EUROPEAN COMMISSION

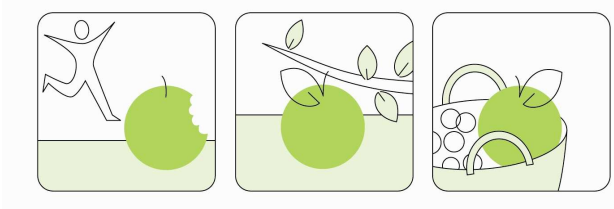
Health & Consumer Protection
Directorate-General

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

A project funded by the European Commission,
Health and Consumer Protection Directorate General

First Interim Report

15/12/2004 – 14/12/2006



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-Jakehittamiskeskus, Finland

National and Kapodistrian University of Athens, Greece

Genetics Research Institute ONLUS, Italy

ASL RM E Department of Epidemiology, Italy

Institut Municipal d'Assistencia Sanitaria, Spain

Karolinska Institutet, Sweden

Collaborating partners

National Center of Public Health Protection, Bulgaria

LIST OF CONTENTS

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:	15/12/2004 – 14/12/2006

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: 1

1) National Centre of Public Health Protection, Bulgaria

Total amount of the project:	2.788.105,28 Euro
EC Co-funding :	1.500.000,00 Euro
First prefinancing payment:	412.555,51 Euro
Second prefinancing request:	

1. EXECUTIVE SUMMARY

Background

The importance of outcome research has become evident as a means to promote best practice and control health expenditure. Monitoring efficiency and efficacy in the health field is acknowledged by most of the EU countries as a guarantee of quality care and outcome measurement. It is a tool to evaluate health care quality, which represents one of the most important areas of interest both at a national and international level. Initiatives have started at the European level to regulate and promote patient circulation as clearly stated in the Patient Rights Charters. These actions require objective and reliable indicators. To this purpose the use of common methodologies is imperative.

Objectives

EUPHORIC is a multidisciplinary project oriented to policy authorities and policy makers that aims at building a consortium of participating countries in order to: cooperate on benchmarking the outcomes of selected health performances; exchange information on quality standards, best practice and effectiveness in public health; and identify suitable common EU elements for a political EU platform that are oriented at best practice guarantees for EU citizens. Since the activities of the project will focus on health outcome indicators, they could be considered complementary to others already carried out by projects related to health indicators like ECHIM and OECD.

Organisation of the project

On 15th December, 2006, nine institutions from seven European countries were involved in the study. However, other European countries will be invited to participate in the study as collaborating partners. Since the beginning, the project had suffered from some administrative problems (withdrawal of a partner, resignation of the project leader) that were solved with the signing of the amendment occurred on 29th January, 2007 (inclusion of partner EFORT-EAR, appointment of the new project leader). The project was initially structured in 3 phases: Survey, Pilot and Dissemination without considering work package (WP) organisation. However, in order to adopt standardised reporting and to make all the interim reports comparable, the description will follow the WP organisation adopted after the signing of the amendment. The project is now organised in 6 WPs:

1. Project management
2. Dissemination strategy
3. Liaison with other EU projects, EU programmes and health stakeholders
4. Indicators development
5. Indicators testing in currently running registry databases
6. Setting up and maintaining an indicators database

Activities undertaken in the period covered in the interim report

The first phase of the project was dedicated to building up the consortium among the partners by strengthening the institutions involved in the study, and to creating a list of diseases amenable to receiving medical procedures whose quality can be assessed in terms of outcome. It was also dedicated to devising a set of theoretical indicators to assess the quality of procedures used on key diseases; to collecting information about the source of data available in the participating countries by means of an *ad hoc* designed questionnaire; to choosing, on the basis

of the collected data, the areas of pathology so as to test some indicators during the second phase (pilot); and to selecting a technological partner to set up a website in order to disseminate the results, and to collect all the information related to the gathered outcome indicators on a database.

