



# EU Health Programme: 2011 Call for Proposals

*Abstracts of the actions selected  
for EU co-funding*

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# Introduction

Ensuring a high level of health for its citizens is one of the concerns and ambitions of the European Union, which is active in many ways in pursuit of this objective.

An important aspect of what the EU does in this field is the co-funding of public health activities across Europe and this brochure provides a comprehensive overview of the most recent actions to have received EU financial support. These actions have all been co-funded in the framework of the second Programme of Community action in the field of public health, more commonly referred to as the EU Health Programme.

With a budget of 321.5 million euro for 2008–2013, the programme touches on a wide range of actions: from discouraging the use of tobacco or abusing alcohol to refining the care of patients with Alzheimer's Disease; from suicide prevention to investigating congenital anomalies; and from averting personal injuries to strengthening Europe's defenses against epidemics.

It aims to overcome inequalities across Europe, whether they concern our lifestyles, such as in access to opportunities for physical activity, or lifesaving interventions, such as quality transplantation systems. It promotes the generation and dissemination of knowledge on innovative treatments and care, whether for rare diseases, or on widespread health challenges such as cardiovascular disease or cancer. It supports the awareness of the rights of patients; it assists in finding responses to specific health issues such as HIV or in easing the lives of people with multiple sclerosis.

The programme operates through annual work plans adopted by the European Commission, which set out the specific priorities and allocate the programme's resources accordingly for each year of the programme. Each annual work plan is implemented through the publication of four calls for proposals, each one of which is targeted to fund specific types of public health actions: projects, conferences, joint actions between the European Commission and the EU Member States and operating grants. The actions highlighted here were selected from those proposals, and most are ongoing at the time of publication. Indicatively, approximately 27 million euros<sup>1</sup> were made available under the 2011 calls for proposals.

To receive EU co-funding under this programme, actions have to contribute to at least one of the three main objectives of the programme:

- to improve citizens' health security;
- to promote health, including the reduction of health inequalities;
- to generate and disseminate health information and knowledge.

They also need to have a European dimension, meaning that partners from a range of European countries have to be involved.

The management of the programme has been delegated by the Commission to the Executive Agency for Health and Consumers. More information about the Agency and about the health programme as a whole is available at <http://ec.europa.eu/eahc>.

<sup>1</sup> OJ C 69, 3.3.2011, p. 5–7

CHAPTER 1 **Health**

# Promotion





## CHAPTER 1

# 1.1. HEALTH PROMOTION PROJECTS

PROJECT NO 20111204



## GOOD PRACTICE ON BRIEF INTERVENTIONS TO ADDRESS ALCOHOL USE DISORDERS IN PRIMARY HEALTH CARE, WORKPLACE HEALTH SERVICES, EMERGENCY CARE AND SOCIAL SERVICES (BISTAIRS)

### *Abstract*

#### *General objectives*

If the best use is to be made of limited healthcare resources in tackling harmful and hazardous drinking, it is important to match the health needs of individuals closely with the right treatment options. Brief interventions (BI) have already proved valuable in primary health care in high income countries as a way of recommending the best course for individual patients. This project encourages the use of BI in other EU countries, and in settings such as workplace health services, emergency care and social services.

#### *Strategic relevance and contribution to the public health programme*

This project forms part of the attempt to promote health under the EU programme on health 2008–2013. Its focus on alcohol use disorders tackles one of the major public-health determinants in Europe, and will help towards achieving the programme's aim of reducing alcohol-related health inequalities. BISTAIRS will address policy makers, networks and associations as well as professionals who have contact with people with harmful alcohol consumption. It will develop evidence-based health information for professionals, and make it widely available in the form of policy recommendations and guidelines. The intended results will be greater understanding of the importance of secondary prevention in relation to alcohol, and improved skills among professionals.

#### *Methods and means*

Information will be gathered from the participating networks via a brief questionnaire, to map how BI is currently practised in the EU. Selected BI approaches will then be evaluated in a series of field tests, in order to create toolkits for professionals. To make sure the tests provide adequate indications of the effectiveness of the toolkits, they will cover all four settings – primary care, workplace health services, emergency care and social services – in five countries, including three countries where there is less experience in the use of BI. Focus groups will be used in the evaluation of the field tests.

#### *Expected outcomes*

BISTAIRS will result in a comprehensive set of tailored and field-tested BI tools, methods and materials. This will include an updated evidence report with a special focus on BI in workplace health care, emergency care and social services, and a map of current implementation status across the EU. On this basis, guidelines will be generated for developing and rolling out future approaches to the use of BI in Europe, as well as plans for spreading the information more widely.



### Keywords and portfolio

**KEYWORDS:**

- Alcohol
- Living and working environment
- Health system
- Implementation
- Brief interventions

**PORTFOLIO:**

- Alcohol

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- Istituto Superiore di Sanità – ISS, Italy
- National Institute of Public Health – NIPH, Czech Republic
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**MAXIMUM EC CONTRIBUTION:**

340,095.00 €

**DURATION:**

36 months

PROJECT NO 20111201



## INFORMATION NETWORK ON RARE CANCERS (RARECARENET)

### *Abstract*

#### *General objectives*

RARECARENet aims to build a network that will provide information on rare cancers to a wide audience ranging from oncologists and general practitioners to researchers, health authorities and patients. The objectives are to speed up accurate diagnosis and to give patients with rare cancers easier access to high quality treatment. It will also identify centres of expertise for rare cancers in Europe, and lead to standardisation of national practices.

#### *Strategic relevance and contribution to the public health programme*

The project will help protect citizens' health, in line with the Second Health Programme (SHP) and Annual Work Plan, and the Public Health Programme (2008–2013), which gives high priority to rare diseases – including rare cancers. Providing European citizens with accurate information on rare diseases is an important part of protection, as the European Commission points out in its Communication "Rare Diseases: Europe's challenge", and as the Recommendations from the Council underline. Differences across Europe in monitoring the incidence of rare cancers lead to different rates of survival and prevalence. This project will identify some of the causes of these inequalities, and will spread the use of effective counter-measures. In close collaboration with the European Partnership for Action Against Cancer (EPAAC), the network will not only increase information about rare cancers in Europe, but will help to make practical use of the information.

#### *Methods and means*

An analysis will be made of hospital performance in a number of countries, using records of treatment, outcome and case volume. Criteria will be defined to identify centres of expertise for rare cancers. These will be tested against information on hospital performance, in conjunction with a survey among members of the European Cancer Patient Coalition (ECPC) on their views of centres of expertise. The list of rare cancers will be revised, and updated figures on incidence, prevalence and survival will be developed from the EUROCARE database. Additional information on diagnosis and treatment will be developed by the project State-of-the-Art Oncology in Europe (START), and new knowledge on very rare cancers will be produced.

#### *Expected outcomes*

The network will help to:

- create a better classification of rare cancers, as a complement to the Orphanet inventory of rare diseases
- spread information about rare cancers more systematically among all stakeholders
- improve diagnosis and treatment of rare cancers, and referral of patients to centres of expertise
- promote international collaboration in researching very rare cancers
- explore why survival rates vary across Europe, and recommend ways of reducing health inequalities
- support planning and allocation of healthcare resources for rare cancers
- empower patients

## Keywords and portfolio

### KEYWORDS:

- Cancer
- Rare diseases and disorders
- Treatment
- Diagnostic
- Healthcare

### PORTFOLIO:

- Rare diseases

### ACTION WEBSITE: -

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- Istituto Superiore di Sanità – ISS, Italy
- National Cancer Registry – NCR, Ireland
- National University Specialised Hospital for Active Treatment in Oncology – NOH, Bulgaria
- The University of Edinburgh – UEDIN, United Kingdom

### MAXIMUM EC CONTRIBUTION:

1,000,630.70 €

### DURATION:

42 months

PROJECT NO 20111202



## SINGLE HUB AND ACCESS POINT FOR PAEDIATRIC RHEUMATOLOGY IN EUROPE (SHARE)

### *Abstract*

#### *General objectives*

SHARE aims to improve care for patients suffering from paediatric rheumatic diseases. It will bring networks and projects in this field together with research teams and all others involved in treatment and development of new technologies or medicines. This should make it easier to exchange ideas, results, data and effective methods, and to modify training programmes for health care professionals accordingly. The project is also designed to give patients better access to information about their disease. It will build on related networks, national registers and European projects, and should trigger research progress, particularly by harmonising treatment approaches and supporting regulatory and policy decisions.

#### *Strategic relevance and contribution to the public health programme*

As the Council Recommendations point out, rare diseases demand an international approach, particularly because of their low prevalence. For paediatric rheumatic diseases, the most serious impediments to European progress are differences in treatment and management, the lack of comparable data, and insufficient links between patients and health care providers. SHARE will lay the foundations for international collaboration by bridging these gaps. Since success will depend on continuity, it will be vital to ensure a sustainable approach, so SHARE will be tied closely to the Paediatric Rheumatology European Society (PReS).

#### *Methods and means*

Country-specific needs for paediatric rheumatic diseases will be defined via a survey amongst healthcare providers in Europe, and a literature overview will identify the best forms of treatment. To allow interactive use of information, the PReS website will host a network for data collection and analysis, linked to other networks. Patients will be represented in discussions, and the ethical and legal issues relating to data collection and informed consent will be explored. Recommendations will be made for modifications to the training programmes of PReS and its members.

#### *Expected outcomes*

- (1) A European Reference Network on paediatric rheumatic diseases that will widen understanding of standards on data and sample collection and best treatments, permit better disease classification, evaluate diagnostic and therapeutic protocols, and carry out case-control studies and clinical trials.
- (2) Agreement on minimal standards of care in each country.
- (3) Greater patient input on research and treatment.
- (4) Support for regulatory and policy decisions.

## Keywords and portfolio

### KEYWORDS:

- Rare diseases and disorders
- Collection of Best Practices
- Treatment
- Health education
- Healthcare

### PORTFOLIO:

- Rare diseases

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- University of Liverpool – UNILIV, United Kingdom
- Univerzita Karlova v Praze – CUNI, Czech Republic
- Univerzitetni Klinični Center Ljubljana – UKCLJ, Slovenia
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### MAXIMUM EC CONTRIBUTION:

860,244.00€

### DURATION:

36 months

PROJECT NO 20111207



## EUROPEAN HAEMOPHILIA NETWORK (EUHANET)

### Abstract

#### *General objectives*

The European Haemophilia Network (EUHANET) is designed to improve care of citizens with inherited bleeding disorders. Health professionals and patient organisations will work together to develop criteria for care provided by haemophilia centres across Europe. A public website will provide information for patients and carers. And EUHANET will collaborate with the European Haemophilia Safety Surveillance System (EUHASS), and the prospective Rare Bleeding Disorders Database (RBDD).

#### *Strategic relevance and contribution to the public health programme*

EUHANET's work will help meet the rare-diseases objectives of the Commission strategy on international exchange of information and support for best practices. It will start to bring together the knowledge which exists at national level in a fragmented form, and will transfer standards of care to every haemophilia centre in Europe, reducing health inequalities. And it will offer tools to spread health information more widely.

#### *Methods and means*

A new European system classifying haemophilia centres in two distinct levels of expertise will be developed. Initially, 125 will submit their performance data to a panel of doctors, patients and nurses who will provide the certification. The "Haemophilia Central" website will provide up-to-date information about guidelines, clinical trials, treatments, and where to find haemophilia centres. The EUHASS adverse event reporting system will be expanded, to cover rare bleeding disorders and platelet disorders. It will also collaborate more closely with the rare bleeding disorders database, which will start to collect prospective data on fibrinogen and factor XIII deficiencies.

#### *Expected outcomes*

The EUHANET network will provide a platform for information, exchange, and collaboration on treating inherited bleeding disorders and other haemophilia-related activities in Europe. It will include news and a question and answer service for patients and professionals, and a mobile phone application locating the nearest haemophilia centre. In addition to defining levels of expertise in centres, it will boost the EUHASS adverse event reporting system to cover platelet disorders.

### Keywords and portfolio

**KEYWORDS:**

- Chronic diseases
- Rare diseases and disorders
- Treatment
- Diagnostic
- Healthcare

**PORTFOLIO:**

- Rare diseases

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- Medical Data Solutions and Services Ltd – MDSAS, United Kingdom
- Universitair Medisch Centrum Utrecht – UMCU, Netherlands

**MAXIMUM EC CONTRIBUTION:**

885,614.00€

**DURATION:**

42 months

PROJECT NO 20111209



## EPODE FOR THE PROMOTION OF HEALTH EQUITY (EPHE)

### *Abstract*

#### *General objectives*

EPHE aims to support the EU's research programme objectives of more equal health status across Europe. It will analyse ways of reducing differences in dietary and physical activity habits of families with children aged 6 to 12, with a focus on families of different socioeconomic profiles where premature mortality significantly exceeds the EU average. It would offer the opportunity of transferring best practices to other regions and countries in the EU.

#### *Strategic relevance and contribution to the public health programme*

The project will promote healthier habits among disadvantaged families, focusing on those with children aged 6–12, since investment in early years carries the highest potential to reduce health inequalities within a generation. But instead of traditional mass communication campaigns, it will work at community level with groups that are often less receptive to messages about healthy living. It will use positive and non-stigmatizing messages that relate more to immediate social and emotional benefits than to long-term health benefits. It will explore the scope for transferring and reproducing a capacity-building framework on a larger scale, especially through support from EU structural funds.

