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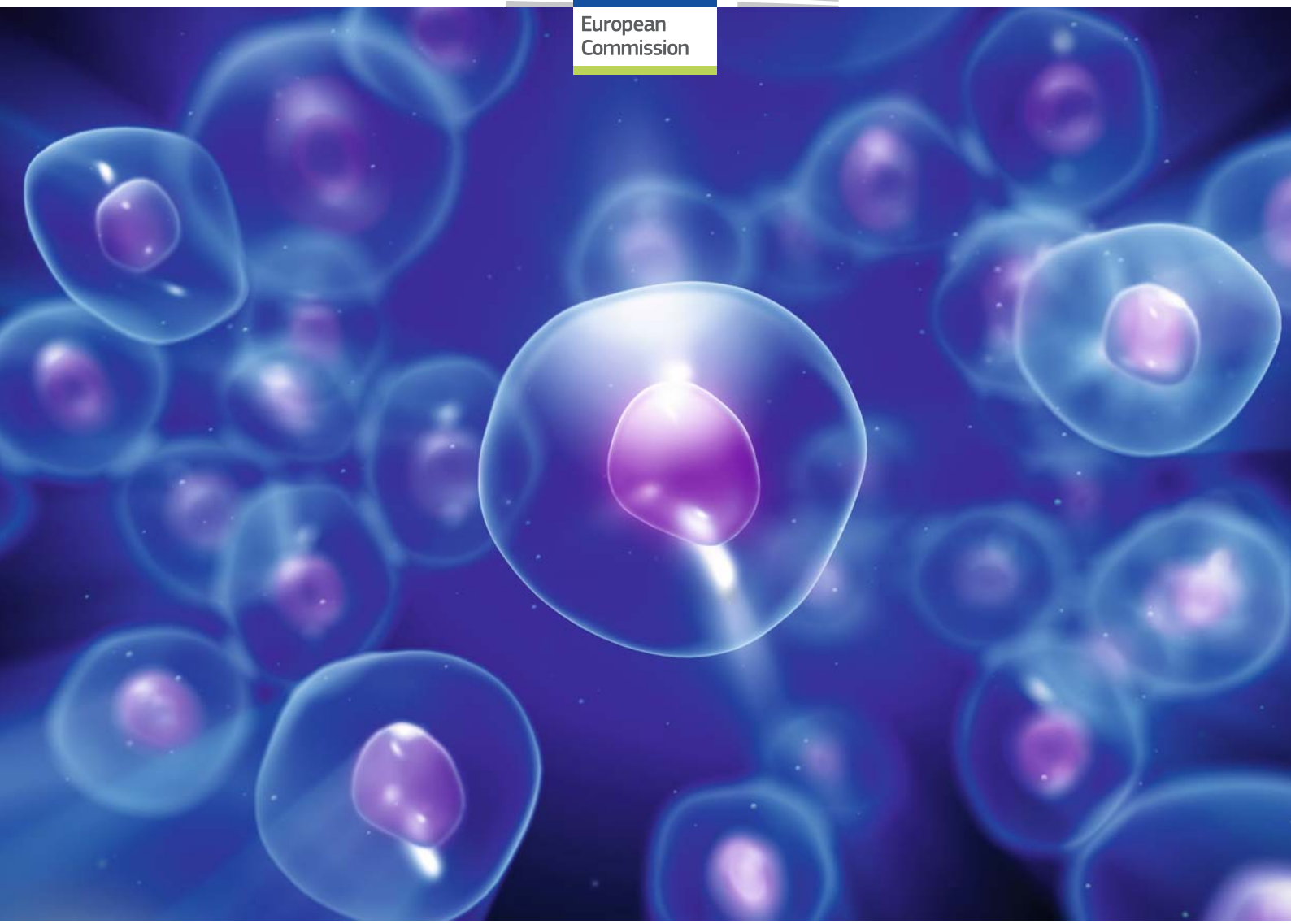

EU Health Programme: 2010 Call for Proposals

Abstracts of the actions selected for EU co-funding

Executive Agency for Health and Consumers

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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, and it 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 having 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 abuse of alcohol to refining the care of patients with Alheimer'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 life-saving 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 program's resources accordingly for each year of the program. The implementation of each annual work plan is done through the publication of four calls for proposals, each one of which is targeted to fund specific type 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 30 million euros were made available under the 2010 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 is 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.

CHAPTER 1

Health Promotion

CHAPTER 1

1.1. HEALTH PROMOTION PROJECTS

PROJECT NO 20101210

A EUROPEAN NETWORK TO FOLLOW-UP THE REFORMULATION OF FOOD; IDENTIFICATION AND EXCHANGE OF GOOD PRACTICES FOR SMES AND CONSUMERS (SALUS)

Abstract

General objectives

SALUS general objectives, on the one hand, are to follow-up the reformulation of the manufactured foods, to analyse the EU context and to identify and exchange the best practices in terms of the reduction of the levels of fat, saturated and trans fats, salt and sugar in manufactured foods and to validate a model of cost effectiveness for the major reformulations.

In addition to them, SALUS specific objectives aim to collect and analyse the available data and information about the food reformulation, rules (laws) and cultural values of food to compare the different situations in the participating countries and to create a European Clearing House for agri-food SMEs and Consumers on food reformulation and labelling to provide and gather all the relevant information and to enhance the networking among existing centres of expertise and databases.

Strategic relevance and contribution to the public health programme

SALUS will collect, process and analyse comparable data and information, for an effective monitoring of the state of health in the EU. This would enable the EC and the MS to increase information for the public and formulate appropriate strategies, policies and actions to achieve a high level of human health protection.

According to the priorities of the Call for Proposal 2010 - Public Health Programme, SALUS will promote the follow-up of the reformulation of manufactured foods – exchange of good practices with regard to the reduction of the levels of fat, saturated and trans fats, salt and sugar in manufactured foods focusing on the technical and economical aspects of reformulations in SMEs. Besides, in line with the EC, EFSA and Food for Life platform recommendations, SALUS actions will take into account that the individual is ultimately responsible for his lifestyle, and that of his children and that only a well-informed consumer is able to make rational decisions.

Methods and means

The project work plan has been structured on the basis of the project objectives. The project activities planned are:

- Study of the literature on the theme and on the different local contexts
- Good practices identification and exchange
- Organization of the follow-up of the food reformulation among European SMEs by a survey to be carried out in all the participating countries aiming to support the follow-up of the implementation of the EC White Paper and to build a better understanding of SMEs issues and concerns pertaining SALUS issues, at least 1000 SMEs will be identified and involved in the survey
- Development of an operational model to evaluate the cost-effectiveness of reformulated products in response to SMEs needs
- Establishment of a European Clearing House for Agri-Food SMEs and Consumers to support the EU in the fight against NCD

Finally, the project will establish a link with all the coordinators of the existing food reformulation EU initiatives to identify a knowledge-base resource to provide an easy access to the lessons learned.

Expected outcomes

SALUS expected results, according to its objectives, will be:

1. to reduce the existing knowledge gaps on healthy food issues in selected target groups;
2. to give an analysis of the evidence-based ways to reduce barriers to implement food reformulation and reduction of fat, sugar and salt in manufactured goods;
3. to establish a EU Clearing House for Agri-food SMEs and Consumers to provide and gather all the relevant information and to enhance the networking among existing centres of expertise and databases.

Moreover, SALUS will aim to transfer the good practices identified during the project implementation to Universities, Research centers, Technical staff from Ministries of Health and Representatives from food manufacturers, the Catering industry, Professional Associations and NGOs.

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EC CONTRIBUTION:
EUR 834688.00

DURATION:
36 month(s)

KEYWORDS:
- Food-Reformulation
- Food-Processing Industry
- Nutrition
- Cost-Effectiveness Analysis
- Follow-up

PROJECT NO 20102201

ALZHEIMER COOPERATIVE VALUATION IN EUROPE (ALCOVE)

Abstract

General objectives

The JA will be contribute to public health programmes in Europe and develop Alzheimers disease (AD) and dementia prevention and care models in different European countries. The aim is to contribute to improvements in health by supporting and facilitating quality and efficiency of public health and healthcare policies and interventions. Synergy and avoidance of duplication with other health and research programs will be ensured.

The aim is to build a sustainable European platform. The objectives of ALCOVE are to accomplish the following during the 2 year project duration:

1. Establish a European statement on Alzheimer s disease: Propose a synthesis regarding AD information and practices in Europe which could be the basis for further implementation at the European level
2. Ability of the JA to support the implementation of good practices in the field of risk prevention with measured results for patients: a focus on the overuse of psychotropics.

Strategic relevance and contribution to the public health programme

ALCOVE is a response to an explicit request by the EU and MS and covers a number of EU MS, incl. CZ, BE, GR, FI, IT, LV, LT, SK, ES, SE, UK and FR, pooling different competences across Europe with diverse experiences for the prevention and care of AD and dementia. Strategic relevance is enhanced by the involvement of various types organisations to provide scientific excellence and develop links for future collaborations between institutions involved in AD and dementia in EU countries. Due to the nature of AD and its impact on ageing and the aged as well as to national health systems (in terms of both social and economic impact) the ALCOVE JA corresponds to the approach outlined in the white paper: Together for Health: A Strategic Approach for the EU 2008-2013. The diagnosis and treatment of AD developpe several of the identified priority areas for 2010, including: Sustainability of health systems in the face of challenges such as the ageing population; Inequalities in health within and between MS; and Health security, surveillance and response to health threats.

Methods and means

The JA will build on methods and tools developed by international EuroCode and Dementia in Europe Yearbook (Alzheimer Europe) and relevant collaborations. It will comprise four fields and share a common question on risk reduction in population with AD, i.e. the overuse of psychotropics. WPs are devoted to: 1 Improvement of knowledge, using existing epidemiological collection data and connecting of these studies with other national info systems. 2 Improvement of risk prevention and diagnosis, based on better knowledge of effectiveness of preventive strategies, using an assessment of implementation of these strategies. Improvement of diagnosis: improvement of operational criteria of diagnosis and assessment of health care systems in order to formulate recommendations. 3 Improvement of existing practices and care models, based on assessment of info about care practices, training practices and evaluation of the rights of the persons with dementia (concerning professional and family carers). 4 Autonomy and dignity of people with dementia from an ethical and legal perspective (incl. ADW, competence assessment w/ overview of good practices.

Expected outcomes

ALCOVE will support effective collaboration for improving the AD public health problem in Europe that brings added value at the European, national and regional levels. The JA aims to bring better knowledge and development of risk prevention and care recommendations to facilitate policy and health care decision making in EU MS. The main outcome will be the establishment of a network for risk prevention and care of dementia in EU, with the hope that EU MS not yet involved in this JA will, in the future, join the network. Exchange of information among agencies will be increased, avoiding duplication of work in the field of AD and other dementia in EU. Availability of information allows MS to adapt recommendations to each situation, allowing better efficacy. Finally, emerging and future developments in the domains of risk prevention and care improvement, will be more easily disseminated and implemented.

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EC CONTRIBUTION:
EUR 613100.00

DURATION:
24 month(s)

KEYWORDS:
- Dementia
- Epidemiology
- Quality of health care
- Ethics
- Antipsychotic agents

PROJECT NO 20101205

AN EU RARE DISEASES REGISTRY FOR WOLFRAM SYNDROME, ALSTROM SYNDROME AND BARDET BIEDL SYNDROME (EURO-WABB)

Abstract

General objectives

The general objective of this project is to support efficient diagnosis, treatment, and research for the overlapping rare genetic diseases Wolfram, Alstrom and Bardet Biedl syndromes and other rarer diabetes syndromes in Europe. We will achieve this by implementing an EU registry for Rare Diabetes Syndromes (RDS), containing clinical, genetic diagnostic and outcome data. The purpose of the registry is: a) to establish the natural history of RDS (their characteristics, management and outcomes); b) to assess clinical effectiveness of management and quality of care; c) to provide an inventory of patients for recruitment to intervention studies; d) to establish genotype-phenotype correlations. We will achieve high usage of the registry by linking it to rapid genetic testing; and to up to date, accurate information, FAQS, and education material.

Strategic relevance and contribution to the public health programme

This supports equal access to genetic testing, education of health professionals, and empowerment of patients. (Council Recommendation on rare diseases); adequate inventorying of RDS diseases (Section II); supporting research (Section III); development of centres of expertise (Section IV); gathering expertise at European level (section V); empowering patient organizations as partners (Section VI); developing sustainability by underpinning a future European Reference Network for RDS diseases (Section VII); supporting the High Level Pharmaceutical Forum Recommendations (2008); and supporting improvement in health outcomes, a key Lisbon Strategy indicator. The contribution to the programme is through: a) increased knowledge on these rare diseases by pooling together data on larger number of patients; b) support for research by allowing access to investigators for epidemiological, clinical, genetic and interventional studies; c) effective dissemination of results via Orphanet; d) advocacy for improved quality of services via EURORDIS; e)balanced participation.

Methods and means

Methods and means. We will use validated, quantitative questionnaires and focus groups of health professionals, to scope the support requirements of centres for submitting data to the Registry. We will develop a consensus on a core dataset for the Registry, then develop a multifunctional web based Registry with user friendly browser-based access. We will create a RDS microarray capable of identifying up to 600 different mutations. We will undertake quantitative questionnaires and focus groups for patients and health professionals to compile their learning and information needs; write education material and patient information on RDS diseases, and use it to support 'meet the expert' platforms, and fora for client groups.