Outcomes and deliverables achieved

During the first phase of the project the following outcomes and deliverables were achieved: definition of nine disease areas and procedures that could be assessed in terms of outcome (cardiovascular disease and surgery, cancer, infectious disease, other chronic disease, orthopaedics, transplantation, emergency, neonatal/maternal, miscellanea); preparation of a list of 54 outcome indicators; collection of information relevant to health systems organisation in each participant country, data source available, data source characteristics, possibility of calculating the selected indicators; selection of the areas of pathology areas in order to test some selected indicators during the pilot phase (orthopaedics and cardiovascular); and appointment of the orthopaedics pilot leader.

Problems encountered and how the problems were resolved

The project started on December 15th, 2004, however unforeseen events occurred in the early stage of the project (withdrawal of a partner and change of the project leader), which have prevented the regular progress of the project itself. These inconveniences were overcome with the official signing of the amendment (29th January, 2007) giving the project the actual possibility of progressing at a steady state. Another consequence of this situation was the delay of the advance payment (partially received in June 2006), and asking the partners to work on their own resources. This caused a stalemate of the activities with a deferral of the milestones envisaged in the initial work plan. Fortunately, with the amendment to the contract signed on January 29th, 2007, the Commission agreed to postpone the deadline of the project (14th December, 2008). Consequently, the overall schedule has been reorganised.

Activities planned for the next period

During the next period the project activities will deal with the reorganisation of the project, intensifying the contact among the partners and establishing new contacts with other projects related to health outcome indicators, the selection of the cardiovascular pilot leader and the definition of the pilot's protocols, the setting up of the final version of the website and of the outcome indicators database. In particular, the cooperation with the ECHIM project and the Working Party on Health Indicators will be mandatory in order to ensure that the indicators, presentation and methods are compatible with ECHI. The 19 countries participating in EAR (European Arthroplasty Register) will be invited to join the project. The following reports will be produced: results of the survey; collection of sheets detailing information about indicators; comparison of hospital discharge records in the participant countries; description of risk adjustment methods.

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 have been identified:

1. Set-up 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 risk of adverse outcome 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 organised in 6 work packages linked to the specific objectives of the study as summarised 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
Set-up 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 risk of adverse outcome for the selected procedures on real data at individual, hospital and country level	WP 5 Development of adverse-outcome risk indicator 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 conference

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.

The final project conference is planned for autumn 2008. Table 2 summarises 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 will be finished by December 2007
5	Development of adverse-outcome risk indicator in real clinical and registry databases, and its possible use in administrative systematic data bases.	Will start 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 summarises the activities/tasks to be undertaken in the project. The work plan (foreseen dates for each activity) has been revised and all the deadlines have been postponed for one year, taking into account the new deadline of the project.

It must be considered that the administrative problems which the project incurred during this first period prevented the regular organisation of the activities. Regarding the meetings, the original plan foresaw 2 meetings for each year of activity. In the period the report refers to (2 years), the coordinators organised only 2 meetings because in that period the project had slowed down. However, since the deadline has been postponed for one year, we can consider only one year of actual activity and therefore this task was completely achieved.

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		70%	Standstill of the project, change of the project leader	Definition of the amendment
	Contacts among all the participants	Communication	06/2006		70%	Standstill of the project, change of the project leader	Definition of the amendment
	Setting up of the work plan	Work plan	03/2006		50%	Withdrawal of a partner	Inclusion of a new partner
	Organisation of coordination meetings	Minutes	2 each year	16/12/2004 09/06/2006	100%		
	Drawing up interim and final reports	Financial and technical reports	02/2007		0%		
	Involvement of other member states	Official letters	06/2008		0%		
	Evaluation of the project	Report	12/2007		0%		
2	Define the diffusion policy	Document	06/2007		0%		
	Preparation of the dissemination plan	Document	12/2007		0%		
	Setting up of a website	Website (beta version)	04/2007		40%	Unavailability of the advance payment to define the technological partner subcontract	Advance payment received on 06/06
		Final version	10/2007				
	Preparation of the final conference	Conference	10/2008		0%		
3	Setting up of contacts with other projects	Sharing of methodologies	12/2007		0%		