#### *Methods and means*

An intervention community and a comparison community will be selected in each of seven locations, and project mediators will coordinate the work locally, creating broadly-based steering committees to increase outreach over two years. A scientific advisory team will agree protocols for evaluation, and will support tailored actions to reduce health inequalities. EPHE coordination teams will provide materials, training and coaching, and activities. Potential use of EU structural funds will be examined.

#### *Expected outcomes*

A practical scientific framework will be created to analyse and address the social gradient in health inequalities in relation to diet and physical activity-related behaviours of the families studied, and some conclusions will be offered from this pilot-test as to how far capacity-building can help tackle health inequalities. A report will recommend strategies and methods proposed for local, regional and national authorities to invest in best practices via structural funds. Awareness will be raised among opinion-formers and decision makers about the potential of this approach, reinforced by evidence of political will among the communities involved to pursue measures to reduce health inequalities.



## Keywords and portfolio

### KEYWORDS:

- Obesity
- Inequalities
- Children
- Prevention

### PORTFOLIO:

- Social determinants and health inequalities

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[www.epode-international-network.com/  
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- Fundatia PRAIS, Romania
- LCA Consulting, United Kingdom
- Nostus Communications & Events Ltd, Greece
- Protein Health Communications, Belgium
- Universidad de Zaragoza, Spain
- Universiteit Gent, Belgium
- Vereniging voor Christelijk Hoger Onderwijs Wetenschappelijk Onderzoeken Patientenzorg (VU) Foundation, Netherlands
- Българска асоциация за изучаване на затлъстяването и съпътстващите го заболявания (Bulgarian association for the study of obesity and related diseases), Bulgaria

### MAXIMUM EC CONTRIBUTION:

834,017.40€

### DURATION:

36 months

PROJECT NO 20111203



## REDUCING HEALTH INEQUALITIES: PREPARATION FOR ACTION PLANS AND STRUCTURAL FUNDS PROJECTS (HEALTHEQUITY-2020)

### *Abstract*

#### *General objectives*

HEALTHEQUITY-2020 aims to assist EU countries and regions in evidence-based actions to reduce health inequalities. It will combine available evidence with social innovation to promote effective change. A toolkit will be developed and tested to support the approach in participating regions, backed up by a website and database, and support for planning to make use of structural funds.

#### *Strategic relevance and contribution to the public health programme*

HealthEquity 2020 not only builds on previous projects related to solidarity and equity in health systems, but offers a link to the strategic dimension of EU Cohesion Policy 2014–2020. Its health investment dimension has particular relevance to promoting employment and supporting labour mobility and promoting social inclusion and combating poverty. It also reflects the objectives of the 'Promote Health' 2011 work plan of identifying the causes of, addressing and reducing health inequalities and promoting investment in health in cooperation with other EU policies & funds.

#### *Methods and means*

A range of working parties will be responsible for coordination of methodology, creating learning workshops and supporting capacity building, developing structured action plans and a toolkit for users, evaluating the impacts, and giving wide publicity to the results.

#### *Expected outcomes*

A database of at least twelve case studies will offer guidance to local actions on access to health care, health-related behaviour, and living and working conditions. The project will also help structural fund beneficiaries to design action plans that are evidence based, integrated with regional development plans and financially sustainable.

### Keywords and portfolio

**KEYWORDS:**

- Inequalities
- Accessibility
- Health system
- Health promotion

**PORTFOLIO:**

- Social determinants and health inequalities
- Healthcare
- Health and structural funds

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- Medical University of Lodz, Poland

**MAXIMUM EC CONTRIBUTION:**

114,504.04€

**DURATION:**

36 months

PROJECT NO 20111205



## REDUCING HEALTH INEQUALITIES: PREPARATION FOR ACTION PLANS AND STRUCTURAL FUNDS PROJECTS (ACTION-FOR-HEALTH)

### *Abstract*

#### *General objectives*

This project aims to improve citizens' health and quality of life by tackling health inequalities through health promotion. It brings together ten countries from across Europe in a partnership that allows them to get full value from their previous experience in this field, and even to create common approaches to improving health and reducing inequalities. European regions will be helped to access structural funds to develop appropriate programmes.

#### *Strategic relevance and contribution to the public health programme*

The combined approach of the project increases the impact of the public health programme in the selected countries. It uses the same methodology across eight countries and several sectors, but it is adjusted to the differences of local and regional culture. Consequently it offers a chance to assess the suitability of the approach more broadly, and could cumulatively provide deeper understanding of the influence of lifestyle and community capacity on health inequalities, ultimately feeding into EU policy making.

#### *Methods and means*

Country and regional analyses on an agreed methodology will identify major public health issues, including sanitary facilities and clean water access, and national objectives will be fixed. Examples of good practice in tackling health inequalities from across the partner countries will be selected and presented. Training will be organised for partners with an emphasis on integrating actions to combat health inequalities into structural funding programmes and regional strategic plans.

#### *Expected outcomes*

The project will provide project partners with new knowledge and skills to tackle health inequalities, which will impact positively on the health behaviour of the target groups. By bringing together public health experts with different sectors in the community and at regional level, more effective connections will be achieved, allowing a more comprehensive picture of the situation, respecting the needs and wishes of the population. Impetus will be given to local actions to enhance the health of the population and awareness of regional stakeholders will be increased about how health inequalities can be tackled.

## Keywords and portfolio

### KEYWORDS:

- Inequalities
- Health system
- Health promotion

### PORTFOLIO:

- Social determinants and health inequalities
- Healthcare
- Health and structural funds

### ACTION WEBSITE: -

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- Institute of Hygiene, Lithuania
- National Center of Public Health and Analyses, Bulgaria
- Országos Egészségfejlesztési Intézet, Hungary
- Trnava University in Trnava, Slovakia
- Universidad de La Laguna, Spain
- University of Brighton, United Kingdom
- Zavod za javno zdravstvo Međimurske županije (Institute of Public Health County of Međimurje), Croatia

### MAXIMUM EC CONTRIBUTION:

588,862.96 €

### DURATION:

24 months



## CHAPTER 1

# 1.2 HEALTH PROMOTION CONFERENCES

CONFERENCE NO 20114202



## HIV IN EUROPE COPENHAGEN 2012 CONFERENCE (HIV IN EUROPE 2012)

### *Abstract*

#### *General objectives*

The HIV in Europe Copenhagen Conference 2012 aims to provide an overview of innovative European initiatives and best practices on bringing people to testing, and consequently to earlier care. It will promote political discussion of guidance on the subject from WHO EURO (2010), ECDC (2010) and ECDC-EMCDDA (2011), and the EU Communication on HIV/AIDS and EP Resolution (2011), and how they are put into practice at national level. It is also intended to encourage the search for creative solutions to unresolved challenges in access for people in need of testing and treatment, and to increase general awareness of the public health problems associated with late presentation for HIV care.

#### *Expected achievements*

Approximately 300 participants are expected to attend. Since the HIV epidemic affects all EU countries, an appropriate balance will be sought, but with an emphasis on inviting – and even offering sponsorship to – participants from eastern Europe. The aim is to obtain an even representation of clinicians, civil society, social scientists and policy officers.

#### *Target audience*

The target participants will be selected based on abstract submissions, scholarship applications, invitations and an open call for participation. Bringing diverse participants together from many different disciplines is central to the initiative as a whole and the conference in particular. Relevant non-European participation will be considered, particularly from the USA, and 40 scholarships will be available for participants (with priority to young investigators) from eastern European and central Asian countries. Policy makers and leading community and institutional representatives from eastern Europe will also be considered for participation. The conference will feature a high level meeting with a political agenda, and plenary and parallel sessions involving groups from Europe working with innovative testing programmes. The focus will be on: lessons learned from using novel national HIV testing strategies; results from testing programmes; scaling up HIV testing and earlier care among hard-to-reach and heavily affected populations; HIV testing and the continuum of HIV care; characteristics of those who present late for HIV care; cost-effectiveness of HIV testing; the links between stigmatisation, criminalisation and other legal issues for the offer and uptake of HIV testing and earlier care; and use and performance of new HIV testing diagnostic technologies. Plenary sessions will examine late presentation and the undiagnosed population, whether targeted testing is the optimal approach, barriers to earlier testing, cost-effectiveness of testing and its contribution to more sustainable health systems; and putting international guidelines into effect at national level. There will also be country updates, and consideration of moving the political agenda forward.



### Keywords and portfolio

#### KEYWORDS

- Inequalities
- Vulnerable groups
- HIV/AIDS
- Collection of Best Practices
- Health promotion

#### PORTFOLIO

- Communicable diseases
- Sexually transmitted diseases

#### ACTION WEBSITE: -

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#### MAXIMUM EC CONTRIBUTION:

100,000.00 €

#### DATE AND PLACE OF THE CONFERENCE:

2012/03/19 in Copenhagen

CONFERENCE NO 20114201



## QUALITY OF LIFE AND SYMPTOM RESEARCH IN CANCER CLINICAL TRIALS (QOL EUROPE)

### *Abstract*

#### *General objectives*

The main objectives of the conference are to educate researchers and clinicians in quality of life and cancer and to increase dialogue between healthcare professionals in oncology clinical trials and public health. It will debate innovative approaches in QOL research across Europe, with a view to helping eliminate health disparities. It will maintain a focus on the patient, and particularly the elderly patient, and assess evaluation measure for clinical trials and new drugs, and how far reporting on QOL should be standardised in clinical trials.

#### *Expected achievements*

The number of participants expected is 500, from across different disciplines, cultures and around 50 countries, with particular focus on new EU member countries. Our outreach is to an international audience of over 10,000 members of related scientific organisations.

#### *Target audience*

We expect oncologists, generalist, radiotherapists, surgeons, palliative care physicians, as well as psychologists, nurses, social workers, biostatisticians, cancer patients and their relatives, and hospital and in-home care assistance experts. No registration fee will be charged. Our aim is to have not only experts in the audience, but also people involved in different aspects of the disease, including patients. Dialogue with the cancer patients is a priority, and invitations will be extended to patient representatives, cancer survivors, cancer patients' families, and adolescents who have grown up with cancer and are now adults who may be willing to share their experience, providing an insight to improve cancer care at the EU level. A fellowship programme will make it easier for young experts in Quality of Life to attend, so they can boost their competencies and give a different perspective on the topic in their own country afterwards.

### Keywords and portfolio

**KEYWORDS:**

- Inequalities
- Innovation initiatives
- Accessibility
- Health system
- Research

**PORTFOLIO:**

- Major and chronic diseases
- Healthcare

**ACTION WEBSITE:**

[www.eortc.be/probe/conference2012.htm](http://www.eortc.be/probe/conference2012.htm)

**MAIN BENEFICIARY (CONFERENCE HOLDER):**

European Organisation for Research and  
Treatment of Cancer – EORTC  
Avenue E. Mounier, 83/11  
PO-BOX  
1200 Brussels  
Belgium  
Tel: +32 2 774 16 30  
Fax: +32 2 779 45 68

**PROJECT LEADER:**

Andrew Bottomley  
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**MAXIMUM EC CONTRIBUTION:**

93,500.00 €

**DATE AND PLACE OF THE CONFERENCE:**

2012/10/17 in Brussels

CONFERENCE NO 20110001



## FIRST EUROPEAN DAY OF THE BRAIN. AGEING, STROKE AND ALZHEIMER'S DISEASE-FINDING INNOVATIVE SOLUTIONS (CFR)

### *Abstract*

#### *General objectives*

The conference will discuss stroke and Alzheimer's disease in the context of society, to highlight the imbalance between the costs to the individual and society of brain disease, and the resources allocated to dealing with the problem. The intention is to help build a more coordinated European research strategy. An analysis of the burden and cost of the disease will provide a basis for discussion amongst patients, policymakers, scientists and doctors, and should lead to conclusions with recommendations to EU countries to tackle these issues better.

#### *Expected achievements*

Giving priority to studies on brain diseases will allow a focus on their importance, both in Poland and across Europe. It should also improve understanding and public awareness of brain diseases, and help decrease consequent stigmatization, marginalization and social exclusion. This will support EU objectives in both health and social policies, and should help in keeping people in the labour market in line with the Europe 2020 Strategy, as well as stimulating funding for research and development and measures to combat inequalities in health. Conference conclusions will be list concrete suggestions, including proposing 2014 as the European Year of the Brain.

#### *Target audience*

The main target audience will be politicians at local and European level. Invitations have been extended to European Commissioners, the President of the European Parliament, and representatives of other EU bodies. Invitations to member state governments included particular attention to Poland, Denmark and Cyprus as the Presidential trio. Other participants include academia, scientists and clinicians, patients' organisations in the field of ageing and brain disorders, and non-governmental organizations and civil society.

### Keywords and portfolio

**KEYWORDS:**

- Non Alzheimer
- Alzheimer
- Dementia
- Mental diseases and disorders
- Collection of Best Practices

**PORTFOLIO:**

- Major and chronic diseases

**ACTION WEBSITE:**

<http://pl2011.eu/en/content/first-european-day-brain>

**MAIN BENEFICIARY (CONFERENCE HOLDER):**

Ministry of Health  
15 Miodowa St.  
PO-BOX N/A  
00-952 Warsaw  
Poland  
Tel: +48 22 5300203  
Fax: +48 22 6355880

**PROJECT LEADER:**

Grzegorz Opala  
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**MAXIMUM EC CONTRIBUTION:**

49,475.00€

**DATE AND PLACE OF THE CONFERENCE:**

2011/11/18 in Warsaw, Poland



## CHAPTER 1

# 1.3 HEALTH PROMOTION JOINT ACTIONS

## JOINT ACTION NO 20112201



## EUCERD JOINT ACTION: WORKING FOR RARE DISEASES (EJA)

### Abstract

#### *General objectives*

EUCERD (the EU Committee of Experts on Rare Diseases)

This Joint Action will focus on enhancing visibility and recognition of rare diseases (RD) and help develop and spread knowledge about them, linking specialized research with healthcare professionals and patients. It will also help improve access to quality services, from diagnosis right through to care, social support, and innovative therapies.