Expected outcomes

Expected outcomes. There will be a step change in volume and quality of clinical research in RDS diseases. The registry will be also be transferable to scientists exploring the mechanisms underlying common diabetes and obesity. This will change our understanding of these rare diseases through increased knowledge of the natural history and genotype phenotype relations informing prognosis. RDS diseases will have increased visibility to the research and health provider communities through Orphanet and EURORDIS. There will be a change in clinical effectiveness of services for RDS patients. The registry will provide data for assessing the clinical effectiveness and cost-effectiveness of standard care and new interventions in a real-world setting. This will lead to improvements in quality of care. The Registry will identify disparities between health care outcomes and provide evidence for health service providers for improvements.

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EC CONTRIBUTION:
EUR 900000.00

DURATION:
36 month(s)

KEYWORDS:
- Wolfram
- Alstrom
- Bardet-Biedl
- Diabetes

PROJECT NO 20101202

BUILDING CONSENSUS AND SYNERGIES FOR THE EU REGISTRATION OF RARE DISEASE PATIENTS (EPIRARE)

Abstract

General objectives

The general objective of this initiative is to build consensus and synergies to address regulatory, ethical and technical issues associated with the registration of rare disease (RD) patients and to draft possible policy scenarios. Specific attention will be given to the scenario of the creation of a EU platform for the collection of data on RD patients and their communication to qualified users, based on a feasibility study. With this in mind, the project will define the options for the preparation of a legal basis, the possible scope to achieve most effective synergies, the corresponding governance framework, and possible options for sustainability. The assessment will cover the feasibility of registration of a minimum data set common to all rare diseases, designed to inform policy-making, the conditions to admit research-driven disease or treatment-specific modules and the ways to ensure a sustainable data flow.

Strategic relevance and contribution to the public health programme

The development of guiding reports for the registration of RD patients - including on the legal and organizational framework - is strategic to build up an evidence base for EU public health policies, health-service management, clinical research and the assessment of the effectiveness and appropriateness of use of orphan drugs. The successful establishment of an EU registration of health data for RDs may pave the way to the EU-wide registration of data on other health conditions. The project prepares the ground for the collection of an agreed common set of data from RD patients, and also provides rules to ensure data quality and data validation, and to improve comparability of data among countries. The adoption of an EU legal basis may confer more statistical power on evidence for EU policies, epidemiological investigations and research. The project envisages taking on the role of the scientific secretariat of an EUCERD WG on Registries and DataBases, to integrate the project in policy development for RD. The ISS and Eurordis will co-chair the EUCERD WG.

Methods and means

(1) A survey will be carried out through registries at universities and among patient associations to identify needs and interests. (2) Legal instruments will be analyzed to provide operational indications for the Commission to start the process leading to the adoption of the most suitable EU-level legal basis. (3) The sustainability of registration of EU RD patients will be pursued by defining the aims and scope of the platform and appropriate governance models. (4) A common data set will be developed consistently with the public health aims; use of different data sets will be considered. (5) The services to be made available through the platform will be identified; practical instruments will be offered to carry out routine tasks for registry users and to facilitate communication with the platform; public reports will be provided; and specific needs of registry users will be met. Special attention is given to the involvement of all relevant stakeholders to promote implementation and sustainability.

Expected outcomes

The dissemination strategy, the link with a specific EUCERD working group, and the project deliverables will together set in motion a mechanism for the approval of the legal base for the EU registration of RD patients. It will provide the Commission with the elements to draft a legislative proposal and submit it to the Council and Parliament. Such legislation will allow the pooling of data from the Member States. Even if the legislation is not approved, the project deliverables and the consensus generated by this project will have beneficial effects. The project will provide common ground on the basis of wide-ranging debate and consensus on a legal basis to be adopted by national health authorities. The Commission could develop and provide the services and facilities described in the project deliverables and tailored to the national health institutions establishing a registry and to those of current “private” registries and databases.

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EC CONTRIBUTION:
EUR 661,402.00

DURATION:
30 months

KEYWORDS:
- Epidemiology
- Rare diseases
- Registries
- Consensus
- Policy scenarios

PROJECT NO 20101211

CAPACITY BUILDING IN COMBINING TARGETED PREVENTION WITH MEANINGFUL HIV SURVEILLANCE AMONG MSM (SIALON II)

Abstract

General objectives

In line with the last Communication on combating HIV/AIDS in the European Union and neighbouring countries (2009-2013) the overall objective of this project is to carry out and promote combined and targeted prevention complemented by a meaningful surveillance among MSM. In other words, the aim is to develop capacity building and know how through both training and on-site coaching under the active supervision and in collaboration with UNAIDS and WHO on: a) prevention needs assessment and prevention actions; b) innovative surveillance methodologies for hard to reach populations like MSM (time location sampling, respondent driven sampling, HIV and STI testing). The project, thanks to the participation of UNAIDS and WHO, will be implemented in both EU and neighbouring countries using the same methodologies (Protocols, UNGASS/ECDC indicators, epidemiological algorithms) and prevention strategies.

Strategic relevance and contribution to the public health programme

The project's strategic relevance lies in the fact that it addresses the need for an effective response in priority regions such as the mostly affected EU Member States and the most affected neighboring countries. Targeting MSM as one of the most at risk populations with the active involvement and participation of gay communities in all the phases of the project actions, including developing specific culturally sensitive strategies of communication for the prevention of HIV and promotion of VCT among MSM, is in line with the Work Plan 2010 objective. The implementation of UNAIDS and WHO recommendations on second generation surveillance systems combining behavioural-biological data with prevention needs information and a formative action research in view of targeted prevention actions respond to the objective: "Promoting combined and targeted prevention complemented by a meaningful surveillance". Contacts with ECDC has been taken to harmonise the project with ECDC activities.

Methods and means

Formative research will be carried out in order to choose the most fitting method for data collection among MSM according to local contexts and for prevention needs assessment. Data collectors (recruited through gay associations / NGOs) will be trained locally on prevention issues and procedures for data collection. The Time-Location Sampling method (TLS) will be adopted. Alternatively, the Respondent-Driven Sampling (RDS)method will be used in countries where the survey has already been implemented with the TLS during the former EU-funded SIALON project. Data on prevention needs and behaviour will be collected through an anonymous questionnaire, linked to the biological samples (serum/oral fluid). A training programme will be carried out to train lab technicians on testing at country level. An aliquot of HIV positive serum samples will be sent to a specialised laboratory (University Hospital Verona) for the calculation of HIV antibodies' avidity index and incidence estimation (STARHS). Approvals from all partners' Ethics Committees will be obtained.

Expected outcomes

The project's results directly feed into practice and create capacity building thanks to training and on-site coaching and participatory, inter-active disseminating methods. In addition the involvement of WHO and UNAIDS brings a substantial added value to the project and is therefore directly and effectively linked to practical use of research results. Finally, the use of outreach strategies and complementary methodologies will maximize the validity and effectiveness of preventive interventions. In conclusion the project will advance harmonisation of surveillance methodologies, generate comparable data on behavioural and epidemiological indicators for MSM communities (ECDC and UNGASS indicators), help to identify unmet prevention needs, inadequacies of prevention policies, and urgent prevention measures and will strengthen a wide network including international (UNAIDS, WHO) and European (ECDC) organizations, National Public Health Institutes and Civil Society (gay NGOs).

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EC CONTRIBUTION:
EUR 989960.00

DURATION:
36 month(s)

PROJECT NO 20102206

DEVELOPMENT OF THE EUROPEAN PORTAL OF RARE DISEASES AND ORPHAN DRUGS (JA-ORPHANET EUROPE)

Abstract

General objectives

The objective is to provide the community at large with an inventory of RD, an encyclopaedia in as many languages as possible, and a directory of expert services in the participating countries. The project aims to improve the update of the encyclopaedia and the update of the directory of services, to put in place a process to ensure swift management of translations, swift collection of data and validation by national health authorities before publication. The project will also improve the governance of Orphanet to ensure its mission at international level. The website will be adapted to offer national front pages in national language(s), and the possibility to disseminate information on national policy documents and national events. Each Member State will benefit from the core infrastructure already developed and will have the opportunity to offer its citizens a national portal at a marginal cost. All the collected information will serve as a source to map health care services in Europe and to build indicators.

Strategic relevance and contribution to the public health programme

RD is a priority for action in the Public Health Programme (2008-2013). A Communication of the European Commission, entitled "Rare Diseases: Europe's challenge" was adopted on 11 November 2008 and followed by Recommendations from the Council on 9 June 2009. In these documents, the importance of providing accurate information on expert services on RD to all European citizens, is clearly stated. The Orphanet database is mentioned as the source of information on which is based what is currently known about the situation of RD in the European Union in the field of RD. Orphanet is currently the number one international website dedicated to RD in general, the only one providing an inventory of RD and giving access to classifications. Orphanet is the only project which establishes a link between the diseases, the textual information about them and the appropriate services for the patients, for health professionals and for policy makers. Orphanet is a key element of any nnational plan or strategy in the field and mentioned as such in the Council Recommendation

Methods and means

The search for information on each RD will be conducted by a systematic search of medical and scientific literature. The production of textual information is all expert authored and peer reviewed. The collection of data for the directory of expert services will be carried out at the country level, using a methodology which is already in place. The data is formated to meet the requirements of the database, validated in terms of relevance for the project, and injected in the database. Once a year every cited professional receives all the information related to his/her speciality for re-validation or modification. Each national team will have access to a user-friedly tool to edit its national Orphanet website and another one to extract its national data for presentation in reports or books for dissemination at coutry level. The data will be available in RDF and OWL format and posted on a new section of the website for other external users.New tools necessary to ease the management of the project will be developed and two new committees will be implemented to improve the governance.

Expected outcomes

The overall outcome is to serve as the reference source of information on RD for European citizens. The inventory of RD will be completed to be as comprehensive as possible and this inventory will be made available as PDF documents for easy use by policy makers and health care managers. The inventory will be published under several formats. The encyclopaedia of RD will be expanded and updated, translated into French, German, Italian, Spanish, and into more languages if a MS decides to support the translation. The directory of expert services will be truly comprehensive. The expert resources will be published as Orphanet Report Series for more effective communication. The whole dataset will be directly accessible for re-use in Rich Data Format (RDF) and Ontology Web Language (OWL), to ensure dissemination of the Orphanet nomenclature of RD and to maximise the use of collected information on expert services. The visibility and friendliness of the website will be improved as well as the governance of the project as a whole to reflect the new involvement of health authorities of MS.

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- The University of Manchester, United Kingdom
- Universitatea de Medicina si Farmacie "Gr.T.Popa" Iasi, Romania
- University Medical Centre Ljubljana , Slovenia
- University of Tartu , Estonia
- Vilnius University Hospital Santariškių Klinikos Centre for Medical Genetics, Lithuania
- Väestöliitto ry - The Family Federation of Finland, Finland
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EC CONTRIBUTION:
EUR 3295857.00

DURATION:
36 month(s)

KEYWORDS:
- Rare Diseases
- Database
- Knowledge bases
- Classification
- Drugs,orphan

PROJECT NO 20101203

EUROPEAN REGIONS ENFORCING ACTIONS AGAINST SUICIDE (EUREGENAS)

Abstract

General objectives

Mental ill health has a unique impact on all aspects of life at individual and community levels and represents a major economic burden. Suicide is never the consequence of a single cause or stressor and its rate can vary between regions and local communities as well as over time and within various risk groups. Given the existing discrepancies in suicide rates within Member States and regions, this project brings together 11 regions with different experiences in suicide prevention, with the objective of undertaking a bottom-up approach for large-scale interventions so as to lower rates of suicide in diverse populations. The development of large-scale and evidence-based programmes has a three-fold aim: 1) strengthening community-based systems of early detection, support and referral of suicidal behaviour 2) creating sustainable networks within each participating region that should ensure continuity of prevention programmes, 3) reduction of suicide rates in risks groups by improving the efficacy of care and support.

Strategic relevance and contribution to the public health programme

The project is focused on implementing evidence-based and culturally adequate suicide prevention programmes. According to the second programme of Community action in the field of public health, the project promotes the use of regional cluster management as an innovative method to improve the existing services. Special attention will be given to tailored-made solutions that would be developed by taking into account target groups, social trends and the contextual needs of each participating region. For instance, the e-conceptual framework, integrating different levels of care, will be developed by involving youngsters in the definition of online services that are addressed to them. By encouraging regional interventions and campaigns dedicated to both target groups and lay people, the project aims to implement the Mental Health Pact in relation to: 1) prevention of suicide, 2) destigmatisation of mental health disorders, 3) promotion of health in youth. Furthermore, the project aims to develop guidelines and promote evidence-based best practices to be included in the Mental Health Compass.