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

		and results					
WP	**Activities/Tasks**	**Outcomes/ Deliverables**	**Date foreseen**	**Date of achievement**	**Level of achievement (*)**	**Justification/ Problems encountered**	**Action to be taken to overcome the problem**
4	Defining a list of outcome indicators	List of indicators	6/2006	6/2006	100%		
	Assessing the current situation in participating countries	Deliverable	6/2006		80%	Standstill of the project, change of the project leader	Definition of the amendment
	Select diseases and procedures to test some indicators (pilot)	Technical presentation	6/2006		10%	Standstill of the project, change of the project leader	Definition of the amendment
5	Cardiovascular pilot: protocol definition risk adjustment methods	Document	7/2007		0%		
	Cardiovascular pilot: indicators testing	Report	9/2008		0%		
	Orthopaedic pilot: protocol definition	Document	7/2007		10%	EFORT-EAR not officially included in the project	Definition of the amendment
	Orthopaedic pilot: protocol testing	Report	9/2008		0%		
	Description of the Hospital discharge record datasets	Report	12/2007		0%		
6	Setting up of the web based DB	Database	6/2007		0%		
	Database input	Database available online	10/2007		0%		
	Database updating	Database updated	12/2008		0%		

* 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

In this work package the following tasks will be undertaken:

1. Establishment of a network among the partners and other European institutions involved in outcome research and outcome assessment.
2. Acting as the contact between all the participants and the DG SANCO
3. Assuring good communication and cooperation among all participants
4. Setting up the work plan of the project and assuring that the described objectives are attained
5. Organisation 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

Activities undertaken

The strengthening of the institutions involved in the project was the main task performed in the period this report refers to. In fact, most of the activities were aimed at building up a consortium which is able to fulfil the objectives of the project. Since there had not been any previous collaboration among the partners, the first step was to introduce the participating institutions. Therefore, all the partners were invited, both during the first meeting and in a more detailed way during the survey, to present themselves by describing their country (political-demographical situation, health care systems) and their institution. They were also asked to give details about the projects related to outcome research that they were carrying out and to describe their potential contribution to EUPHORIC. The main beneficiary, ISS, kept in contact with all the partners by exchanging information via e-mail and organising coordination meetings.

The main beneficiary acted also as a contact between the participants and the DG SANCO both for administrative and technical issues. It participated in the meeting of the Health System Working Party on April 26th, 2005 and presented the project. It also participated in the meeting of December 5th, 2006.

Coordination meetings organisation

Two coordination meetings were organised during the period this report refers to.

1st coordination meeting – Rome

On December 16th, 2004, during the workshop "TOWARDS A NEW HEALTH CARE SYSTEM" (Annex 1), organised by the main beneficiary (ISS - Istituto Superiore di Sanità), the EUPHORIC Project was officially presented to the Italian scientific community together with the results of the national projects related to outcome research led by ISS and funded by the Italian Ministry of Health in 2002. All the associated beneficiaries were invited to participate at a round table to present themselves and their contribution to EUPHORIC. The presentations will be available on the Euphoric project website.

At the end of the workshop the main beneficiary organised a coordination meeting to present to all the partners the structure and the work plan of the project and to discuss the organisation of the first phase (survey).

2nd coordination meeting – Rome

The second coordination meeting was held in Rome at the Istituto Superiore di Sanità on 9th June. All the associated beneficiaries and collaborating partners participated in the meeting. EFORT-EAR replaced HFA (Austrian Heart Foundation) as partner who had withdrawn from the project in Spring 2005. It participated in the meeting since its inclusion in the project had been accepted by the Commission, although the amendment would be officially signed in January 2007.

The agenda of the meeting covered:

1. Update of all the bureaucratic issues
2. Results of the survey
3. Preparation of the first deliverable
4. Planning of future activities

During the meeting EFORT-EAR was put in charge of the orthopaedic pilot (see work packages 4 and 5) during the second phase of the project. Moreover, the technological partner (CASPUR) involved in the setting up of the website was presented.

The results of the second EUPHORIC coordination meeting are described in detail in the minutes of the meeting (Annex 2).

Problems encountered

Several problems arose at the beginning of the project, thus preventing its regular development.