#### *Strategic relevance and contribution to the public health programme*

There is an urgent need to share experience and expert opinion in rare diseases, since no country can tackle the challenges individually. Investments to date have led to the development of widely-accepted collaborative tools and expertise, and the success of EU policies is demonstrated by the enthusiasm among other countries to join in planning for rare diseases. The Joint Action will integrate the various strands of work, so that they are improved and embedded in future policy, to ensure their sustainability.

#### *Methods and means*

Assistance will be given to policy makers through workshops and an interactive public health network, involving national alliances of RD patient groups. A RD nomenclature will be developed, and best practices will be explored for integrating care of RD patients into social policies and services. Current practices in care of RD will be examined, and national centres of expertise will be investigated. The Joint Action will also seek links with other RD initiatives across Europe and at national level.

#### *Expected outcomes*

A comprehensive proposal will be made for a sustainable framework for recognising rare diseases and sharing knowledge and expertise. RD action plans covering the different sectors involved at national level will be established by 2013. The provision of social services and healthcare will be mapped, from prevention through to diagnosis, care and rehabilitation. An international classification of RD will be created, along with tools to help the RD research community.



## Keywords and portfolio

### KEYWORDS:

- Rare diseases and disorders
- Health system
- Pharmaceuticals
- Survey
- Implementation

### PORTFOLIO:

- Rare diseases

### ACTION WEBSITE: -

### MAIN BENEFICIARY:

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United Kingdom  
Tel: +44 191 222 6000

### PROJECT LEADER:

Kate Bushby  
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### ASSOCIATED PARTNERS:

- European Organisation for Rare Diseases – EURORDIS, France
- Institut National de la Santé et de la Recherche Médicale – INSERM, France
- Instituto Nacional de Saúde Doutor Ricardo Jorge – INSA, Portugal
- Istituto Superiore di Sanità – ISS, Italy
- Johann Wolfgang Goethe Universität Frankfurt am Main – GUF, Germany
- Ministry of Health, Social Policy and Equality – MSPSI, Spain
- Ministry of Social Affairs and Health – STM/MSAH, Finland

### MAXIMUM EC CONTRIBUTION:

2,994,162.00€

### DURATION:

42 months



CHAPTER 2 **Health**

# Information





## CHAPTER 2

# 2.1 HEALTH INFORMATION PROJECTS

PROJECT NO 20111301

## SUPPORT CREATION OF PILOT NETWORK OF HOSPITALS RELATED TO PAYMENT OF CARE FOR CROSS BORDER PATIENTS (HONCAB)

### *Abstract*

#### *General objectives*

The project aims to help hospitals prepare for the new conditions that will apply once EU rules on patients' rights to cross-border care come into force. As EU countries decide how to transpose the directive, the project will fill an information gap by making available some preliminary but real data on the impact of patient mobility. It will refine methods for classifying and comparing tariffs for hospital care, and provide a framework for a pilot hospital network that can give participating hospitals practical experience of the opportunities and critical issues of cross-border care, and share problems and solutions.

#### *Strategic relevance and contribution to the public health programme*

The creation of a model that can yield information on the impact of greater patient mobility and the scale of cross-border movement could be useful both for EU legislators and national governments in monitoring the effects of the directive. This also meets one of the principal objectives of the 2nd programme of Community action in the field of health: "Generating and disseminating health information and knowledge".

#### *Methods and means*

The project will set up a consultation process with patients, healthcare providers, national and regional ministries and policy makers. It will also map the outcomes of related projects. Field research will assess information already in hospital information systems on costs and numbers of cross-border patients, and analyse potential prediction methods for eight common elective treatments in a range of European countries. The effectiveness of the tools for information collection will be evaluated, particular on their clarity, coherence, and user-friendliness. Training will be provided on the data collection and data entry procedures. And guidelines will be developed on ethical considerations, in relation to privacy.

#### *Expected outcomes*

A network of hospitals will benefit from a functioning organisational structure with established means of communication and knowledge management systems for exchanging information on administrative issues related to payment of care for cross-border patients and feedback from patients on reimbursement costs and quality of care. Information will also be generated on the main problems facing hospitals over payment of care for cross-border patients, covering diagnosis categories and tariffs and discrepancies across different countries. Estimates will be produced of the impact of cross-border care in financial terms, for hospitals and for patients, as well as of patient satisfaction over reimbursement and quality of care. Recommendations will be made for the organisation of cross-border management of payment issues.

## Keywords and portfolio

### KEYWORDS:

- Healthcare costs
- Hospital
- Health system
- Financing healthcare
- Healthcare

### PORTFOLIO:

- Improving healthcare

### ACTION WEBSITE: -

### MAIN BENEFICIARY:

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### PROJECT LEADER:

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### ASSOCIATED PARTNERS:

- 2nd Regional Health Care Administration of Piraeus and Aegean Islands, Greece
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- Azienda per i Servizi Sanitari N.5 “Bassa Friulana”, Italy
- Azienda Ospedaliera Universitaria San Luigi Gonzaga, Italy
- Centre Hospitalier Universitaire de NICE (General teaching hospital of Nice), France

- General Hospital of Rhodes, Greece
- HOPE – European Hospital and Healthcare Federation, Belgium
- Hospices Civils de Lyon, France
- KABEG – Landeskrankenanstalten-Betriebsgesellschaft – Landeskrankenhaus Villach, Austria
- Ministry for Health, the Elderly and Community Care, Malta
- Ministry of Health, Italy
- National Institute for Quality- and Organizational Development in Healthcare and Medicines, Hungary
- National Institute Of Public Health, Slovenia
- Niederösterreichischer Gesundheits- und Sozialfonds (Lower Austrian Health and Social Fund), Austria
- Ospedali Riuniti Bergamo, Italy
- Splosna Bolnisnica Izola – General Hospital Izola, Slovenia
- Technische Universität Berlin, Germany
- Università Commerciale Luigi Bocconi, Italy

### MAXIMUM EC CONTRIBUTION:

529,880.00 €

### DURATION:

36 months





## CHAPTER 2

# 2.2 HEALTH INFORMATION CONFERENCES

CONFERENCE NO 20110002



## HIGH LEVEL EHEALTH CONFERENCE 2012 (EHEALTH)

### *Abstract*

#### *General objectives*

The overall objectives of the High Level eHealth Conference 2012 is to showcase solutions that focus on the chronically ill and to discuss aspects of efficient implementation of eHealth solutions through standards and efficient governance structures. It also aims to look at innovations where eHealth is seen as a means for improved quality, efficiency and effectiveness under the heading “smart health – better lives”. The themes to be addressed include the role of ICT in creating coherent pathways across sectors, eHealth as a means promoting empowerment in support of chronically ill patients, promoting efficient uptake of eHealth, the needs of clinicians, and the opportunities and challenges of cross-border healthcare. The conference will give greater visibility to eHealth, and create a link with the EU 2020 Strategy support for information technologies. And as the tenth such conference, it will ensure continued focus on eHealth, supporting increased collaboration on eHealth across member states. The voluntary network of health authorities envisaged in the cross-border health directive will have its first meeting during the conference.

#### *Expected achievements*

The estimated number of participants at the three-day conference is 250, of which approximately two-thirds would be from ministries of health from EU member states, EEA countries and candidate countries.

#### *Target audience*

The principal targets are experts and policy makers from ministries and national institutes, representatives of the European Commission, WHO EURO, and relevant European platforms, agencies, and NGOs.

### Keywords and portfolio

**KEYWORDS:**

- eHealth + telemedicine

**PORTFOLIO:**

- eHealth

**ACTION WEBSITE: -****MAIN BENEFICIARY (CONFERENCE HOLDER):**

Ministeriet for Sundhed og Forebyggelse  
(Ministry of Health)  
Holbergsgade 6  
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1057 København K  
Denmark  
Tel: +45 72 26 90 00

**PROJECT LEADER:**

Niels Würgler Hansen  
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**MAXIMUM EC CONTRIBUTION:**

300,000.00 €

**DATE AND PLACE OF THE CONFERENCE:**

2012/05/07 in Copenhagen

CONFERENCE NO 20114302



## “ACTIVE AGEING CITIZENS AT THE CENTRE OF EU HEALTH POLICY”. 6TH EUROPEAN PATIENTS’ RIGHTS DAY (ACTIVE AGEING & HEALTH POLICY)

### *Abstract*

#### *General objectives*

The conference aims to encourage ageing citizens to enforce their rights as patients and as active citizens in EU countries. This means not just greater empowerment in managing their own disease and dealing with the health care system, but also participating in the governance of health-care systems in the community. This will also show how empowered ageing patients and users can help in meeting the challenges facing the European social model and changing demography, and can minimise the risk of diseases leading to social exclusion. It will promote a broader alliance between citizens’ and patients’ organisations and with other health professionals, health institutions and health care structures.

#### *Expected achievements*

The number of participants expected is 200, mainly from across European countries, with about a third from European networks and other stakeholders in Brussels. Speakers and session moderators should include representatives of major European networks on health, national partners, health industries, and health authorities. The conference will be held on European Patients’ Rights Day and last for one and a half days. It will feature roundtable discussions, best practices presentations, workshops on the themes of the conference, and recommendations and guidelines.

#### *Target audience*

The main targets will be citizens and patients’ organizations which deal particularly with ageing patients’ issues, as well as health professionals and national health authorities. Efforts will be made to guarantee the greatest diversity of stakeholders. European institutions will also be involved.

### Keywords and portfolio

**KEYWORDS:**

- Patients rights
- Elderly
- Health system

**PORTFOLIO:**

- Ageing

**ACTION WEBSITE: -****MAIN BENEFICIARY (CONFERENCE HOLDER):**

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**PROJECT LEADER:**

Antonella Nalli  
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**MAXIMUM EC CONTRIBUTION:**

68,375.68 €

**DATE AND PLACE OF THE CONFERENCE:**

2012/05/11 in Brussels

CONFERENCE NO 20114301

MALTA 2012

## FIFTH EUROPEAN PUBLIC HEALTH CONFERENCE (MALTA 2012)

### *Abstract*

#### *General objectives*

The conference is designed to promote exchange of knowledge, policy and best practice across Europe, so as to strengthen the capacity of public health professionals, researchers and policy makers. It aims to create and support links among European public health networks, organisations and schools of public health. It will help meet the third objective of the second Health Programme (2008–2013), to generate and disseminate information and knowledge. The parallel scientific programme of the conference will focus on priorities in the Work Plan, including quality of healthcare and patients' safety, sustainability of health systems, and inequalities in health. Working groups will cover priorities in mental health, communicable diseases and child and adolescent health.

#### *Expected achievements*

It is expected to attract more than 1,000 participants from 60 countries worldwide. The conference programme includes 70 parallel sessions and 20 pre-conferences.

#### *Target audience*

The target group is broad, including public health professionals, researchers, education and training professionals, students, policy makers and representatives of international and European networks and organisations. Special efforts will be made to allow public health experts from low income countries and countries in central and eastern Europe to attend. To attract young researchers and students, a special conference fee and specific competency workshops and networking possibilities are offered. The choice for Malta as a conference venue and the programming of workshops addressing specific regional issues is expected to draw a substantial number of experts from southern European countries and smaller EU Member States.

### Keywords and portfolio

**KEYWORDS:**

- Networking

**PORTFOLIO:**

- Interest groups
- Steering EU Public Health

**ACTION WEBSITE: -****MAIN BENEFICIARY (CONFERENCE HOLDER):**

European Public Health Association  
Otterstraat 118-124  
PO-BOX 1568  
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Netherlands  
Tel: +31 30 2729 719  
Fax: +31 30 2729 729

**PROJECT LEADER:**

Dineke Zeegers Paget  
E-mail: office@eupha.org

**MAXIMUM EC CONTRIBUTION:**

100,000.00 €

**DATE AND PLACE OF THE CONFERENCE:**

2012/11/07 in Malta

CONFERENCE NO 20114304



## STRENGTHENING THE EUROPEAN DIMENSION IN HEALTH SERVICES RESEARCH (STRENGTHENING EUROPEAN HSR)

### *Abstract*

#### *General objectives*

The main aim is to raise the quality of internationally comparative health services research (HSR). It is intended to review the state-of-the-art across countries and make recommendations on how to improve the contribution to policy. It also aims to help national decision makers make use of international research evidence, which is why the event includes plans for better exchanges and networking opportunities, including through workshops and websites and social media. Sessions will aim to promote contacts among international researchers and policy makers, and to align research agendas to make best use of available resources.

#### *Expected achievements*

By building on the network established through previous conferences, up to 400 participants from across Europe, and from the research community and from policy makers, should be brought together to focus on information exchange and joint learning on health services research and policy. Plenary sessions will be interspersed with targeted workshops, round table meetings and discussion forums, looking at transferability of research findings across national borders, data availability and comparability, statistical analyses, and strategies for decision makers in finding and using cross-country research outcomes to assist in policy development. This should have the benefit of promoting scientific underpinning of health care policies.

