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EU Public Health Outcome Research and Indicators Collection
EUPHORIC Project
Grant Agreement n°2003134

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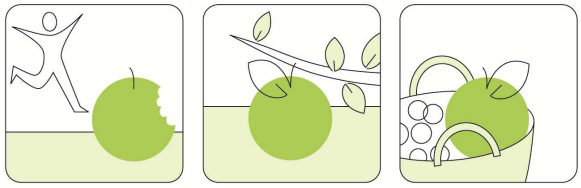
Second Interim Report

15/12/2006 – 14/12/2007

March 2008



EUPHORIC Project

MAIN BENEFICIARY

Istituto Superiore di Sanità, *Italy*

ASSOCIATED BENEFICIARIES

EFORT/EAR Verein zur Unterstützung der Tätigkeit von nationalen Endoprothesenregistern, *Austria*

Sosiaali- ja terveysalan tutkimus- ja kehittämiskeskus, *Finland*

National and Kapodistrian University of Athens, *Greece*

Genetics Research Institute ONLUS, *Italy*

ASL RM E Department of Epidemiology, *Italy*

Institut Municipal d'Assistència Sanitària, *Spain*

Karolinska Institutet, *Sweden*

COLLABORATING PARTNERS

National Center of Public Health Protection, *Bulgaria*

Catalan Agency for Health Technology Assessment and Research, *Spain*

Slovak Arthroplasty Register, *Slovak Republic*

Arthroplasty Register Tyrol, *Austria*

Ludwig Boltzmann Institut Health Technology Assessment, *Austria*

French Society of Orthopaedic and Trauma Surgery, *France*

BQS Bundesgeschäftsstelle Qualitätssicherung gGmbH, *Germany*

Israel Society for the Prevention of Heart Attacks at NCRI, *Israel*

The report, based on the contributions submitted by each partner, was prepared by Marina Torre[1]

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PROJECT FACT SHEET

Contract number:	2003134
Proposal title:	EU Public Health Outcome Research and Indicators Collection Project
Acronym:	EUPHORIC

Starting date:	15/12/2004
Duration of the project:	3 years + 1 year extension
Reporting period:	15/12/2006 – 14/12/2007

Main partner: ISS – Istituto Superiore di Sanità (Italy)

Number of associated partners: 7

1) EFORT/EAR Verein zur Unterstützung der Tätigkeit von nationalen Endoprothesenregistern, Austria
2) Sosiaali-Ja Terveysalan Tutkimus-Jakehittamiskeskus, Finland
3) National and Kapodistrian University of Athens, Greece
4) Genetics Research Institute ONLUS, Italy
5) ASL RM E Department of Epidemiology, Italy
6) Institut Municipal d'Assistencia Sanitaria, Spain
7) Karolinska Institutet, Sweden

Number of collaborating partners: 8

1) National Centre of Public Health Protection, Bulgaria
2) Catalan Health Technology Assessment and Research, Spain
3) Arthroplasty Register Tyrol, Austria
4) Ludwig Boltzmann Institut for Health Technology Assessment, Austria
5) French Society of Orthopaedic and Trauma Surgery, France
6) Slovak Arthroplasty Register, Slovak Republic
7) BQS Bundesgeschäftsstelle Qualitätssicherung gGmbH, Germany
8) Israel Society for the Prevention of Heart Attacks, Israel

Total amount of the project:	2,788,105.28 Euro
EC co-funding :	1,500,000.00 Euro

1. EXECUTIVE SUMMARY

Background

EUPHORIC project (www.euphoric-project.eu) is currently a consortium of 16 institutions from 11 countries (Austria, Bulgaria, Finland, France, Germany, Greece, Israel, Italy, Slovak, Spain, and Sweden) whose aims are: to define and test outcome indicators in some relevant area of pathology, and to produce protocols for data collection, harmonization and analysis integrating the ECHI list.

The first phase of the project consisted in a survey aiming at identifying the tools and the operational conditions which are useful for the implementation of the second phase of the project (pilot).

Based on a critical analysis of the international literature, the websites, and the documents of validated collections of indicators, it was possible to select nine areas of pathology and, for each area, the most relevant diseases and/or procedures where outcome indicators were adopted in European and Extra-European countries. Therefore, a list of 54 outcome indicators was defined and a questionnaire was designed to collect information from the participating countries on the following three topics: health care systems; health data sources available for the selected diseases/procedures, and their link to other archives; selected outcome indicators, specifying basic units of analysis and variables available for stratified analysis.

Objectives

This report refers to the activities carried out in 2007.

The aims of the activities carried out in this period were:

- the input of the information collected with the questionnaire on a web-based database
- the finalization and collection of detailed information about the selected indicators
- the definition of the protocols of both pilots (cardiovascular and orthopaedic)

Activities undertaken in the period covered in the interim report

The first phase of the project (survey) paved the way to the second phase (pilot) producing a list of 54 outcome indicators. All the detected indicators were described in detailed technical sheets that will be published on the website. All the information collected during the survey and relevant to the data sources available in each participant country to compute the 54 indicators were input on the web-based database. On the basis of the survey results, orthopaedic and cardiovascular areas were chosen for the pilot study, not only for their high clinical and political relevance, but also because of the availability of data. The pilot protocols were defined. The pilot will use the available sources of information, such as routinely collected data, clinical data, and registries, by focussing its activities on Acute Coronary Syndrome and Joint Arthroplasty.

The aims of the cardiovascular pilot are:

1. To define a simple set of factors that determine quality of health care outcome (in-hospital mortality, and a combined end-point of in-hospital mortality, re-MI or angina post infarction) in myocardial infarction patients who underwent CABG, coronary angiography, or percutaneous revascularization. These indicators will be analyzed in the context of characteristics at individual, hospital and country levels.
2. To apply the indicators to information obtained routinely for administrative purposes, and to benchmark hospitals and countries according to their adjusted risk of the two types of outcomes. This might provide systematic information to end-users (doctors, health staff, health administration, decision makers, policy makers, and EU population).

3. To make recommendations as to how to develop monitoring systems with outcome indicators in cardiovascular diseases in Europe in view of the results of the former objectives.

The orthopaedic pilot will conduct:

1. A systematic review of all arthroplasty registers in Europe and related projects
2. A systematic review of outcome registers in Sweden and Finland, two countries which have a very well developed system of outcome measurement by registers.
3. Extended literature research concerning the value of different data sources (registers, meta-analyses of clinical studies, surveys) for outcome research in arthroplasty.
4. An analysis concerning the value of existing instruments (registers, public health implant failure and monitoring institutions), surveillance by the manufacturers and other datasets (clinical literature) concerning the detection of inferior outcome.
5. A report on specific requirements for outcome measurement from statistical point of view.
6. A proposal for a quality label system for the datasets and information to be used in indicators computing.

Among the 54 outcome indicators identified during the survey phase, the following were selected to be tested during the pilot: in-hospital and 30-day deaths following CABG operation; in-hospital, 30-day and 6-month deaths following PTCA operation; in- hospital and 30-day deaths following admission to hospital with acute myocardial infarction; joint replacement revision rate; and joint replacement revision burden. Four of them were submitted to the ECHIM project as possible candidates for the short list.

The following new collaborating partners joined the project: the Israel Society for the Prevention of Heart Attacks at the Neufeld Cardiac Research Institute (Israel), the Slovak Arthroplasty Register (Slovak Republic), the BQS Bundesgeschäftsstelle Qualitätssicherung GmbH (Germany), the Ludwig Boltzmann Institut for Health Technology Assessment (Austria), the Arthroplasty Register Tyrol (Austria), the French Society of Orthopaedic and Trauma Surgery (France). They will contribute to the project by either providing the data which is useful for the implementation of both pilots from their own databases or supporting the dissemination of the results and the connection with other projects that are relevant to the same topics. In particular, the Israel Society for the Prevention of Heart Attacks at the Neufeld Cardiac Research Institute will contribute to the further development of the cardiovascular pilot study by supplying the EUPHORIC cardiovascular database with the ICSIS database 2000-2006 from Israel; and the Ludwig Boltzmann Institut for Health Technology Assessment has been working on the connection with the EUnetHTA project.

Outcomes and deliverables achieved

During the period this report refers to, the following outcomes and deliverables were produced:

List of deliverables

D1	"Survey: results of the first phase"	Submitted in June 2007
D2	"Glossary"	Attached to the 2nd interim report
D3	"Evaluation Plan"	"
D4	"Indicators submitted to ECHIM to be considered in the short list"	"
D5	"Dissemination Plan"	"
D6	"Detailed sheets of the collected outcome indicators (long list)"	"
D7	Systematic review of the literature Bosch X, Loma-Osorio P, Marrugat JJ "Platelet glycoprotein IIb/IIIa blockers for percutaneous coronary intervention, and as initial treatment in Non-ST segment elevation Acute Coronary Syndromes	"

D8 "Protocol for the Cardiovascular Pilot study" "

D9 "Protocol for the Orthopaedic Pilot study" "

D10 "Risk adjustment methodologies" "

D11 "Web-based Questionnaire: completion guideline" "

WP1 Management of the project

Improvement of communication among partners and between the EUPHORIC consortium and DG SANCO; organization of the project in WPs; reorganization of the work plan; organization of coordination and core working group meetings; inclusion of 5 new collaborating partners; contacts established with 2 other collaborating partners; cooperation with ECHIM; and preparation of the evaluation plan (D3).

WP 2: Dissemination strategy

Preparation of the dissemination policy and of the dissemination plan (D5); translation of the leaflets; setting up of the website; publications and reports.

WP 3: Liaisons with other EU projects, EU programmes and health stakeholders

Contacts with the following projects were established: ECHIM, eHID, EUnetHTA, EUGLOREH, OECD (Health Quality Indicators Project), HDP, European Patients' Forum; and submission to ECHI of some selected indicators to be considered for the short list (D4).

WP 4 Indicators development

Detailed sheets of all the 54 selected outcome indicators; Glossary on "Best practices/Benchmarking" (D2); "Survey: results of the first phase" Report (D1); "Detailed sheets of the collected outcome indicators (Long list)" Report (D6).

WP 5 Development of adverse outcome risk indicator in real clinical and registry databases and its possible use in administrative systematic databases. (pilot)

Sub WP 5.1 cardiovascular pilot

Appointment of Prof. Jaume Marrugat as cardiovascular pilot leader; databases participation in cardiovascular pilot (MASCARA Study 2005, EURO Heart Survey 2000, EURO Heart Survey 2005, ACSIS 2004 and 2006); cardiovascular pilot protocol (D8); and systematic review of the literature (D7).

Sub WP 5.2 Orthopaedic pilot

Official inclusion of partner EAR; appointment of Dr. Gerold Labek as orthopaedic pilot leader; orthopaedic pilot protocol (D9).