Methods and means

It is clear that suicide prevention requires an innovative, comprehensive multi-sectoral approach, including both health and non-health sectors. Our aim is to achieve sustainability through a bottom-up approach focusing on GP training, media campaigns, community events and intervention with risk groups. A crucial aspect is the creation of sustainable networks connecting the new and existing community players in suicide prevention on a routine basis. However due to budget limitations, the evaluation of the work will be piloted for each type of intervention in at least 5 regions. Tailored interventions will be adopted to reach risk groups such as the so-called survivors, namely persons bereaving the loss of a relative or friend due to suicide. A key aspect of the project will be to increase scientific and clinical knowledge on efficacy of support groups for suicide survivors.

Expected outcomes

The project aims to promote evidence-based suicide prevention interventions through pilot interventions. Expected qualitative and quantitative outcomes include:• An increased level of awareness and change in attitude towards mental ill health in lay people and other stakeholders. • An improved understanding of the health and socio-economic causes of suicide in the general population and in specific target groups. • Establishment of stable networks between multipliers, namely local players and GPs and mental health providers. • Increased scientific and clinical knowledge on the efficacy of support groups for suicide survivors, overcoming the gap in this field. Finally assessing the benefits of this approach with respect to other more structural and expensive therapeutic options. • Decreased suicides rates in the general population of the regions involved in the project. This objective cannot be assessed during the life-cycle of the project but represents a long-term outcome.

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EC CONTRIBUTION:
EUR 750000.00

DURATION:
36 month(s)

PROJECT NO 20101204

EUROPEAN HEART HEALTH STRATEGY II (EUROHEART II)

Abstract

General objectives

- Providing the most up to date statistics on CVD in Europe (including a cost of disease study in the EU) and analysing these data
- Identifying the most effective and cost effective CVD prevention policies
- Predicting future CHD trends
- Sharing knowledge on nutrition, physical activity and the prevention of cardiovascular diseases in Europe
- Building capacity in the cardiovascular patients community

Strategic relevance and contribution to the public health programme

CVD is the main cause of death and a major cause of disability in Europe. 80% can be prevented. Small reductions in incidence and mortality: lead to large health gains; reductions in direct and indirect health care costs. CVD: costs the EU economy € 192 billion/year; is the main contributor to inequalities in health; health gains will particularly benefit less-advantaged groups. EuroHeart II will: act on EU policy documents on CVD; follow up on EuroHeart I: build on the WHO Europe document 'Gaining health - Analysis of policy development in European countries for tackling noncommunicable diseases'; contribute to the programme by providing data in an easily accessible format; informing policy makers by offering tools to support selection of most (cost) effective CVD prevention policies; allow knowledge-sharing (e.g. on nutrition & physical activity); build capacity in the NGO community involved in CVD prevention; evaluate the impact of the joint diabetes/CVD guidelines.

Methods and means

A partnership of academia, research centres, NGOs and health professionals has been established to achieve the objectives of EuroHeart II. A steering committee will be established to ensure implementation of the work packages as well as facilitate communication between the work package leaders. The steering committee will be supported by an external advisory board with representatives from WHO and the European Commission to maximise synergies. Representatives from national health ministries will be invited to European, regional and national meetings.

Specific objectives will be achieved through research, interviews, conferences and workshops and collection of clinical data. Research results will be made available in reports (in print and on relevant websites) and at meetings with partners and stakeholders.

Expected outcomes

- allowing decision makers to develop CVD prevention policies based on the most up- to-data statistical and economic data, analyses and scientific impact models;
- empower wider stakeholders groups to assess and address the situation in their countries
- help empowering the CVD NGO sector to have a larger impact on health related nutrition and physical activity policy in their countries through conferences and meetings presenting the latest evidence;
- assist in strengthening the impact of the CVD patient community in the decision making process through sharing of knowledge and experience;
- contribute to improving the outcome of diabetic patients with CVD through providing information on practice characteristics related to the implementation of the diabetic guideline and changes in health outcomes and comparing countries in Europe where the guideline has been extensively disseminated and those countries where the guideline has been poorly disseminated

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EC CONTRIBUTION:
EUR 450000.00

DURATION:
30 month(s)

KEYWORDS:
- Public Health
- Health Resources
- Public policy
- Health services needs and demand
- Research

PROJECT NO 20102202

EUROPEAN PARTNERSHIP FOR ACTION AGAINST CANCER (EPAAC)

Abstract

General objectives

The general objective of this Joint Action is to contribute to the reduction of cancer burden in the EU by actions in the areas of health promotion and prevention, screening and early diagnosis, cancer related health care, coordination of cancer research and cancer information and data. The overall objective is to support Member States (MSs) in the development of their National Cancer Plans (NCPs). (Please find the entire text in the accompanying Word document, Annex 1b).

Strategic relevance and contribution to the public health programme

EPAAC contributes to health protection and safety of citizens through actions in the field of cancer control. It contributes to better knowledge of and information on the prevention, diagnosis and control of cancer, as an ageing related topic. It places emphasis on promoting a healthy lifestyle. EPAAC helps to identify the causes of cancer inequalities within the EU and to exchange the best practices to tackle them. This issue is one of the priorities of the 2d Health Programme, due to the enlargement of the European Union and possible further enlargements. EPAAC is a response to an explicit request by EC and MSs for bringing considerable added value in tackling major health challenges more effectively, through information sharing and exchange of expertise and best practice. (Please find the entire text in the accompanying Word document, Annex 1b).

Methods and means

The state-of-play in the development of NCPs in the EU will be established. An analysis of the content of the existing plans will be conducted using specifically prepared questionnaires. Areas of key importance will be identified and guidelines for a high level standard NCP which will include the listed key areas will be prepared. To promote cancer prevention measures EU Week Against Cancer II-EWAC II will be organized. Schools of Screening Management will be initiated and exchange of information and collaboration between MSs will be promoted. Best practices in cancer care will be identified and assessed. Published experiences will be reviewed, existing regional networks will be mapped and workshop with experts will be organized. Surveys, mapping and workshops will be used to develop, review and harmonize clinical guidelines. Questionnaires on cancer research will be prepared. An European map of cancer information will be built.(Please find the entire text in the accompanying Word document, Annex 1b).

Expected outcomes

The outcomes of EPAAC will be an improved quality of health care and an improved quality of peoples' life. Member States will be supported in the development of their National Cancer Plans (NCPs), public health programmes designed to ensure coordinated and centrally managed implementation of evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation, palliation and research for innovative solutions, and to evaluate outcomes. The EPAAC activities will contribute to the higher awareness of the importance of cancer prevention and positive change in people's behavior is expected. Early diagnosis of cancer will be facilitated, medical knowledge of health professionals regarding screening and early diagnosis will be enhanced, treatments of patients will be improved, financial resources for cancer research will be used properly, data concerning cancer will be readily available in a united EU data map (Please find the entire text in the accompanying Word document, Annex 1b).

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- ERI 3 INSERM Cancers & Populations, France
- European Health Management Association Ltd, Ireland
- European Hospital and Healthcare Federation, Belgium
- European Oncology Nursing Society, United Kingdom
- European School of Oncology, Italy
- European Society for Clinical Nutrition and Metabolism, Belgium
- Federale Overheidsdienst Volksgezondheid, Veiligheid van de Voedselketen en Leefmilieu (Federal Public Service Health, Food Chain Safety and Environment), Belgium
- Fondacione IRCCS "Istituto Nazionale dei Tumori", Italy
- Foundation Nederlands Normalisatie Instituut, Netherlands
- Institut Catala d'Oncologia, Spain
- INSTITUT NATIONAL DU CANCER, France
- Institute of Oncology Ljubljana, Slovenia
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- Irish Cancer Society, Ireland
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EC CONTRIBUTION:
EUR 3154994.00

DURATION:
36 month(s)

KEYWORDS:
- CANCER
- PREVALENCE
- RESEARCH
- PREVENTION
- SCREENING

PROJECT NO 20101206

EUROPEAN PHYSICAL ACTIVITY PROMOTION FORUM (MOVE)

Abstract

General objectives

The project aims to identify, qualify and implement good practices in cross-cutting community initiatives to promote health-enhancing physical activity in socio-economically disadvantaged areas. Specific objectives are

- Identification of good practices
- Qualification/valorization of good practices
- Promotion of good practices
- Mobilization of cross-cutting partnerships and networks in physical activity
- Implementation of pilot actions

Strategic relevance and contribution to the public health programme

The MOVE project builds on and complements a number of related actions:

- EAHC funded projects in particular IMPALA, PASEO, EPODE, EEN, HEPS, LifeCycle, PATHE, and SHAPE UP.
- The 9 EC Sport Unit Actions in Health, in particular HCSC, YOU NEED EXERCISE, SANTE and The HUB.

To this should be added the strong European dimension of the project – to engage a very wide range of European/international stakeholders in a committing cooperation, and indeed to use this as a model for both national and local partnerships of the same nature.

In particular, MOVE Partners have addressed the links to the EU platform for action on Diet, Physical Activity and Health (which will see clear promotional added value) as well as to the extensive work and projects of WHO Europe/HEPA network (MOVE partners are already involved).

Methods and means

a) identification of good practice: MOVE will build on existing experience and literature and adapt and define its own methodology relevant for the specific Project Target Groups.
b) qualification/valorization of good practices: The practices will be grouped to allow aggregation of common quality traits, feeding in the overall best practice handbook and best practice guidelines.
c) promotion of good practices: Hands-on initiative and dialogue with relevant stakeholders to take up the project results in new actions via two specialized congresses and the WeMOVE web platform (with three well-defined target groups)
d) mobilization of cross-cutting partnerships: Performing substantial international cross-sector networking to facilitate specific future partnerships via the NETWORKPLACE methodology. International networking will motivate similar cooperation on a national/local level (via Associate Partners) and allow shared promotion/lobby efforts.
e) implementation of pilot actions: Collaborating Partners will engage in intensive consultation process in order to initiate new pilots.

Expected outcomes

- 5 new European level/international cross-cutting partnerships to promote physical activity have been established
- 8 new national cross-cutting partnerships to promote physical activity have been established with motivation and inspiration from the international cross-cutting partnership behind the MOVE proposal
- 45 new local cross-cutting partnerships to promote physical activity have been established with motivation and inspiration from both the international and the national cross-cutting partnerships
- 15 pilot actions on national or local level initiated

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EC CONTRIBUTION:
EUR 676020.00

DURATION:
36 month(s)

KEYWORDS:
- Physical Activity
- Public Private Partnerships
- Conferences
- Health Promotion
- Sport

european register euroms project of european multiple sclerosis platform

PROJECT NO 20101213

EUROPEAN REGISTER FOR MULTIPLE SCLEROSIS – A TOOL TO ASSESS, COMPARE AND ENHANCE THE STATUS OF PEOPLE WITH MS THROUGHOUT THE EU (EUREMS)

Abstract

General objectives

With the general aim of establishing a European Platform for systematic collection, exchange and analysis of longitudinal data on Multiple Sclerosis (MS) in Europe, the EUReMS project is set up by an international consortium to address the currently unmet needs of People with Multiple Sclerosis (PwMS) that have been identified by the Consortium as:

- lack of knowledge on the causes of MS;
- scarce knowledge on effectiveness of MS disease modifying drugs;
- lack of data on the burden of MS in Europe.
- EUReMS is underpinned by the following principles:
- it should be built on already existing national or regional data collections;
- it should involve and combine the expertise of clinicians, researchers and patient organizations;
- it should address questions at an international level;
- it should include highest available expertise concerning its organization and technical solutions;
- it should ultimately contribute to improve access for PwMS across Europe to evidence-based health care services and offer a cutting-edge research tool to gain further insight into various aspects of MS.

Strategic relevance and contribution to the public health programme

The European Commission through its latest Communications on health issues has expressed its willingness to tackle more effectively health inequalities faced by the EU citizens such as the provision of health services, the design of health promotion and health protection activities, living and working conditions. The Commission intends to provide support to the Member States in identifying successful strategies to reduce health inequalities and in their implementation: by improving data collection and monitoring on health inequalities and by identifying and prioritizing areas of improvement and best practices that can be shared between the Member States. The EUReMS project addresses the current lack of data at a EU level on treatment and care of PwMS. In doing so, the EUReMS will meet the expectation and the main objective of the European Union health policies to improve quality of health care and treatment and ultimately, quality of life of PwMS throughout Europe.

Methods and means

- Draft and disseminate to the SC and the SAB as early as M3 the first draft of the Report 1 and the Agenda of the First Consensus Meeting;
- The preliminary data set (M4) will be distributed by mail and decision making will be supported by established processes such as the Delphi technique;
- Pseudo-likelihood approaches to data analysis strategies will be utilized;
- An electronic data capture application that is already operative at the WP Leader is selected;
- A training course on the usage of the Portal for exchange of MS information will be offered by WP Leader 4 at the M16 to all users;
- Test the EUReMS pulling data from the group of national registers that is already partnering in the project;
- Consult legal advisor(s)and organise open discussion with all partners on the Register Charter;
- Develop a set of admission and recognition criteria for EUReMS participation;
- Organise two Workshops with all EMSP members at M11 and M16 to discuss sustainability and continuous recruitment of DPs for EUReMS.

