



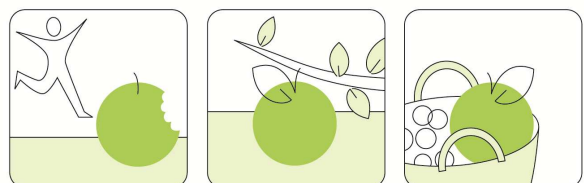
**EU Public Health Outcome Research and Indicators Collection
EUPHORIC Project
Grant Agreement n°2003134**

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EUPHORIC Project

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ASL RM E Department of Epidemiology, *Italy*



Institut Municipal d'Assistència Sanitària, *Spain*



Karolinska Institutet, *Sweden*

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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*



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

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INTRODUCTION

EUPHORIC is a multidisciplinary project oriented to policy authorities and policy makers. It 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.

Health contributes to the quality of life and well-being, and human health is fundamental to sustainable development. Thus, the objectives of the EUPHORIC project are fully in line with the strategy for sustainable development formulated by the European Union and renewed by the European Council in June 2006. It aims at bringing together the many strands of economic, social and environmental policies under one overarching objective: to continually improve the quality of life of Europeans and citizens worldwide, and to guarantee the well-being of future generations.

Moreover, EUPHORIC will contribute to assure a functional health information system by providing a set of outcome indicators and data relevant to their implementation in some MS.

Defining a policy about the dissemination of health knowledge is mandatory within this context. Exchanging knowledge and best practice related to cooperation between health systems becomes a key issue for EUPHORIC's success.

The website (www.euphoric-project.eu) will be the main tool for its dissemination. It will provide a brief overview of the national and international context with regard to health systems, information on outcome indicators, risk adjustment models, data sources, data collection methods and validation procedures. Also, it will be possible to download technical documents from the website. As well, a list of useful contacts (links to institutions, associations, scientific societies, organizations operating in the health field) will be available so as to export the health outcome monitoring system to other countries.

However, the dissemination strategy will go beyond setting up a website and participating in conferences. The existence of the database, available on the website, and of the results of the pilot study will be made known to the academia, policy makers, stakeholders, public health institutions, other European projects, ECHIM and the OECD. The dissemination network of each participant in the consortium, the cooperation set up with other projects, the EU public health portal, and all the addressees suggested by DG SANCO and the HSWP will be useful channels to implement this activity. The dissemination strategy will be planned by also considering the collection of feedback (comments, suggestions) received from the addressees.

This document describes how EUPHORIC has been disseminating and will continue to disseminate the results.

The report is organized in six sections related to: the dissemination policy approved by the consortium (1); some proposals for the dissemination of the results in a general context (2) and specifically for the pilots (3, 4 and 5); specific actions to be undertaken by the other partners to disseminate the results in their countries (6).

1) EXPLOITATION AND DISSEMINATION OF THE RESULTS

This document, that was prepared by partner IMAS-IMIM and approved by the consortium during the meeting held in Helsinki on 9 October 2007, summarizes the strategies for the dissemination of the results achieved by the project and the policy-related benefits.

A) *Dissemination of the results*

Dissemination strategies are divided in several general categories according to the targeted people.

1. Directed to targeted citizens:

Diffusion of the project's results using informative leaflets, dissemination manuscripts and electronic media to describe simple indicators and indicator quality evaluation criteria to European and international citizens as well as communication media.

The following items will be considered to be distributed to European and international citizens:

- Leaflet explaining the project. It has been distributed among European and international citizens since 2005 (downloadable from the website www.euphoric-project.eu). The leaflet is available in all the languages of the countries participating in the EUPHORIC consortium (associated beneficiaries and collaborating partners).
- Dissemination of the scientific manuscript.
- Brochure explaining the project's results in terms of describing simple indicators and indicator quality evaluation criteria. The brochure is available in all the languages of the countries participating in the EUPHORIC consortium (associated beneficiaries and collaborating partners).
- A website with all the practical results (deliverables) and project characteristics (ongoing since 2005).