Sub WP 5.3 Use of the available sources of information in participant countries in order to develop a standardized statistical methodology for comparative evaluation of outcomes

"Risk adjustment methodologies" Report (D10)

WP 6 Setting up and maintaining indicators database

Setting up of the electronic form. Input of the previously collected data (questionnaires used during the survey). Validation of the questionnaires by some partners. Organization of the members' area. Guideline to correctly input the indicators data on the database (D11).

Problems encountered and how the problems were resolved

The new project leader was appointed on 26 January 2007.

Partner GRI, on the basis of their expertise, was supposed to establish cooperation with Eurocare (cancer) and with other EU projects related to transplantation and to support the project for all the activities related to both these topics. However, they neither fulfilled their duty nor gave any other active contribution to the development of the project. Therefore, the entire project consortium asked for their withdrawal. The question regarding the definition of partner GRI's further participation, which started at the end of May 2007 and ended on 6

February 2008, was an additional hindrance for the regular development of the project that had already experienced a lot of difficulties in the first two years.

A procedure to submit an amendment to the contract to recover the residual GRI budget and to adapt the budget to the new organization of the project, is still ongoing. It was agreed to disseminate results on the cancer area through OECD and to establish contacts with project Eurochip (European Cancer Health Indicator Project).

Indicators sheets relevant to transplantation were prepared by partner NKUA while the main beneficiary, ISS, revised and updated those relevant to cancer (prepared by GRI in a draft form).

Partner EAR-EFORT was officially included in the project on 26 January 2007 when the survey had already been concluded. The organization of the pilot and the delay in receiving the payments prevented them hiring a person responsible for collecting all the information requested during the survey. This activity will be done during 2008. The information collected by partner NKUA allowed the completion of only one questionnaire (1 indicator). The collaborating partner NCPHP (Bulgaria) did not validate their questionnaires. Therefore, they were requested to check and validate the indicators already input on the database and to integrate the missing records.

The software, requested by the former project leader from the company MEDISOFT in order to implement a system able to gather data on a real time basis, seemed useless considering the new organization of the project (testing of indicators on data extracted from existing databases at specified dates). The MEDISOFT product will be considered as a feasibility study and the contract will be interrupted. Change in the budget will be considered in the submitted amendment.

Activities planned for the next period

WP1 Management of the project

Preparation of the amendment; keep improving contacts among partners; organization of coordination meetings; coordination of the core working group (coordinator and pilot leaders); keep intensifying contacts between partners and HSWP; implementation of the protocol for internal and external evaluation of the project and analysis of process evaluation data; and organization of the final workshop.

WP 2 Dissemination strategy

Implementation of the dissemination plan; set up of a newsletter; updating of the website; preparation of a paper presenting the list of the selected indicators; translation of the leaflet in the languages of the newly included countries.

WP 3 Liaisons with other EU project, EU programmes, and health stakeholders

Keep improving cooperation with the previously contacted project and set up contacts with other projects, if any, in order to enlarge the network which is useful for the dissemination of the results; set up the website links to the websites of the contacted projects; contribution to be included in the EUGLOREH report; make a proposal for possible cooperation with the European Patients' Forum and Eurochip (European Cancer Health Indicator Project).

WP 4 Indicators development

Implementation on the website of all the information collected in the detailed sheets

WP 5 Development of adverse outcome risk indicator in real clinical and registry databases and its possible use in administrative systematic databases. (pilot)

Sub WP 5.1 cardiovascular pilot

Testing of some selected indicators on the available databases; merging and preparing databases; statistical analyses; mathematical function development; gathering health information system databases from EUPHORIC partners; testing the functions on health information system databases; implementation of the proposed functions on the EUPHORIC website for self assessment of hospitals in Europe; and initiation of the dissemination plan.

Sub WP 5.2 Orthopaedic pilot

Implementation of the pilot protocol; setting up of a system to assess the validity of information from different datasets and guidelines for the proper use of the information in public health decision making as well as outcome measurement; collection from the existing sources of some basic data to calculate figures for the proposed indicators; preparation of reports, publication of the results in scientific journals and scientific conferences according to the dissemination plan; supporting the recognition of the EUPHORIC webpage and its content in the scientific community of orthopaedic surgeons via the EFORT network and its facilities (EFORT: European Federation of National Associations of Orthopaedics and Traumatology).

Sub WP 5.3 Use of the available sources of information in participant countries in order to develop a standardized statistical methodology for comparative evaluation of outcomes

Organization of coordinating meetings; preparing the detailed protocol of the WP; report about the information collected through the hospital discharge records in the participating countries; report about the information collected through registers, surveys, and other datasets in the participating countries and the statistical procedures applied up to now; defining different statistical procedures to be applied to each national register in the EU area, according to the available information included in the existing databases and assumptions; evaluating whether, for some outcomes, the same results can be obtained using the information available from national registers or from the health care information system at national level; summarizing the most important clinical variables for adjusted comparative evaluation of the outcomes being studied that should be added to risk adjustment models including variables only based on hospital discharge records information.

WP 6 Setting up and maintaining an indicators database

Starting of a forum to discuss the new indicators proposed by the cardiovascular pilot; publication in the public area of the information related to the selected indicators as soon as the paper describing them has been submitted; development of a search engine on the questionnaire database.

2. PROJECT SPECIFICATIONS

2.1 General objective of the project:

The general objective of the project is the following:

To build a consortium of participating countries in order to:

a) cooperate on benchmarking the outcomes of selected health performances;
b) exchange information on quality standards, best practice and effectiveness in public health;
c) identify suitable common EU elements for a political EU platform oriented at best practice guarantees for EU citizens

by proposing a list of outcome indicators and elaborating protocols for data collection, harmonization and analysis of the selected outcome indicators.

2.2 Specific objectives of the project

The following specific objectives were identified:

1. Setup of a high quality framework – consortium.
2. Create a list of diseases amenable to receiving medical procedures whose quality can be assessed in terms of outcome.
3. Devise a set of theoretical outcome-based indicators of quality for procedures used on these diseases.
4. Select diseases, procedures and outcomes suitable for a pilot study to develop and test some indicators adjusted for individual, hospital and country characteristics.
5. Complete the pilot studies to develop adjusted estimates of adverse outcome risk for the selected procedures using real data at individual, hospital and country level.
6. Disseminate the results on a European Union scale.

2.3 Work packages and deliverables

EUPHORIC is organized in 6 work packages linked to the specific objectives of the study as summarized in the following table.

In the same table the most important deliverables that each work package will produce are listed.

Table 1 Summary of the specific objectives of the project, work packages and deliverables

Specific objectives of the project	Work package(s)	Deliverables
Setup of a high quality framework - consortium	WP 1 Management of the project	Useful communication within the project for both scientific and administrative tasks
	WP 3 Liaison with other EU projects, EU programmes and health stakeholders	Networking of the initial consortium with other groups
Create a list of diseases amenable to receiving medical procedures whose quality can be assessed in terms of outcome	WP 4 Indicators development	Technical report based on a worldwide analysis of literature and existing health related websites
	WP 3 Liaison with other EU projects, EU programmes and health stakeholders	Compatibility of presented indicators and methods with ECHI
	WP 6 Setting up and maintaining an indicators database	Web-based database
Devise a set of theoretical outcome-based indicators of quality for procedures used on the selected diseases	WP 4 Indicators development	List of indicators
Select diseases, procedures and outcomes suitable for a pilot study to develop and test some indicators adjusted for individual, hospital and country characteristics	WP 4 Indicators development	Technical presentations
Complete the pilot studies to develop adjusted estimates of adverse outcome risk for the selected procedures on real data at individual, hospital and country level	WP 5 Development of adverse outcome risk indicators in real clinical and registry databases, and its possible use in administrative systematic data bases.	Technical reports, protocols for data analysis
	WP 6 Setting up and maintaining indicators database	Web-based database
Disseminate the results on a European Union scale	WP 2 Dissemination strategy	Website (www. euphoric-project.eu), scientific and informative publications, guidelines for benchmarking hospitals and MS, final workshop

2.4 Time table and overview of the activities

The EUPHORIC project started at the end of 2004. The initial planned duration was 36 months. However, due to administrative problems, it was necessary to postpone the deadline of the project to the end of 2008 (2nd amendment to the contract approved on 26 January 2007).

The final project workshop is planned for autumn 2008. Table 2 summarizes the time table of the 6 work packages.

Table 2 Work packages time table

WP No	Title	Time table
1	Management of the project	Carried out during the whole duration of the project
2	Dissemination strategy	Carried out during the whole duration of the project
3	Liaison with other EU projects, EU programmes and health stakeholders	Carried out during the whole duration of the project
4	Indicators development	Started at the beginning of the project and finished by December 2007
5	Development of adverse outcome risk indicators in real clinical and registry databases, and its possible use in administrative systematic databases.	Started in 2007 and will continue until the end of the project
6	Setting up and maintaining an indicators database	Started at the end of 2006 (setting up of the website) and will continue until the end of the project

Table 3 summarizes the activities/tasks undertaken in the project. The third year of activity (2007) was devoted to carrying out the following activities: to enhance the cooperation among the partners and to enlarge the consortium, to define a dissemination strategy, to establish connections with other EU projects, to finalize the results of the first phase which are relevant to the selection and thorough description of the outcome indicators, to select the areas for pilot implementation, to appoint the pilot leaders, to finalize the pilot protocols, and to set up a web-based database of the selected outcome indicators.

It must be highlighted that, despite the administrative problems which the project incurred during the first period (2004-2006) that prevented the regular organization of the activities, the project was reorganized thanks to the concerted efforts made by the coordinator and the pilots' leaders. Following DG SANCO's suggestions, it was possible to recover the time lost and to be ready to achieve the foreseen objectives by the deadline.

After the appointment of both project leaders it became evident that the use of existing recent population-based registers, in order to fit predictive functions of outcome after the selected procedures, and validation of these functions on routinely collected hospital discharge data, was more feasible as well as more efficient and effective than the originally proposed organization of the pilot based on active collection. Therefore, the main coordinator proposed that the amount initially allocated to perform the clinical monitoring be moved from theirs to the pilot leaders' budget. This is a very important activity when active data collection is organized, but not useful when routine data are used.

The pilots' leaders were requested to invest more resources than those planned in the contract in force in order to finance the requested additional duties. These additional figures were included in their financial report, submitted together with this report, and will be formalized in the ongoing amendment to the contract.