Expected outcomes

Short-term Outcomes:

- A Critical mass of national and regional MS centers for collaborative and sustainable European research in the field of MS;
- An IT platform for collaboration and dissemination of knowledge on MS;
- Contribution to EU policies.
- Long-term Outcomes:
- Higher awareness of MS among both, clinicians and general public in the European Union;
- Improved knowledge and management of MS;
- Implementation of a quality management policy for diagnosis and management of MS;
- Sense of community for affected people and their families

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EC CONTRIBUTION:
EUR 987198.00

DURATION:
36 month(s)

KEYWORDS:

- multiple sclerosis
- disease registers
- data collection
- codes of ethics

PROJECT NO 20102204

EUROPEAN SURVEILLANCE OF CONGENITAL ANOMALIES (EUROCAT)

Abstract

General objectives

To facilitate the reduction of the public health burden of congenital anomalies (CA) by epidemiological surveillance through the EUROCAT network of population-based congenital anomaly registers.

Strategic relevance and contribution to the public health programme

Congenital anomalies are a major group of mainly rare diseases where concerted action across Europe has been identified as a priority in the Council Recommendation of 8 June 2009 on an action in the field of rare diseases, and in the Communication from the Commission on Rare Diseases: Europe's challenges of November 2008. These recognise the need for registries and databases co-ordinated at a European level, for pooling of expertise at European level, for improving the coding and classification of rare diseases, for comparable epidemiological data at EU level, and for identifying the possibilities for primary preventive measures – all these areas being central to EUROCAT's activities. Moreover, they emphasise the need for sustainability of successful European networks in these areas.

Methods and means

The EUROCAT network has been in existence since 1979, in the last ten years co-funded by DG Sanco's Rare Diseases and Public Health Programmes. 1.5 million births per year, comprising 28% of births in the European Union as well as some non-European countries, are covered by 38 Registries in 21 countries. Cases of congenital anomaly among livebirths, stillbirths and terminations of pregnancy following prenatal diagnosis, are registered using multiple sources of information. A standard anonymised dataset is transmitted by each member Registry, using common software, to a central database at EUROCAT Central Registry, and subject to data quality validation. The Central Registry ensures the provision of updated prevalence and related data on the EUROCAT website in a user-driven interactive table generation format (www.eurocat-network.eu). It further conducts statistical monitoring for trends and clusters, and will provide data and assistance to the other workpackages to answer a variety of questions pertinent to prevalence, prevention and prenatal screening.

Expected outcomes

1. Available and accessible epidemiological info updated to 2011 on prevalence of CA, perinatal mortality due to CA, and prenatal detection rates, on EUROCAT website
2. The detection, investigation and reporting of clusters and trends in CA prevalence
3. Assessment of teratogenic impact of new or changing environmental exposures, including swine flu related exposures as well as maternal chronic diseases
4. Evaluation of potential for linkage between registers and e-info systems on exposure
5. A framework for national plans for primary prevention of CA, and evaluation of progress in the prevention of neural tube defects by raising periconceptional folic acid status
6. Evaluation of impact of delayed childbearing and changes in prenatal screening techniques as well as policies on Down Syndrome
7. The development of EUROCAT's role as core pregnancy-related pharmacovigilance system in Europe (EUROmediCAT)
8. The addition of at least 3 new registries to network, inc 2 new EU countries, the provision of guidelines and related software to interested regions/countries
9. Improved coding and classification of CA
10. Two European Symposia on Prevention of CA

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EC CONTRIBUTION:
EUR 1106302.00

DURATION:
36 month(s)

KEYWORDS:
- Rare Diseases
- Congential Anomalies
- Prevention
- Prevalence
- Epidemiological Surveillance

PROJECT NO 20101201

EUROPEAN REGISTRY AND NETWORK FOR INTOXICATION TYPE METABOLIC DISEASES (E-IMD)

Abstract

General objectives

The overall aim of the European registry and network for Intoxication type Metabolic Diseases (E-IMD)is to promote health for individuals affected with rare organic acidurias (OADs) or urea cycle defects (UCDs). E-IMD has two specific objectives:

(1) To establish a European patient registry describing the disease course, epidemiology, diagnostic and therapeutic strategies for OADs and UCDs and to provide information to national and EU healthcare authorities. Anonymised data collection via a web-based password-protected EU registry will be based on routine follow-up parameters in 15 EU countries.

(2) To provide European evidence-based consensus care protocols for patients with OADs and UCDs. Based on the largest available collection of patient data (see objective 1) and a systematic literature search, a European consensus group will describe the best evidence available for the diagnosis and treatment. Consensus care protocols will be translated into official EU languages, provided via the E-IMD website and serve as a template for national guidelines and patient brochures.

Strategic relevance and contribution to the public health programme

E-IMD focuses on patients affected with one of the ten OADs or UCDs. Each of these intoxication type metabolic diseases has an estimated prevalence of 1 in 50,000 to 200,000 newborns within the EU. Given the particularly low number of patients and the complexity of the diseases, no national or regional project in Europe would be able to perform this work. The registry will bring together physicians, carers, scientists, patients and industry from at least 15 European countries. The countries with fewer resources will benefit from those with more resources i.e. access to consensus guidelines in their own language. It will map onto the evolving national rare disease plans and is complementary to existing rare disease networks such as Orphanet, CEMARA and CIBERER. In accordance with the second Health Programme E-IMD promotes health, improves quality of life, and reduces health inequalities for patients with rare IEM. It provides best scientific evidence, empowers patients and their families and strengthens the Community's status in the field of rare IEM.

Methods and means

E-IMD will set up the first web-based password-protected EU registry for OADs and UCDs entering relevant parameters of patients with the 4 most common OAD (methylmalonic, propionic, isovaleric aciduria, and glutaric aciduria type I) and 6 UCD (inherited deficiency of N-acetylglutamate synthase, carbamoylphosphate synthase 1, ornithine transcarbamylase, arginase, argininosuccinate synthase and lyase). This provides a unique basis for improving our knowledge and understanding of the natural history of these diseases and their impact for patients and their families, and for evaluating patient care and outcome. Differences between centres and countries will be evaluated, and actions taken to address inequalities i.e. provision of advice and consensus care protocols. The registry and systematic literature search are important sources to provide evidence-based up-to-date information and consensus care protocols to patients and their families as well as health care professionals. Consensus care protocols will be developed according to the Scottish Intercollegiate Guidelines Network (SIGN).

Expected outcomes

The overall intended impact is to improve access to rapid diagnosis and care for patients with OADs and UCDs; the E-IMD philosophy is that all patients in all MS should have an equal right to the best up-to-date care.

E-IMD will help make this happen by

1) objectively measuring and evaluating current management strategies and outcome of patients in at least 15 European countries which is an important basis to better understand the natural history of these rare diseases, to optimize current treatment strategies and to initiate cohort clinical studies,
2) providing evidence-based and consensus-agreed diagnostic and management protocols which will increase the transparency for patients and experts, will help to harmonise current diagnostic and therapeutic approaches, and will be adapted to specific country infrastructures, and
3) empowering patients and patient organisations by providing up-to-date information in their own language.

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EC CONTRIBUTION:
EUR 779746.00

DURATION:
36 month(s)

KEYWORDS:

- Rare Diseases
- Metabolism, Inborn Errors
- Registries
- Guidelines
- Evidence-Based Medicine

PROJECT NO 20102203

JOINT ACTION ON HEALTH INEQUALITIES (EQUITY ACTION)

Abstract

General objectives

The General Objectives of the joint action are to help to reduce health inequalities by:

- developing knowledge for action on health inequalities
- supporting the engagement of Member States, regions and other stakeholders in action to tackle socio-economic and geographic health inequalities
- sharing learning between Member States and other actors
- supporting the development of effective action to tackle socio-economic health inequalities at the European policy level.

Action to tackle health inequalities is required at EU, national, regional and local level, with a wide range of stakeholders across a range of policy areas. The joint action aims to strategically engage with key players to develop, evidence and knowledge of what works.

Strategic relevance and contribution to the public health programme

The current Joint Action directly supports the Commission Communication responding to the actions:

1. Develop health inequalities audit approaches through the Health Programme in Joint Action with member states willing to participate
2. Include health inequalities as one of the priority areas within the ongoing cooperation arrangements on health between the European regions and the Commission.
3. Review the possibilities to assist Member States to make better use of Cohesion policy and structural funds to support activities to support activities to address factors contributing to health inequalities.
4. Develop ways to engage relevant stakeholders at European level to promote the uptake and dissemination of good practice.'

It responds directly to the 2010 Work Plan call for a Joint Action on health inequalities, and is a direct outcome of deliberations between interested member states and the European Commission on how to deliver a structured programme of work.

Methods and means

The project will develop a common understanding of a Health in All Policies approach,and its application at EU, MS and sub-national level. Consensus will be developed on methodologies for conducting policy orientated HIA with an equity focus (HIAef), and Health Equity Audits (HEA). This will be achieved by reviews of current practice, identifying effective practice, and collaboratively identifying components of the tool. Countries will test an HIAef or HEA, with an HEAs being carried out at EU level. Processes for developing an effective cross-government health equity focus will be discussed.

A regional network will be established which will identify through a case study approach the focus, information, resources, drivers, opportunities and barriers to regional action on HI, and access to structural funds. Recommendations will be made to inform the future drafting of structural funds.

A scientific and technical advisory board will be established to review evidence, and inform scientific discussion.

Stakeholder engagement will take place on two agreed themes and EU level meetings.

Expected outcomes

The primary outcome will be increased engagement and mutual learning of the EU and MS on tackling socio-economic and area based inequalities in health. The JA will lead to a greater consensus on approaches which work, and knowledge and awareness of tools and methods which promote a cross government equity focus.

The JA will foster greater engagement of regions in EU wide work, and in particular through the CoR.

An intended outcome is to influence the drafting of the 2014-20 structural funds guidelines to enable them to be more effectively used to address SDH at regional level, and identify effective use of the funds for tackling HI.

The JA will engage new stakeholders on a number of themes and increase knowledge of the potential levers and drivers to cross-sectoral working to meet equity standards.

To the extent that MS and the EU are able to put the learning into practice, the JA will support the long-term objective of the EU communication on reducing health inequalities within and between countries, and assist in the development of action to tackle the underlying societal causes.

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EC CONTRIBUTION:
EUR 1699999.00

DURATION:
36 month(s)

KEYWORDS:
- Public Health
- Factors socio-economic
- Inequalities
- Promotion of Health
- Population Groups

EuroSafe
European Association for Injury Prevention and Safety Promotion

PROJECT NO 20102205

JOINT ACTION ON MONITORING INJURIES IN EUROPE (JAMIE)

Abstract

General objectives

The objective of JAMIE is to have by the end of 2013 in the majority of MSs a common hospital based surveillance injury system in operation enabling EC and MSs to monitor injury risks. JAMIE will:

- refine the current methodology for collecting hospital based injury data with a view to allow data collection also in less resourced settings and to ensure that the quality of data will meet the EuroStat-quality requirements; and

- incorporate in 26 out of the eligible countries (EU31) into the European IDB monitoring system and into the IDB-exchange mechanism.

The Joint Action will make available national capacities and resources for applying a pro-active approach to Member States, by offering assistance: such as standardized trainings for national data administrators, twinning programmes, on-site consultations and country specific coaching for countries which still have to start or restart a system, continuous supervision, and joint monitoring actions levels of implementation in each MS.

Strategic relevance and contribution to the public health programme

Current health statistics statistics do not provide sufficient information as to the causes and circumstances of injuries. In order to fill this information gap, in past decade 13 Member States (MSs) have developed an injury monitoring system in hospitals: the European Injury Database (IDB). It is now time to work towards a full geographical coverage of EU MSs and to enhance the quality of data as regards to representativeness, accuracy, comparability. This will also allow IDB to become eligible for being included within the European Statistical System (OJ L 354/70, 31.12.2008).

JAMIE supports the aims of the second Health Programme 2008-2013 of complementing, supporting and adding value to the policies of the MSs with a view of protecting and promoting health and safety (OJ L 301/3, 20.11.2007) as well as the implementation of the Council Recommendation on the prevention of injuries which calls for Community-wide injury information based on national injury surveillance instruments (OJ C 164/1, 18.7.2007).

Methods and means

The practically achievable level of quality will be defined in accordance with EuroStat (ESS) criteria in consultation with an international scientific advisory group and EuroStat experts for injuries and public health statistics.

Training will be given to national data administrators (NDAs), project leaders in reference hospitals and key persons responsible for national injury reporting through standardized training events, twinning programmes and standardized reporting on compliance with the standards.

Country specific work plans will be developed and executed. For “new-comers” seed-money will be offered. With IDB reference hospitals standardized collaboration contracts will be concluded. For all NDAs central support for the implementation will be provided (counselling on technical and other practical questions).

The MSs-data (including quality audits) will be centrally checked and released for annual upload by DG Sanco. Two new annual reports on “Injuries in the EU” will be produced. IDB data clearing house will be continued.

Expected outcomes

EU-wide consensus will be achieved on IDB data quality requirements and confidence intervals for IDB based estimates. The great majority of MSs will be able to report IDB-data on a regular base, allowing benchmarking between MSs and EU-level monitoring.

It is expected that after the completion of the action, at least 26 countries have designated national injury data administrators, who are well trained in the Community approach in injury surveillance and capable to implement the system if this is not yet achieved in the course of the action. There will be an increased use of IDB data for prevention purposes at national level.