First of all the withdrawal of the associated partner, Austrian Heart Foundation (HFA), from the project in spring 2005. The main beneficiary (ISS) was forced to replace it with an another partner in order to maintain the EU contribution.

Secondly D.ssa Fulvia Seccareccia resigned as project leader (communication of 10th April, 2006).

Unfortunately, formalizing all these changes took a long time and the related amendment was agreed upon by the European Commission in December 2006 and received by the main beneficiary duly signed in February 2007. Owing to these inconveniences the project came to a standstill and consequently there was a deferral in the milestones envisaged in the initial work plan. For this reason the overall schedule has been reorganised.

As a consequence, the pre-financing payment was delayed and the beneficiaries (who first had signed the Grant) received it in June 2006.

How problems were resolved

At the end of 2005, a new partner, EFORT-EAR, with all the requirements defined in the Grant Agreement, was selected as a new associated beneficiary by ISS. EAR (European Arthroplasty Register) is a project within EFORT (European Federation of National Associations of Orthopaedics and Traumatology).

In April 2006 a request of an amendment to the Grant Agreement was sent to the European Commission by the main beneficiary, including:

- the formalisation of EFORT-EAR as associated beneficiary
- the request for the extension of the project duration for another year (new deadline 14th December, 2008)
- the replacement of D.ssa Fulvia Seccareccia with Dott. Ing. Marina Torre as project leader

In June 2006, the advance payment was delivered to those partners already included in the contract.

Activities planned for the next period

- Intensify contacts among partners by sending out regular updates on the achievements of the project and information on the coordination meetings
- Implementation of an intranet platform on the project website to facilitate communication and exchange of documents among the partners
- Organisation of coordination meetings (2 meetings with all the partners (April 2007 and October 2007), 4 meetings with the project coordinator and pilot leaders in order to define the detailed pilot WPs and to check the progress of the pilot's implementation
- Definition of the management structure: formation of a core working group (coordinator and pilot leaders) and of specific working groups for each pilot
- Organisation of the projects in WP and detailed definition of the deliverables including each partner's specific tasks
- Reorganisation of the work plan according to the new deadline
- Coordination of the core working group (coordinator and pilot leaders)
- Intensify contacts between partners and HSWP by forwarding information/requests received by the HSWP and by forwarding the partners' comments to HSWP
- Start of the enlargement of the consortium by including as collaborating partners most of the countries participating in EAR (European Arthroplasty Register www.ear.efort.org, a network of 23 arthroplasty registers in 19 European countries)
- Become part of the network of the Working Party on Health Indicators
- Planning of a protocol for internal and external evaluation of the project:
  - preparation of a questionnaire implemented in the members area of the website
  - collection of data for process evaluation
  - collection of suggestions for improvement
  - analysis of process evaluation data

WP 2 Dissemination strategy

Dissemination plan available: [X] no [ ] 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 will be achieved through the network of both the MS health authorities and the scientific societies and participation in conferences.

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 conference of the project will be organised in autumn 2008.

The main tool supporting the dissemination of the results will be a user-friendly website. The website will have the following structure:

- The project: providing a description of the project and a presentation of the partners
- Research: providing a description of the survey and of the pilot phase
- Indicators: providing the final list of the outcome indicators and an application to browse them
- Events: listing all the events related to the project
- Dissemination: providing downloadable .pdf files (deliverables, publications, leaflets, brochures)
- Link: providing a list of useful stakeholder contacts from both the public and private sector (e.g. health authorities, institutions, associations, scientific societies, other EU projects)
- Members: providing an intranet area for all of the participants in the project.

It will be periodically updated and linked to the EU official website in order to make the results available to EU authorities, institutions, study participants and citizens. It will be achieved by following the W3C accessibility guidelines and the usability rules.

Information will be put online as it becomes available instead of waiting until the end of the project (as stated in the Grant Agreement).

Activities undertaken

Identification of the project

To characterise the project while disseminating the results, a logo (Annex 3) has been designed to be used in all of the publications related to EUPHORIC (website, publications, reports, presentations). The logo represents a faun. In Greek mythology the faun participated in the Dionysus procession in euphoric gaiety. The logo was presented to all of the partners during the 2nd coordination meeting.