Table 3 Overview of the activities

WP	Activities/Tasks	Outcomes/ Deliverables	Date foreseen	Date of achievement	Level of achievement (*)	Justification/ Problems encountered	Action to be taken to overcome the problem
1	Establishment of the initial network	Consortium	06/2006	12/2006	100%	Withdrawal of a partner	Inclusion of a new partner
	Contact between participants and DG SANCO	Communication	06/2006	02/2007	100%	Standstill of the project, change of the project leader	Definition of the 1st amendment
	Contacts among all the participants	Communication	06/2006	02/2007	100%	Standstill of the project, change of the project leader.	Definition of the 1st amendment.
						Moreover Partner GRI did not fulfil their duties. All the partners agreed in requesting their withdrawal	A further amendment to the contract was requested
	Setting up of the work plan	Work plan	03/2006	08/2007	100%	Reorganization of the project according to the suggestion received from DG SANCO	Meeting with DG SANCO officer (23/04/2007) Submission of the revised first interim report
	Organization of coordination meetings	Minutes	2 each year	24/04/2007 09/10/2007	100%		
	Drawing up interim and final reports	Financial and technical reports	02/2007	02/07 first submission 08/2007 submitted in revised form	100%%	Reorganization of the project according to the suggestion received from DG SANCO	Meeting with DG SANCO officer (23/04/2007) Submission of the revised first interim report
	Involvement of other countries (MS and non MS)	Official letters	06/2008		80%		

* Level of achievement measured by the current project leader in the period covered in the interim report

WP	Activities/Tasks	Outcomes/ Deliverables	Date foreseen	Date of achievement	Level of achievement (*)	Justification/ Problems encountered	Action to be taken to overcome the problem
1	Evaluation of the project: preparation of the protocol	Document	12/2007	02/2008	100%	Not considered in the original project. Lack of a description of a detailed defined structure to build up the evaluation activity (WP organization, indicators, milestones). First time included in the template for reporting received from DG SANCO in June 2007.	Organization in WP. Definition of what to evaluate (meetings and project progress) to be implemented only during the last year of activity.
	Evaluation of the project: administration of the questionnaire	Report	12/2008				
2	Define the diffusion policy	Document	06/2007	04/2007 in draft form. 10/07 in final form	100%	Approval of the document by all the partners during the Helsinki meeting (09/10/2007)	
	Preparation of the dissemination plan	Document	12/2007	11/2007 in draft form. 02/2008 in final form	100%	Collection of the information from the partners	Sending reminder mail
	Setting up of a website	Website (beta version)	04/2007				
		Final version	10/2007		100%		
	Preparation of the final workshop	Workshop	10/2008		10%		

* Level of achievement measured by the current project leader in the period covered in the interim report

WP	Activities/Tasks	Outcomes/ Deliverables	Date foreseen	Date of achievement	Level of achievement (*)	Justification/ Problems encountered	Action to be taken to overcome the problem
3	Setting up of contacts with other projects	Sharing of methodologies and results	12/2007	10/2007	100%		
4	Defining a list of outcome indicators	List of indicators	06/2006	06/2006	100%		
	Assessing the current situation in participating countries	Deliverable	06/2006	04/2007	100%	Standstill of the project, change of the project leader	Definition of the amendment (26/1/2007)
	Select diseases and procedures to test some indicators (pilot)	Technical presentation	06/2006	04/2007	100%	Standstill of the project, change of the project leader, appointment of pilot leaders	Definition of the amendment (26/1/2007)
5	Cardiovascular pilot: protocol definition risk adjustment methods	Document	07/2007	07/2007 draft version. 09/2007 final version	100%	Definition of the databases to be included and of the protocols allowing sharing of data among partners. Inclusion of new collaborating partners.	The protocol was defined in its draft form on July 2007 and presented to all the partners in its final form on October 2007
	Cardiovascular pilot: indicators testing	Report	09/2008		30%		
	Orthopaedic pilot: protocol definition	Document	07/2007	09/2007	100%	Definition of the contribution of each partner. Inclusion of new collaborating partners.	The protocol was defined in its draft form on July 2007 and presented to all the partners in its final form on October 2007
	Orthopaedic pilot: protocol realisation	Report	09/2008		30%		

* Level of achievement measured by the current project leader in the period covered in the interim report

WP	Activities/Tasks	Outcomes/ Deliverables	Date foreseen	Date of achievement	Level of achievement (*)	Justification/ Problems encountered	Action to be taken to overcome the problem
5	Description of the hospital discharge record datasets	Report	12/2007		30%	Avoiding duplication with the information requested by the cardiovascular questionnaire	Inclusion of all the information in a single questionnaire (decision adopted during the Helsinki meeting 09/10/2007). Definition of additional WP 5.3
6	Setting up of the web-based DB	Database	06/2007	06/2007	100%		
	Database input	Database available online	10/2007	10/2007	100%	Database is available online in the members' area	
	Database updating	Database updated	12/2008		20%	Missing information in some countries	Participants requested to integrate the existing information

* Level of achievement measured by the current project leader in the period covered in the interim report

3. TECHNICAL IMPLEMENTATION OF THE PROJECT

3.1 ACTIVITIES RELATED TO HORIZONTAL WORK PACKAGES

WP 1 Management of the project

This work package foresees the following tasks:

1. Establishment of a network among the partners and other European institutions involved in outcome research and outcome assessment.
2. Act as the contact between all the participants and DG SANCO.
3. Assure good communication and cooperation among all participants.
4. Set up the work plan of the project and assure that the described objectives are attained.
5. Organization of coordination meetings.
6. Drawing up of the interim and final reports.
7. Involvement of the highest number of MS.
8. Evaluation of the project.

EUPHORIC started on 15 December 2004. In the first 2 years of activity it "suffered" a partner withdrawal and the resignation of the previous project leader. The formalization of both changes (substitution of the partner and appointment of the new project leader) was defined on 26 January 2007. Since then, in agreement with DG SANCO officers' suggestions, the consortium has been working very hard to redesign the project in order to start the pilot phase and achieve the foreseen objectives respecting the new work plan. The reorganization of the project mainly concerned two issues: the use of existing recent population-based registers to fit predictive functions, and testing on routinely collected hospital discharge data instead of organizing active data collection; and the proposal to the Commission to consider additional WPs to fill in the gap left by partner GRI not having fulfilled their duties. These additional WPs will give the project added value by offering the opportunity to include the achievement of supplementary objectives not originally considered in the proposal (Annex 1). As a consequence, the partners who were appointed as pilot leaders were requested to invest more manpower than that foreseen in the contract and an amendment to the contract was requested to the Commission.

Activities undertaken

The strengthening of the institutions involved in the project is a vital task in carrying out a project. Therefore, in the period this report refers to, contacts among partners were intensified by sending out regular updates on the achievements of the project and information on the coordination meetings. An intranet platform on the project website was implemented in order to facilitate communication and exchange documents among the partners. To fulfil the stated objectives, and to respect the project's new organization, a management structure was defined considering both a core working group (coordinator and pilot leaders) and specific working groups for each pilot. The whole project was organized in WPs and the main deliverables were detailed and included each partner's specific tasks. The work plan was reorganized according to

the new deadline (14 December 2008). The new structure of the project was described in the first interim report submitted in August 2007.

Contact between partners and the HSWP were intensified by forwarding information/requests received by the HSWP and by forwarding the partners' comments to HSWP (see participation in the preparation of the HSWP glossary (section Benchmarking - Best practices) (Attachment 1) and submission of some proposals to the Network of Working Party Leaders for future SANCO actions in the health information and knowledge domain (Attachment 2)). The project coordinator regularly sent the HSWP secretariat the requested progress reports.

During 2007, EUPHORIC cooperated with the ECHIM project by proposing some outcome indicators to be considered for the short list (see WP 3 Liaison with other projects).

The main beneficiary, ISS, kept in contact with all the partners by exchanging information via e-mail and organizing coordination meetings.

The main beneficiary acted also as a contact between the participants and DG SANCO, both for administrative and technical issues.

A protocol for the evaluation of the project was set up (Attachment 3).

In the period this report refers to, the activities performed were relevant to the preparation of the pilot study (second phase of the project). The focus was on cardiovascular and orthopaedic areas.

Coordination meetings organization

During the period referred to, the following meetings were organized. All the information (agenda, minutes of meeting, presentations), when available, was put on the website.

Project meeting, Barcelona, 15-16 January 2007 (CAHTA) (joint meeting EAR-EUPHORIC).

Participants: Project leader, orthopaedic pilot coordinator (EAR), partner IMAS-IMIM, partner CAHTA. The meeting was hosted by CAHTA. It was organized so as to share with CAHTA the experience in setting up arthroplasty registers (15 January 2007) and was aimed at establishing cooperation in the orthopaedic pilot and possible cooperation between EUPHORIC and partner IMAS-IMIM (16 January 2007). After this meeting, CAHTA asked to be included in the project as collaborating partner (Annex 2).

Core group project meeting , Barcelona, 11 April 2007 (IMIM)

Participants: Project and pilots' leaders. The meeting was hosted by IMIM. The aims of the meeting were: 1) to officially put partner EFORT-EAR (after their inclusion in the project) and partner IMAS-IMIM in charge of the orthopaedic and cardiovascular pilots; 2) to define the organization of the pilot phase. (Annex 3)

3rd Project meeting, Luxembourg, 24 April 2007 (DG SANCO)

Participants: All the partners, DG SANCO (M. Artur Furtado). The meeting was held at HITEC Building (DG SANCO Luxembourg). The aim of the meeting was to involve all of the partners in the pilot phase, define WPs, tasks and deliverables. (Annex 4)

Core group project meeting, Barcelona, 4-5 July 2007 (IMIM)

Participants: Project leaders and the pilots' leaders. The meeting was hosted by IMIM. Aims 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 of both pilots. (Annex 5 and 6)

Project meeting: Helsinki, 8 October 2007 (STAKES)

Participants: ISS, EAR, IMAS-IMIM, NKUA, STAKES. The meeting was hosted by STAKES. The aim of the meeting was the definition of an additional WP about risk adjustment and statistical analyses, transversal to both pilots. Partner IMAS-IMIM supported the project leader in the preparation of the minutes. (Annex 7)

4th Project meeting: Helsinki, 9 October 2007 (STAKES)

Participants: All the partners. The meeting was hosted by STAKES. The aims of the meeting were the presentation of both pilots' protocols, the introduction of new collaborating partners and the planning of the activities of the following semester. Representatives of ECHIM, OECD and HDP participated in the meeting. Partner IMAS-IMIM supported the project leader in the preparation of the minutes. (Annex 8)

Project meeting: Athens, 4 December 2007 (NKUA)

Participants: Project leader, pilots' coordinators, NKUA partner. The meeting was hosted by NKUA. The aim of the meeting was to plan the detailed contribution of partner NKUA to the WP on statistics and risk adjustment. (Annex 9)

Participation in the HSWP meetings

The project leader and the IMAS-IMIM partner (cardiovascular pilot leader) participated in the 8th HSWP meeting (Luxembourg, 11-12 June 2007). The project leader participated in the 9th HSWP meeting (Luxembourg, 19-20 November 2007). During the Helsinki meeting, the project leader invited all the partners to register on the HSWP website in order to be updated about the HSWP activities.