2. Directed to health policy makers and hospital management:

- Executive summary and technical reports related to outcome research, outcome indicators and tools to benchmark hospitals by taking into account basic characteristics for a selected set of indicators.

3. Directed to scientists, and clinical practitioners:

Results will be communicated within the scientific community through the publication of scientific papers, participation in conferences and in workshops.

3.1 Scientific papers

A detailed list of all the publications (published, in the process of revision, submitted, and in preparation for their submission) will be made available on the website.

As agreed among the EUPHORIC consortium, all the scientific partners that have cooperated and have been actively involved in the specific study will appear as authors in these papers. In any case, the list of authors will end "on behalf of the EUPHORIC working

group" and the names of the participants in the working group will be listed in the acknowledgements.

3.2 Conferences and workshops

The EUPHORIC project and its results were presented at the following conferences:

15th European Conference on Public Health (EUPHA) held in Helsinki from 11 to 13 October 2007.

European Arthroplasty Register Session, EFORT Congress 2008 held in Nice from 29 May to 1 June 2008.

16th European Conference on Public Health (EUPHA) held in Lisbon from 6 to 8 November.

After these presentations, results of the EUPHORIC project will be presented at other American, European, and national congresses according to the approved dissemination plan.

Efforts will be made so that the information will reach the general media (press, radio, tv) on the occasion of EUPHORIC presentations at scientific events.

B) Policy related benefits

The EUPHORIC design has permitted the establishment of validated standards for quality assessment of a selection of indicators based on simple routine data. Consequently, guidelines for benchmarking hospitals and countries by taking into account basic characteristics for the selection of indicators of a set of condition/procedures will be possible.

The Council Resolution of June 28 1999 on Consumer Policy 1999 to 2001 (199/C 206/01) underlines the aim of the Community in "protecting the health, safety and economic interest of consumers and their right to information". The Health and Consumer Protection EU Policy paper underlines (point 2 – Protection of economic interest) the aim of DG SANCO "to ensure that the interests of consumers are given due consideration in the development of other European Union policies", and also the scientific research interests of DG SANCO in the Sixth Framework Programme point out that "in order to develop a good consumer policy and effective health protection in the future, it is vital that the consumer's interests are taken into account in the upstream scientific research activities which are being carried out today".

Not only consumers but also hospitals will take advantage of the results of EUPHORIC thereby improving European Health Systems' competitiveness.

Moreover, The Community Action Programme on Health Promotion (OJ No L095, 16.4.1996, p 1) establishes as a measure (point 5) "the promotion of analysis, evaluation and exchange of experience, information and support for innovative measures for the prevention of cardiovascular and cerebrovascular diseases".

Thus, the EUPHORIC project will fully satisfy the aims of the EU Community action on EU public health.

2) GENERAL

Since the results of EUPHORIC were available at the end of 2008, most of the dissemination was carried out after the official deadline of the project (14 December 2008) and will continue after the submission of the final report. In April 2008, the main beneficiary started cooperating with the scientific publisher ZADIG that gave an important boost to the dissemination activities by facilitating communication between EUPHORIC scientific partners and the partners' external relations office.

The main beneficiary has been responsible for the following items:

1. Organization of the final workshop

The final workshop of the project was held in Rome at the ISS on 11-12 December 2008. All the information (programme, introductory poster, summary of the workshop, presentations) is available on the website (see Section: Final workshop <http://www.euphoric-project.eu/?q=node/397>).

2. Preparation of the General Report according to the Grant Agreement.

Responsible for its realization: ISS.

The report refers to all the specific technical reports submitted by the partners.

Delivered to DG SANCO in May 2009.

3. Preparation of a brochure describing the project and the results to be placed on the website and translated in all the languages spoken in the project so as to provide information to the policy makers and the health stakeholders

Responsible for its realization: ISS in cooperation with ZADIG after having agreed on the contents with DG SANCO.

Other partners involved: partners DEASL for the scientific contents revision, all the partners for the final linguistic revision.

Presented as a deliverable that will be sent to the EU Commission and made downloadable from the project website after approval by the Commission.

