for other purposes (particularly the statutory, large registers) can be utilised for purposes of quality monitoring.

In defining the term of 'Quality Registers' in Finland for the purposes of the EUPHORIC pilot, the following parameters served as a basis for the inclusion of a register in the review:
- OECD HCQI project conceptual framework (effectiveness, safety, patient-centeredness, responsiveness);
- Nationwide coverage;
- Sufficiently large number of patients.

On the basis of the main chapters of the orthopaedic pilot questionnaire, Persephone has summarised her preliminary findings captioned 'Interim Results' and classified I to III, ranging from information collected on register organisation (legal status, staff) via a historical outline of register development in Finland and an overview of the data collection methods presently applied, up to a listing of possible linkage of register data with other relevant Finnish data-bases and the prevailing kinds of register publications.

Apart from pointing out the problem areas and questionnaire gaps (pages 10-11 of the slides) and putting them forward for discussion, Persephone provides a comparative overview of emerging models ('Centralised' versus 'Local/De-centralised'; see slides, page 12), and presents the PERFECT *(PERFormance, Effectivenes and Cost of Treatment)* Project, which may serve as a valuable reference in the final report (slides, page 13).

Both Persephone's hand-out and her PowerPoint slides are included in the Annex to these minutes.

5. DISCUSSION OF DRAFT REPORTS; PLANNING OF COMPARATIVE ANALYSIS AND REPORTING

Naturally, the discussion focuses on the problem areas as well as on the comparative aspects to be included in the final report.

The following issues are discussed:

A. Structuring information about individual registers:

► Apart from the good and useful suggestions already put into practice in the presentations, it is deemed a main issue to include
- when a register was started;
- from which point in time the data collected and presented can be regarded as reliable; and
- which impact its development, structure and organisation has on the outcome.

B. Definition of >Nationwide< Registers:

Contrary to Sweden, quality/outcome registers are also nationwide in Finland.

► Thus the issue of definition(s) should be worked out in detail for each country and for comparative purposes.

C. One of the main problems with quality registers (Sweden) / smaller registers (Finland): to select the 'good ones' out of a multitude of registers/register projects

Sweden, for instance, presently has about 200 'quality registers', but only about 35 to 40 of them are really of interest.

► It is agreed to reduce the number of registers treated to a reasonable amount, but on the basis of a certain rationale.
Gerold suggests to start out from the question *'Why is a register called a register?'*, which implies that specific criteria have to be established for proper and uniform reference.

► In this context, Persephone comments that a clear set of such criteria will actually be indispensable, in order to avoid problems with the non-included registers, among other things.

D. Multiple funding:
This item is especially discussed for Sweden: non state-funded registers are usually dependent on multiple funding and are thus continuously exposed to potential budget cut-downs or even fund withdrawals resulting in a limitation of activities, staff reduction or, at the worst, in the complete cessation of activities.
(As to Finland, on the basis of the criteria selected for inclusion, small, non state-funded registers have not been considered that much.)

E. Difficulty of getting in contact with registers / Register staff:
Christina and Weimin report on problems when contacting registers for information: it is generally not easy to get hold of staff members – and even more time-consuming to reach a competent person who is able and entitled to provide the information requested.

► This problem is suggested to serve as a starting point for a concrete proposal to the Commission:
- every register needs a constantly available contact person / secretary / deputy;
- definition of the minimum staff requirement (e.g. number of persons, hours per week, etc.).

This point is also discussed as a difference between the two models (centralized vs. decentralized): in the centralized model, it is easier to put in place the communications infrastructure for the register and organise availability of staff for information provision.

F. Legal background:
► A chapter on the legal system and its effect on registers/register operation shall be included in both the Swedish and the Finnish report. In this context it will also be crucial to raise the issues of *data ownership* and *data access*.

G. Publications:
Dealing with this issue has turned out to be quite complex.

► As to the apparently high number of new register publications in Sweden it is generally agreed that a link to the web site, scientific article, etc., will suffice as a reference.