Coordination meetings with DG SANCO

1) 23 April 2007 - Luxembourg

The project leader and the pilots' leaders met M. Artur Furtado on 23 April 2007 in order to discuss the new organization of the project following the amendment signed by the Commission on 26 January 2007. This meeting eventually solved some administrative issues that had prevented the regular progress of the project, such as the substitution of HFA with EFORT-EAR and the change of the project leader. The EUPHORIC project was originally structured in 3 phases: Survey, Pilot and Dissemination. The proposed organization of the pilot was based on active collection of data and the use of existing databases. However, on the basis of the results obtained during the Survey phase (Deliverable N. 1 submitted to DG SANCO in its final form in June 2007), it appeared that the use of existing recent population-based registers to fit predictive functions of outcome after the selected procedures, and testing these functions on routinely collected hospital discharge data was feasible and more efficient and effective for the project's purpose. Moreover, the outputs produced might be more easily implemented in the routine health information flow systems. Therefore, it was proposed that both pilots use only these types of data. Dr Gerold Labek (partner EAR-EFORT, Austria) and Prof. Jaume Marrugat (partner IMIM, Spain) were appointed as leaders of the orthopaedic and the cardiovascular pilots respectively. It was agreed that special efforts would be made to enlarge the consortium by including as many countries and databases as possible. According to this new organization and in order to respect the new work plan and achieve the stated objectives, partners IMAS-IMIM and EAR-EFORT were requested to invest immediately more manpower than that foreseen in the contract, without waiting for the signature of the amendment. The formalization procedure of the amendment regarding this issue is still ongoing.

2) 20 November 2007 – Luxembourg

The project leader met the officers of DG SANCO Unit C1 (M. Jean Luc Sion and M. Dimitri Agneskis) and Unit C2 (M. Artur Furtado) in order to discuss how to proceed

regarding the changes in the main coordinator and pilot coordinator budgets, and partner GRI who did not fulfil their duties (see below). It was agreed to prepare a single amendment to the contract including both issues.

Inclusion of collaborating partners

The following new collaborating partners have been included in the project:

- Catalan Health Technology Assessment and Research, Spain (27/03/2007)
- Slovak Arthroplasty Register (Slovak Republic) (18/7/2007)
- Ludwig Boltzmann Institut for Health Technology Assessment (Austria) (17/10/2007)
- Arthroplasty Register Tyrol (Austria) (17/10/2007)
- French Society of Orthopaedic and Trauma Surgery (France) (17/10/2007)

The following Institutions were contacted during the period this report refers to and included afterwards:

- BQS Bundesgeschäftsstelle Qualitätssicherung GmbH (Germany) (21/12/2007)
- Israel Society for the Prevention of Heart Attacks at Neufeld Cardiac Research Institute (Israel) (21/12/2007)

The new collaborating partners will contribute to the project by either providing the data which is useful for the implementation of both pilots from their own databases or supporting the dissemination of the results and the connection with other projects regarding the same topics.

In particular, the Israel Society for the Prevention of Heart Attacks at the Neufeld Cardiac Research Institute will contribute to the further development of the cardiovascular pilot study by supplying the EUPHORIC cardiovascular database with the ICSIS database 2000-2006 from Israel. Moreover, the cooperation with this institution will facilitate the inclusion on the same database of the Euro Heart Surveys 2000 and 2005 on Acute Coronary Syndrome from the European Society of Cardiology.

The other collaborating partners will closely cooperate within the orthopaedic pilot. Best practice strategies for the work with data collections and registries, definition of criteria for data collections to be used in health technology assessment and other disciplines, and translation of this to requirements for data collections were identified as topics of shared interest with LBI HTA.

Cooperation with ECHIM

Within the framework of updating the ECHI short list, on 2 October 2007, the project leader was invited by Prof. Pieter Kramers (former project leader of the ECHI project) to compare the short list and the EUPHORIC indicator list in order to suggest a maximum of five EUPHORIC indicators to be included on the ECHI short list. A thorough analysis of the ECHI short list and of the indicators included in the ICHI (International Compendium of Health Indicators) was carried out in cooperation with both pilots' leaders (EAR-EFORT, IMAS-IMIM). The following four indicators were selected as possible candidates to be included on the ECHI short list: AMI case fatality rate; fatality rate after CABG; revision rate (orthopaedic); and revision burden rate (orthopaedic). The description of the indicators was prepared according to the ECHI requests and submitted in order to be discussed during the WP on health indicators held in December 2007 (Attachment 4). This deliverable, which currently includes only the submitted documents, will be integrated with a description of the comparative analysis performed with ECHI and ICHI, and the rationale supporting the choice. All will be submitted to the Commission by April 2008.

Evaluation plan

Following the suggestions received by DG SANCO officers when the first interim report was submitted, a protocol for the evaluation of the project was set up (see Attachment 3). It must be stated that the initial project neither foresaw an organization in WPs nor a detailed definition of the activities and of the related indicators to monitor their progress. It is evident that, in this situation, this kind of tool's usefulness is limited and its application will be restricted to the last year of activity. Therefore, it was decided to focus the development of the evaluation plan on two aspects: 1. Active participation of both associated and collaborating countries in the project activities; 2. Respect of scheduled milestones and deliverables according to the project WPs. The meetings were a key event for establishing good relationships among the partners, and so it was decided to collect information about their participation, suggestions and feedback by means of an *ad hoc* developed questionnaire that might be implemented in the members' area of the website. In order to evaluate the second aspect, a set of indicators was defined. Measurements will be taken after the final workshop. A report including the analyses of the collected data will be produced.

Problems encountered

On the basis of their expertise, partner GRI proposed a contribution to the EUPHORIC project by establishing cooperation with Eurocare. Therefore, following this request, they were given the responsibility, together with partner STAKES, of leading the WP 3 "Liaisons with other EU projects" at the beginning of April 2007. They promised also to prepare a proposal for possible cooperation with other EU projects related to transplantation. This document had never been submitted by GRI to the coordinator. During the core group meeting held in Barcelona on 4July it was decided that also the orthopaedic pilot leader would request information about future GRI contribution to the pilot phase. However, neither the project leader nor the orthopaedic pilot coordinator had received any proposals about the GRI contribution to the project. Even though the coordinator highlighted the importance of the Luxembourg meeting (24 April 2007) for the whole organization of the project and stressed partner participation, partner GRI did not attend. Similarly, they did not attend the last meeting held in Helsinki that was also a crucial event for the development of the project (in fact both pilots' leaders were requested to describe in detail the organization of each pilot and to organize the contribution of each partner). Furthermore, they did not even inform of the reasons for their absence. The question regarding the further participation of partner GRI, which started at the end of May 2007 and ended at the beginning of February 2008, was a hindrance to the regular development of the activities.

How problems were resolved

During the Helsinki meeting (8 -9 October 2007) all the participating partners agreed in requesting the exclusion of the partner GRI from the consortium and in making a proposal describing additional WPs which were relevant to both pilots and could be funded using the residual GRI budget. The technical proposal (Annex 1) was discussed with M. Furtado who approved it.

This decision was made because the introduction of another associated beneficiary into the current work plan was difficult (both because most of the activities had already started and because the administrative procedures to substitute a partner with another one would need some time) and that the remaining time frame would make it very difficult for any institution to perform a work package designed for a 3-year period within several months.

Partner GRI withdrew from the project on 6 February 2008. The procedure to submit the amendment is still ongoing.

Activities planned for the next period

- Preparation of the amendment.
- Keep improving contacts among partners by sending out regular updates on the achievements of the project and information on the coordination meetings.
- Organization of coordination meetings (1 meeting with all the partners, March 2008, Innsbruck), 3 meetings specifically for the pilots and the interaction with the risk adjustment/statistics WP.
- Coordination of the core working group (coordinator and pilot leaders)
- Keep intensifying contacts between partners and the HSWP by forwarding information/requests received by the HSWP, and by forwarding the partners' comments to the HSWP.
- Implementation of the protocol for internal and external evaluation of the project and analysis of process evaluation data.
- Organization of the final workshop (October 2008).

WP 2 Dissemination strategy

Dissemination plan available: no [X] yes

The aim of this WP is to define the diffusion policy and to carry out the dissemination of the results.

Dissemination of the results will be performed by cooperating with the Health System Working Party (HSWP), the Working Party on Health Indicators and other European health projects. This objective will be achieved through the MS health authorities network, the scientific societies, the stakeholders, and the academic world.

The results will be available both as scientific and informative publications for policy makers, stakeholders and citizens as well as guidelines for benchmarking hospitals and MS. A final workshop of the project will be organized in autumn 2008.

The main tool supporting the dissemination of the results is the project website (www.euphoric-project.eu). The EUPHORIC website is both an output of the project and the means by which most of the results will be disseminated to the international audience. The website contains special pages with contributions from each WP. A password protected access to the website enables only the EUPHORIC participating countries to contribute to the development of the website and enter the relevant information. While on the other hand, public access to the web guarantees the dissemination of the information to both the scientific audience and the public. The website will be publicized by the partnership organizations and links to the website will be made available from other appropriate websites.

Information will be put online as it becomes available instead of waiting until the end of the project (as stated in the Grant Agreement). All the disseminated documentation, information or material will be free of charge and accessible by internet.

During the 4th EUPHORIC meeting held in Helsinki, all the partners agreed in considering the preparation of an electronic bulletin (newsletter) as an additional instrument to support the dissemination. Therefore, a newsletter will be published during 2008. The electronic bulletin will summarize the data presented on the website and will be sent by e-mail to selected institutions in the participating and non-participating EU countries. It will also be sent to European and international institutions (European Commission, WHO, etc.), and to people who register for this service on the website.

Activities undertaken

- The ECHIM project coordinator, Prof. Arpo Aromaa, and the Finnish coordinator of the OECD HCQI project, Dr Päivi Hämäläinen were invited to the 4th EUPHORIC meeting held in Helsinki. It was agreed to share all the results achieved by the project and to circulate them in the ECHIM network. The same will be done with OECD.
- A proposal by Dr Gerold Labek (orthopaedic pilot coordinator – partner EAR) related also to the use of the EFORT portal was sent to DG SANCO on 6 October 2007.
- A dissemination plan (see Attachment 5) was prepared. It includes the description of the dissemination policy that was proposed by partner IMAS-IMIM and approved by all the partners during the 4th EUPHORIC meeting. All the partners were asked to consider the dissemination of the EUPHORIC results in their own networks (public health, scientific societies, universities) also taking into consideration the collection of feedback (comments, suggestions,) which comes from the addressees.
- The first deliverable "Survey: results of the first phase", finalized in May 2007, was distributed within the ECHIM network and sent to the Working Party on Health Indicators members (ECHIM project) and to other projects dealing with health indicators and the use of routinely collected data (e.g. eHID, HDP).