4. Preparation of an executive summary giving a technical overview of the project and its results to be placed on the website and translated in all the languages spoken in the project so as to provide information to the scientific community interested in outcome research and outcome indicators

Responsible for its realization: ISS in cooperation with ZADIG after having agreed on the contents with DG SANCO.

Other partners involved: all the partners for the final linguistic revision.

Presented as a deliverable that will be sent to the EU Commission and made downloadable from the project website after approval by the Commission.

5. Preparation of a video dealing with the subject of outcome indicators to be placed on the project website and on the EU website

Prepared following a specific request by DG SANCO.

Responsible for its realization: ISS in cooperation with ZADIG after having agreed on the storyboard and the script with DG SANCO.

Other partners involved: interviews with the cardiovascular pilot leader (Jaume Marrugat, IMAS-IMIM), the orthopaedic pilot leader (Gerold Labek, EAR), the person

responsible for the WP3 "Liaisons with other projects" (Unto Häkkinen, STAKES) and the ECHIM project leader (Arpo Aromaa).

6. Virtual Table of Discussion

In cooperation with the project coordinator, ZADIG set up a Virtual Table of Discussion in February 2009. Interviews were done with epidemiologists that are an important reference at an international level with the aim of presenting different opinions about the publication of the data resulting from the use of the outcome indicators (for example, in benchmarking hospitals).

Furthermore, some European networks, especially those connected to patient associations, that are interested in the EUPHORIC results and possible further developments were involved in the discussion. Starting from these first contributions, the discussion was launched by asking for the participation of other interlocutors: patient associations and citizens, policy makers, etc.

The results will be summarized in a report that will be sent to the EU Commission and made downloadable from the website.

7. Publication of the Newsletter

Responsible for its realization: ISS in cooperation with ZADIG.

Started in June 2008. All the issues are available on the website (<http://www.euphoric-project.eu/?q=taxonomy/term/3>).

The following issues were published:

27/06/2008 Newsletter N. 1, Year 2008

28/07/2008 Newsletter N. 2, Year 2008

05/11/2008 Newsletter N. 3, Year 2008

05/12/2008 Newsletter N. 4, Year 2008

29/01/2009 Newsletter N. 5, Year 2009

Newsletter N. 6 will be published after the approval of the final report.

8. Bridging with other future projects

The functions of the cardiovascular algorithm are currently available only in the restricted area of the EUPHORIC website since they have to be considered a "beta" version and need to be validated. This activity will be carried out in future projects and EUPHORIC will carry out all the necessary bridging activities. In particular, cooperation with HOPE (European Hospitals and Healthcare Federation) will be established in order to disseminate the results in both networks.

Moreover the project leader cooperated with CASPUR to prepare a paper (1) describing the activities carried out in the project. The paper will be published in the CASPUR - Annual Report 2009 and will be made available in the project website.

1) Andrea Paladin, Marina Torre, Marco Costantini. Il progetto EUPHORIC. 2009, CASPUR – Annual Report (in press).

3) CARDIOVASCULAR PILOT

(by partner IMAS, cardiovascular pilot coordinator)

The results achieved by the cardiovascular pilot will be disseminated by the following means:

1. **The specific contribution of the WP 5.1 (Cardiovascular pilot) to be included in the General Report requested in the Grant Agreement and the technical reports to be attached to it.**

(see section 2 GENERAL).

2. **The publication in the Cochrane Library of a systematic review on GPIIb-IIa inhibitor used in revascularisation procedures.**

Responsible for its preparation: IMAS.

Presented as a deliverable attached to the second interim report (Deliverable n. 7 downloadable from the project website <http://www.euphoric-project.eu/?q=node/70>).

3. **Scientific presentations at the European Society of Cardiology, European Public Health Association (EUPHA), European Epidemiology Federation of the International Epidemiology Association and national societies of cardiology, epidemiology and public health.**

Responsible for its preparation: IMAS, ISS.

4. **At least one scientific publication has been planned in an international journal.**

Responsible for its preparation: IMAS.