► It is further discussed that one purpose of looking into this subject area more closely is to find out who actually has access to the data, and draw the respective conclusions.

► Another important aspect that should not be neglected is the *language of publication*.

H. Data access, use of data:
► This subject matter is agreed to be a particular issue in the comparison between the two countries (general framework; specific contexts, e.g. how to establish a new contact with former patients etc.).

► Analysis shall also include the principal purpose of data collection (e.g. economic reasons, benchmarking, research).

- Example for comparison:
Karolinska: data collected for research purposes only – vs. STAKES: both areas are covered, statistics for benchmarking purposes and research. (If comparison is extended to other countries: data collection frequently performed without any scientific interest!)

► Extended perspective:
Data collections / Registers could also act as a stimulus for research work.

I. Influence factors on data validity:
► It is decided to analyse the impact of changes within a register (e.g. changes in strategy, etc.) on the validity of data, including the reasons for change, from two perspectives:
- the scientific and
- the practical or public health point of view.

J. Evaluation:
► It is agreed to cross-reference to the EUPHORIC List of Indicators.

K. Other issues of presentation:
► Report should generally focus on *methodology*, i.e. how a register system is working.

► Links to special/serious reports should be included.

► Presentation of budget information:
Should show annual budget roughly split into several relevant sub-categories, e.g. staff, IT, etc., possibly indicating basic or peak values.
The important part of the information finally is to mention the overall amount available to them per year.

► To be included in report:
- overlapping of European systems;
- suggestions,
- reference to EUPHORIC List of Indicators for outcome evaluation;
- impact of different definitions in data collection contexts (structural assessment or personal statement).

6. MEDICAL DEVICE AUTHORITIES: UPDATE ON QUESTIONNAIRE CIRCULATION AND RESULTS

● As to the German countries EAR is responsible for, Gerold reports on having received information that some national institutions do not perform evaluations referring to groups of medical devices (such as Total Hip Implants), which would, however, be a prerequisite for the scheduled evaluation. This might be an explanation for the observation that hardly any specific data coming from public health authorities are to be found in published reports. Moreover, it proved to be very difficult to get any answer from the national institutions involved.

● Persephone also gives an update of the situation with regard to contacting the medical device authorities in the assigned countries:
Contact points were identified through the EC list of Competent Authorities for the reporting of medical device failures. The indicated persons were contacted with an email, where the purpose of the pilot was explained and the questionnaire was provided as an attachment. The request was extended to provide contact information to another suitable person or authoritiy in case the message was wrongly addressed. So far, no country has responded.

● From KAR, Fang Fang is taking care of this issue, so there is no information about her progress. – Weimin declares not being aware that Fang Fang has received the documents with the project description and share of duties. Gerold will send them again (done in the meantime).

► Gerold asks the other partners to proceed with the collection of information, but to bear in mind that it might turn out to be impossible to reach the initial goal since it is not realistic to assume that national institutions will perform evaluations on demand for EUPHORIC.

► It is thus agreed to have a second round of contacts (email or phone), and if that does not yield any responses, this is what will have to be reported on the subject.

7. CONCLUSIONS & FURTHER PLANNING

To sum up, it is the objective of the present activities to

a. find the problems and
b. finally get answers to the important questions in order to
c. make a suggestion to the Commission of how to run a register successfully.

A further meeting to present and discuss the final results is scheduled for

10 September 2008 in Stockholm.

8. CLOSING OF THE MEETING

The meeting is closed at 17:45.

ANNEX TO THESE MINUTES:

- **POWERPOINT SLIDES – WEIMIN YE (SWEDISH REGISTERS-0613)**
- **POWERPOINT SLIDES – CHRISTINA PERSSON (7 SWEDISH REGISTERS)**
- **POWERPOINT SLIDES – PERSEPHONE DOUPI (FINNISH REGISTERS)**
- **DRAFT REPORT ON FINNISH QUALITY REGISTERS BY PERSEPHONE DOUPI**