Information Leaflet

In November 2006, a leaflet of the project was designed. The leaflet was approved via e-mail by all of the partners. It was distributed to all of the participants at the Health System Working

Party meeting held in Luxembourg on December 5th , 2006 and will be downloadable from the website.

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 up 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 organised in 5 main steps:

1. production of a static web page 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 services and usability
5. housing and maintenance of the Euphoric site up to the end of 2008

The first step was concluded during the period this report refers to. It was dedicated to:

- discussing the information structure of the website (actors involved, information workflow etc.)
- selecting the more appropriate Content Management System (CMS) platform
- defining the site architecture and create the pages' graphical frame
- registering the domain name and set up the site hardware/software configuration

Publications

The last trimester of 2006 was devoted to finalising the collection of all the useful information for the publication of the first deliverable "Survey: results of the first phase"

In December 2006, a presentation of the project was published in the ISS Bulletin. The paper is now available on line on the ISS website at the following address:
http://www.iss.it/binary/publ/cont/Vol.%2019%20n.%2012%20def.1170331401.pdf

Problems encountered

Impossibility in defining the subcontract with the technological partner for the website construction until the advance payment had been available.

How problems were resolved

Availability of the advance payment in June 2006.

Activities planned for the next period

- Definition of a dissemination plan
- Definition of a dissemination policy
- Finalisation of the first deliverable "Survey: results of the first phase"

- Distribution of the deliverable 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)
- Finalisation of steps 2, 3 and 4 in the developing of the website
- Translation of the leaflet in all the languages of the countries participating in the project and make them downloadable from the website

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 act 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 could have connections and/or interests in outcome research or are using similar methodologies even if not focussing on outcome research. In this way it may be possible to create synergies and, if possible, to share knowledge by also bridging different fields.

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

In particular, cooperation with the ECHIM project and the Working Party on Health Indicators will be mandatory in order to ensure that the indicators, presentation and methods are compatible with ECHI.

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

Activities undertaken

In the period considered by this interim report the possibility of establishing contacts with the OECD (Health Quality Indicators Project) and Eurocare has been considered. During the second coordination meeting, STAKES and GRI were willing to set up contacts with the OECD project and Eurocare respectively.

Problems encountered

The standstill that occurred with the project related to the administrative problems and prevented the regular development of this WP.

How problems were resolved

Working at a constant rate after the official signing of the amendment.

Activities planned for the next period

- Below is the first list of the project that will be considered in this WP:
  - ECHIM
  - OECD

  - eHID
  - EUnetHTA
  - EUGLOREH
  - HDP
  - Eurocare
- Contacting ECHIM Project Secretariats (KTL and Stakes, Helsinki, Dr Arpo Aromaa; ISS, Rome, Dr Emanuele Scafato). These institutions also participate in EUPHORIC (main beneficiary [ISS] and associated beneficiary [Stakes])
- Submitting the deliverables to the WP on Health Indicators

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 us to do:

- comparative evaluation of hospital performances;
- comparative evaluation between groups of facilities with similar organisational and/or process characteristics (for example, treatment volumes, technological equipment);
- comparative evaluation between populations resident in different areas or of different socio-economic status;
- analysis of a trend over a period of time.

Aim of WP4 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 necessary to be used in the experimental phase (pilot).

Methodology applied as planned

The survey has been organised in 3 phases:

1. Defining a list of outcome indicators
2. Assessing the current situation about outcome indicators in the participant countries
3. Selecting diseases and procedures to test some indicators in the experimental phase (pilot)

1. Defining a list of outcome indicators

The definition of the indicators list was performed using the following tasks: literature review, inventory of the existing studies, collecting outcome indicators, preparation of summary tables of outcome indicators and list of procedures

The starting point was the experience consolidated within the “Outcome Measurement” research of the Italian Mattoni Project, the project launched in 2003 by the Italian Ministry of Health in order to redesign the National Health System. The aim of this research line was “to identify and experiment suitable methodologies to define, measure and evaluate outcomes”.