4) ORTHOPAEDIC PILOT

(by partner EAR, orthopaedic pilot coordinator)

The results achieved by the orthopaedic pilot will be disseminated considering the preparation, and contribution to the preparation of the following reports:

- 1. The specific contribution of the WP 5.2 (Orthopaedic pilot) to be included in the General Report requested in the Grant Agreement and the technical reports to be attached to it.**

(see section 2 GENERAL).

- 2. A report with special consideration to the interests and needs of orthopaedic surgeons.**

Responsible for its realization: EAR.

It will be based on the General Report summarizing the most important topics from the orthopaedic pilot and content which are useful for orthopaedic surgeons.

To be disseminated at the 10th EFORT Congress (Vienna, 3-6 June 2009) and made public available on the EFORT portal.

- 3. A handout concerning the development and realization of outcome research registers.**

Responsible for its realization: EAR.

A manual for developing projects with the aim of synchronisation at the European level to support comparability of the results and reports for the future.

To be disseminated at the 10th EFORT Congress (Vienna, 3-6 June 2009) and made public available on the EFORT portal.

- 4. Scientific publications**

Responsible for its realization: EAR.

EAR will submit scientific publications to peer-reviewed scientific journals.

- 5. Participation in congresses**

Responsible for its realization: EAR.

The following activities were carried out during the project:

- Presentation at the Annual Congress of the Romanian Arthroplasty Society
- 9th EFORT Congress (Nice, 29 May–1 June 2008): organization of a scientific session dedicated to arthroplasty registers

The following activities will be carried out:

- 10th EFORT Congress (Vienna, 3-6 June 2009): to document the main content presentation by video and publish it via the EFORT portal (www.efort.org); to include a short introductory article and a link to the EFORT website where the entire content presented at the Vienna congress will be uploaded in an EFORT e-newsletter that will be sent to 35,000 addressees by the end of June. The EFORT e-newsletter addressees include all orthopaedic surgeons in Europe and other registered stakeholders such as manufacturers and public health institutions.
- EFORT Congress 2010 in Madrid: to dedicate a “plenary session” about registers and outcome research, since EAR has decided to continue with the methodological studies started in the EUPHORIC project (particularly with the testing of the validity of outcome data using the developed methodology)

5) RISK ADJUSTMENT and STATISTICS

An important dimension of the activities of DEASL is the functioning and outcome assessment of health services. It also provides information to support decision making processes at different levels. These levels are of an extraordinary diversity and one of the challenges is to work with them and to benefit not only from their experiences but also from their diversity. DEASL targets three levels:

- policy makers, policy decision makers and designers, belonging directly to the policy arena or to their supporting staff. They are situated at the local, regional, national scenes. They belong to governmental, or non-governmental organizations, to public administrations as well as to private ones;
- scientific community;
- health care providers at the regional and local levels.

According to these levels, the results achieved by the WP 5.3 and in general by the Euphoric project will be disseminated by the following means:

- 1. The specific contribution of the WP 5.3 (Available sources of information in participant countries and development of a standardized methodology for comparative evaluation of outcomes) to be included in the General Report requested in the Grant Agreement and the technical reports to be attached to it.**

(see section 2: GENERAL).

- 2. At least one scientific publication has been planned in a peer-reviewed international journal.**

Responsible for its realization: DEASL.

- 3. Scientific presentations at national or international association/societies of epidemiology, statistics and public health.**

Responsible for its realization: DEASL.

- 4. Publication of the Euphoric results on the website: http://www.asplazio.it/VIS_lazio/vis_index.php.**

Responsible for its realization: DEASL.

- 5. Organization of appropriate seminars and discussions about Euphoric results in the most relevant master courses.**

Responsible for its realization: DEASL.

- 6. Organization of appropriate seminars about the Euphoric results for health policy makers, hospital management personnel, and clinical practitioners.**

Responsible for its realization: DEASL.

6) OTHER PARTNERS' AND RELATED PROJECTS' SPECIFIC CONTRIBUTIONS

Specific proposals received by the partners are reported in this section.