Information Leaflet

The leaflet approved by all the partners was translated into all the languages of the associated beneficiaries and is downloadable from the website. (Annex 10)

The design of a website and the selection of the technological partner

In September 2006, the Inter-University Consortium for the Application of Super-Computing for Universities and Research (CASPUR www.caspur.it), selected by the main beneficiary as technological partner, started the design and construction of the EUPHORIC website. CASPUR's role in the EUPHORIC project is to provide technical support for both the design and the implementation of the website together with the deployment and the housing of the site itself.

The website development has been organized in 5 main steps:

1. production of a static webpage protected by a password.
2. production of the beta version of the EUPHORIC website.
3. production of the first public version of the website.
4. setting up of a second site version that improves the website's services and usability.
5. housing and maintenance of the Euphoric site up to the end of 2008.

During the period this report refers to, the first beta version of the website and the public part of the website were completed and put online on 9 March 2007. The website is housed at CASPUR and is reachable at www.euphoric-project.eu. The website hosts also the web- based database of the selected outcome indicators. Please see the WP 6 (Setting up and maintaining indicators database) for a more detailed description of this topic.

Moreover, the following activities were carried out:

- The set of information from the new collaborating partners was included in the project and is now visible on the internet and available on the database site.
- The leaflet of the project was translated in the languages of the participant countries and made available on the website.
- The members' area was organized.
- The database was implemented (see WP 6).

Publications and Reports

- Deliverable n.1"Survey: results of the first phase" was submitted to DG SANCO in June 2007 (internal report).
- Deliverable n.6 "Detailed sheets of the collected outcome indicators (long list)" was submitted to the EU Commission and attached to this report (internal report) (Attachment 6).
- M. Torre, C. Morciano, P. D'Errigo, A. Allepuz, D. Fusco, U. Häkkinen, G. Labek, K. Lyubomirova, J. Marrugat, D. Psaltopoulou, E. Taioli, W.Ye "The EUPHORIC project: outcome indicators collection in Europe. Results of the first phase". Presented as a poster at the 15th EUPHA Conference. The submitted abstract was published in the European Journal of Public Health Volume 17, Supplement 2:213 (Annex 11).
- Deliverable n.7 Bosch X, Loma-Osorio P, Marrugat JJ "Platelet glycoprotein IIb/IIIa blockers for percutaneous coronary intervention, and as initial treatment in Non-ST segment elevation Acute Coronary Syndromes". The systematic review of the literature was completed by partner IMAS-IMIM and published in the Cochrane Library which is used in the clinical field as the basis for evidence-based medicine practice. Its aim was to release a clinical recommendation on the use of GPIIbIIIa platelet inhibitors in percutaneous revascularisation (Attachment 7).
- Baglio G, Torre M, Sera F, Cardo S, Romanini E, Labek G. The validity of arthroplasty register and hospital administrative data for outcome measurement after hip replacement. Prepared by partners ISS and EAR and submitted to the Journal of Bone and Joint Surgery (Br).
- Partner STAKES introduced the draft of outcome indicators (considering years 1998-2003) in their national context during a seminar organized in May 2007. Reports were published about the use of outcome indicators in Finland for the following topics: AMI, very low birth weight infants, stroke, hip and knee replacements.

Problems encountered

The non-fulfilment of partner GRI left the areas of cancer uncovered.

How problems were resolved

It was agreed to disseminate results on this area through OECD and to establish contacts with project Eurochip (European Cancer Health Indicator Project).

Activities planned for the next period

The following activities have been planned to be carried out during 2008:

- Implementation of the dissemination plan. Participation at workshops, congresses and conferences will be communicated to DG SANCO as soon as they are confirmed.
- Set up of a newsletter. The newsletter user registration will be placed on the website's public area to improve the dissemination of the project to other institutions, stakeholders, projects and also among citizens and patients.
- The website will be updated as soon as the information is available (protocols and results of the pilot phase; information about the project, the participants and possible new collaborating partners).
- A paper presenting the list of the selected indicators has been prepared and will be submitted in the next weeks for publication. Afterwards, all the information related to indicators, now available only in the members' area, will be published in the public area.
- The leaflet will be translated in the languages of the most recently included countries.
- Organization of the final workshop (October or November 2008).

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

In general, the results achieved in a project increase their value if they are shared in as wide as possible context. Therefore, it is important not to work in an isolated situation but to be part of a network by establishing as many synapses as possible.

Thus, the aim of WP 3 "Liaison with other EU projects, EU programmes and health stakeholders" is to establish connections with key persons participating in projects currently running in Europe that have connections and/or interests in outcome research or are using similar methodologies, even if they do not focus on outcome research. In this way, it may be possible to create synergies and share knowledge by also bridging different fields.

Participation in the HSWP and connection with the ECHIM project and the Working Party on Health Indicators have opened several opportunities to establish useful contacts.

In particular, cooperation with the ECHIM project and the Working Party on Health Indicators has allowed the project to verify that the indicators, presentation and methods were compatible with ECHI.

EUPHORIC is distinctive in that it analyses outcome indicators and most of them could be considered complementary to those already listed in the International Compendium of Health Indicators (ICHI list).

Activities undertaken

During the third coordination meeting, partner STAKES was appointed as coordinator of this WP. In the period considered by this interim report, contacts with the following projects were established: ECHIM, eHID, EUnetHTA, EUGLOREH, OECD (Health Quality Indicators Project), HDP, and the European Patients' Forum.

ECHIM

The project coordinator (ISS) and the partner STAKES contacted the ECHIM project secretariats (KTL and Stakes, Helsinki, Dr Arpo Aromaa; ISS, Rome, Dr Emanuele Scafato). The first deliverable "Survey: result of the first phase", including the list of the 54 outcome indicators, circulated within the ECHIM network. Later, EUPHORIC was asked to submit a set of indicators to be considered on the ECHI short list. The following four indicators were selected: (AMI case fatality rate (or survival); CABG case fatality rate; revision rate (orthopaedic); revision burden rate (orthopaedic)) (Attachment 4).

eHID

The coordinator of the eHID project, Dr Douglas Fleming, was contacted by the project leader during the 8th HSWP meeting. Reports were exchanged. eHID focuses on information collected by GP for 4 specific indicators: incidence and prevalence of diabetes, burden of mental illness, and the prevalence of ischaemic heart disease. During the 4th EUPHORIC meeting (Helsinki, 9 October 2007) it was agreed that the leader of the cardiovascular pilot would check the usability in the cardiovascular project of the data collected by the eHID project since the analysis refers to British local prevalences.

EUnetHTA

The leader of the orthopaedic pilot, Dr. Gerold Labek (EAR) contacted EUnetHTA via the beneficiary partners CAHTA (now AQURA) in Barcelona, Spain and a meeting was organized. During the meeting both projects were presented. Taking into account the situation of both projects (EUnetHTA is in its final stage), it was stated that presently it is not possible and reasonable to establish direct cooperation. However, it was agreed that cooperation in potential future projects concerning health technology assessment and market monitoring is recommended. Bilateral information was agreed. The two partners of EUnetHTA (CAHTA, Spain, and LBI-HTA, Austria) were included as collaborating partners of EUPHORIC. Their

interests, ongoing activities, and competence are complementary to EUPHORIC and their cooperation will give additional value to the whole EUPHORIC consortium. On 23 January 2008, the link to the EUPHORIC website was added to the EUnetHTA home page (http://www.eunethta.net/HTA/HTA_Networks/).

EUGLOREH

The project leader, Marina Torre contacted Dr 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 cooperate with EUPHORIC, therefore, he proposed considering a section dedicated to EUPHORIC or to report the results of both EUPHORIC pilots in the specific sections (2.3.1; 2.3.11).

OECD

Dr Päivi Hämäläinen, Finnish coordinator of the OECD Quality Indicator Project, was invited to the 4th EUPHORIC meeting (Helsinki, 9 October 2007). EUPHORIC will cooperate with the OECD in order to share and mutually disseminate the results in both networks. Partner STAKES will coordinate this activity.

HDP

Dr Olli Nylander, Finnish coordinator of the Hospital Data Project, was invited to the 4th EUPHORIC meeting (Helsinki, 9 October 2007). Cooperation with the HDP can be useful in gathering specific information needed by both pilots. Partner DEASL will follow this activity.

European patients' forum

During the 9th HSWP meeting (Luxembourg, 19-20 November) the project leader met Dr Roxana Radulescu, who is responsible for the European Patient's Forum project. They agreed that disseminating the results is a key issue of each project. Targeting citizens and patients is imperative in the context of public health. In regards to this aim, the European Patient's Forum would be an optimal channel to reach patients and disseminate the results. It was agreed to evaluate the possibility of establishing this kind of cooperation.

Problems encountered

Partner GRI proposed themselves as being responsible for the interactions with Eurocare. However, they did not fulfil their duties in 2007.

How problems were resolved

Cooperation with Eurocare was initially proposed to cover the area of cancer. Therefore, to fill in the gap relating to the non-fulfillment by partner GRI, it was agreed to share results in this area through OECD. Contacts with project Eurochip (European Cancer Health Indicator Project) will be considered.

Activities planned for the next period

- Keep improving cooperation with the previously contacted project and set up contacts with other projects, if any, in order to enlarge the network, which will be useful for the dissemination of results. STAKES is a Finnish co-coordinator in the OECD Health Quality Indicators Project (HCQI). Thus, they will coordinate the co-operation with EUPHORIC and the OECD project.
- Set up the website links to the websites of the contacted projects.
- To prepare the contribution to be included in the EUGLOREH report on the basis of the pilots' results.
- A proposal to cooperate with the European Patients' Forum and Eurochip (European Cancer Health Indicator Project).

3.2 ACTIVITIES RELATED TO PROJECT OBJECTIVES (CORE WORK PACKAGES)

WP 4 Indicators development

The usefulness of outcome indicators is widely documented in the literature since they allow:

- comparative evaluation of hospital performances;
- comparative evaluation between groups of facilities with similar organizational and/or process characteristics (for example, treatment volumes, technological equipment);
- comparative evaluation between populations resident in different areas or of different socioeconomic status;
- analysis of temporal trends.

The aim of WP 4 is to achieve the following specific objectives:

1. Create a list of diseases amenable to receiving medical procedures whose quality can be assessed in terms of outcome.
2. Devise a set of theoretical indicators to assess the quality of procedures used on key diseases and based on outcome.
3. Select diseases and procedures suitable for a pilot study to test some indicators.