#### *Target audience*

Sufficient representation from researchers and decision-makers is a key element to the success of the meeting. Invitations are extended to experts from research and policy in all member states, in with places available to other interested parties across Europe. Better application of scientific evidence will result in more effective policy measures and health care systems that are both efficient and responsive to the needs of European citizens.



### Keywords and portfolio

**KEYWORDS:**

- Innovation initiatives
- Accessibility
- Health system
- Research
- HIA

**PORTFOLIO:**

- Healthcare

**ACTION WEBSITE:** -**MAIN BENEFICIARY (CONFERENCE HOLDER):**

Stichting Nederlands Instituut voor onderzoek  
van de Gezondheidszorg  
Otterstraat 118-124  
PO-BOX  
3513 CR Utrecht  
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Fax: +31 30 2729 729

**PROJECT LEADER:**

Johan Hansen  
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**MAXIMUM EC CONTRIBUTION:**

29,406.00 €

**DATE AND PLACE OF THE CONFERENCE:**

2012/11/07 in Malta

CONFERENCE NO 20114303



## EUROPEAN CONFERENCE ON RARE DISEASES AND ORPHAN PRODUCTS 2012 BRUSSELS (ECDR 2012)

### *Abstract*

#### *General objectives*

The objectives are to present up-to-date information on the rare disease environment to patients and their representatives, academics, health care professionals, industry and policy makers, and to examine EU actions in the field. The conference will also aim at promoting exchanges with people living with rare diseases. Specific and achievable objectives should be presented, at both European and national levels, to reduce health inequalities for rare disease patients.

#### *Expected achievements*

The expected number of participants at the three-day event is 700, covering patients and their representatives from more than 40 countries, health professionals, academia, industry and policy makers. Patients in particular will benefit from the information provided at European and national level and from training workshops and networking opportunities.

#### *Target audience*

The target audiences include rare disease patients and patients' representatives, academia and scientists active in the field of rare diseases, health professionals eager to learn more about rare diseases, and pharmaceutical and biotech industry representatives involved in orphan drug development, who are interested in policy orientations and priorities at a European level. Access for persons with disabilities will be facilitated, and a separate fellowship programme will offer patients in central and eastern European countries the opportunity to attend.

### Keywords and portfolio

**KEYWORDS:**

- Non communicables diseases
- Healthcare
- Socio economic factors
- Taking Action against Diseases

**PORTFOLIO:**

- Rare diseases

**ACTION WEBSITE:** -**MAIN BENEFICIARY (CONFERENCE HOLDER):**

European Organisation for Rare Diseases  
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Fax: +33 1 56 53 52 15

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**MAXIMUM EC CONTRIBUTION:**

100,000.00 €

**DATE AND PLACE OF THE CONFERENCE:**

2012/05/23 in Brussels

CONFERENCE NO 20114305



## 22ND ALZHEIMER EUROPE CONFERENCE: CHANGING PERCEPTIONS, PRACTICE AND POLICY (22 AEC)

### *Abstract*

#### *General objectives*

The conference aims to focus on the priorities of the Commission Communication on a European initiative on Alzheimer's disease: early diagnosis of dementia, shared European research, national solidarity and exchange of best practices, and respect for the rights of people with dementia. It plans to organise an exchange of experiences in medical and scientific areas of diagnosis, prevention and epidemiology, as well as on social and care aspects, legal and ethical issues, and the impact of dementia on public health.

#### *Expected achievements*

Some 400 participants are expected. The conference will involve people with dementia as speakers and participants, and a special bursary system exists to encourage their participation. During the two conference days, four plenary sessions will feature medical and scientific updates, presentations on care approaches and Ambient Assisted Living, new work on capacity assessment of patients, and the results of selected national Alzheimer strategies.

#### *Target audience*

Because of the multi-disciplinary approach chosen for the conference, the programme is targeted at different audiences. The hope is to attract not only health care professionals, researchers, academics and people involved in Alzheimer associations, but also policy makers, and people with dementia and their carers. Special efforts will be made to attract mental health and public health experts. To encourage delegates from eastern Europe, a reduced registration fee is offered.

### Keywords and portfolio

**KEYWORDS:**

- Patients rights
- Elderly
- Neurological diseases and disorders
- Dementia
- Secondary care

**PORTFOLIO:**

- Ageing
- Mental health

**ACTION WEBSITE:**

<http://www.alzheimer-europe.org>

**MAIN BENEFICIARY (CONFERENCE HOLDER):**

Alzheimer Europe  
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**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

60,000.00 €

**DATE AND PLACE OF THE CONFERENCE:**

2012/10/04 in Vienna



## CHAPTER 2

# 2.3 HEALTH INFORMATION JOINT ACTIONS

## JOINT ACTION NO 20112302



## CROSS-BORDER PATIENT REGISTRIES INITIATIVE (PARENT)

**Abstract****General objectives**

The aim is to support EU countries in developing adequate patient registries in important areas such as chronic and rare diseases. If these registries were harmonised so that they were comparable and coherent, it would become possible to conduct analyses of secondary data of value for public health and research purposes.

**Strategic relevance and contribution to the public health programme**

PARENT is a response to an explicit request by the European Commission and member states to boost capacity to tackle major health challenges more effectively by making use of shared information and expertise. The Joint Action will deliver practical value to the partners by helping to develop registries and to make better use of them. In this way, it supports the second programme of Community action in the field of health, with guidelines on generating and disseminating health information and knowledge, and particularly in respect of the support that cross-border eHealth instruments can provide to medical information and research. Indirectly, PARENT also helps in reducing health inequalities.

**Methods and means**

The current state of development of registries in the EU will be established and analysed, to help identify challenges and needs. Guidelines and recommendations for developing registries and for further collaboration will be prepared through workshops. The potential of eHealth-enabled registers will be explored, particularly in relation to the cross-border health directive.

**Expected outcomes**

Direct outcomes will include a better base for efficient and high quality Health Technology Assessment at EU and national or regional level, as well as reduced costs in managing and using data, and wider pools of data for analysis. The reduced cost of quality data, and the higher volumes of data available, will also make it easier to develop HTA business cases for rare diseases or other clinical fields with low disease incidence, where the cost of HTA has been a drawback. Better collaboration will be possible on eHealth tools at national and EU-level through clearer links with registries, which should also help align policy actions. Indirect outcomes include a sustainable reduction of resources needed for governance and operation of patient registries, and stronger foundations for clinical and therapeutic research.



## Keywords and portfolio

### KEYWORDS:

- HTA
- eHealth + telemedicine
- Health system
- Medical devices
- Patients registries

### PORTFOLIO:

- Data collection
- eHealth
- Cross-border care

### ACTION WEBSITE: -

### MAIN BENEFICIARY:

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### PROJECT LEADER:

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### ASSOCIATED PARTNERS:

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- Hrvatski Zavod Za Javno Zdravstvo – HZJZ, Croatia
- Direção-Geral da Saúde – DGS, Portugal
- Ministry for Health, the Elderly and Community Care – MHEC, Malta
- Ministero della Salute – MDS, Italy
- Ministrstvo Za Zdravje – MOH, Slovenia
- National and Kapodistrian University of Athens – NKUA, Greece
- National Institute for Quality and Organizational Development in Healthcare and Medicines – GYEMSZI, Hungary
- Národné centrum zdravotníckych informácií – NCZI, Slovakia
- Terveyden Ja Hyvinvoinnin Laitos – THL, Finland

### MAXIMUM EC CONTRIBUTION:

2,016,231.00€

### DURATION:

36 months



JOINT ACTION NO 20112301

## EUROPEAN NETWORK FOR HTA JOINT ACTION 2 (EUNETHTA JA 2)

### *Abstract*

#### *General objectives*

This Joint Action is intended to strengthen practical collaboration on cross-border health technology assessment (HTA). It will develop a general strategy and a proposal for European HTA collaboration, in line with the directive on cross-border healthcare. This should feed into assisting the European Commission and member states in setting up a sustainable structure for HTA in the EU.

#### *Strategic relevance and contribution to the public health programme*

The JA responds to a request by the EU and member states for a sustainable network for HTA. It has strategic relevance for bringing the directive into effect, and particularly for the EU obligation to support HTA cooperation through a voluntary network across the member states. The JA will test how far national HTA institutions are able to cooperate in assessments and in making use of common structured HTA information in producing their local reports. It will provide some experience of managing and running such a network, and generate information on the costs and benefits, offering an empirical basis for the decisions that will have to be made on the design and operation of the voluntary HTA network.

#### *Methods and means*

Core information relating to HTA will be produced collaboratively for priority technologies (i.e. those for which information needs are identified by the partners). This will be based on the methods and recommendations generated in the EUnetHTA Project and the current JA1, and will be used to produce local HTA reports that take account of national context-specific issues. At the same time, tools already developed for knowledge management will be refined and additional methodologies, guidelines and models will be developed. Manufacturers will be involved in the development of a data template for submissions, and training will be provided to partners and stakeholders on the use of EUnetHTA tools.

#### *Expected outcomes*

The main outcome will be to consolidate the permanent HTA network, because its benefits will be more widely recognised. The exchange of information among agencies will be increased, which will help to reduce unnecessary duplication of work. Having core HTA information available allows agencies to redirect their resources to assessing more context-dependent aspects, which will make HTA increasingly responsive to the needs of decision-makers by rapidly putting locally relevant information at their disposal. The experiences and the information generated will feed into the decision-making process for putting the cross-border health directive into effect.

## Keywords and portfolio

### KEYWORDS:

- HTA
- Medical devices
- Pharmaceuticals

### PORTFOLIO:

- Health technology assessment

### ACTION WEBSITE: -

### MAIN BENEFICIARY:

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### PROJECT LEADER:

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### ASSOCIATED PARTNERS:

- Agencja Oceny Technologii Medycznych – AHTAPOL, Poland
- Agencija Za Kvalitetu i Akreditaciju u Zdrastvu – AQAHC, Croatia
- Agenzia Nazionale per i Servizi Sanitari Regionale – AGENAS, Italy
- Agenzia Sanitaria e Sociale Regionale \* Regione Emilia-Romagna – ASSR RER, Italy
- Centre Fédéral d'Expertise des Soins de Santé – KCE, Belgium
- College voor Zorgverzekeringen – CVZ, Netherlands
- Deutsches Institut für Medizinische Dokumentation und Information – DIMDI, Germany
- Lääkealan Turvallisuus- ja Kehittämiskeskus – FIMEA, Finland
- Gesundheit Österreich GmbH – GÖG, Austria
- Haute Autorité de Santé – HAS, France
- Health Information and Quality Authority – HIQA, Ireland
- Department of Health Technology Assessment – HSR/DHTA, Denmark

- Inštitut Za Ekonomska Raziskovanja – IER, Slovenia
- Instituto de Salud Carlos III – ISCIII, Spain
- Agenzia Italiana Farmaco – AIFA, Italy
- Ludwig Boltzmann Gesellschaft GmbH – LBGG, Austria
- Hauptverband der Österreichischen Socialversicherungsträger – HVB, Austria
- Ministry for Health, the Elderly and Community Care – MHEC, Malta
- Ministerstvo Zdravotníctví České Republiky – MZ, Czech Republic
- Ministry of Health of Cyprus – MOH, Cyprus
- Autoridade Nacional do Medicamento e Produtos de Saude I.P. – INFARMED, Portugal
- National Center of Public Health and Analyses – NCPHP, Bulgaria
- National Institute for Health and Clinical Excellence – NICE, United Kingdom
- Terveyden Ja Hyvinvoinnin Laitos – THL, Finland
- Gyógyszerészeti és Egészségügyi Minőség és Szervezetfejlesztési Intézet – GYEMSZI, Hungary
- Inštitut Za Varovanje Zdravja – NIPH, Slovenia
- National School of Public Health Special Research Account – NSPH, Greece
- National School of Public Health, Management and Professional Development in Health Bucharest – NSPHMPDHB, Romania
- University of Southampton – NETSCC, United Kingdom
- Regione del Veneto – REGVEN, Italy
- Nadácia ZRAK – SLOVATA, Slovakia
- State Health Care Accreditation Agency under the Ministry of Health of Lithuania – VASPVT, Lithuania
- Stiftung für Qualität und Wirtschaftlichkeit im Gesundheitswesen – IQWiG, Germany
- Statens Beredning för Medicinsk Utvärdering – SBU, Sweden
- Nacionālais Veselības Dienests – NHS, Latvia
- Nasjonalt Kunnskapssenter for Helsetjenesten – NOKC, Norway
- Tartu Ülokool – UTARTU, Estonia

### MAXIMUM EC CONTRIBUTION:

6,599,777.00€

### DURATION:

42 months



CHAPTER 3

Health

# Security





## CHAPTER 3

# 3.1 HEALTH SECURITY PROJECTS

PROJECT NO 20111101

**ASHT!**

## ALERTING, SURVEILLANCE AND REPORTING SYSTEM FOR CHEMICAL HEALTH THREATS, PHASE III (ASHT PHASE III)

### *Abstract*

#### *General objectives*

This project aims to improve EU readiness to respond to health emergencies from chemical threats, by boosting cooperation at regional and national level and between sectors. It plans to develop the Rapid Alerting System for Chemical Health Threats (RAS-CHEM) so that it is easier and faster to use, and promote it more widely amongst EU countries. Gaps were identified in risk communication, assessment and management in previous projects, and this project is intended to remedy the deficiencies.