The entire IDB system (its methodological basis, geographical coverage, data quality, organizational processes) will be considerably improved, and therefore ready for starting the next phase, which is the political, technical, and legal consultation process of an actual transfer to the European Statistical System, as part of the set of public health statistics.

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EC CONTRIBUTION:
EUR 785323.06

DURATION:
36 month(s)

KEYWORDS:
- wounds and injuries
- accidents
- data collection
- hospitals
- euro

NEW1P | NIGHTLIFE EMPOWERMENT & WELL-BEING IMPLEMENTATION PROJECT

PROJECT NO 20101207

NIGHTLIFE EMPOWERMENT AND WELL-BEING IMPLEMENTATION PROJECT (NEW IMPLEMENTATION)

Abstract

General objectives

1 To improve field work interventions: improving and standardizing existing interventions reducing synthetic drugs related harm, facilitating their transferability and implementation.
2 To adapt responses to partygoers mobility: increasing harm reduction behaviors among tourist partygoers and reducing crisis situations in recreational settings.
3 To develop innovative responses adapted to youth cultures: developing individual harm reduction strategies through the use of interactive technology tools and emerging media.
4 To develop community empowerment: improving health settings and reducing harm related through community empowerment among European night clubs and events, implementing "Party+" labels within EU cities or regions and involving big summer festivals organizers in harm reduction responses.
5 To implement new projects and to enlarge the network: initiating and supporting emerging projects reducing synthetic drugs related harm in nightlife settings.
6 To improve the rapidity and quality of field responses in relation with new trends, new substances and adulterants.

Strategic relevance and contribution to the public health programme

By developing community empowerment, involving local policy makers and nightlife professionals, the project will "involve new (non-traditional) actors for health in sustained, cooperative and ethically sound actions, both at regional or local level and across participating countries" and support the "importance of a holistic approach to public health".

By improving nightlife settings and promoting peer education, the project will "place emphasis on improving the health condition of young people and promoting a healthy lifestyle and a culture of harm prevention among them".

By improving and implementing on the field reproducible and transferable best practices, it will address problems connected with the standardisation of practices across member states
By implementing responses in EU member states and regions where safer nightlife projects are not yet implemented, it will "reduce health inequalities in and between EU member states and regions".

By allowing in the future the field's involvement in the EU Civil Society Forum on Drugs, it will contribute to the EU Drug Strategy.

Methods and means

- The "Party+" WP will promote safer clubbing labels in new cities, contributing to community empowerment.
- The WP8 will organise 6 common interventions in big music festivals based on peer education, harm reduction information and community empowerment including festival organisers and new member states. The European teams will adapt the interventions to tourist partygoers, use emerging media and contribute to the trends reports.
- The TEDI WP will set up a database of synthetic drug checking results as well as report on new trends to improve the rapidity of responses.
- The WP7 will develop individual harm reduction strategies through the use of interactive technology tools.
- The WP5 will collect, adapt and support the implementation of good practice standards and guidelines, improving interventions.
- The WP6 will organise training sessions and study visits in order to improve existing interventions, involving nightlife professionals and participants from new member states.
- The WP dissemination will organize a conference, produce a Website and organise the NEW EU Night.

Expected outcomes

- 30 european NGOs implementing standards guidelines
- In 6 big festivals (180.000 partygoers), 20% of the partygoers declaring having changed their behaviors positively.
- Among the 200 night clubs involved in "Party +", reducing 20% of tourist partygoers crisis situations reported by club owners.
- To improve knowledge on synthetic drugs-related harm and how to reduce it among people reached by Emerging Media
- To improve nightlife stakeholders' community empowerment among "Party +" cities and 6 summer festivals
- 200 night clubs involved in a safer party label process. Generate New labels processes.
- Reduction of 20% of crisis situation reported in "Party +" clubs and the big summer festivals
- 5 new projects developing synthetic drugs harm reduction interventions
- 20 new member projects integrating the network from 12 countries
- 30 projects from 14 countries having adapted their interventions by using the alerts, recommendations and trend reports.
- Increase the knowledge of 300 stakeholders on synthetic drugs and new adulterants through the TEDI news letters.

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EC CONTRIBUTION:
EUR 900000.00

DURATION:
36 month(s)

KEYWORDS:
- Drugs
- Risk reduction
- Nightlife
- Community empowerment
- Field work

PROJECT NO 20101214

PREVENTING DEPRESSION AND IMPROVING AWARENESS THROUGH NETWORKING IN THE EU (PREDI-NU)

Abstract

General objectives

The objectives of PREDI-NU are:

1) To use more systematically the possibilities offered by information and communication technologies (ICT) for mild depression.This enables reaching many male patients with mild depression who are reluctant to seek medical help.Such interventions consistently show positive effects among adult populations and adolescents.
2) To improve early identification of depression and related mental health difficulties. Therefore,a depression awareness training programme will be developed combining training materials for implementation of an internet based self-management intervention with depression awareness elements,that have been proven to be effective among health care professionals,in particular general practitioners (GPs) and community facilitators working with young people and adults. This programme will be sustained by a Train-The-Trainer (TTT) model.
3) To develop a European Mental Health website, comprising modules on E-Awareness and E-Self-management to enhance wider implementation and sustainability of the PREDI-NU intervention.

Strategic relevance and contribution to the public health programme

PREDI-NU contributes to the EC's Health Programme for the implementation of the second programme of community action in the field of health (2008-2013),supporting the strand 3.3.2.5"Mental health".Key objectives of the PREDI-NU intervention programme are in line with key priorities of the EC Health Programme.PREDI-NU will focus on the implementation of an internet-based guided self-management intervention for young people and adults with mild depression,which will increase the likelihood for depressed people who are reluctant to seek treatment from traditional mental health services,to receive adequate treatment.A TTT model to implement the intervention and increase awareness,and establishment of a multi-lingual European Mental Health website will assure wider implementation and sustainability of the internet-based guided self-management intervention.PREDI-NU builds upon networks established by the European Alliance Against Depression(EAAD) and aims to further develop and strenghten multidisciplinary networks to enhance depression awareness and prevent attempted suicide and suicide.

Methods and means

The PREDI-NU intervention programme will be developed, implemented and evaluated according to the following steps:

Prior to implementation an intervention for self-management of mild depression using ICTs with a version for adults (25 and over) and a version for young people aged 15-24 years will be developed. Also modules of evidence based depression awareness sessions for health care professionals, in particular GPs and community facilitators working with young people and adults will be developed. These awareness modules will be implemented along with the materials for the self-help package, using a TTT model. In order to ensure sustainability, modules on E-Depression Awareness and E-Self-management will be integrated in a European Mental Health website and made available in eight languages. Six European intervention regions in Austria, Spain, Hungary, Ireland, Estonia and Germany have been selected for a two-phase implementation plan of the PREDI-NU intervention programme. Independent process and outcome evaluation will be conducted by the WP03 partners.

Expected outcomes

The PREDI-NU intervention programme is expected to contribute to increased uptake of treatment by young people and adults with mild forms of depression. It is expected that a larger population of men, who otherwise would not receive any help, will be reached. By increasing awareness of depression among health professionals and community facilitators, PREDI-NU will contribute to early identification of depression and help to prevent attempted and completed suicides. These expected outcomes are initially expected to be observed in the six PREDI-NU intervention regions. However, by making the PREDI-NU intervention materials available in eight languages through the European Mental Health website, it is expected that the predicted outcomes will expand to other European countries. Considering that the intervention will be implemented according to a TTT model, it is expected that implementation of the PREDI-NU interventions will be sustained within and across European countries beyond completion of the PREDI-NU project after three years.

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EC CONTRIBUTION:
EUR 1099032.00

DURATION:
36 month(s)

KEYWORDS:
- Mild depression
- Self-management
- Internet
- Prevention
- Mental health

PROJECT NO 20101208

PROMOTING HEALTHY WORK FOR EMPLOYEES WITH CHRONIC ILLNESS – PUBLIC HEALTH AND WORK (PHWORK)

Abstract

General objectives

Chronic conditions and diseases have a substantial impact on the labour market and working life. This urges the need for effective job retention and workplace-based return-to-work (RTW) strategies and interventions, as this is a means of preventing employees with a chronic illness of moving into disability or early retirement pensions.

The proposed project will contribute towards the implementation of effective workplace health practices within corporate policies of enterprises in Europe, aimed at retaining and encouraging the return-to-work (RTW) of chronically ill employees. Comprehensive workplace health management and promotion (WHP) offers an effective approach combining individual and organisational interventions supporting employees with chronic conditions. Ultimately this may lead to a better quality of life and functioning, and an improvement of social economic outcomes.

Strategic relevance and contribution to the public health programme

The strategic relevance of this proposal derives from the opportunity to establish public health – private sector partnerships, and to strengthen the general case for investing in workplace health. This process allows for developing exemplary approaches to enhance job retention and RTW, and to encourage other sectors to improve their respective practices.

The proposal relates to one of the general objectives of the 2nd Health Programme, promoting health and preventing disease by addressing health determinants across all policies and activities. In particular, it will play a role in reaching the objectives in the current work plan. Health and Work and the defined actions. The proposal is to implement a campaign of action at national/regional level which would develop and maintain a community of interested stakeholders, both end user enterprises and supra-enterprise level stakeholders. This action would be complemented by dissemination activities at European level.

Methods and means

The methods involved for the implementation of the proposed actions include collecting good workplace health practices with regard to job retention and RTW targeted to chronic illnesses, bringing together public health agents and stakeholders from the employment side, and deploying an overall European campaign disseminating guidelines for good practice with national campaigns in 19 countries.

The proposed project shall deliver a mechanism for continuous networking at regional, national and European level by establishing communities of interested enterprises/employers who commit themselves to the principles of good workplace health practices and policies which enhance job retention and return-to-work of chronically ill employees.

Expected outcomes

- The main expected outcomes of the project proposal are:
- increased awareness of job retention and return-to-work needs and benefits among the various stakeholders at enterprise and supra-enterprise level;
- improved standard of workplace health strategies and interventions aimed at job retention and return-to-work among the various stakeholders at enterprise and supra-enterprise level;
- improved commitment of the various stakeholders at enterprise and supra-enterprise level to invest in job retention and return-to-work based on workplace health approaches;
- improved workplace health practice of job retention and return-to-work, including improved communication, collaboration, and coordination between healthcare providers and workplace;
- improved exchange of experiences in the field of job retention/return-to-work/workplace health promotion (WHP), and enhanced cross-border knowledge-transfer; and
- enhanced policy development in the field of job retention and return-to-work in general.

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- TNO, Netherlands
- University Medical Centre Ljubljana, Slovenia
- Upper Austrian Sickness Fund, Austria
- Work Research Centre, Ireland

EC CONTRIBUTION:
EUR 587574.83

DURATION:
24 month(s)

KEYWORDS:
- Workplace
- Chronic disease
- Promotion of Health
- Work retention
- Return to work

PROJECT NO 20101209

PROMOTION OF YOUNG PEOPLE'S MENTAL HEALTH THROUGH TECHNOLOGY-ENHANCED PERSONALIZATION OF CARE (PRO-YOUTH)

Abstract

General objectives

The general objective of PRO-YOUTH is the promotion of mental health of young people aged 15 to 25 through personalized stepped care integrating prevention, early diagnosis, immediate intervention and appropriate management of eating disorder (ED) related mental health problems. Specifically, the project aims at the improvement of young people's quality of life, by reducing the number of individuals affected by ED and minimizing the burden and duration of suffering for those affected. Moreover, PRO-YOUTH focuses on reducing inequalities, reaching underserved populations, and de-stigmatising mental disorders by psychoeducation and peer support. Young people's self-management skills are strengthened and they are encouraged to seek the best and most effective health care assistance. The inclusion of different settings, contexts, and stakeholders together with the respective capacity building will provide a knowledge base that better enables young people and their health care providers to adopt proven strategies to promote mental health and prevent mental illness.

Strategic relevance and contribution to the public health programme

The promotion of mental health and the prevention of mental illness in young people deserve full attention by the European health strategies. Mental illness accounts for a considerable proportion of the disease burden in Europe and for a growing proportion of the associated costs. Healthcare systems in various countries face similar challenges (e.g. late diagnosis, inadequate treatment of mental illness). PRO-YOUTH will contribute to the second Health Programme's objective "Promote Health", specifically to the promotion of mental health.

The project involves young people in the development and implementation of online platforms for mental health promotion (specifically the prevention of eating disorders) in educational settings (schools, universities). Special emphasis is given to the collaboration between PRO-YOUTH partners and local / regional authorities and health institutions. Sound anchoring of the PRO-YOUTH initiative within the respective region-specific structures will ensure long-term sustainability of the implemented interventions.

Methods and means

The PRO-YOUTH network includes partners from seven countries who are well connected with regional or national health care institutions. The network will take advantage of the Internet platform Es[s]prit developed and successfully evaluated by the main partner. Only easy-access and broadly available information and communication technologies (ICT) will be used ensuring easy and low-threshold access to the platforms. The chosen strategy will allow to address large samples at reasonable time and effort. Special emphasis will be given to capacity building by training key persons delivering the intervention including young people who will serve as student moderators.