It was proposed to share with all of the partners the methodological approach adopted in the Italian Outcome Mattoni Project and therefore it was decided to update and integrate the first results obtained in Italy by taking into account the different contexts of the participating

countries. This was the first attempt at a cross border sharing of the outcome research knowledge of each partner and gives an added value to each expertise through the synergy derived from the EUPHORIC consortium.

Therefore, a literature search of the outcome studies as well as a review of risk adjustment methods to compare health care outcomes were performed by all of the partners on the PubMed database. Moreover, the "outcome" related websites were explored worldwide (~40). The main purpose of this analysis was the identification of those outcome indicators validated and usually adopted in European and Extra-European countries that could be a good starting point for the introduction of outcome evaluation in the European context. The result of this analysis was the selection of nine areas of pathology (cardiovascular disease and surgery, cancer, infectious disease, other chronic disease, orthopaedics, transplantation, emergency, neonatal/maternal, miscellanea) and a preliminary list of outcome indicators adopted in European and Extra-European countries.

The final list of outcome indicators was defined on the basis of the following selection criteria: availability, relevance to clinical level, relevance to policy level and to the international scientific community.

Therefore, the following classes of outcome indicators, which are appropriate to monitor healthcare quality, were identified:

- Volume indicators
- Mortality indicators for inpatient procedures
- Mortality indicators for inpatient conditions
- Utilization indicators
- Survival indicators

Moreover, a list of keywords related to outcome research was collected in order to build up a glossary as a support tool for the participants in the project.

2. Assessing the current situation about outcome indicators in the participant countries

In order to assess the current situation about outcome indicators in the participant countries in terms of data availability and comparability an *ad hoc* designed questionnaire consisting of 4 parts was organised (Annex 4) by gathering a collection of information from the participating countries about their internal organisation regarding health care system and health data sources available for the selected outcome indicators.

The first part was aimed at gathering information from each participant country about the political-demographical situation and the health care system organisation. The participants were also requested to give a brief description of the method employed in filling in their respective questionnaire and to give an overview of the current situation regarding the data sources available in their country for a possible testing of the selected outcome indicators.

The second part requested each partner to provide detailed information about the source of data existing in their respective country regarding a list of diseases/procedures within the selected nine areas of interest. For each disease/procedure, the following were specified:

- Covered area (national, regional, other)
- Electronic form (yes/no)
- Type of data source
- Linkage with other archives (e.g. Hospital Discharge, Mortality Records)
- Notes

The third part was aimed at listing databases or registers or other studies that could be active within two years after the beginning of the study.

The fourth part of the questionnaire aimed at assessing the current situation regarding the possibility of testing the selected outcome indicators in each country using "risk adjustment methods". The indicator profile was specified as follows:

- outcome indicators number
- source of data
- crude/adjusted (if adjusted it was specified by: age, gender comorbidities, other confounding factors)
- age range
- disaggregated by: gender, hospital, geographical area, national, other.

It should be pointed out that all the information gathered could not be exhaustive of the all existing sources of data at a local and at a national level.

3. Selecting diseases and procedures to test some indicators in the experimental phase (pilot)

The aim of this task was the assessment of the possibility of defining a common outcome indicators set to be tested during the experimental phase. The selection was based on the data collected during the survey. At the end of the period this report refers to, the orthopaedic and cardiovascular areas of pathology were more likely to be taken into consideration for the pilot study because of their high clinical and political relevance, and also because all the participants are able to provide information in these areas. Detailed definition of the diseases and the procedures will be carried out in the next period.

Involvement of partners and target groups

All of the partners.

Coordination with other projects or activities

In order to carry out these activities, some beneficiaries have cooperated with other projects actively running at the same time in their countries:

- Project Perfect in Finland (http://info.stakes.fi/perfect/EN/index.htm)
- Project Mattoni in Italy (http://www.mattoni.ministerosalute.it/)

Outcomes and deliverables achieved

Outcomes:

- List of outcome indicators
- Collection of information relevant to the health system organisation, data source available, data source characteristics, possibility of calculating the selected indicators.
- Definition of the areas to be carried out in the pilot phase.