#### *Strategic relevance and contribution to the public health programme*

The EU has identified the need for better planning and coordination of public health approaches in health emergencies, including cross-border health threats and risks. This project will help in defining the right actions, since making sure that accurate information is rapidly available at all levels is critical to manage a cross-border chemical health threat or incident with minimal social disruption and economic consequences. Close collaboration between among national authorities and response centres and the European Commission are essential to agree the best communication procedures for an operational European network on chemical health threats.

#### *Methods and means*

The project will develop standardized medical treatment sheets for chemical exposures, and create a toxidrome matrix to identify unknown chemicals from presented clinical features. It will also evaluate the potential of automated mining of data in EU poisons centres as an aid to surveillance and public health risk assessment. And it will explore the feasibility of creating a 'network of experts' to monitor reported toxicological data, so as to improve overall health awareness.

#### *Expected outcomes*

Better readiness and response planning to chemical health threats will help protect the citizens of the EU. The member states will have better structures and mechanisms for coordination in response to major cross-border chemical health threats. And tools for communicating, assessing and managing chemical incidents will be improved.



## Keywords and portfolio

### KEYWORDS:

- Chemical agents
- Early warning systems (EWRS, RAS...)
- Diagnostic
- Prevention
- Screening

### PORTFOLIO:

- Preparedness and response

### ACTION WEBSITE: -

### MAIN BENEFICIARY:

Health Protection Agency  
HPA, CRCE, Chilton  
PO-BOX  
OX11 0RQ Didcot  
United Kingdom  
Tel: +44 1235 824865  
Fax: +44 1235 833891

### PROJECT LEADER:

Raquel Duarte-Davidson  
E-mail: Raquel.Duarte-Davidson@hpa.org.uk

### ASSOCIATED PARTNERS:

- Centre Hospitalier Universitaire de Lille – CHRU-Lille, France
- General University Hospital – GUH, Czech Republic
- Health Emergency Situations Centre – HESC, Lithuania
- Istituto Superiore di Sanità – ISS, Italy
- Helsedirektoratet – PIN, Norway
- Universitaetsmedizin Göttingen-Georg, Georg-August-Universitaet Göttingen – UMG-GOE, Germany

### MAXIMUM EC CONTRIBUTION:

497,760.00€

### DURATION:

30 months

PROJECT NO 20111102



## PROJECT ON CRISIS COMMUNICATION IN THE AREA OF RISK MANAGEMENT (CRICORM)

### *Abstract*

#### *General objectives*

The project aims to improve communication during public health emergencies, to increase population compliance with recommendations. Plans include guidelines for health crisis communication, based on experiences with the EHEC outbreak and Fukushima event, and improved European networks. In particular, a European approach will be considered, in collaboration with other EU and WHO agencies and other relevant EU projects.

#### *Strategic relevance and contribution to the public health programme*

An improvement of the common crisis communication strategy was called for in the 2010 Council conclusions on lessons learnt from the A/H1N1 pandemic, and this is what the project aims to address, with a focus on better understanding of crisis communication dynamics and effective tools. It will also help meet the objective of the 2nd programme of Community action in the field of health in "protection of health and safety of citizens", "serious cross-border health threats with worldwide dimension", "development of the European e-Health Area", and "effectiveness of existing and future networks in the field of public health".

#### *Methods and means*

Work will take place at national and regional level, addressing the communication aspect of policies, and taking into consideration the tools available for crisis communication, including elements of behavioural science. It will include a review of experiences from work at EU level in food safety, animal health, chemicals, medicines, civil protection and nuclear safety, and will involve public health institutions, health professionals, consumers' associations, patient group and media. The reasons for differing public reactions to the measures taken to control H1N1 will be analysed, and improvements will be suggested to existing guidance. A web-platform and feed service will be created, and appropriate training will be organized.

#### *Expected outcomes*

The review of evidence and experience in crisis communication management and the compilation of a list of relevant EU stakeholders will lead to guidelines for more effective messages, suggested strategies and actions, and training. This will increase public confidence in recommended interventions. New web tools for health crisis communication will permit effective two-way communication with the public.

## Keywords and portfolio

### KEYWORDS:

- Early warning systems (EWRS, RAS...)
- Accessibility
- Health system
- Collection of Best Practices
- Prevention

### PORTFOLIO:

- Risk communication
- Preparedness and response

### ACTION WEBSITE: -

### MAIN BENEFICIARY:

Azienda Sanitaria Locale della Provincia di  
Brescia  
Viale Duca degli Abruzzi 15  
PO-BOX  
25124 Brescia  
Italy  
Tel: +39 030 383 84 83  
Fax: +39 030 383 80 61

### PROJECT LEADER:

Carmelo Scarcella  
E-mail: servizio.educazioneallasalute@aslbrescia.it

### ASSOCIATED PARTNERS:

- Inovamais – Serviços de Consultadoria em Inovação Tecnológica S.A. – INOVA +, Portugal
- Ludwig-Maximilians-Universität München – LMU, Germany
- Universidad de Murcia – UMU, Spain
- Università degli Studi di Brescia – UNIBS, Italy

### MAXIMUM EC CONTRIBUTION:

299,972.38 €

### DURATION:

36 months



## CHAPTER 3

# 3.3 HEALTH SECURITY JOINT ACTIONS

## JOINT ACTION NO 20112102



## ACHIEVING COMPREHENSIVE COORDINATION IN ORGAN DONATION THROUGHOUT THE EUROPEAN UNION (ACCORD)

### Abstract

#### General objectives

ACCORD intends to exploit the full potential of organ transplantation across the member states, and to improve cooperation between them. It plans live donor registries and international sharing of data on live donation, as well as exchange of expertise in organ donation and transplantation through twinings. The objectives include increased availability of organs from deceased donors by strengthening cooperation between intensive care units and donor transplant coordinators.

#### Strategic relevance and contribution to the public health programme

The JA will support the alignment of provisions and procedures at the moment that national provisions of the directive are being worded, and will help in reaching the full potential of deceased and living donation. Its innovations also include the first common basis for registries of live donors, and a model to ease the deceased donation process.

#### Methods and means

A survey of current registries and expert discussion will be required. So too will a study of the varied care pathways for patients with a devastating brain injury and the factors in successful organ donation. The specific twinning initiatives envisaged will require the development of ad-hoc protocols which could then be developed into a guide for further and wider twinings. A plan will also be devised for the tools to ensure wide promotion of the findings and sustainability of the procedures recommended.

#### Expected outcomes

Recommendations for setting up living donor registries will result in better international data sharing, wider adoption of standards, and improved results in terms of volume and safety. Variability will be reduced in end-of-life practices applied to brain-injured patients. Donor potential is expected to expand, and the deceased donation process will be optimized. Expertise will be transferred among member states, and models developed for wider twinning actions. The Joint Action will help to ensure that the organ directive is consistently applied across the EU by helping member states in meeting the objectives of the Action Plan and enhancing cooperation between them.

## Keywords and portfolio

### KEYWORDS:

- Tissue, cell and organ transplants
- Twinning visits
- Organ Transplantation

### PORTFOLIO:

- Organ Transplantation

### ACTION WEBSITE: -

### MAIN BENEFICIARY:

Organización Nacional de Trasplantes  
C/ Sinesio Delgado, 6–8  
PO-BOX  
28029 Madrid  
Spain  
Tel: +34 902 300 224  
Fax: +34 902 300 226

### PROJECT LEADER:

Rafael Matesanz Acedos  
E-mail: rmatesanz@mspsi.es

### ASSOCIATED PARTNERS:

- Agence de la Biomédecine – ABM, France
- Autoridade para os Serviços de Sangue e da Transplantação – ASST, Portugal
- Deutsche Stiftung Organtransplantation – DSO, Germany
- Helsedirektoratet – HDIR, Norway
- Dutch Transplantation Foundation – DTF, Netherlands
- Executive Agency for Transplantation – BEAT, Bulgaria
- Feidhmeannacht na Seirbhíse Sláinte – HSE, Ireland

- Hellenic Transplant Organisation – HTO, Greece
- Zavod Republike Slovenije za presaditve organov in tkiv Slovenija Transplant – Slovenika Transplant, Slovenia
- Istituto Superiore Di Sanità – ISS, Italy
- Koordinační středisko transplantací – KST, Czech Republic
- Ministry for Social Policy, Health, the Elderly and Community Care – MHEC, Malta
- Ministry of Health of the Republic of Cyprus – MOH CY, Cyprus
- Ministarstvo zdravlja Republika Hrvatska – MOHSW, Croatia
- Agenția Națională de Transplant – ANT, Romania
- Nacionalinis transplantacijos biuras – NTB, Lithuania
- National Health Service Blood and Transplant – NHSBT, United Kingdom
- Országos Vérellátó Szolgálat – HNBTS, Hungary
- Paula Stradiņa Klīniskā universitātes slimnīca – PSCUH, Latvia
- Sihtasutus Tartu Ülikooli Kliinikum – TUH, Estonia
- Socialstyrelsen – SOS, Sweden
- Centrum Organizacyjno-Koordinacyjne ds. Transplantacji “Poltransplant” – POLTRANSPLANT, Poland

### MAXIMUM EC CONTRIBUTION:

1,440,000.00 €

### DURATION:

42 months

## JOINT ACTION NO 20112101



## EUROPEAN UNION NETWORK FOR PATIENT SAFETY AND QUALITY OF CARE (PASQ)

### Abstract

#### *General objectives*

The aim is to strengthen cooperation on quality of health care, including patient safety and patient involvement. The network, bringing together EU countries, international organisations and EU stakeholders, will aim to establish principles of good quality healthcare, and consider how to ensure EU collaboration even after the grant ceases. It also aims to promote patient involvement in improving patient safety and quality of care.

#### *Strategic relevance and contribution to the public health programme*

Providing safe and high quality healthcare for all EU citizens is repeatedly emphasised as an EU objective, because it can improve an individual's health outcome, and can help make cost-effective use of resources. It appears notably in the 2009 Council Recommendation on patient safety, which notes the importance of sharing knowledge and experience, and evaluation of the transferability of interventions to protect patient safety. It also features in the Agreement in the Working Party on Public Health at Senior Level to enhance collaboration on healthcare quality. The same Working Party has also requested the Commission to help member states to exchange good practices in the field of patient involvement.

#### *Methods and means*

The Joint Action will provide a platform for exchanging good practices. Member states will be involved in a supervisory role and to promote its achievements. There will be coordination of platforms involving national stakeholders, and exchange of information through site visits and interviews with national stakeholders. Conferences and integration of materials in national campaigns will spread the best practices. And experts will share their experiences on putting plans into effect for patient involvement, transferability of approaches, and promotion of the concepts.

#### *Expected outcomes*

There will be benefits for governments, health-care providers and patients from sharing experiences and solutions in patient safety and quality of care. An EU-level network for patient safety will be strengthened and given a more permanent character, and its remit enlarged to address quality issues. The involvement of member states should help establish corresponding national networks or platforms involving national stakeholders. Voluntary exchange of experiences could lead to a peer review system for quality management systems in health care.



## Keywords and portfolio

### KEYWORDS:

- Collection of Best Practices
- Safety evaluation and monitoring
- Survey
- Healthcare

### PORTFOLIO:

- Patient safety

### ACTION WEBSITE: -

### MAIN BENEFICIARY:

Haute Autorité de Santé  
(National Authority for Health)  
2, avenue du stade de France  
PO-BOX  
93218 Saint-Denis La Plaine CEDEX  
France  
Tel: +33 1 55 93 70 00  
Fax: +33 1 55 93 74 20

### PROJECT LEADER:

Jean Bacou  
E-mail: j.bacou@has-sante.fr

### ASSOCIATED PARTNERS:

- Agency for Quality and Accreditation in Health Care and Social Welfare, Croatia
- Agency for Quality in Medicine, Germany
- Agenzia Nazionale per i Servizi Sanitari Regionali (National Agency for Regional Healthcare Services), Italy
- Avedis Donabedian Institute, Spain
- Azienda Unità Locale Socio – Sanitaria 10 “Veneto Orientale”, Italy
- Centrum Monitorowania Jakości w Ochronie Zdrowia (National Center for Quality Assessment in Healthcare), Poland
- Comité Permanent des Médecins Européens/ Standing Committee of European Doctors, Belgium
- Council of European Dentists, Belgium
- Danish Society for Patient Safety, Denmark
- Department of Health, United Kingdom
- European Federation of Nurses Associations, Belgium
- European Health Management Association Ltd., Ireland
- European Hospital and Healthcare Federation, Belgium
- European Patients’ Forum, Luxembourg
- Health Information and Quality Authority, Ireland

- Healthcare Surveillance Authority, Slovakia
- Ministry for Health the Elderly and Community Care, Malta
- Ministry of Health, Italy
- Ministry of Health of the Slovak Republic, Slovakia
- National and Kapodistrian University of Athens, Greece
- National Center Of Public Health and Analyses, Bulgaria
- National Institute for Quality and Organizational Development in Healthcare and Medicines, Hungary
- National Institute for Health and Welfare, Finland
- NHS Institute for Innovation and Improvement, United Kingdom
- Norwegian Knowledge Centre for the Health Services, Norway
- Paracelsus Medical University, Austria
- Pharmaceutical Group of the European Union, Belgium
- Radboud University Nijmegen Medical Centre, Netherlands
- Riga East University Hospital (title in the national language: SIA “Rīgas Austrumu klīniskā universitātes slimnīca”), Latvia
- Scoala Nationala de Sanatate Publica, Management si Perfectionare in Domeniul Sanitar Bucuresti (National School of Public Health, Management and Professional Development – Bucharest), Romania
- Spanish Ministry of Health, Social Services and Equality, Spain
- State Health Care Accreditation Agency, Lithuania
- Stichting Nederlands Instituut voor Onderzoek van de Gezondheidszorg (Netherlands Institute for Health Services Research), Netherlands
- The National Board of Health and Welfare, Sweden
- Union Européene de l’Hospitalisation Privée (or European Union of Private Hospitals), Belgium
- Universidad Miguel Hernandez de Elche, Spain
- Universitaetsklinikum Bonn, Germany

### MAXIMUM EC CONTRIBUTION:

3,496,164.00€

### DURATION:

36 months



CHAPTER 4

# Operating Grants



## CHAPTER 4

# 4.1 HEALTH PROMOTION OPERATING GRANTS

## OPERATING GRANT NO 20113209



## HEALTH ACTION INTERNATIONAL (HAI\_FY2012)

*Abstract**Mission and vision of the operating grant holder*

Health Action International (HAI) Europe is a non-profit, independent, European network of consumer groups, public interest NGOs, healthcare providers, academics and individuals. Its mission includes increasing access to essential medicines, improving the rational use of medicines, and promoting citizen participation in medicines policy. It monitors and encourages EU policy-making around these three priorities. It generates data, publishes commentary and promotes the exchange of information on the impact of medicines policy on public health. It operates on the basis of a belief that poverty and social injustice represent the greatest barriers to sustainable health and development, and it works for a society where people can participate in decisions affecting their health and well being, including the allocation of resources.