All the activities related to this WP consist in a survey aimed at defining the tools and the operational conditions which are necessary for the experimental phase (pilot).

Methodology applied as planned

The first two years of activity were devoted to the definition of a list of outcome indicators, to the assessment of the current situation about outcome indicators in the participant countries, and to the selection of the areas of interest for the experimental phase (pilot): (see Deliverable n.1 “Survey: results of the first phase”). Among the areas with the highest burden of diseases, cardiovascular and orthopaedics were chosen for the pilots’ implementation on the basis of the following criteria:

- high impact in public health
- not already investigated by other EU projects (in terms of outcome measurements)
- availability of expertise inside the EUPHORIC consortium
- possibility of receiving data which is available in the countries participating in the EUPHORIC consortium.

Within the two areas, the following procedures were selected considering their high prevalence: Acute Coronary Syndrome for cardiovascular pilot and Arthroplasty for the orthopaedic pilot. More detailed information about the selected procedures was sent to M. Furtado in October 2007 as additional comments to the first interim report.

On the basis of the literature review, a summary sheet for each indicator containing the following information: title, rationale, numerator, denominator, statistical methods, how to use it, and references, was prepared. All the sheets were collected in the Deliverable n.6 “Detailed sheets of the collected outcome indicators (long list)” (Attachment 5).

Following a request by the HSWP, received on 29 May 2007, EUPHORIC contributed to the preparation of the glossary by providing information about “Best practices/Benchmarking”

(Attachment 1). The following partners participated: ISS, DEASL, KAR, EAR-EFORT, IMAS-IMIM.

Involvement of partners and target groups

The following partners participated in the preparation of the detailed sheets describing the indicators: ISS, DEASL, NKUA.

In recent years, STAKES has established seven expert groups in order to develop outcome indicators for hospital care in the Finnish national context. The groups include consultants, health professionals, participants of scientific societies and health care providers as well as experts in health economics and statistics. These expert groups focus on several indicators on outcome and costs the following of which are also included in EUPHORIC:

- Acute myocardial infarctions including, PTCA GABG
- Hip fracture
- Hip and knee replacements
- Very low birth weight infants
- Stroke.

Coordination with other projects or activities

- Project Mattoni in Italy (http://www.mattoni.ministerosalute.it/). The Mattoni project (2004-2007) published its final report in February 2007. During the project, 7 areas were selected and 43 indicators developed. The first list, elaborated by the Mattoni project, was presented by the ISS to the EUPHORIC consortium as a starting basis to develop a final list to be used in a European context. The aim of the Mattoni project was to perform a description of the Italian health system situation by providing benchmarking among regions and hospitals. By using this as a starting point, EUPHORIC expanded it to an international context. Therefore, the methodology developed in the Mattoni project (based on the possibility of using risk adjustment methods) was adopted and adapted by the EUPHORIC project in order to provide a thorough analysis of the different contexts of the participating countries. Moreover, not all the indicators selected by the Mattoni project resulted as useful in achieving the EUPHORIC objectives, since most of them referred to the particular Italian context. Therefore, the proposed list was updated considering both the literature research performed by each partner and their experience in the specific fields. As a result, a long list consisting of 54 outcome indicators in 9 areas of pathology was defined. The results of this first phase of the project (survey) were collected in the deliverable n.1 “Survey: the first phase of the project” (submitted in 2007).
- Partner STAKES-CHESS has been coordinating the PERFECT project in Finland (PERFormance, Effectiveness and Cost of Treatment episodes, http://info.stakes.fi/perfect/EN/index.htm). The project aims at developing methods for register-based measurement of the cost effectiveness of treatment. It also aims to create a comparative database that shows the treatments given and to compare their costs and effectiveness (outcomes) between countries, hospitals, hospital districts, regions and population groups.

  From the Finnish perspective, the EUPHORIC and PERFECT projects are coordinated so that the Finnish part of the international comparative research for EUPHORIC was done in close cooperation with the PERFECT project. PERFECT is a joint project by the Social Insurance Institution of Finland, STAKES and university hospital districts that covers the period 2004-2007. The project, which is part of the Academy of Finland's Research Programme on Health Services Research, is also funded by the Finnish Funding Agency of

Technology and Innovation (FinnWELL - Future Health Care Technology Programme) and SITRA (the Finnish Innovation Fund).

Outcomes and deliverables achieved

Outcomes:

- Detailed sheets of all the 54 selected outcome indicators.
- Glossary on “Best practices/Benchmarking”.

Deliverables:

- Finalization and presentation of the Deliverable n.1 “Survey: results of the first phase”.
- Preparation of the Deliverable n.6 “Detailed sheets of the collected outcome indicators (long list)” (Attachment 6).
- Deliverable n.2 “Glossary” (Attachment 1).
- The outcome indicators draft (considering years 1998-2003) were introduced by the Finnish partner STAKES in a seminar in May 2007. Four basic reports on indicators were published (see WP 2 Dissemination strategy/Publications and reports). These basic reports include: 1) Basic information on patients such as number of patients, age structure, comorbidity; 2) Indicators describing length of stay, outpatient visits, and use of procedures, drugs, and cost of care. Process indicators such as percentage of patients treated in specific high quality units; 3) Indicators describing outcome of patients. The indicators are available both at regional and hospital level.

Problems encountered

On the basis of their expertise, partner GRI offered their cooperation during the first phase of the project in order to prepare the detailed sheets regarding cancer and transplantation. However, despite this agreement, they did not respond to the request from the project leader for either the financial or for the technical issues and did not submit the sheets relevant to transplantations. Moreover, the sheets relevant to cancer did not meet the required standards and needed to be revised.

How problems were resolved

Partner NKUA offered their help in preparing the sheets regarding transplantation. The main beneficiary, ISS, revised and updated those regarding cancer.

Activities planned for the next period

- Implementation of all the information collected in the detailed sheets on the website.

WP 5 Development of adverse outcome risk indicators in real clinical and registry databasesand its possible use in administrative systematic databases. (pilot)

The results obtained from the survey paved the way for the preparation of the pilot phase. In fact, retrieving the country’s specific information through the analysis of the questionnaire completed by each participant, permitted the assessment of the availability of existing data in the respective countries. Therefore, orthopaedic and cardiovascular areas of pathology were taken into consideration for the pilot study, not only for their high clinical and political relevance, but also because all the participants were able to provide information in these areas.

The originally proposed organization of the pilot was based on an active collection of data and the use of existing databases. However, on the basis of the results obtained during the survey phase (Deliverable n.1), it appeared that the use of existing recent population-based registers to fit predictive functions of outcome after the selected procedures, and additionally, the validation of these functions on routinely collected hospital discharge data were feasible and more efficient and effective for EUPHORIC. Moreover, the outputs produced would be more easily implemented in the routine health information flow systems. Therefore, as reported in the first interim report submitted on 9 August 2007, the pilot phase was organized so as to use only these types of data. Dr Gerold Labek (partner EAR-EFORT, Austria) and Prof. Jaume Marrugat (partner IMIM, Spain) were appointed as leaders of the orthopaedic and the cardiovascular pilots respectively. Special efforts were made to enlarge the consortium by including as many countries and databases as possible.

For a better description of the activities performed in this WP, the following sub-work packages were considered:

5.1 Cardiovascular pilot

5.2 Orthopaedics pilot

During the meeting held in Helsinki on 8-9 October 2007, the importance of considering, all the activities related to risk adjustment and statistics as a separate sub-work package was highlighted. Therefore, with respect to the first interim report, the sub-work package 5.3 “Use of the available sources of information in participant countries in order to develop a standardized statistical methodology for comparative evaluation of outcomes” was added.

Since Acute Coronary Syndrome and Arthroplasty have been selected to be tested in the EUPHORIC pilots, partner STAKES started two special research projects for these topics in Finland in 2007. Regarding CABG and PTCA procedures, they gathered data which is similar to that available from Spain in order to analyze outcome differences between hospitals during the years 1998-2005. The first results of the study were given in a seminar on 8 February 2008. Similar studies were started for hip and knee replacements.

WP 5.1 Cardiovascular pilot

The specific aims of the cardiovascular pilot, set up after some modifications since the last report, are the following:

1. To define a simple set of factors that determine quality of health care outcome (in-hospital mortality, and a combined end-point of in-hospital mortality, re-MI or angina post infarction) in myocardial infarction patients who underwent CABG, coronary angiography, or percutaneous revascularization. These indicators will be analyzed in the context of characteristics at individual, hospital and country levels.
2. To apply the indicators to information obtained routinely for administrative purposes. To benchmark hospitals and countries according to their adjusted risk of the two types of outcomes. This might provide systematic information to end-users (doctors, health staff, health administration, decision makers, policy makers, EU population).
3. To make recommendations as to how to develop monitoring systems with outcome indicators in cardiovascular diseases in Europe in view of the results of the former objectives.
4. To develop and update a systematic review of the literature on the efficacy of GPIIb-IIIa inhibitors in the ACS.

Methodology applied as planned

All the activities related to this objective started in 2007 after the appointment of the pilot leader.

Involvement of partners and target groups

During the EUPHORIC meeting held in Luxembourg on 24 April 2007, the availability of the other partners was investigated. After the EUPHORIC meeting held in Helsinki it was decided to prepare an agreement in order to share anonymized hospital discharge data between partners IMAS-IMIM and STAKES.

During the period from 15 December 2006 to 14 December 2007, partner IMAS-IMIM developed preliminary statistical analyses to evaluate whether the use of information from the registries can be applied to health information systems, in terms of controlling for patient case mix and for the most important clinical variables for comparative evaluation of outcomes and benchmarking.

Coordination with other projects or activities

Collaboration is being set up with the former co-ordinator of the Euro Heart Survey Programme, Dr Shlomo Behar, from the Neufeld Cardiac Research Institute, included in EUPHORIC as collaborating partner on 21 December 2007,. During the HSWP, on April 26, 2005, Dr Anselm Gitt – the current chairman of this programme - stated his interest in EUPHORIC and in finding a way of joining the effort. However, even if Prof. Jaume Marrugat participated in the 8th HSWP meeting (Luxembourg, 12 June 2007) and met Dr Gitt in order to define the involvement of EHS in the EUPHORIC cardiovascular pilot, Dr Gitt never responded to the invitation.

Thanks to further contacts made by Prof. Marrugat that led to a formal invitation to Dr. Behar, it was possible to include the databases detailed below in the cardiovascular pilot.