Associated Beneficiary STAKES (Finland)

One of the main activities of STAKES is the functioning and outcome assessment of health services. It also provides information to support decision making processes at national, regional and service-unit levels. STAKES has a specific communications group which is responsible for the coordination and development of communications, public image issues, customer and media communications, and internal communications. In addition, STAKES publishes manuscripts prepared by its personnel or by outsiders if the subject matter falls within the priority area, e.g. outcomes of health services. STAKES also publishes several periodicals, two of which (Impakti, a newsletter on health technology assessment and CHESS online, a newsletter for all those interested in health economics research) are specifically dedicated to health services. All the above-mentioned channels will be used to disseminate the project. In addition, Euphoric results will be discussed in a seminar organized by CHESS (<http://groups.stakes.fi/CHESS/EN/index.htm>). In Finland, the new National Institute for Health and Welfare (THL) started operations on 1 January 2009, following the merger of the National Public Health Institute (KTL) and the National Research and Development Centre for Welfare and Health (STAKES). Thus, from the beginning of the year 2009, the new channels developed for THL will be used to disseminate the project.

Associated Beneficiary NKUA (Greece)

NKUA will present the results of the analyses undertaken in peer-reviewed journals, conferences and workshops.

Previously discussed future activities in this work package will be presented in a leaflet named "Euphoric-Greece" containing the results of the Greek Euphoric team endeavour and on the website of the Nutrition Unit of the Department of Hygiene and Epidemiology of the National and Kapodistrian University of Athens (www.nut.uoa.gr/). The results of the analyses undertaken by EUPHORIC will be hosted on this site as another way of disseminating them to health policy makers, hospital management personnel, scientists, and clinical practitioners

Associated Beneficiary KAR (Sweden)

Both project leaders, Rino Bellocco and Weimin Ye, who work in academia, will disseminate the Euphoric results within the Karolinska Institutet through the institutional channels available. The most important is the KI information journal which is published every month and is available on the website (www.ki.se). At a department level, Euphoric results will be published on Praesepe (www.ki.se/meb). Results will be further made available by organizing appropriate seminars and discussions in the most relevant PhD courses at Karolinska.

Finally, they will inform both medical and patient associations in Sweden through well-established contacts about Euphoric, specifically the Swedish County Councils and the quality registers which are under their supervision.

Collaborating Partner NCPHP (Bulgaria)

The reference person for the project, Prof. Karolina Lyubimorova became an associated professor in toxicology at the Medical University Sofia, Faculty of Public Health, Department of Preventive Medicine in 2007.

Her new workplace is extremely suitable for disseminating the project. The results of the projects will be presented in the Journal of Health Management - which is read by many of the health policy makers and hospital directors in Bulgaria. Also, the results will be presented in lectures in the master courses held in the faculty: health management, health care organization and management, and many others. Presentations will be done at public health conferences and seminars organized by the faculty where politicians, scientists and patients take part.

Collaborating Partner BQS (Germany)

In order to disseminate the results of the EUPHORIC project, a reference to the results will be presented on the BQS website, so that experts as well as the interested public can learn about the project.

Also, the aims and results of the EUPHORIC project will be presented within the Bundesgeschäftsstelle für Qualitätssicherung (National Institute for Quality in Healthcare, BQS) so that the results can, if possible, be incorporated in the national quality assurance programme.

Since BQS develops, conducts and continually improves national quality assurance programmes in currently 26 measurement areas, it works closely with national expert groups in those areas. BQS will introduce the results of EUPHORIC to those expert groups whose current work will benefit from the results.

Collaborating Partner TILAK (Austria)

The arthroplasty register is under the scope of the Institute of Clinical Epidemiology of TILAK. This institute runs the Cancer Registry of Tyrol, the Perinatal Registry of Austria and is directly involved in public health indicators both in the field of oncology and perinatology. These experiences were also brought into the discussion at the final meeting of the EUPHORIC project in Rome in December 2008.