*Strategic objectives and specific activities*

To increase access to essential medicines and improve their rational use, it promotes research excellence and evidence-based advocacy. It contributes to developing innovation models in which the cost of R&D is separated from the issue of medicines prices. It works in partnership with other health stakeholders to promote equitable licensing principles in publicly funded R&D. It advocates changes to EU internal market laws that hinder citizens' access to affordable medicines by commenting on anti-competitive practice in the pharmaceutical sector, presenting the citizens' perspective to policy makers, formulating evidence-based policy materials to inform policy on intellectual property (IP) enforcement, and helping build the capacity of civil society organizations on issues related to IP and access to medicines. It promotes the use of medicines that have tangible and proven therapeutic advantage, and are acceptably safe and cost-effective.

It educates civil society about the link between promotional messages, over consumption of medicines and medicine-induced harm, and advocates treatment decisions based on objective information. It supports effective and robust medicines regulation, and fosters greater patient involvement in monitoring medicines safety, to reduce threats to public health. It supports initiatives for greater public funding of independent health advocates, forging partnerships with health NGOs in member states to amplify their voice at EU level. It urges high levels of transparency and independence in the EU's medicines policy process.

*Expected outcomes*

HAI will deliver in terms of monitoring the EU's IP policies and other practices that obstruct competition in the pharmaceutical sector, examining prices that impact on patient access to medicines, and offering expertise on strategies to improve access and reduce healthcare costs. It will also advance EU actions on the exploration of new models of medical innovation, through partnerships, publications and public events. It will promote health security by highlighting the link between objective information and safe medicines use, and investigating unethical medicines promotion and monitoring EU policies on medicines information and safety. And it will support democratisation of medicines policy by monitoring the transparency and independence of EU decisions on medicines, bringing the citizen perspective to EU consultations, and advising and contributing to EU dialogues on health & development. It will also support civil society organisations and equip youth and student advocates with the skills to be effective in their medicines policy advocacy.

### Keywords and portfolio

**KEYWORDS:**

- Patients rights
- Safety
- Pharmaceuticals
- Socio economic factors

**PORTFOLIO:**

- Interest groups

**ACTION WEBSITE:**

<http://haieurope.org>

**MAIN BENEFICIARY:**

Stichting Health Action International  
Overtoom 60-2  
PO-BOX  
1054HK Amsterdam  
Netherlands  
Tel: +31 20 683 3684  
Fax: +31 20 685 5002

**PROJECT LEADER:**

Katrina Perehudoff  
E-mail: [katrina@haieurope.org](mailto:katrina@haieurope.org)

**MAXIMUM EC CONTRIBUTION:**

218,000.00€

**DURATION:**

12 months

## OPERATING GRANT NO 20113208



## EUROPEAN COUNCIL ON ALCOHOL REHABILITATION RESEARCH AND EDUCATION (EUROCARE\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

Eurocare is the leading independent NGO working on alcohol policies in Europe. Its mission is to raise awareness among EU decision makers of the harm caused by alcohol so they take this into consideration, and to promote evidence-based policies that reduce the burden of alcohol. It collaborates with other organizations sharing its concerns, and monitors policy developments and the marketing practices of the alcohol industry. It also gives wide circulation to its views through reports, position papers, and newsletters. Its vision is of a Europe where alcohol-related harm is no longer a leading risk factor for ill-health, early death, violence and disability. It wants to see an end to innocent third parties suffering from the drinking of others, and a firm acknowledgement from the EU and its member states of the harm done by alcohol, backed by the implementation of effective and comprehensive policies to tackle it.

#### *Expected outcomes*

Eurocare will actively seek to influence decision makers in the member states and the EU institutions, with a focus on health in all policies. Events will take place to exchange knowledge and promote Eurocare views at EU and national level, including encouragement for the development of a new EU strategy. Eurocare's members will be better equipped to engage in decision-making processes at all levels and to foster cooperation and exchange of knowledge. A strategy for sharing information widely will be generated, and timely, accurate and useful information will be provided to members, including via the website, the bimonthly newsletter and policy briefings. Eurocare will coordinate members' input into the activities of the EU Alcohol and Health Forum and the EU Health Policy Forum.

#### *Strategic objectives and specific activities*

The general objective is to prevent and reduce alcohol related harm in Europe by influencing the European institutions and member states so that they acknowledge and challenge the problem. Eurocare has set targets it wishes Europe to meet: a fall of 20% in total alcohol consumption by 2020, raised public awareness and understanding of the risks and problems, and children and young people less affected by the harm caused by alcohol. Specific objectives are a minimum age for purchasing alcoholic beverages of 18 and no marketing of alcoholic beverages targets young people, low and properly enforced blood alcohol limits for driving, and accurate product information on alcohol labels.

In pursuit of these objectives, Eurocare advocates effective and evidence-based policies to prevent and reduce alcohol-related harm, and informs and trains its members accordingly. It conducts campaigns and responds to consultations, and helps in the collection and analysis of data on alcohol consumption.



### Keywords and portfolio

**KEYWORDS:**

- Harm reduction
- Alcohol
- Chronic diseases
- Prevention
- Policy recommendation

**PORTFOLIO:**

- Interest groups
- Alcohol

**ACTION WEBSITE:**

<http://www.eurocare.org>

**MAIN BENEFICIARY:**

European Alcohol Policy Alliance  
Rue des Confederes 96-98  
PO-BOX  
1000 Brussels  
Belgium  
Tel: +32 2 736 05 72  
Fax: +32 4 748 300 41

**PROJECT LEADER:**

Mariann Skar  
E-mail: [Mariann.Skar@eurocare.org](mailto:Mariann.Skar@eurocare.org)

**MAXIMUM EC CONTRIBUTION:**

99,000.00 €

**DURATION:**

12 months



OPERATING GRANT NO 20113207

## THE EUROPEAN NETWORK FOR SMOKING PREVENTION (ENSP\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

ENSP is an international non-profit association that aims to reduce tobacco consumption and develop a common strategy amongst organisations active in smoking prevention and tobacco control throughout Europe. It aims to make Europe completely smoke-free by 2040. The ENSP vision is of a future where Europeans will not suffer ill health and early death caused by tobacco, where children can grow up without being targeted with messages seeking to lure them into a lifetime of addiction, and where all Europeans can breathe air unpolluted by tobacco smoke. Although tobacco control is at different stages in European countries, ENSP members agree on common policy and speak with one voice, strengthening the European tobacco control effort and reinforcing European public health messages. ENSP advocates high taxes, bans on direct and indirect advertising of tobacco, smoking bans in public and workplaces, strong warnings on tobacco packages, and moves towards standardised packaging.

#### *Strategic objectives and specific activities*

ENSP has supported European Commission efforts to improve and promote health through the Europe Against Cancer Programme and the Public Health Programmes. The association's actions are in line with objective 2 of the Public Health programme (promoting health, including the reduction of health inequalities). It acts through communication and coordination, and by building alliances for smoking prevention and tobacco control, supporting collaboration among its members and other networks. It stimulates and participates in joint projects at European level, and collects and distributes relevant information to a wide audience. It serves as a platform of best practices for policy analysis, advocacy, research and training.

#### *Expected outcomes*

Input will be made to the revision of the EU's 2001 tobacco directive, and progress will be monitored on putting into effect the Framework Convention on Tobacco Control. Much of the focus will be on developing smoke-free workplaces, cessation, communication, industry influence, and addressing health determinants to promote and improve health. Other areas of focus will be enforcement of tobacco control legislation in the EU, and providing a complement to the EU Communication campaign on tobacco prevention focused on young adults.

### Keywords and portfolio

**KEYWORDS:**

- Tobacco
- Chronic diseases
- Health promotion
- Prevention
- Policy recommendation

**PORTFOLIO:**

- Interest groups
- Tobacco

**ACTION WEBSITE:**

[www.ensp.org](http://www.ensp.org)

**MAIN BENEFICIARY:**

European Network for Smoking and Tobacco  
Prevention – ENSP  
Chaussée d'Ixelles 144  
PO-BOX  
1050 Brussels  
Belgium  
Tel: +32 2 230 65 15  
Fax: +32 2 230 75 07

**PROJECT LEADER:**

Francis Grogna  
E-mail: [francis.grogna@ensp.org](mailto:francis.grogna@ensp.org)

**MAXIMUM EC CONTRIBUTION:**

201,473.00 €

**DURATION:**

12 months

OPERATING GRANT NO 20113202



## EUROPEAN FEDERATION OF THE ASSOCIATIONS OF DIETITIANS (EFAD\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

The federation's mission is to support its members in developing the role of dietitians in reducing inequalities and improving nutritional health in Europe. It aims to develop dietetics at a scientific and professional level and promote the development of the dietetic profession. Its vision is of a Europe where improved nutrition reduces socioeconomic health inequalities and contributes to economic prosperity. To achieve this, it supports high-quality dietetic education, professional practice, research and partnership. In this way it addresses health determinants and creates supportive environments for healthy lifestyles and prevention of disease through nutrition.

#### *Strategic objectives and specific activities*

EFAD's members are working strategically and engaging in broad stakeholder engagement in pursuit of its goals. One of its objectives is to inform health policy development. It contributes nutrition and health data to NGOs such as the European Public Health Alliance or the European Nutrition Health Alliance, so that reliable nutrition planning can be embedded in other policies. It is securing an evidence base to improve nutritional health: baseline data on differentials in nutrition and dietetic provision and care in member states make it possible to identify risk. It also passes on information about health-promoting initiatives and best practice to dietitians or national governments, especially in eastern Europe. EFAD also aims to diminish the differences in European dietetic education, especially in new member states, so as to reduce inequalities of care.

#### *Expected outcomes*

EFAD will adopt a more systematic approach to promoting high-quality engagement of dietitians who can effectively address health determinants and create supportive environments for healthy lifestyles and prevention of disease through nutrition. Dietetic education and research activity in Europe will be strengthened. Areas where nutrition action is most urgently required will be identified and the effectiveness of interventions will be monitored. And dietitians will be equipped with greater advocacy skills through workshops and discussions.

### Keywords and portfolio

**KEYWORDS:**

- Obesity

**PORTFOLIO:**

- Interest groups
- Nutrition

**ACTION WEBSITE: -****MAIN BENEFICIARY:**

European Federation of the Associations  
of Dietitians – EFAD  
Ziegeleiweg 4  
PO-BOX  
46446 Emmerich  
Germany  
Tel: +49 282 268 367

**PROJECT LEADER:**

Judith Liddell  
E-mail: secretariat@efad.org

**MAXIMUM EC CONTRIBUTION:**

172,694.00€

**DURATION:**

12 months

OPERATING GRANT NO 20113211



PREVENT (PREVENT\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

ENWHP is committed to developing and promoting good workplace health practice (WHP). It works towards a vision of healthy employees in healthy organisations, in the context of EU strategies for growth, jobs and cohesion. Workplace health promotion has a key role, linked to the concept of quality in work. This contributes to a high level of health protection and sustainable economic and social development in Europe. ENWHP aims to contribute especially to the reduction of health inequalities, to the development of a European health information system, and to improving health determinants.

#### *Strategic objectives and specific activities*

ENWHP believes that supportive WHP infrastructures should be in place in all its member countries. It wants to see a major increase in the number of European employees in workplaces committed to practices and policies for promoting health. It advocates national networks for WHP, supporting national platforms that give access to all stakeholders and offer information exchange on workplace health. This helps reduce the gap between action at European and national level, and shifts workplace health higher on political agendas. Advice for companies is provided, as well as tools for auto-evaluation and a menu of programmes that covers many workplace health issues and settings. The federation also runs campaigns to promote workplace health.

#### *Expected outcomes*

Planned outcomes include increased numbers of employees working in enterprises committed to policies for promoting health, wider networks and greater visibility and support for WHP, and new efforts on campaigns, training and research. Communication will also be developed with stakeholders and with the media at national and European level.