Outcomes and deliverables achieved

Activities undertaken since the last interim report (i.e., during 2007):

- Prof. Jaume Marrugat, principal investigator of the IMAS-IMIM partner, accepted the leadership of the cardiovascular pilot.
- A number of European investigators were contacted to cooperate with other existing projects and/or registers. The aim of these contacts was to gather myocardial infarction or Acute Coronary Syndrome patient databases. DG SANCO Unit C2 supported the pilot leader in contacting the EHS project and in checking the rules to be followed to transfer data among partners. Presently, the following databases' owners have committed to participating in the EUPHORIC cardiovascular pilot study:
    1. MASCARA Study 2005: approximately 8,500 Acute Coronary Syndrome patients from 37 Spanish hospitals. PI Prof. Dr Gaietà Permanyer, Cardiology Dpt, Hospital Vall d'Hebron, Barcelona, Spain.
    2. EURO Heart Survey 2000 on Acute Coronary Syndrome: approximately 3,000 myocardial infarction patients from more than 20 European countries. PI Prof. Shlomo Behar, Israel.
    3. EURO Heart Survey 2005 on Acute Coronary Syndrome: approximately 6,500 Acute Coronary Syndrome patients from more than 20 European countries. PI Prof. Shlomo Behar, Israel.
    4. Israeli Center for Disease Control on the platform of ACSIS IHS is also willing to cooperate and send the ACSIS 2004 and 2006 databases (4,000 patients from 25 hospitals). PI Prof. Shlomo Behar, Israel.
- Definition of the objectives of Work package 5.1 (see above).
- Development of a proper protocol for the cardiovascular pilot study (enclosed in Attachment 8 and summarized below).

Cardiovascular pilot protocol (summary)

Acute Coronary Syndrome (ACS) was selected for the EUPHORIC pilot study since it was judged to be the easiest: admission is always required, there are many ongoing registers, and in-hospital and 6month procedure use and outcome are relatively easy to monitor.

The protocol of the pilot study included the following procedures related to acute myocardial infarction:

- Coronary artery bypass graft (CABG),
- Coronary angiography,
- Thrombolysis,
- Percutaneous revascularization (angioplasty with or without stenting),
- General MI management,
- GPIIbIIIa blocker use (meta-analysis).

The outcomes considered included:

- Mortality at 30 days after the selected procedures.
- A combined end-point of 30-day mortality, re-infarction or angina post-infarction.

Benchmarking hospitals

Real life data from existing population-based registries will be used to validate the former. The comparison will be established in terms of procedure use and outcome rate risk by procedure benchmarking (interquartile and 5th and 95th percentiles will be provided for hospitals and countries - the latter only if the EHS-ACS can be analyzed).

Hospital, country, and individual characteristics are probably at the origin of varying procedure outcomes used in ACS. Therefore, a number of such characteristics will be taken into account in the analyses. To collect this information, an *ad hoc* questionnaire (included in the cardiovascular pilot protocol, Attachment 8) was developed by the cardiovascular pilot leader (partner IMAS-IMIM) involving partners ISS, EAR, NKUA and DEASL. At present, partner KAR has provided the cardiovascular pilot leader, Prof. Jaume Marrugat, with the Swedish country level basic characteristics for the cardiovascular disease pilot study and filled in all the required information.

Conclusions

In the discussion on the approach of how to complete the objectives of this EUPHORIC pilot, a number of considerations were raised in the light of the preliminary results:

1. The assessment of drug use in the assessed procedures was not foreseen in the initial protocol. Platelet GPIIbIIIa blocker use is currently an important practice in PTCA procedures: partner IMAS-IMIM deemed it necessary to assess its usefulness in a meta-analysis that will be published in the prestigious Cochrane Library (Deliverable n.7, Attachment 7).
2. Furthermore, it was judged important to include as many myocardial infarction hospital registries from as many countries as possible so as to consider country characteristics variability. This necessity will require looking for such registries and expand the planned manpower assigned to pilot management, data management, and statistical analysis.
3. Thirdly, partner IMAS-IMIM initially considered the three above-described procedures used in the management of myocardial infarction. At this time, we have also considered the compelling necessity of including the outcome for the general management of acute myocardial infarction admission.

Problems encountered

None.

How problems were resolved

Does not apply.

Activities planned for the next period

The following indicators, some of them not previously included in the list enclosed in the Deliverable n.1 "Survey: results of the first phase of the project", have been proposed to be tested during the cardiovascular pilot:

- 30-day mortality in patients with discharge diagnosis of myocardial infarction;
- 30-day mortality in patients with discharge diagnosis of myocardial infarction and were submitted to CABG;
- 30-day mortality in patients with discharge diagnosis of myocardial infarction and were submitted to PCI;
- 30-day mortality in patients with discharge diagnosis of myocardial infarction and were submitted to thrombolysis;
- 30-day mortality in patients with discharge diagnosis of myocardial infarction and were submitted to PTCA

STAKES can also play an important role in the pilot phase since almost all indicators in Finland are available from registers and there is the possibility of linking different registers. Therefore, an agreement between STAKES and IMAS-IMIM to share data will be considered.

Activities on the registry:

- Merging and preparing databases
- Statistical analyses
- Mathematical function development
- Gathering health information system databases from EUPHORIC partners
- Testing the functions on health information system databases
- Implementation of the proposed functions on the EUPHORIC website for self -assessment of hospitals in Europe
- Initiation of the dissemination plan.

WP 5.2 Orthopaedic pilot

During the period this report refers to, the European Arthroplasty Register (EAR) was officially included in the project as associated beneficiary (Amendment of 29 January 2007). This formal act allowed it to establish their leadership for the orthopaedic pilot, adapt the existing EAR network according to the EUPHORIC requirements, and substantially start their scientific activities.

The aims of the orthopaedic pilot are to complete these specific tasks:

1. A systematic review of all arthroplasty registers in Europe and related projects.
2. A systematic review of outcome registers in Sweden and Finland, 2 countries with a very well developed system of outcome measurement by registers.
3. Extended literature research concerning the value of different data sources (registers, meta-analyses of clinical studies, surveys) for outcome research in arthroplasty.

4. An analysis concerning the value of existing instruments (registers, public health implant failure and monitoring institutions), surveillance by the manufacturers and other datasets (clinical literature) concerning the detection of inferior outcome.
5. A report on specific requirements for outcome measurement from a statistical point of view.
6. A proposal for a quality label system for the datasets and information to be used in computing indicators.

From an organizational point of view, EAR carried out the following activities:

- Starting the scientific activities of the scientific working group in Austria based on the EARcore members. Due to the delay of the entire project and consequently of the payments (EAR received their advance payment in May 2007), a large proportion of the workload needed to be covered by the partner's own resources, i.e. advance payments/resources made by EFORT-EAR and by the Medical University Innsbruck, Orthopaedic Department.
- The orthopaedic pilot network was enlarged and included additional collaborating partners, which might give added value to the project by providing their specific expertise and/or access to their databases.
- The work packages of the orthopaedic pilot were set up in detail in cooperation with all the partners involved (Karolinska, Stakes, ISS, NKUA, DEASL and the new collaborating partners Arthroplasty Register Tyrol, Ludwig Boltzmann Institut for Health Technology Assessment, French Society of Orthopaedic and Trauma Surgery, Slovak Arthroplasty Register, BQS Bundesgeschäftsstelle Qualitätssicherung gGmbH).
- In cooperation with partners ISS, KAR, STAKES and CAHTA, two ad hoc specific questionnaires were developed to: 1) collect information about arthroplasty registers already existing in Europe; 2) collect information about arthroplasty registers existing in Sweden and Finland. Both questionnaires are included in the orthopaedic pilot protocol (Attachment 9).
- The whole concept was agreed at the EUPHORIC-meeting held in Helsinki inOctober 2007. All partners were requested to start their activities as soon as possible with respect to the time schedule of the entire EUPHORIC project.
- EAR supported the cardiovascular pilot by collecting information concerning specific cardiovascular projects in Austria.
- In the context of active participation in EUPHORIC, EAR worked at the reorganization of the existing arthroplasty registers network. The main aim was to make these sources of data available for their implementation by the European Commission in the future of regular monitoring and market surveillance activities. Therefore, a contract was set up and delivered to the national EFORT-EAR partners. Romania has already signed, and the other countries are in the process of consultation. Since the referred datasets contain personalized data, it is necessary to check all the legal aspects carefully. This activity might require more time than the remaining period of the EUPHORIC project, however, EAR will support it even after the EUPHORIC deadline. Arthroplasty was proposed to the Network of Working Party Leaders as an area for future SANCO actions in the health information and knowledge domain (see Attachment 2 prepared to answer the request "Gaps assessment for future SANCO action" circulated among the HSWP members on 15 June 2007).
- An agreement with the Medical University Innsbruck was reached concerning cooperation in handling budgets and accountancy as well as manpower contracts by the end of 2007. Starting from January 2008, one administrative/translation co-worker and 2 medical/scientifically focused co-workers have been actively involved in the project.

Methodology applied as planned

The network of partners and institutions mentioned in the first interim report was realized and the pilot protocol was defined (Attachment 9).

Some further institutions were contacted in order to carry out the additional WPs proposed to DG SANCO and aimed at filling in the gap related to the exclusion of partner GRI who did not fulfil their duty. They are ready to start cooperating as soon as the amendment of the Grant Agreement is finalized since the basic requirements, like the cooperation agreement, persons involved, or activity definitions, have already been done.

Details concerning institutions and proposed activities are available in Annex 1.

Involvement of partners and target groups

Karolinska, Stakes, ISS, NKUA, DEASL and the following new collaborating partners: Arthroplasty Register Tyrol, Ludwig Boltzmann Institut for Health Technology Assessment, French Society of Orthopaedic and Trauma Surgery, Slovak Arthroplasty Register, BQS Bundesgeschäftsstelle Qualitätssicherung gGmbH.

Coordination with other projects or activities

EAR – European Arthroplasty Register

EUnetHTA - European Network for Health Technology Assessment

Outcomes and deliverables achieved

- Definition of the orthopaedic pilot protocol (Attachment 9). Two additional indicators (E8, E9) were proposed. The same indicators had been submitted to ECHI to be considered as candidates for the short list (Attachment 4).
- The questionnaires were finalized for the summary report on existing arthroplasty register projects. Partner KAR provided the full description of the two quality registers in Sweden which are of main interest to these pilot studies: the Knee Arthroplasty Registry (SKAR) in Lund and the Hip Arthroplasty Registry in Gothenburg.

Problems encountered

The question regarding defining the further participation of partner GRI, which started at the end of May 2007 and ended at the beginning of February 2008, was a hindrance for the planning and development of the orthopaedic pilot protocol. The uncertainty relating to the possible further participation of partner GRI, and the fact that partner GRI's contribution to the project was not clear, resulted in the orthopaedic pilot leader preparing two concepts for the orthopaedic pilot protocol: one with and one without GRI (and with and without a budget). This was necessary for the optimal organization of the project but indeed time and resource consuming.