The implementation of the PRO-YOUTH platforms will ensure the provision of seamless care from prevention to early intervention to treatment. Support will be provided in part via automated, but personalized online modules. If need for more intense help is detected, expert support will be provided via the Internet and if necessary face-to-face.

Expected outcomes

PRO-YOUTH will promote mental health and prevent ED through the reduction of ED risk factors and providing timely support if needed. The personalized stepped care approach promises to have a positive effect on the healthy life years (HLY) which should result in less sick days and improved academic performance. Furthermore, the early detection of health problems will lead to less severe symptom courses resulting in reduced treatment costs. The internet allows for anonymous, low intense offers, encouraging students to get help according to their personal needs. If indicated, online-counsellors can use the first anonymous contact to motivate students to use more intense programme components or refer them to the regular health system.

PRO-YOUTH will help to reduce inequalities by ensuring accessibility to everyone by using only technologies which are broadly available. This promises an extensive reach especially to rural and remote areas. Inequalities will be reduced by providing specific versions for minorities.

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EC CONTRIBUTION:
EUR 930378.00

DURATION:
36 month(s)

KEYWORDS:
- Public Health
- Primary Prevention
- Eating Disorders
- Health Services Research
- Delivery of Health Care

PROJECT NO 20101212

TOOLS TO ADDRESS CHILDHOOD TRAUMA, INJURY AND CHILDREN'S SAFETY (TACTICS)

Abstract

General objectives

The aim of TACTICS is to take the successful work of the recent Child Safety Action Plan (CSAP) project, extend it to the balance of Member States, link it with key outcomes of other child health and safety projects, and develop practical tools and resources or building blocks for policy at both national and sub-national (regional and municipal) levels to promote child safety as an achievable objective. Through applied study TACTICS will address knowledge gaps related to understanding: 1) inequities and child injury; 2) where responsibility for child injury prevention lies within countries and the EU; and 3) why there isn't more effective multi-sectoral action at the national and sub-national levels in EU Member States.

Strategic relevance and contribution to the public health programme

- TACTICS will provide a significant contribution to the second health programme and 2010 work plan. The suite of activities meets a wide remit of topic issues specifically mentioned in the 2010 call. In addition to topic 3.3.2.9 for injury prevention it also contributes to generating and disseminating health and safety information and knowledge related to 3.3.2.1 Children and young people, 3.3.1.3 Reduction of health inequalities, 3.3.1.2 Public health capacity building and 3.3.1.1 Health in all policies. TACTICS also contributes to progress on the EC Recommendation on Injury Prevention, ECHI indicator work and the EU Health Strategy - Together for Health. Planned linkages with a range of other initiatives and organisations that address child health and/or safety (e.g. CEHAPE, ENHIS, CHILD, AdRisk, PHASE, ChildonEurope, Safe Communities Network, Child Friendly Cities) ensure existing knowledge is built upon and strengthen the resulting impact.

Methods and means

TACTICS will achieve its aim through the coordinated action of a team of experts and practitioners in the areas of child injury, inequities, health indicators, benchmarking and indexing, and sub-national policy management who will undertake:

- good practice policy benchmarking through report cards in 27 EU MS
- devising a comprehensive Child Safety Index and toolkit
- building better understanding of why more effective action is not taken at national and sub-national levels through case study analysis
- mapping responsibility for child safety in the EU, Member States and 6 regions
- applying knowledge gained to develop targeted good practice advocacy tools for sub-national levels
- facilitate 3 countries that have not previously participated to develop national child safety action plans
- involve networks working with the target audiences (e.g. Child Friendly Cities, ChildonEurope, Safe Communities Network) and through targeted dissemination maximising existing mechanisms and networks to increase uptake of tools and resources by a wide variety of decision makers.

Expected outcomes

This more targeted approach should lead to 1) stronger tools to facilitate informed action, 2) more targeted and specific advice to decision makers, particularly with respect to enhancing use of limited resources and 3) increased standardisation of actions taken within and between Member States, leading to reductions in inequities with respect to child injury both within and between EU Member States.

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- Ministry of Health, Cyprus, Cyprus
- Ministry of Health, Latvia, Latvia
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- National and Kapodistrian University of Athens, Special Accounts for Research Grants, Greece
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- Nordic School of Public Health, Sweden
- Portuguese Association for Child Safety Promotion, Portugal
- Public Health Authority of the Slovak Republic , Slovakia
- Sociedad Espanola de Cirugia Infantil, Spain
- State Environmental Center, Lithuania, Lithuania
- Swansea University, United Kingdom
- Swedish Civil Contingencies Agency, Sweden
- The Icelandic Safety House - Forvarnahúsið, Iceland

EC CONTRIBUTION:
EUR 837951.00

DURATION:
36 month(s)

KEYWORDS:
- wounds and injuries
- prevention and control
- evidence based practice
- child
- adolescent

CHAPTER 1

1.2. HEALTH PROMOTION CONFERENCES

PROJECT NO 20100002

ACTION FOR PREVENTION (PREVACT)

General objectives

In accordance with the subsidiarity principle, it is the responsibility of each Member State to implement its own health policy, but there are areas where Member States can not act alone effectively (i.e. reducing marketing pressure on children) or where Members States can learn a lot from each other.

Thus, the overall aim of the Conference is to support Member States and stakeholders to work more efficiently in addressing the burden of NCDs, using innovative cooperations and governance structures. The conference, by bringing together leading European stakeholders with a common objective, will provide Member States and other stakeholders with a forum for sharing information, resources, best practise and expertise in primary prevention by addressing three of the key health determinants (nutrition, physical activity and tobacco control). The Conference should also help identifying common actions at EU level that can provide added-value to national efforts.

In addition, the Conference aims to reduce health inequalities existing between Member States by giving a particular attention to Central and Eastern European countries and new Member States.

Considering

- the diversity of national public health systems in the European Union;
- that the action plans of Member States are not widely disseminated;
- that public health indicators of new Member States and Central and Eastern European (CEE) countries are similar to each other and far behind those of the EU-15

the specific objectives of the Conference are:

1. to present effective public health systems and sustainable action plans;
2. to identify and share best practices and know-how at EU, national and local levels;
3. to promote interdisciplinary cooperation and exchange of experiences between experts working in three different areas (nutrition, physical activity, tobacco control);
4. to provide an opportunity for new Member States and Central and Eastern European countries to present their activities.

Expected achievements

200 delegates from each EU-27 countries are expected to attend the Conference. Given the central location of the hosting country and the sponsorship offered for Member States, a strong representation of each Member State is foreseen, however, about one-third of the participants is envisaged to arrive from Hungary and neighbouring countries.

The Conference aims at reaching an equal representation of experts from the three areas (i.e. nutrition, physical activity and tobacco control) as well as a balanced representation of different sectors:

- about 25% from government departments and policy makers at national level
- about 25% from DG SANCO, WHO EURO and international bodies and agencies
- about 35% from academic sector
- about 15% non-profit organizations and NGOs

Target audience

The Action for Prevention Conference is restricted to invited experts and decision makers. A total number of 200 participants is expected, out of which 72 participants will have their travel and accommodation costs covered (invited speakers and 2 delegates per Member State).

Target audience of the Conference is:

- experts and policy makers from Ministries and national institutes;

relevant WHO EURO National Counterparts, EU National Focal Points and HLG members;

- representatives of DG SANCO, WHO EURO, European Platform on Diet, Physical Activity and Health and relevant European agencies;
- health professionals;
- non-profit organizations and NGOs.

Because the Conference will build upon networks such as EU National Focal Points for Tobacco Control or Nutrition, HLG, that cover all Member States, it is envisaged to be attended by each EU-27 countries.

Conference programme

The PREVACT Conference is a 2-day event, to be held in the Royal Palace of Godollo on 30-31 May 2011. The conference date will coincide with the World No-Tobacco Day. In two days there will be 4 plenary sessions, 3 parallel workshops and a special session dedicated to Award winning poster presentations.

The first two plenary sessions will focus on presenting well-functioning public health systems and effective and sustainable action plans. Afterwards, participants can take part in three parallel workshops (Actions at EU/national/local levels). These workshops will give an opportunity to experts working in different fields to share their experiences and know-how in relation to specific questions such as PPP, sustainability or cost-effectiveness. The last plenary session of the day will be dedicated to disseminating actions from the CEE region.

In the first plenary of the second day, representatives of DG SANCO, EAHC and key experts will discuss lessons learnt in relation to the 2nd Health Programme and identify possible action areas for the next Health Programme. The 2nd day will also provide time for reporting back conclusions of the workshops and for Award winning poster presentations.

In addition to the presentations and workshops, there will be a poster session where each Member State may present 2 national or local actions selected according to criteria previously defined. Furthermore, Member States will have an opportunity to present their national or local programmes in an interactive and attractive way in an exhibition. The Conference intermissions will be thematic breaks relating to the three main health determinants.

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EC CONTRIBUTION:
EUR 75624.00

DATE AND PLACE OF THE CONFERENCE:
2011/05/30 in Budapest

KEYWORDS:
- Physical Activity
- Nutrition
- NCD
- Governance
- Tobacco control
- Non-chronic

PROJECT NO 20104201

EUROPEAN CONFERENCE ON TOBACCO OR HEALTH 2011 (ECTOH2011)

General objectives

The general objective of the conference is to support in implementation of EU policy on tobacco control, in particular with respect to raising awareness on health risks.

More specific this can be divided in:

1. Policy objectives
   a. Improved national implementation of the FCTC guidelines in Europe.
   b. Continued and intensified tobacco control policies and activities through (new) long lasting and comprehensive tobacco control programs and campaigns at EU level (e.g. EU HELP campaign) and at national level; e.g. the Dutch tobacco control program will end by 2011;
   c. Understanding tobacco industry tactics (that prevent implementation of FCTC guidelines (especially article 5.3) and tobacco control across Europe) and knowledge about how to counteract them;
   d. Better understanding (at the policy level) how tobacco control improves the health of the population and decreases health risks, which are prerequisites for economic productivity and prosperity.
2. Cooperation and Networking objectives
   a. Enable networking and the creation of new alliances among participants and countries;
   b. Increased cooperation and exchange of knowledge, experience and products between eastern and western European countries (according to article 152 of the EC Treaty);
   c. More and better trained next generation professionals in tobacco control throughout Europe, and the establishment of an ongoing platform for these professionals.
3. Action objectives
   a. Youth empowerment across Europe to undertake activities in their own country;
   b. Introduction of new approaches to ensure that measures also reach underprivileged populations.
4. Media and target group objectives
   a. The conference will be covered by European and international media;
   b. The conference will be perceived by the target group as an important next step in tobacco control in Europe.

Expected achievements

Based upon the experience of four ECToH conferences, about 600 people are expected to attend the 5th ECToH conference.

- Western European countries: we expect most participants to come from Western European countries (more or less 65%);
- Eastern European countries: we aim to attract more Eastern European colleagues then the previous ECToH conferences. About 15% of the participants were from Eastern Europe then, and this time we aim to attract about 20-25% of the Eastern European participants;
- Overall about 80% of the EU Member States is covered by all participants;
- Non-EU countries: we hope to have also some participants from non-EU countries, such as the Russian Federation and the United States of America.

In order to achieve the participation of colleagues from Eastern European countries, members of ECL and ENSP have been asked to make scholarships available for attendees from lower income European countries that cannot find resources to participate in this meeting. The webcast of keynote speakers is also available for colleagues from lower income countries who where unable to attend the meeting.

At this point some abstract (symposium and oral) have been submitted with special focus on migrants and vulnerable groups, that might attract participants from these countries, too.

Target audience

This 2011 conference will be the 5th ECToH conference in a row (4th in Basel (2007), 3rd in Warsaw (2002), 2nd in Las Palmas (1999) and the first in Helsinki (1998). Every three to four years a member of the ECL organizes the ECToH conference. ECToH conferences are therefore well known and well visited by tobacco control experts from a substantial number of European countries over the last decade. The ECToH primarily focuses on policy implementation of evidence based measurements for European professionals. Therefore, the majority of attendees are policy makers, scientists, health educators, advocates and health professionals from several European Countries. Previous conferences have taught us that tobacco control advocates from all over the world are interested and attend the conference.

The Executive Committee will make efforts so that advocates from Europe's lower income countries (such as eastern European countries) are able to attend the conference. One of the planned post-conference activities is a webcast of the keynote speakers. This is available for colleagues unable to attend the meeting, and colleagues who whish to listen to the presentations again and asks\ some questions via chat. The European dimension is clearly integrated in the program, as lessons that can be learned from different countries that will be presented and discussed. The implementation of the FCTC is important as well throughout the program. EC guidelines and directives are in some sessions the basis for the content and presentations. The ENSP and INWAT are asked to organize a complete symposium within the program. Furthermore, the conference provides a platform for National NGO representatives, Framework Alliances, Society for Research on Nicotine and Tobacco (SRNT) conference participants, and governmental officials etc.

Conference programme

Based upon the kick off meeting of the conference in December 2009, a draft program outline was developed by the Scientific Board. The Executive Committee agreed with the outline of the program. All board members (scientific, international, national and youth) are asked to give feedback on the suggested setup, options for sessions/content and suggestions for keynote speakers as well.