Deliverables:

Preparation of the first deliverable "Survey: results of the first phase"

Problems encountered

Interpretation and compilation of the questionnaire.

How problems were resolved

Instruction given by phone and via e-mail.

Activities planned for the next period

- Finalisation and presentation of the deliverable "Survey: results of the first phase"
- On the basis of the literature review, the preparation of a summary sheet for each indicator containing the following information: title, rationale, numerator, denominator, statistical methods, how to use it, references
- Preparation of a deliverable collecting all the sheets and presenting how the sheet was designed. All the information collected in the deliverable will be used to update and detail the indicators database implemented on the website
- Detailed definition of the pathologies and/or procedures to be considered for the pilot study
- Detailed description of the selected keywords in order to create a glossary that is useful for the project and will contribute to the glossary developed inside the HSWP

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

The results obtained through the survey paved the way for the preparation of the pilot phase. In fact, retrieving the country 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 have been taken into consideration for the pilot study, not only for their high clinical and political relevance, but also because all the participants are able to provide information in these areas.

At present, it seems that the use of the available sources of information, such as routinely collected data, clinical data, registries, is the most suitable approach to carry out the pilot, instead of the organisation of active *ad hoc* designed data collection.

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

5.1 Cardiovascular pilot

5.2 Orthopaedics pilot

WP 5.1 Cardiovascular pilot

The specific aims of the CV pilot are to:

- collect detailed information on health outcome indicators for CV diseases;
- develop a standardised methodology for such a collection;
- assess quality of care for selected health procedures;

- provide systematic information to end-users (doctors, health staff, health administration, decision makers, policy makers, EU population);
- provide a common standardised monitoring system for outcome indicators in CV diseases in Europe;
- investigate validity of routinely collected data;
- create an inventory of reference structures for the procedures whose outcomes are evaluated in the project itself.

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

To be decided on the basis of the survey results.

Coordination with other projects or activities

A collaboration with the co-ordinator of the Euro Hearth Survey Programme, Dr Anselm Gitt, is being set up. During the HSWP, on April 26th, 2005, he stated his interest in EUPHORIC and in finding a way of joining the effort.

Outcomes and deliverables achieved

None.

Problems encountered

Selection of the CV pilot leader.

How problems were resolved

Even if the problem was not completely solved in the period the report refers to, the Coordinator (ISS) has worked to find the best candidate, to be appointed as CV pilot leader, among the associated beneficiaries and other institutions interested in cooperating with the project as collaborating partners.

Activities planned for the next period

- Selection of the leader of the cardiovascular pilot
- Identification of possible cooperation with other existing projects and/or registers (e.g. Project MASCARA, EHS)
- Definition of WPs
- Preparation of pilot protocol

WP 5.2 Orthopaedic pilot

During the meeting of the 9th June, 2006, in Rome, the associated beneficiary EFORT-EAR, Dr. Gerold Labek being the Vice President of EAR (a network of arthroplasty registers in Europe) was put in charge of coordinating the orthopaedic pilot (arthroplasty project). He started to organise the activities even though his official inclusion in the project occurred afterwards, in January 2007.

The aims of the orthopaedic pilot are the following:

- Prepare a summary about all existing European arthroplasty registers including detailed information on their structure and their organisation in order to study their inclusion in a EU system and to produce guidelines for the development of further national registers based on present experience. This activity will consider not only the inclusion of the "conventional arthroplasty register", but also innovative approaches such as clinical forms and quality of life scores or fracture and ACL-registers.
- Assess the reliability and validity of the proposed outcome indicators in the different data sources. EAR has already proposed the inclusion of "Revision Burden" and "Revision Rate" as new indicators that are typically reported by arthroplasty registers.
- Compare arthroplasty registers and other instruments like clinical studies, surveys and public health datasets that concern validity and organisation.
- Assess the different instruments (registers, clinical studies, public health sources, manufacturers) that concern outcome measurement quality control issues (e.g. the possibility of detecting high revision rates in meta-analyses or public datasets in comparison to arthroplasty registers).
- To set up a system to assess the validity of information from different datasets and guidelines for the proper use of these information in public health decision making as well as outcome measurement
- To collect from the existing sources some basic data (e.g. Revision Burden in different countries).