In order to disseminate EUPHORIC results to all local people who are interested in outcome research and collection of indicators for public health, a link to the EUPHORIC homepage was included on the IET website (<http://www.iet.at/index.php?id=1666>).

Collaborating Partner LBI-HTA (Austria)

The Ludwig Boltzmann Institute for Health Technology Assessment is located in Vienna (<http://hta.lbg.ac.at>). The contact person is Stefan Mathis.

The institute maintains contacts to a great many key players and decision makers of the Austrian health system. It conducts periodic meetings with Austrian hospital representatives and operates a communication platform for various health care operators. It has five scientific programmes that are highly coordinated with European and international health technology assessment agendas. The LBI-HTA publishes a monthly newsletter containing current findings from HTAs and other up-to-date topics in the interest of health care. The institute has agreed to announce an editorial on the EUPHORIC project that will reach over 900 recipients.

Collaborating Partner CAHTA (Spain)

The dissemination plan of the EUPHORIC project from the Catalan Agency for Health Technology Assessment and Research (CAHTA) includes the following tasks:

- A summary of the EUPHORIC project and a list of the main beneficiary, the associated and collaborating partners have been included on CAHTA's website in English (<http://www.gencat.net/salut/depsan/units/aatrm/html/ca/dir214/doc13231.html>). It was also made available in February 2009 in Catalan and Spanish.
- Information of CAHTA's collaboration in the EUPHORIC project has been included in CAHTA's newsletter that will be published in a near future. This newsletter is distributed in paper format to 9,000 mailing addresses (about 5,000 in Catalan, 3,000 in Spanish and 1,000 in English) and an online version to 1,400 contacts.

- A summary of the EUPHORIC Final Report will be included in the next edition of CAHTA's newsletter (approx. June 2009).

Collaborating Partner ISPHA (Israel)

The reference person for the EUPHORIC project, Prof. S. Behar, MD, is a cardiologist and Director of the Coordinating Center of ISPHA and is responsible for the research activities of the Israel Heart Society. Since 1992 those two institutions have carried out 2-month surveys (ACSIS) assessing the characteristics, management and outcome of all hospitalized patients with acute coronary syndrome (ACS) in all operating cardiac departments in the country. These surveys are conducted every two years.

Being responsible for the ACSIS project, which requires continuous contact with all cardiac departments in the country as well as health providers and health insurance companies, ISPHA is very well placed for the countrywide dissemination of the EUPHORIC aims and results to scientists, media and general public.

Collaborating Partner SAR (Slovak Republic)

The Slovak Arthroplasty Register (SAR) is a national tool for data collection and evaluation. The project leader, Libor Necas, was invited as the register expert for the final EUPHORIC meeting in Rome.

The EUPHORIC orthopaedic pilot project has shown the efficacy of the registers. SAR will disseminate the results through the website <http://sar.mfn.sk>. A link to the EUPHORIC homepage was included on both Slovak and English SAR homepages and leaflets (in Slovak and in English) were made downloadable. The results will also be incorporated into the SAR report 2008 as well and the medical and patient associations in Slovakia will be informed about the Euphoric project.

OECD

Dr Sandra Garcia Armesto, the coordinator of the HCQI project, who had been invited to the final Euphoric workshop (Rome 2008), agreed to cooperate in the EUPHORIC results dissemination using the OECD network or another suitable form for this aim.

Patient associations

The European Patients' Forum and the European Heart Network agreed to cooperate in the dissemination of the results.

CASPUR (Inter-University Consortium for the Application of Super-Computing for Universities and Research)

The technical partner CASPUR ((Andrea Paladin) in cooperation with the project coordinator (Marina Torre) prepared a paper describing the context and the main results of EUPHORIC. The paper was published in the CASPUR Annual Report, a publication that presents the most important activities of the Inter University consortium CASPUR. The CASPUR Annual Report is printed in 1000 copies that are distributed among all the Institutions participating in the consortium like Ministries, Universities, Hospitals. The paper will also be available on the CASPUR website. A link will be also included in the Paper section of the EUPHORIC website.