The conference program contains three main tracks:

1. Tobacco control policy (e.g. product regulation, special populations, cessation and smokefree environment)
2. Tobacco industry tactics (e.g. marketing youth and women, internal tobacco documents, smuggling)
3. Tobacco control practice (e.g. mass media campaigns, health education and communication, treatments)

These topics are translated into a suggested program setup, with the following type of work forms:

- plenary sessions with invited key note speakers (EU health Commissioner speakers, L. Joossens)
- parallel sessions
- poster sessions (possibly with speed presentations of main outcomes plenary)
- conferences (for instance organized by International Network of Women Against Tobacco (INWAT)
- debates, round table discussions, café setup, etc
- satellite meetings are to be considered
- meet the experts meetings and ask the expert meetings at the end of the day

Every day one topic will be highlighted in plenary sessions given by experts in the field. Speakers are not yet selected, but will include leading experts in the field of tobacco control. The conference will try to balance scientific evidence and practical experience from both Eastern and western European countries.

Throughout the conference „empowerment of youth and next generation experts" is important. The innovative approach of the conference should support this empowerment, not only for young people, but also with young people. Creative ideas using new media will be developed in the months previous to the conference.

A copy of the draft program including a list of Keynote speakers is attached to the proposal.

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EC CONTRIBUTION:
EUR 50000.00

DATE AND PLACE OF THE CONFERENCE:
2011/03/28 in Amsterdam

KEYWORDS:
- Tobacco industry
- Health Determinants
- Tobacco control
- FCTC

PROJECT NO 20100001

INNOVATIVE APPROACHES FOR CHRONIC ILLNESS IN PUBLIC HEALTH AND HEALTHCARE SYSTEMS (CHRONIC DISEASES)

General objectives

The objective of the conference is to present concrete initiatives related to prevention and organisation of healthcare systems, in order to stimulate innovative approaches at European level for chronic illness. The output of the conference is to bring conclusions on chronic diseases to the EPSCO Council.

- Prevention: Develop a program of prevention with all sectors concerned (Health in all policies): While there is a large consensus on the fact that most chronic diseases are preventable through interventions against the major risk factors, environmental and societal influences on these risk factors at the population level have received less attention although they play an important role to understand chronic diseases. For example, urban design may permit access to environments that can be either an encouragement or a barrier to physical activity and active living. The development of such strategies requires a multi-disciplinary approach, drawing on diverse paradigms, many of which are outside the domain of Health.
- Healthcare system organisation: In order to respond to the challenges posed by chronic diseases on healthcare systems, several countries have experimented with new models of healthcare delivery that can achieve better coordination of services across the continuum of care. Although each system must find its own solution, the objective of the conference concerning the healthcare systems is to focus on their necessity to be adapted to the needs of patients living with long-term and complex chronic conditions, including those living with multiple chronic conditions

Expected achievements

- Max 150 participants
- Ministers and 2 representatives for each EU countries
- representatives of patient organisations

Target audience

Ministerial conference with the Ministers of Public Health and high level officials of EU Member States from Ministries of Public Health and other relevant sectors, with representatives of patients organisations, representatives of the European Commission and representatives of other relevant stakeholders

Conference programme

Pre-conference on Respiratory Diseases (October 19th 2010):
9.00: opening - 9.40: impacts and problems - 11.30: 3 parallel workshops on the common challenges and solutions in the area of Chronic respiratory diseases
14.00: reports from the workshops - 15.30: panel discussion on actions and solutions
17.00: conclusions

Pre-conference on Rheumatic and Musculoskeletal Diseases (October 19th 2010):
10.00 :opening - 10.45: plenary session - 14.00: 4 parallel workshops: (1) improving health now and in the future, (2)new approach and best practices in patient involvement, (3) disease management and patient-centred partnership, (4) chronic diseases as a challenge for health care systems / new models of health care delivery
16.00: reports from the workshops - 16.45: conclusions session

Ministerial Conference on Chronic Diseases (October 20th 2010):
9.00: welcome and opening session - 10.00: breakout sessions: (1) lifestyles and general environment, (2) Innovative, effective and evaluated policies, (3) hstakeholders committment to tackle common risks factors in chronic diseases (4) the perception on chronic ill people including the identity and the disability perspective - 11.30: plenary: reporting back: (1) reports of the two pre-events, (2) reports from the breakout sessions
14.00: plenary: healthcare systems in support of chronic ill patients - 14.30: breakout sessions: (1) secondary prevention, (2) patient's related new technologies (3) management of chronic illness (4) patient empowerment - 16.30: pleary: reporting back and concluding remarks: (1) roundtable, (2) reports from breakout sessions, (3) concluding remarks.

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EC CONTRIBUTION:
EUR 89158.07

DATE AND PLACE OF THE CONFERENCE:
2010/10/19 in Brussels

KEYWORDS:
- Prevention
- Surveillance
- Chronic diseases
- Multi-disciplinary
- Continuum of care

EuroSafe
European Association for Injury Prevention and Safety Promotion

PROJECT NO 20104202

TACKLING THE CHALLENGES OF IMPLEMENTING GOOD PRACTICES IN SAFETY PROMOTION (INJURYCONF-2011)

General objectives

The specific objectives of InjuryConf-2011 are to:

1. offer a forum for the exchange of experiences in implementing and in monitoring the impact of national strategies and actions amongst Member States and for benchmarking policies and their outcomes;
2. highlight successful safety promotion initiatives and actions as evidenced through the various European collaborative projects, to encourage the uptake of good practices and to facilitate their implementation in particular in New Member States;
3. highlight opportunities and challenges to mainstream injury prevention and safety promotion into relevant policy domains; and to
4. enhance the involvement of relevant stakeholders within countries (i.e. government, NGO's, academia and private sector) and to foster sustainable and collaborative commitments as to actions for injury prevention and safety promotion in Member States.

Special attention will be given to EU-collaborative actions and programmes that have been initiated in the framework of the health programme. These actions relate to the priorities as identified in the 2007-Council Recommendation.

All priority issues will be profiled during the conference, with special emphasize on:

- the development of proper injury surveillance and monitoring infrastructures in MSs; and
- stimulating evidence-based action to address injury prevention priorities at national, regional and municipal levels in the EU, through co-ordinated processes of assessing and benchmarking progress in safety programmes in countries.

The conference will build upon international evidence presented at the Safety 2010 World Conference in London and profile models of European and national adaptation and implementation of the international evidence base.

Expected achievements

The conference is expected to be attended by up to 300 delegates, and up to 30 of the EU-32 region countries being represented, including all New Member States. Given the central location of the host country and fee waivers/ scholarship offers, it is envisaged to ensure a strong representation of candidate and neighbouring countries.

As to the institutional backgrounds of the participants, a well balanced representation is envisaged. Previous EuroSafe-conferences (Vienna-2006/ Paris-2008) attracted:

- a least one quarter of participants representing government departments (health/ interior/ transport/ justice/ economy/ sports/ civil protection/ education),
- also one quarter from governmental agencies (public health institutes, safety and health agencies, health promotion agencies, road safety centres, testing agencies),
- another quarter from academia (medical schools/ departments of public health/ biostatistics and epidemiology/ environment and health/ design and technology),
- at least ten percent from NGOs (rescue organisations, consumer and family organisations, victim organisations, child safety advocates),
- and also about ten percent representing the private sector (social insurers, health insurers, risk management consultants and global companies).

Target audience

Main target groups for the European Conference are:

- Senior policy makers in government and in public institutions, including regulators and standardisers;
- Representatives of national and European agencies that have a vested interest in health promotion, consumer safety, road safety, safety at work and the prevention of violence;
- Health professionals, consumer protection officers, injury prevention experts, safety promotion practitioners, and researchers;
- Professionals in the private sector, such as the insurance business, leisure and hospitality industry, care services and product manufacturing and retail;
- Policy officers in non-governmental organisations and organisations that represent civil society, e.g. exposed risk groups and groups of victims.

The conference will enable policy makers and professionals to share the evidence as regards the impact of the injury issue on today's society and solutions for creating a safer Europe.

The conference will also build upon networks that cover all Member States, EEA and candidate countries, including:

- the 32-countries EuroSafe/IDB-network of national injury data administrators and their national partners;

- the 26-countries network of the EuroSafe-Child Safety Alliance and their national partners;
- the 51-countries WHO-Euro network of national focal persons on injury prevention.
- the 27-MSs network of EU-governmental experts on injury prevention

About 150 delegates will be offered free registration (fee waivers), including:
- 2 representatives from governments (2 governmental experts per MSs)
- maximum 50 scholarship fellows (mandatory requirement: accepted poster/ break out session presentation);
- 25 members of national committee and main organisers.

A budget line is foreseen for sponsoring travel and accommodation of two delegates from each of the New MSs. The participation of civil society organisations representing major risk groups is also strongly encouraged.

Conference programme
- Plenary sessions will alternate concurrent break out sessions and poster presentations and highlight the public health leadership role and the opportunities for mainstreaming injury prevention in other policies. These sessions will include speakers from EC, WHO, public health leaders and EU-NGO's.

Plenary session 1: The challenge
- Welcome by Minister of Health in Hungary
- EU injury prevention policies (high rank rep DG SANCO)
- Inequalities in injury risks in Europe (WHO-EURO director)
- Challenges in implementing national strategies (HU-expert)

Plenary session 2: Mainstreaming injury prevention
- Deprivation and social inequalities
- Youth and risk taking behaviour
- Alcohol and drugs
- Physical activities and health promotion
- Plenary session 3: Integrated approaches
- Family counselling and support
- School based intervention programmes
- Empowering young people and youth participation
- Safe communities

Plenary session 3: The way ahead
- Keynote in injury surveillance: facts as basis for prevention
- Conclusion from the conference by the conference chair and co-chair
- Closing speech by a high level representative of the Hungarian government
- Concurrent break out sessions and workshops will in particular focus on priority issues as identified in the Council recommendation, i.e. vulnerable groups such as children, elderly people, persons with disabilities and vulnerable road users, and to sports and leisure injuries, injuries caused by products and services, violence and self-harm. Poster sessions will be organised based on poster abstracts sent in by participants and those who have been leading an EU-funded project over the past 6-8 years.

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EC CONTRIBUTION:
EUR 85000.00

DATE AND PLACE OF THE CONFERENCE:
2011/06/16 in Budapest

KEYWORDS:
- Injury Prevention
- Successful promotion initiatives
- National strategies
- Networks

PROJECT NO 20104204

CHILD - COMBATING HEALTH INEQUALITIES IN LIFE-THREATENING DISEASES (BRIDGES FOR CHILD)

General objectives

The main objective of the conference is to create a platform for a multi-professional, inter-and trans-disciplinary group of stakeholders with diverse experiences and perspectives on health inequalities in the treatment of children with major organ diseases. Prospective participants from old and new MS, candidate MS and Western Balkan countries will be actively invited if they are either actively involved into the high-end care of those severely sick children or passively afflicted by the respective inequalities. By involving highly qualified and experienced people in all areas concerned the conference holder will also be able to ensure overall coverage of matters related to structure, funding and policies.

The conference is intended

- to raise awareness about the extent and consequences of health inequalities and heighten political attention for the different life-expectancy of children with major organ disease
- to identify and spread good practices in high-end care for children with major organ disease by presenting selected best practice examples to the participants and further putting them into practice within the conference working groups
- to articulate and critically reflect existing health inequalities in the field of childhood major organ disease, to provide a list of inequalities and to prioritize them and finally to translate the most striking inequalities into a conference list for urgent actions so to help bridging these differences
- to link existing projects and groups to support and facilitate both local high-end care for children with major organ disease and the access to cross-border health-care, by implementation of a partnering system at the conference
- to foster task forces for future specific European interdisciplinary network projects tackling inequalities in health
- To facilitate dialogue within a group of stakeholders with diverse professional and cultural background the conference is designed following the basic model of the "Future Search Method". The conference itself, by providing a multi-professional, inter-and trans-disciplinary platform, is intended as a start for subsequent projects, all of them with the objective to reduce health inequalities in the treatment of children with major organ diseases in new MS, candidate MS and Western Balkan countries.

Expected achievements

The goal is to have approximately 80 -100 participants from at least 10 Member States, but also from candidate MS and Western Balkan countries to widen participation. The participants will roughly evenly divided between paediatricians, other medical specialists involved in the health care of children with major organ disease or organ failure, representatives from health care authorities, insurance companies and humanitarian organisations, politicians and laypersons as patients and delegates from parents organisations and industry. The conference holder/steering committee is generally looking to reach a critical mass of participants within each participating country to increase the output short term but rather intent to plant a seed for further development in the right directions.

The main activities for the group of 30-40 preselected experts (Steering Committee, Scientific Committee and invited speakers) will be oriented towards sharing and dissemination of specific knowledge on existing health inequalities and best practice examples in our topic.

A very high priority is the identification of those participants from Eastern Europe who might benefit most from participation and who can contribute uniquely to the conference.

The main activity of the group of 25-30 conference participants invited by the committees is to broaden the non-medical shareholders influence and to further expand the participation of non-academic participants. Finally, the open inclusion of non-preselected participants via initiative registration (25-30 people) will ensure that the conference is open to non pre-selected topics and attitudes. Criteria for the choice of layperson participants include their ability to speak English, and the ability and willingness to participate in the round-table parallel workshops. These participants should also have a documented interest that is consistent with the purpose and objectives of the conference.