### Keywords and portfolio

**KEYWORDS:**

- Workers
- Health at work
- Non communicables diseases
- Socio economic factors
- Lifestyle

**PORTFOLIO:**

- Interest groups

**ACTION WEBSITE:** -**MAIN BENEFICIARY:**

PREVENT vzw  
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Belgium  
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Fax: +32 2 643 44 40

**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

93,898.00 €

**DURATION:**

12 months

OPERATING GRANT NO 20113210



## STICHTING AIDS FONDS – SOA AIDS NEDERLAND (SANL\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

Stichting Aids Fonds – Soa Aids Nederland (SANL) hosts the AIDS Action Europe network (AAE), which aims to unite civil society in a more effective response to the HIV epidemic in Europe and central Asia. Its mission is to achieve better protection of human rights and universal access to prevention, treatment, care and support, with reduced health inequalities among at-risk populations, particularly in the epidemic in central and eastern Europe and central Asia. The vision is of a world where people living with and affected by HIV and AIDS can also enjoy life free from stigma, discrimination, and persecution.

#### *Strategic objectives and specific activities*

AAE's objectives in Europe and central Asia include contributing to regional and national policies related to HIV and AIDS, assuring exchange among NGOs on relevant good practices and lessons learned, and strengthening its network. Its advocacy focuses on those most at risk, including men having sex with men, people using drugs, and migrants. It collaborates with organisations with related aims, and maintains close dialogue with decision-makers, playing a role in the development of the EU HIV/AIDS Communication 2009–2013. It maintains an online database on HIV and AIDS for Europe and central Asia with daily updates, and carries out a wide range of communications activities.

#### *Expected outcomes*

The outcomes should include strengthened civil society input to regional and national HIV/AIDS policies and programmes, and support to NGOs in national advocacy and in keeping them well-informed about relevant policy developments. In addition, the exchange of effective methods will be encouraged, and the increased visibility of AAE will assist in attaining its objectives.



### Keywords and portfolio

**KEYWORDS:**

- Ageing workforce
- Employment
- Workers
- Chronic diseases
- Collection of Best Practices

**PORTFOLIO:**

- Interest groups
- Major and chronic diseases

**ACTION WEBSITE:**

[www.soaaid.nl](http://www.soaaid.nl)

**MAIN BENEFICIARY:**

Stichting Aids Fonds – Soa Aids Nederland  
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**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

250,000.00 €

**DURATION:**

12 months

OPERATING GRANT NO 20113212



## EUROPEAN ORGANISATION FOR RARE DISEASES (EURORDIS\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

EURORDIS is a patient-driven alliance of patient organisations (POs) and individuals active in the field of rare diseases (RD), representing an estimated 29 million EU citizens. Its mission is to build a strong pan-European community of POs and People Living with RD (PLWRD), and to be their voice at the European level in fighting against the impact of RD on their lives.

#### *Strategic objectives and specific activities*

To consolidate and give a voice to the community of EU RD patients, EURORDIS promotes RD as a public health priority at national, European and global level, and raises public awareness on RD and RD databases. It also organises the European Conference on Rare Diseases and Orphan Products. To play a role in the EU context, it supports effective implementation of the Commission Communication and Council Recommendations on RD, evaluates the impact of legislation and strategies on RD patients, supports therapeutic development and patient access, takes part in EMA processes, promotes cooperation among patient groups, experts, companies and regulators, and supports improvements in the research policy framework. And it helps build the skills and competences of its member organisations and volunteers.

#### *Expected outcomes*

Effective communication will be maintained with POs, stakeholders and the public. Patient representatives will be better equipped to conduct advocacy. Member organisations will be strengthened, particularly in new member states and in central and eastern Europe. Patients will be more closely involved and better supported in EMA activities. And RD research policy will be boosted with greater patient involvement in research.

### Keywords and portfolio

**KEYWORDS:**

- Patients rights
- Rare diseases and disorders
- Accessibility
- Health system
- Pharmaceuticals

**PORTFOLIO:**

- Interest groups
- Rare diseases

**ACTION WEBSITE:**

[www.eurordis.org](http://www.eurordis.org)

**MAIN BENEFICIARY:**

European Organisation for Rare Diseases –  
EURORDIS  
96 Rue Didot  
PO-BOX  
75014 Paris  
France  
Tel: +33 1 56 53 52 10  
Fax: +33 1 56 53 52 15

**PROJECT LEADER:**

Yann Le Cam  
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**MAXIMUM EC CONTRIBUTION:**

580,000.00 €

**DURATION:**

12 months

OPERATING GRANT NO 20113205



## EUROPEAN PORPHYRIA NETWORK: PROVIDING BETTER HEALTHCARE FOR PATIENTS AND THEIR FAMILIES (APHP-EPNET\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

EPNET's mission is to improve the lives of porphyria patients, by improving diagnosis and treatment. A key step in achieving this mission is to create an effective network of specialist porphyria centres throughout the EU. This has been realised only in part, with 28 specialist centres in 17 European countries now working together to develop an up-to-date approach to the management of patients and families with porphyria. But care is not yet equal in all member states, as porphyria centres and clinical experts are still lacking in some EU countries – notably Bulgaria, Greece, Portugal, and Croatia.

#### *Strategic objectives and specific activities*

The principal objectives are achieving faster and more accurate diagnosis, and expanding the number of European specialist diagnostic and clinical centres that conform to agreed quality criteria. Part of the work consists of improving knowledge and understanding of porphyrias through updated information and best practice guidelines to patients and healthcare professionals, including about medicines. The European porphyria registry is also being widened to collect clinical manifestations and their complications, to assess the effectiveness of current therapies, and to form a database for future clinical trials and research. Research into porphyrias through EU collaboration is also promoted.

#### *Expected outcomes*

One of the expected outcomes is the extension of EPNET to all member states. An overview will also be generated of the status of laboratory-based porphyria services in the EU, with best practice guidelines for providing diagnostic services, which should improve performance and reduce diagnostic errors. The EU porphyria registry will be enhanced as a network of inter-linked registries across Europe, with development of disease-specific protocols and collection of clinical data from additional countries. Additional information on drugs will be made available for patients with acute porphyria. And exchange of experience between patient groups in Europe will be expanded through contacts with eight patient groups in Europe.

### Keywords and portfolio

**KEYWORDS:**

- Chronic diseases
- Rare diseases and disorders
- Collection of Best Practices
- Patients registries
- Healthcare

**PORTFOLIO:**

- Interest groups
- Rare diseases

**ACTION WEBSITE:**

[www.porphyrria-europe.org/](http://www.porphyrria-europe.org/)

**MAIN BENEFICIARY:**

Assistance publique des hôpitaux de Paris  
3, Avenue Victoria  
PO-BOX  
75184 Paris  
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Tel: +33 1 47 60 63 34  
Fax: +33 1 47 60 67 03

**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

94,287.00 €

**DURATION:**

12 months

OPERATING GRANT NO 20113203



## THE EUROPEAN WILSON'S DISEASE NETWORK (AP-HP-WILS\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

The mission of the European Wilson's Disease Network is to improve the quality of care and access to multi-disciplinary expertise for EU patients with Wilson's disease (WD). Members include medical, scientific, and para-medical professionals, as well as EU authorities and patient associations. Its goals include support for patients and patient associations in the EU, and serving as a research and knowledge centre for WD. Its members participate in European and international activities with the aim of transferring knowledge to other networks, patient registries and national authorities and policy makers.

#### *Strategic objectives and specific activities*

To improve information and services to patients it is developing up-to-date online information and educational material for patients and families, in their own language, and setting up EU patient meetings to transfer experience among national associations. To increase knowledge about WD, it continues to enter newly diagnosed patients in registries to allow analysis evolution of care, and it is aiming a creating one database on WD that will provide all national policy makers with the information they need for resource decisions. To improve access and quality of biochemical and genetic testing, it encourages new labs to participate in a standardised mutation quality assay.

#### *Expected outcomes*

Better information and services to patients will be supplied as a result of a survey of patient need and expectations in France, UK, Germany and Denmark. Knowledge of WD will be increased with a new database that includes new cases and follow-up data. Higher-quality care should result from network efforts to improve awareness, recruitment of clinicians from under-represented countries, and educational material adapted for psychologists, social workers, physiotherapists, speech therapists and nurses.

### Keywords and portfolio

**KEYWORDS:**

- Chronic diseases
- Rare diseases and disorders
- Health education
- Patients registries
- Healthcare

**PORTFOLIO:**

- Interest groups
- Rare diseases

**ACTION WEBSITE:**

[www.eurowilson.org](http://www.eurowilson.org)

**MAIN BENEFICIARY:**

Assistance publique des hôpitaux de Paris  
3, Avenue Victoria  
PO-BOX  
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**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

159,150.00€

**DURATION:**

12 months

## OPERATING GRANT NO 20113201



## ALZHEIMER EUROPE (AE\_FY2012)

**Abstract*****Mission and vision of the operating grant holder***

Alzheimer Europe's mission is changing perceptions, practice and policy in order to improve the access of people with dementia and their carers to treatment options and care services. Its guiding philosophy is promoting autonomy and self-determination of people with dementia and their carers throughout the course of the disease. It wants to make dementia a European priority.

***Strategic objectives and specific activities***

To make dementia a European priority, it partners European institutions – such as with the European Alzheimer's Alliance, comprising Members of the European Parliament – and contributes to policy discussions on health subjects. To be able to support policy with facts, it carries out inventories of national legislation on legal issues affecting people with dementia and their carers, and has set up a European Dementia Observatory to compare national systems and identify best practices. To ensure its actions are based on ethical principles, it has set up the European Dementia Ethics Network, and analyses ethical issues in detail, publishing recommendations on such issues as end-of-life care for people with dementia and the ethical implications of assistive technologies. And to build a stronger organisation it has set up a European Working Group of People with Dementia, organised conferences, and coordinated a study on the socio-economic impact of dementia.

***Expected outcomes***

Expected outcomes include a more coherent view of national dementia strategies and policies, which will look closely at policies of those countries which have not yet developed formal strategies. It will also analyze national laws on restrictions of freedom and coercive measures from an ethical perspective and develop recommendations. The European Working Group of People with Dementia will meet regularly and will compare national involvement strategies. Communication work will focus on policy developments and scientific information on new treatments and new care approaches.



### Keywords and portfolio

**KEYWORDS:**

- Patients rights
- Elderly
- Alzheimer
- Dementia

**PORTFOLIO:**

- Interest groups

**ACTION WEBSITE:**

[www.alzheimer-europe.org/](http://www.alzheimer-europe.org/)

**MAIN BENEFICIARY:**

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Fax: +352 29 79 72

**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

190,000.00€

**DURATION:**

12 months

OPERATING GRANT NO 20113206



## EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

EPHA's mission is to bring together the public health community to stimulate leadership and change, so as to build the capacity for equitable solutions to European public health challenges, and to improve health and reduce health inequalities. Its vision is of a Europe with universal good health and well-being, where all those living in it have access to a sustainable and high quality health system.

#### *Strategic objectives and specific activities*

For 2011–2015, EPHA's overall objective is to promote good health and well-being, and to reduce disease and health inequalities. More specifically, it aims to improve overall population health and healthy life years, to increase equity and access in health and reduce health inequalities, and to support a European institutional and policy framework that promotes health. In addition, it aims to strengthen and increase effective public health capacity. EPHA focuses on cooperation in the geographic areas of greatest need, and with underrepresented groups, particularly vulnerable groups or those suffering discrimination. It conducts advocacy and builds cooperation and partnerships in public health policy. It relays information widely, giving publicity to its policy positions and briefings, and sharing best practice among its members and other contacts. And it provides advocacy training and on EU and health issues and supports the generation of evidence-based reports and policy recommendations.

#### *Expected outcomes*

Actions on health factors of diet, alcohol consumption, physical activity; smoking and the early years of life will help improve population health and healthy life years through disease prevention and healthy ageing, with a focus on cancer and chronic disease prevention. Continued tracking of EU initiatives in the area of health will contribute to pressure for increasing access to health and reducing health inequalities. And strengthened and increased public health advocacy at national level will ensure raised awareness and interest in the EU processes and their impact on the population's health.

### Keywords and portfolio

**KEYWORDS:**

- Healthcare
- Non communicables diseases
- Socio economic factors
- Lifestyle

**PORTFOLIO:**

- Interest groups

**ACTION WEBSITE:**

[www.ephaproject.org](http://www.ephaproject.org)

**MAIN BENEFICIARY:**

European Public Health Alliance – EPHA  
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PO-BOX  
1040 Brussels  
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**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

549,232.00 €

**DURATION:**

12 months

OPERATING GRANT NO 20113204



## THE ASSOCIATION OF SCHOOLS OF PUBLIC HEALTH IN THE EUROPEAN REGION (ASPHER\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

ASPHER is dedicated to strengthening the role of public health (PH) by improving the education and training of professionals. Its members are committed to promoting the highest standards in building up the capacity of public health authorities, with an evidence-based approach and models of innovation and good practice.

#### *Strategic objectives and specific activities*

General objectives include creating a single forum for interested academic institutions with involvement in global health, so as to develop a European voice on global health issues, developing quality criteria in education that would relate to PH performance standards, advanced research and recommendations on a common European PhD training programme, and devising an ethical framework for PH teaching and practice. It also aims to secure the future of schools of PH in times of economic crisis, and help health systems in Europe to integrate an educated PH workforce. Cooperation with international organisations such as EU and WHO is also an important aspect of building up the capacity of the PH workforce.