How problems were resolved

In close cooperation with the project leader and the commission officer, Mr Artur Furtado, partner EAR tried to clarify the availability of GRI by either finding an agreement for future cooperation or defining the withdrawal from the partnership.

Activities planned for the next period

- Implementation of the defined work packages with respect to the time schedule of the entire project.
- Coordination of the activities in close cooperation with all partners involved.

- Setting up of a system to assess the validity of information from different datasets and guidelines for the proper use of this information in public health decision making as well as outcome measurement.
- Collection from the existing sources of some basic data to calculate figures for the proposed indicators (e.g. revision burden in different countries).
- Preparation of the reports according to the dissemination plan (Attachment 5).
- Publication of the results in scientific journals and scientific conferences.
- Support the recognition of the EUPHORIC web page and its content in the scientific community of orthopaedic surgeons via the EFORT network and its facilities (EFORT: European Federation of National Associations of Orthopaedics and Traumatology).

WP 5.3 Use of the available sources of information in participant countries in order to develop a standardized statistical methodology for comparative outcomes evaluation

As discussed in the Working Group on Statistics held at Helsinki, Finland – 8 October 2007, the WP 5.3 must be considered a support WP to the two pilots (WP 5.1 and WP 5.2).

The aims of this WP are:

1) to describe the general quality and verify the possibility of standardizing the categories and the variables of the data collected for EUPHORIC:
   - from population or hospital registries, surveys, clinical trials, in the WP 5.1 and WP 5.2.
   - health care systematic information (hospital discharge databases) data.
2) to test a standardized methodology for the calculation of the chosen indicators in WP 5.1 and 5.2. To compare the outcomes of the selected pathologies and procedures in individual hospitals within each European country, using health care systematic information (hospital discharge databases) data.

Therefore, there is the real need to have detailed information about the structure of these databases in terms of collected variables and methodology for data collection in order to develop procedures that allow benchmarking of participant hospitals and countries by using routinely collected data (mostly hospital discharge records).

Moreover, the increasing demand for comparative outcomes evaluation requires the development and diffusion of epidemiologic research, the ability to correctly conduct analyses and to interpret results. However, when health care outcomes are used for comparing quality of care across providers, or countries, failure to use robust adjustment methods to control for potential confounders (i.e., variation in patient, hospital or country characteristics) can lead to biased results.

This WP 5.3 will coordinate with WP 5.1 and 5.2 the quest for a definition of the best standardized adjustment methodology for the calculation of the indicators so as to safely compare outcomes of the selected pathologies and procedures across the participating countries when using health care systematic information (hospital discharge databases) data.

Based on the proposal submitted by partner DEASL, after the 3rd EUPHORIC meeting (Luxembourg, 24 April 2007), the coordinator asked partner DEASL to prepare a deliverable describing the risk adjustment methodologies to be used as a support for further activities.

Methodology applied as planned

A deliverable about the methodologies related to risk adjustment procedures to be used when comparing data was prepared (Deliverable n.10, Attachment 10). The purpose of this review was to provide a detailed but easy-reading document with the different risk adjustment methodologies so as to compare health care outcomes. Even if the preparation of this

deliverable had been decided before the definition of WP 5.3, it can be considered as preparatory to this WP and included in it. The other activities related to this objective will start in 2008.

Involvement of partners and target groups

During the meeting held in Helsinki, partner EAR offered their help for the coordination of the WP 5.3. Afterwards, partner DEASL proposed their candidature for this job. The leadership of partner DEASL was approved during the meeting held in Stockholm on 31 January 2008 by the main coordinator (ISS) and partners involved in the orthopaedic pilot (EAR, STAKES, KAR). Partners IMAS-IMIM and NKUA sent their approval by e-mail or telephone.

Coordinator: Partner DEASL. Involved partners: IMAS-IMIM, EAR, STAKES, KAR, NKUA.

Coordination with other projects or activities

Collaboration with the HDP (Hospital Data Project) will be considered.

Outcomes and deliverables achieved

Deliverable n.10 “Risk adjustment methodologies” (Attachment 10).

Problems encountered

None.

How problems were resolved

Not applicable.

Activities planned for the next period

- Organization of coordinating meetings;
- Preparing the detailed protocol of the WP;
- Preparing a deliverable about the information collected through the hospital discharge records in the participating countries. To produce this deliverable, cooperation with the EU HDP (Hospital Data Project) project will be considered;
- Preparing a deliverable about the information collected through registers, surveys, and other datasets in the participating countries and the statistical procedures applied up to now;
- Defining different statistical procedures to be applied to each national register in the EU area, according to the available information included in the existing databases and assumptions;
- Evaluating whether, for some outcomes, the same results can be obtained using the information available from national registers or from the health care information system at national level;
- Summarizing the most important clinical variables for adjusted comparative evaluation of the outcomes under study that would be added to risk adjustment models including variables only based on hospital discharge records information.

WP 6 Setting up and maintaining indicators database

To carry out this task, ISS collaborated from the beginning and continues to collaborate closely with CASPUR in a joint effort. The aim of this work package is to set up a database of the indicators selected during the first phase of the project, the survey. The database will collect

all the information related to the indicators such as the synthetic description of the indicators (definition, numerator and denominator) as well as the detailed information derived from the literature analysis and collected in the indicators sheets (see Deliverable n.6). Indicators will be organized according to the areas of pathology defined during the survey. The same database will also include all the information collected during the survey and relevant to the sources of data available in the participating countries and to the selected indicators. The database will be located on the website of the project and will be made available to the public. Particular attention will be paid in developing a user-friendly operation to search the database.

In 2006, the former EUPHORIC project leader (Dr Fulvia Seccareccia) gave MEDISOFT the task of preparing software aimed at providing data in real time as it comes from several remote terminals on a central server.

Methodology applied as planned

During the period this report refers to, the first beta version of the website and the public part of the website were completed and put online on 9 March 2007. The website is housed at CASPUR and will be reachable at www.euphoric-project.eu. Moreover, the following activities were carried out:

- An electronic form was developed to input and validate the information collected during the survey phase. This information is related to the data sources available in the participating countries and the outcome indicators identified by EUPHORIC (including the detailed information, collected in the specific indicators sheets). The form is now available in the members' area.
- All the information collected during the survey was input on the database by ISS. All the partners were requested to validate and, if necessary, update it under their responsibility.
- As technical support for all the partners, ISS prepared and sent them a guideline to correctly input the indicators data on the database (Attachment 11). The definition of the protocol to validate all the records (by the administrator, ISS - project coordinator) is now operative.

Involvement of partners and target groups

The main beneficiary regarding the design of the website, the contents definition and the input of the information collected during the survey and already available in the first deliverable. The technical partner, CASPUR for the implementation. All the partners for their own pages. Partners ISS, IMAS-IMIM, STAKES, KAR, NKUA, DEASL validated the collected information.

Information about the new collaborating partners will be put on the website. However, the new collaborating partners will not be requested to collect information about indicators in their countries for 2 main reasons: 1) they did not participate in the survey phase in 2007; 2) they were included in order to cooperate in the development of the pilot and they did not receive any budget to invest in this extra activity.

Coordination with other projects or activities

None.

Outcomes and deliverables achieved

Setting up of the electronic form. Input of the already collected data. Validation of the questionnaires by some partners. Organization of the members' area.

Preparation of a guideline to correctly input the indicators data on the database (Deliverable n.11, Attachment 11).

Problems encountered

Partner EAR-EFORT was officially included in the project on 26 January 2007 when the survey was already concluded. The organization of the pilot and the delay in receiving the payments, prevented them in hiring a person responsible for collecting all the information requested during the survey.

Partner NKUA was allowed to complete only one questionnaire with the information collected (1 indicator). Therefore, they were requested to check if it was possible to improve their contribution by also filling in the questionnaire related to other indicators.

The collaborating partner NCPHP (Bulgaria) did not validate their questionnaires.

On the basis of the new organization of the project (the testing of indicators on data extracted from existing databases at specified dates) it seemed useless to implement a system that gathers data on a real time basis. Nevertheless, this kind of approach is useful for the development of possible future projects requiring this kind of technology whose application, at present, is beyond the defined EUPHORIC objectives.

How problems were resolved

Partner EAR-EFORT will integrate and update the information about data source and databases available in Austria during 2008. ISS will support them from a technical point of view.

All other partners were requested to check and validate the indicators already input on the database and to integrate the missing records.

The MEDISOFT product will be considered as a feasibility study and the contract will be interrupted. Changes in the budget will be considered in the submitted amendment.

Activities planned for the next period (to be provided by CASPUR)

- The definition of the cardiovascular pilot enhanced the possibility of testing other indicators not previously considered in the first list. A forum will be set up and moderate on the website's members' area to improve the brainstorming among project participants, especially on this issue.
- A paper presenting the list of the selected indicators has been prepared and will be submitted in the next weeks for publication. Afterwards, all the information related to indicators, now available only in the members' area, will be published in the public area.
- The validation of the indicators data, received from the partners and gathered using the electronic questionnaire now on the site's members' area, will be completed and the results of this data collection will be published on the website's public area.
- A search engine will be developed on the questionnaire database to help users make advanced searches on the questionnaire web-based database.

4. ANNEXES/ATTACHMENTS

List of Annexes

1. Description of additional WPs
2. Agenda of Meeting (Barcelona 15-16/01/2007)
3. Minutes of Meeting (Barcelona 15-11/04/2007)
4. Agenda and Minutes of Meeting (Luxemburg 24/04/2007)
5. Minutes of Meeting (Barcelona 04/07/2007)
6. Minutes of Meeting (Barcelona 05/07/2007)
7. Agenda and Minutes of Meeting (Helsinki 08/10/2007)
8. Agenda and Minutes of Meeting (Helsinki 09/10/2007)
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10. Leaflets
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List of Attachments

1. Deliverable n. 2. “Glossary”
2. Proposals for future activities HSWP-DGSANCO by EAR
3. Deliverable n. 3 “Evaluation Plan”
4. Deliverable n. 4 “Indicators submitted to ECHIM to be considered in the short list”
5. Deliverable n. 5 “Dissemination Plan”
6. Deliverable n. 6 “Detailed sheets of the collected outcome indicators (long list)”
7. Deliverable n. 7 “Systematic review of the literature: Bosch X, Loma-Osorio P, Marrugat JJ “Platelet glycoprotein IIb/IIIa blockers for percutaneous coronary intervention, and as initial treatment in Non-ST segment elevation Acute Coronary Syndromes””
8. Deliverable n. 8 “Protocol for the Cardiovascular Pilot study”
9. Deliverable n. 9 “Protocol for the Orthopaedic Pilot study”
10. Deliverable n. 10 “Risk adjustment methodologies”
11. Deliverable n. 11 “Web-based Questionnaire: completion guideline”