Methodology applied as planned

In order to prepare the pilot phase, EFORT-EAR performed the following activities in the second semester of 2006:

- Establish a scientific working group in Austria based on the EAR core members: the main centres are the Medical University Innsbruck/Orthopaedic Department and the General Hospital Linz (AKH Linz).
- Contact all 23 national arthroplasty registers in 19 countries in Europe and organise their cooperation in the EAR Network.
- Set up a detailed concept for the EAR part of the EUPHORIC project including an agreement between EFORT and the Medical University Innsbruck/Orthopaedic Department to support EUPHORIC and EAR.

Involvement of partners and target groups

EFORT-EAR Leader of the pilot.

Coordination with other projects or activities

EAR – European Arthroplasty Register.

Outcomes and deliverables achieved

- The establishment of a scientific working group in Austria based at the Medical University Innsbruck/Orthopaedic Department and at the General Hospital Linz (AKH Linz).
- All 23 national arthroplasty registers in 19 European countries were contacted in order to organise their cooperation

- The identification, on the basis of published information, of a remarkable number of different projects relating to cardiovascular and orthopaedics. Those projects presented methodological overlapping that was useful in identifying optimal tools and methods to collect data in both fields and to set up a network of experts for future projects to support EU requests.
- Basic research on existing cardiovascular projects similar to the arthroplasty registers in order to find common issues which are useful for the parallel development of both pilots.

A remarkable number of different projects were detected and superficially assessed based on the published information.

Problems encountered

Administrative difficulties in the official involvement of EFORT-EAR in the role of partner.

How problems were resolved

The request to include EFORT-EAR as a partner was sent in April 2006. In June 2006 all the administrative requirements were satisfied. The partner was officially recognised in January 2007 (signing of the amendment to the contract) and financed in May 2007.

Activities planned for the next period

- Definition of the detailed WPs
- Preparation of pilot protocol
- Involvement of the following partners: ISS, IMAS-IMIM, DEASL, NKUA, STAKES, KAR and description of the contributions expected from each partner
- Cooperation with other projects related to HTA and eHealth (connection with WP3)
- Start of the assessment of the existing data collection projects in the different countries (indicators implementation and validation, structures organisation, structures performance concerning completeness of data and outcome in terms of impact on quality in medical treatment and public health affairs)
- Start of the assessment of the relevance of the existing indicators both for scientific purposes and for medical scientific issues by means of a specific literature review and comparison with data published in technical register reports

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 objective 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 the Deliverable in WP 4 “Indicators development”). Indicators will be organised 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.

Methodology applied as planned

During the period this report refers to, the first step of the development of the website was completed. During this step, a set of static web pages protected by a password was produced. The website is housed at CASPUR and will be reachable at www.euphoric-project.org.

Further developments will consider the implementation of an easily searchable database with all the information gathered during the survey.

Involvement of partners and target groups

The main beneficiary regarding for the design of the website and the contents definition. The technical partner, CASPUR for the implementation. All the partners for their own pages.

Coordination with other projects or activities

Outcomes and deliverables achieved

Preparation of the first beta version that will be online in March 2007.

Problems encountered

The impossibility of formalising the contract with the technological partner (CASPUR) before the receipt of the advance payment.

How problems were resolved

Receipt of the payment in June 2006.
Start of the contract with CASPUR in September 2006

Activities planned for the next period

- Input on the website of the information collected during the survey which will be relevant 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)
- Preparation of an instruction guide to correctly input the data on the database and the definition of the protocol to validate all the records (by the administrator, ISS - project coordinator)
- Inclusion on the database of the defined set of information from the new MS included in the project (new collaborating partners) will become available as soon as possible.

4. ANNEXES

1. Programme of the Workshop “TOWARDS A NEW HEALTH CARE SYSTEM”
2. Minutes of the 2nd Coordination meeting
3. Logo
4. Questionnaire