#### *Expected outcomes*

A European Forum for Public Health Competencies could emerge from a series of meetings with other organisations, defining the governance of a European system of public health competencies. Continuing training and lifelong learning for PH in Europe is also expected to result from work on harmonised education, and a Young Researchers Forum will be created for advanced students to present their work to a select audience of peers and key representatives of the European public health community.

### Keywords and portfolio

**KEYWORDS:**

- Education
- Health education
- Healthcare

**PORTFOLIO:**

- Interest groups

**ACTION WEBSITE:**

[www.old.aspher.org](http://www.old.aspher.org)

**MAIN BENEFICIARY:**

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in the European Region – ASPHER  
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**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

80,000.00 €

**DURATION:**

12 months



## CHAPTER 4

# 4.2 HEALTH INFORMATION OPERATING GRANTS

OPERATING GRANT NO 20113304



## THE EUROPEAN MULTIPLE SCLEROSIS PLATFORM (EMSP\_FY2012)

### Abstract

#### *Mission and vision of the operating grant holder*

EMSP represents 38 national multiple sclerosis (MS) societies from 34 European countries in its mission of securing high quality equitable treatment and support for people with MS (PwMS) throughout Europe, to allow them to lead their life independently and to recognise them as equal members of the society. Its vision is to move from high-quality treatment and support to a world without MS.

#### *Strategic objectives and specific activities*

EMSP main goals for 2012–2014 include equity of access to health and social care for PwMS, their families and their carers, regardless of where they live, or their economic status. Enhancing the ability of PwMS to represent their collective interests is another major goal, as is encouragement of the MS research agenda at European level. EMSP also aims to strengthen its voice in Europe, working in partnership with other stakeholders and helping its member organisations to contribute to and benefit from it as their platform. It will also aim at excellence in its own performance and delivery, through effective management, organisational development and evaluation of its human resources.

#### *Expected outcomes*

EMSP will gain in visibility – through an MS Awareness Day in the European Parliament, photo-journalistic messages aimed at the general public, and consequent increased media attention. Greater involvement of patients and carers in training courses and in consultations with health agencies will highlight the needs of PwMS. Increased partnerships, effective advocacy and proactive policy setting are also expected, partly through better mutual understanding of working priorities with sponsors, and closer links with neurologists. The restructuring of the secretariat will be finalised, to respond to new EMSP priorities and goals.



### Keywords and portfolio

**KEYWORDS:**

- Chronic diseases
- Rare diseases and disorders
- Collection of Best Practices
- Health education
- Healthcare

**PORTFOLIO:**

- Interest groups
- Rare diseases

**ACTION WEBSITE:**

[www.emsp.org](http://www.emsp.org)

**MAIN BENEFICIARY:**

The European Multiple Sclerosis Platform  
Aisbl – EMSP  
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**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

294,588.00 €

**DURATION:**

12 months

OPERATING GRANT NO 20113302



## EUROPA DONNA – THE EUROPEAN BREAST CANCER COALITION (ED\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

EUROPA DONNA (ED), the European Breast Cancer Coalition, is an independent, non-profit pan-European coalition of grassroots groups with a mission to ensure that all women have access to accurate information and the highest quality breast cancer screening, diagnosis and treatment. Its vision is of greatly increased early detection, with consequent drastic decreased mortality, as well as quality of treatment at the highest level, and increased prevention through educating all European women about healthy lifestyles.

#### *Strategic objectives and specific activities*

The principal objectives are to ensure that women are aware of EU breast cancer resolutions of 2003 and 2006, and that these resolutions are delivered on in terms of good practice in cancer-related healthcare. In support of these objectives, ED develops advocacy programmes at European and national levels, and is intensifying its European presence, bringing BC issues to the attention of MEPs and the Commission both directly and via expert meetings and conferences. It runs training courses to educate new advocates, a biennial conference at which 5,000 participants learn about the latest scientific advances, and Breast Health Day, an annual prevention campaign. Its information programme provides women with accurate, up-to-date information on breast cancer issues via websites and publications. And national groups are helped to find solutions to issues they face.

#### *Expected outcomes*

Simple, clear scientifically sound information will be produced that national organisations can use in their advocacy efforts and in providing up-to-date breast health information to women and girls in their countries. Members from across Europe will be able to learn from one another through the exchange of ideas, experiences and best practices, and expert advocates will be available on key breast cancer issues to mentor ED members, helping to overcome inequalities by bringing every country up to the optimum level of breast health service. Ultimately, mortality resulting from breast cancer should decline, and prevention increase.

### Keywords and portfolio

**KEYWORDS:**

- Women
- Breast
- Implementation

**PORTFOLIO:**

- Interest groups
- Major and chronic diseases

**ACTION WEBSITE:**

[www.europadonna.org](http://www.europadonna.org)

**MAIN BENEFICIARY:**

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The European Breast Cancer Coalition  
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**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

273,415.00 €

**DURATION:**

12 months

OPERATING GRANT NO 20113301



## EUROPEAN PATIENTS' FORUM (EPF\_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

EPF's mission is to be the collective voice of patients at EU level, reflecting the solidarity, power and unity of the EU patients' movement, and putting patients at the centre of EU health policy and programmes. Its vision is of a patient-centred, high quality, equitable healthcare for all patients throughout the EU.

#### *Strategic objectives and specific activities*

EPF's goals include equal access to best quality information and healthcare for EU patients and their informal carers and families, meaningful patient involvement in EU health-related policy-making, integrating a patients' perspective – including human rights and quality of life issues – in EU-level developments on health economics and health efficacy, encouragement of inclusive, effective and sustainable representative patient organisations, and promoting solidarity and unity across the EU patients' movement. Its key activities include developing an evidence-base on patients' experience, input at major health events, and building dialogue and cooperation with representatives of EU institutions. It collaborates widely with other health stakeholders and EU-level platforms. It supports its membership through training, and promotes national patient coalitions. Its priorities in policy include patient safety and quality of care, health inequalities, access to therapies, clinical trials, medical devices, information to patients/health literacy, Health Technology Assessment, innovation, and eHealth.

#### *Expected outcomes*

Youth meetings reflect the ambition of training younger members and volunteers and advocacy seminars targeting Mediterranean member states and candidate countries reflect the ambition to provide support across all associations. The EPF impact on policy will be seen in a continuing focus on topical issues including chronic diseases, patient safety, falsified medicines, information to patients, personalised medicine, clinical trials, cross-border healthcare, pharmacovigilance, and healthy and active ageing.

### Keywords and portfolio

**KEYWORDS:**

- Patients rights
- Vulnerable groups
- Chronic diseases
- HTA
- Health promotion

**PORTFOLIO:**

- Interest groups

**ACTION WEBSITE:**

[www.eu-patient.eu](http://www.eu-patient.eu)

**MAIN BENEFICIARY:**

European Patients' Forum – EPF  
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**PROJECT LEADER:**

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**MAXIMUM EC CONTRIBUTION:**

568,488.00€

**DURATION:**

12 months

OPERATING GRANT NO 20113303



## EUROPEAN HEALTH MANAGEMENT ASSOCIATION LIMITED (EHMA \_FY2012)

### *Abstract*

#### *Mission and vision of the operating grant holder*

EHMA's aim is to improve the quality and build the capacity of health management across the European region, through exchange of ideas and practices among academics, researchers, managers, clinicians, policy makers and consumers. Its vision embraces quality and inclusion in health and healthcare; innovation in health management; and sustainable health systems.

#### *Strategic objectives and specific activities*

In pursuit of quality and inclusion, it has looked at reducing health inequalities through tackling the social determinants of health. To promote innovation, it runs a special interest group on management development, an annual award for innovative health management, and work on managing eHealth. And to help develop sustainable health systems, it works with transitional countries, professional mobility and the health workforce, managing cross border care, innovative primary care, and ageing. In addition, other core objectives relate to developing leadership, boosting education and training, improvement of health management practice, and support for research and development and the transfer of research findings into practice.

#### *Expected outcomes*

Ideas on improving the quality of mental health systems are expected from involvement in the European Mental Health Systems Network, a forum where senior policy makers, managers and researchers share expertise, with a view to creating new service models. A focus on change management in eHealth will look at major issues such as acceptance by health professionals, citizen participation, and equity of access. A taskforce on managing the future workforce will deepen understanding of how sustainable health systems can be maintained in the face of capacity gaps. Strategies should emerge on health management in new EU countries and its neighbours, with a focus on building high quality management education and response to health threats.

### Keywords and portfolio

**KEYWORDS:**

- Health at work
- Healthcare
- Socio economic factors

**PORTFOLIO:**

- Interest groups

**ACTION WEBSITE:**

[www.ehma.org](http://www.ehma.org)

**MAIN BENEFICIARY:**

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**MAXIMUM EC CONTRIBUTION:**

184,755.00€

**DURATION:**

12 months





# Main beneficiaries by country of establishment

### *Belgium*

European Organisation for Research and Treatment of Cancer – EORTC  
Quality of Life and Symptom Research in Cancer Clinical Trials (QOL EUROPE)

European Alcohol Policy Alliance  
European Council on Alcohol Rehabilitation Research and Education (Eurocare\_FY2012)

European Network for Smoking and Tobacco Prevention – ENSP  
The European Network for Smoking Prevention (ENSP\_FY2012)

PREVENT vzw  
Prevent (Prevent\_FY2012)

European Public Health Alliance – EPHA  
European Public Health Alliance (EPHA\_FY2012)

The Association of Schools of Public Health in the European Region – ASPHER  
The Association of Schools of Public Health in the European Region (ASPHER\_FY2012)

The European Multiple Sclerosis Platform Aisbl – EMSP  
The European Multiple Sclerosis Platform (EMSP\_FY2012)

### *Denmark*

Kobenhavns Universitet (University of Copenhagen)  
HIV in Europe Copenhagen 2012 Conference (HIV in Europe 2012)

Ministeriet for Sundhed og Forebyggelse (Ministry of Health)  
High Level eHealth Conference 2012 (EHEALTH)

Sundhedsstyrelsen/National Board of Health – NBOH  
European network for HTA Joint Action 2 (EUnetHTA JA 2)

### *France*

PROTEINES SAS  
EPODE for the Promotion of Health Equity (EPHE)

European Organisation for Rare Diseases  
European Conference on Rare Diseases and Orphan Products 2012 Brussels (ECDR 2012)  
European Organisation for Rare Diseases (EURORDIS\_FY2012)

Haute Autorité de Santé (National Authority for Health)  
European Union Network for Patient Safety and Quality of Care (PaSQ)

Assistance publique des hôpitaux de Paris  
European Porphyria Network: providing better healthcare for patients and their families  
(APHP-EPNET\_FY2012)  
The European Wilson's Disease Network (AP-HP-WILS\_FY2012)

*Germany*

Universitätsklinikum Hamburg-Eppendorf – UKE

Good practice on brief interventions to address alcohol use disorders in primary health care, workplace health services, emergency care and social services (BISTAIRS)

European Federation of the Associations of Dietitians – EFAD

European Federation of the Associations of Dietitians (EFAD\_FY2012)

*Ireland*

European Health Management Association Limited – EHMA

European Health Management Association Limited (EHMA\_FY2012)

*Italy*

Fondazione IRCCS “Istituto Nazionale dei Tumori”

Information network on rare cancers (RARECARENet)

Azienda Ospedaliera Universitaria Integrata Verona

Support creation of pilot network of hospitals related to payment of care for cross border patients (HoNCAB)

Cittadinanzattiva Onlus

“Active Ageing citizens at the centre of EU health policy”. 6th European Patients’ Rights Day (Active Ageing & health policy)

Azienda Sanitaria Locale della Provincia di Brescia

Project on crisis communication in the area of risk management (CriCoRM)

EUROPA DONNA – The European Breast Cancer Coalition

EUROPA DONNA – The European Breast Cancer Coalition (ED\_FY2012)

*Luxembourg*

Alzheimer Europe

22nd Alzheimer Europe Conference: Changing perceptions, practice and policy (22 AEC)

Alzheimer Europe (AE\_FY2012)

European Patients’ Forum – EPF

European Patients’ Forum (EPF\_FY2012)

*Poland*

Ministry of Health

First European Day of the Brain. Ageing, Stroke and Alzheimer’s Disease-finding innovative solutions. (CFR)

*Slovenia*

Zavod za zdravstveno varstvo Murska Sobota/Institute of Public Health Murska Sobota

Reducing health inequalities: preparation for action plans and structural funds projects (ACTION-FOR-HEALTH)

Inštitut Za Varovanje Zdravja – NIPHRS

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Organización Nacional de Trasplantes

Achieving Comprehensive Coordination in ORgan Donation throughout the European Union (ACCORD)

*The Netherlands*

Universitair Medisch Centrum Utrecht – UMCU

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Universiteit Maastricht

Reducing health inequalities: preparation for action plans and structural funds projects (HEALTHEQUITY-2020)

European Public Health Association

Fifth European Public Health Conference (Malta 2012)

Stichting Health Action International

Health Action International (HAI\_FY2012)

Stichting Aids Fonds – Soa Aids Nederland

Stichting Aids Fonds – Soa Aids Nederland (SANL\_FY2012)

Stichting Nederlands Instituut voor onderzoek van de Gezondheidszorg

Strengthening the European Dimension in Health Services Research (Strengthening European HSR)

*United Kingdom*

The University of Sheffield – USFD

European Haemophilia Network (EUHANET)

University of Newcastle upon Tyne – UNEW

EUCERD Joint Action: working for rare diseases (EJA)

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