The many different stakeholders from respective committees of healthcare specialists laypersons, policymakers, NGOs and industry are very likely to exchange their different points of view in the joint sessions.

Target audience

Participation in this conference is considered a first step towards a novel multiprofessional, inter-and transdisciplinary platform to decrease health care inequalities in the care of children with major organ disease and organ failure in the EU, candidate MS and Western Balkan countries.

Thus, target participants are all those actively involved (health care specialists, NGOs, industry, policy makers, EU officials and health care providers) and passively afflicted (laypersons, patients, parents organisations) players/representatives from EU (old MS, new MS) and non- EU countries (candidate MS and Western Balkan countries). It is within the main strategic concept of the conference to involve people from the latter countries to give them a voice within the dialogue in the new Europe of the future.Furthermore, to learn about their experiences may motivate others to engage themselves even a little more and to work for the future of children in Europe.

A significant proportion of the participants (about one third, appr. 30-40 people) will be experts and members of the Steering and the Scientific Committee who will be preselected by the organisers. Invited speakers are expected to stay for the whole two-day conference period.

Another third (appr. 25-30 people) will be invited by the Steering Committee for the purpose of further diversification and non-medical stakeholder participation. Invited stakeholders are expected to use their international reputation, expertise and membership in respective European associations to initiate future projects as best practice programmes, international collaborative networks and focal points for task forces. So ample use will be made of the networks provided by the chairpersons, committee members and rapporteurs.

The last third of participants (appr. 25-30 people or more) will not be preselected but reached by one of the marketing and communication strategies, thus the conference is open for alternative and unexpected topics or interest groups. All participants should have a documented commitment or demonstrable need that is consistent with the purpose and objectives of the conference.

Altogether of the 80-100 participants at least 15 people will be from non EU member states.

Opportunities will also be sought to expand participation and to open the plenary sessions for policy makers,NGOs, industry and other people with relevant interests from governmental, public and private sectors, journalists, postgraduates and students.

Conference programme

This two-day conference will establish a community for reducing inequalities in paediatric high end care. It will provide a platform for a diverse group of relevant stakeholders to develop a common vision and to agree on concrete projects. The participants are encouraged to explore the past, the present and the future and to make action plans based on common understanding.

In the CHILD conference, the first half-day plenary session deals with the question „Where do

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EC CONTRIBUTION:
EUR 96500.00

DATE AND PLACE OF THE CONFERENCE:
2011/11/17 in Vienna, Austria

KEYWORDS:
- Children health
- Inequalities
- Life threatening diseases

we come from?" It will identify the status quo of inequalities and the challenges of the current system. A special focus will be laid on mutual understanding both in the plenary session and in the round table discussions.

The second half-day session deals with the key question on how to create ideal futures in both parallel working groups and a plenary session. The aim is to show best practice and project possibilities to guarantee that the participants gain the required instruments to pursue the final goal: reduction of inequalities in paediatric care.

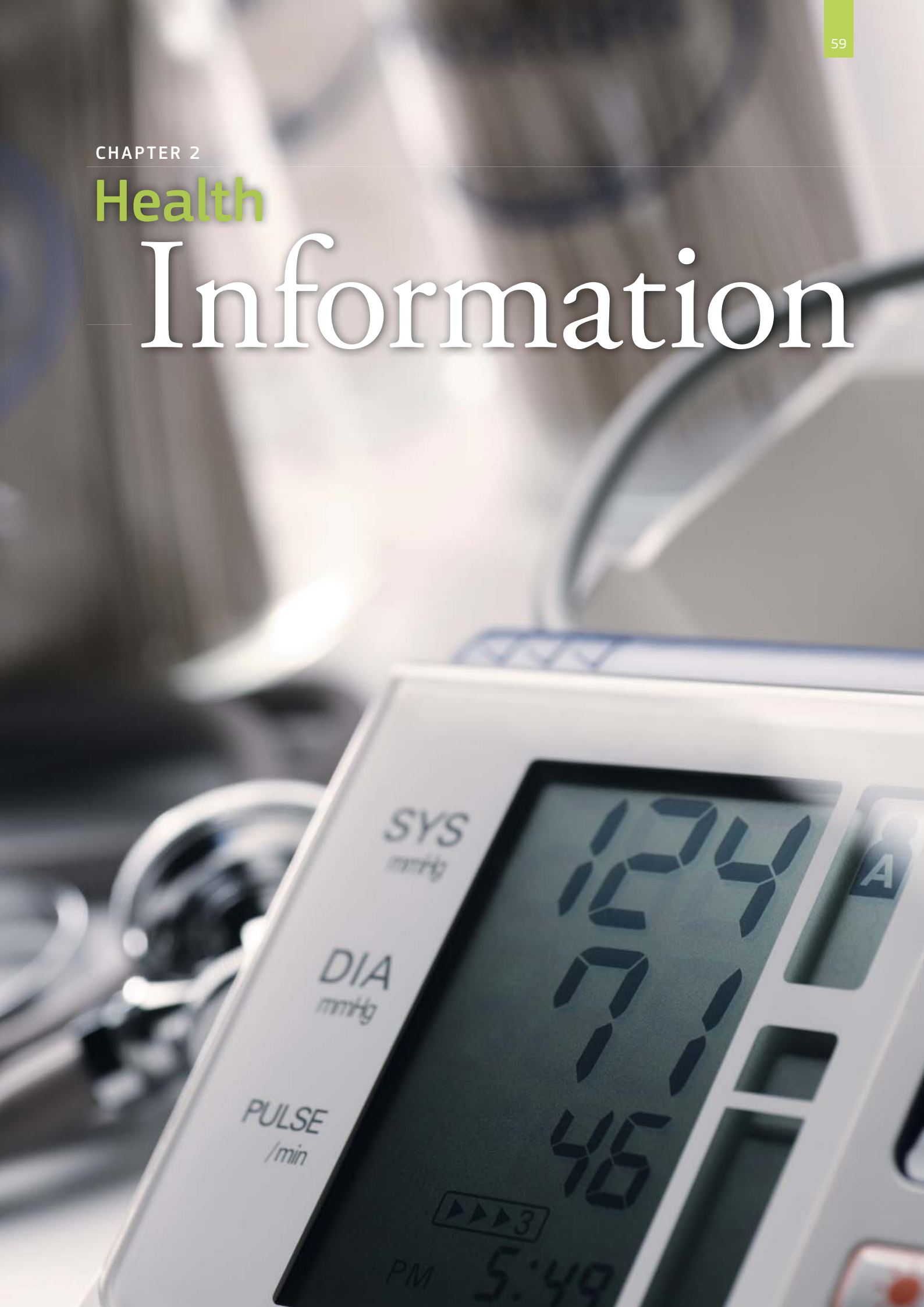
This will finally lead to ad hoc creations of task forces in the third half day session (open space). Conclusion, final remarks and the identification of the next steps are given in the final discussion and closing remarks session.

The sessions in the morning after the conference will not be open to public and will be reserved for evaluation of the conference outcome and identification for further action areas for the CHILD task force.

The conference design reflects the complexity of the topic. The structure of the programme is designed to support the interdisciplinary discussion of the topic and will also provide optimal settings for development of intercultural trust. By elements which are „state of the art" in moderation methods like World Cafe approaches, open space technology and Future Search Conference, the potential of the interdisciplinary group can be tapped so to achieve the goals of the conference. As is elucidated within the programme parallel working groups in 8-10 round tables will be used to explore the present situation and to create ideal futures. With this format, CHILD will serve as a start and mobilization tool for the future reduction of the existing health inequalities.

CHAPTER 2

Health Information



CHAPTER 2

2.1. HEALTH INFORMATION PROJECTS

PROJECT NO 20102301

EUROPEAN HEALTH AND LIFE EXPECTANCY INFORMATION SYSTEM (EHLEIS)

General objectives

The Healthy Life Years (HLY) indicator is a Summary Measure of Population Health (SMPH) indicating the number of remaining years that a person is expected to live free of disability. HLY was included as a Structural Indicator in 2005 with the main purpose to monitor health trends and gaps in Europe.

The objective is to increase the utility of HLY through the consolidation and further development of the EHLEIS information system, increased comparability with US and Japanese SMPH and greater use by MS in national policy-making. The JA will: (i) compute and disseminate HLY through an online information system and annual country reports, (ii) monitor EU trends in LE and HE to identify public health priorities, (iii) develop methods for computing comparable HE by socio-economic status, (iv) contribute towards identifying the main determinants of healthy life in Europe,(v) integrate the former Task Force on Health Expectancies (TFHE) into an annual meeting to further engage MS with HLY, and (vi)propose a blue print for a common international SMPH with the US and Japan.

Strategic relevance and contribution to the public health programme

Key cross-cutting EU policies such as the Lisbon agenda and the Sustainable Development Strategy include HLY within their list of indicators. In 2005 the Commission stated that "increasing HLY is crucial in attracting people into the labour market" (COM 2005/24). More HLY means a healthier workforce, less retirement due to ill health and potentially less health and social care use and is thus a means of reducing the economic and social risks associated with demographic change. Accurate monitoring of HLY across MS is crucial to plan for our ageing population but also to understand the impact of national policies to increase healthy ageing.

The JA will contribute directly to two of the three objectives of the Second Programme of Community Action in the Field of Health 2008-2013: to promote health, including the reduction of health inequalities – specifically increasing healthy life years and promoting healthy ageing; and to generate and disseminate health information and knowledge.

Methods and means

A wide range of methods will be necessary to achieve the aims. Computational and web methodologies and standard demographic techniques will form the basis for the Information System. The substantive analyses of trends and gaps will use statistical techniques including macro, micro and multi-level analyses. Linguistic methods will be used to extend the web facilities to multiple European languages.

Expected outcomes

The main outcomes will be: (i) an Information System allowing online calculation of various health indicators (prevalence, LE and HE) – all current HLY-related websites will be reorganized in a new EHLEIS website, (ii) annual Country reports on health expectancy translated into national languages, (iii) proceedings of the annual meetings to replace the TFHE, (iv) improved statistical tools for attribution and decomposition, (v) technical reports and scientific papers on key methodological advances and substantive results on inequalities between MS and potential drivers, (vi) blueprint for an internationally harmonized summary measure of population health (SMPH).

Our target groups are MS in general, health and non-health policy makers at MS and EC level, health professionals and researchers as well as the media and general public.

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- Robert Koch Institute, Germany
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EC CONTRIBUTION:
EUR 637158.00

DURATION:
36 month(s)

KEYWORDS:
- Population health surveillance
- Health Status Indicators
- Gender
- Socioeconomic status
- Public Health

eHealth Governance Initiative eHGI

PROJECT NO 20102302

JOINT ACTION EHEALTH GOVERNANCE INITIATIVE (JA-EHGOV)

Abstract

General objectives

The Joint Action aims to support the eHealth Governance Initiative (eHGI) which functions as platform for technical & political co-operation between Member States on eHealth including their relationship with eHealth Stakeholder Groups which include EU level organisations representing health professionals, hospitals, patients, standards developing organisations & industry. The results of which (recommendations,guidelines) will furthermore support the work of the eHealth Network set up in accordance with Art.14 of the Directive on patients' rights in cross-border healthcare. In the framework of the eHealth Network, the Commission & Member States will discuss and agree on political & strategic issues related to eHealth, in accordance with Art.14 of the Directive, including political prioritization in the eHealth interoperability roadmap and its implementation. To ensure coordination, coherence and consistency between the political level (the eHealth Network) and the expert level (the JA on eHGI), the eHealth Network shall provide guidance for the work of the Joint Action as appropriate.

Strategic relevance and contribution to the public health programme

Many Member States are today in the process of initiating or rolling out large-scale eHealth investment and implementation programs. Some Member States have been granted financial support from European Structural or Regional Funds in order to reform their national healthcare systems. Thereby, we have a unique window of opportunity to build national solutions on common European or Global standards that enable continuity of care across borders. If we fail, there is a clear risk that national investments will be less efficient, more expensive and not providing the potential benefits for our citizens that otherwise would be possible. National projects could benefit if we can find joint solutions to challenge.

Furthermore, European cooperation on the eHealth area has been running successfully with the support of the European Commission for several years, with an extensive exchange of experiences at expert level. Substantial funding for developing eHealth has been allocated through Community research funds, and MS have moved towards concrete actions to launch cross-border services.

Methods and means

The JA proposal is not a classic technical IT project but intends to create a political driven mechanism to coordinate ongoing and future activities on eHealth in MS and the European space. In order to tackle Council Conclusions and transform words into action it is proposed to define a European eHealth Governance Model based on MS cooperation with an organization and management suited to attain its ambitious objectives. Conceptual and Operational components of the Governance initiative are organized at three levels:

1. Decision Makers' level and political governance;
2. Strategy level and
3. Operational Level.

In the model proposed, the policy group will be responsible for analysing and acting on inputs by strategic and operational level, interacting with the Commissions and stakeholders, annual or periodical review of strategy and declaration of priorities and adopting Strategy Plans and Work Programmes proposed by the Core Strategy Group.

Expected outcomes

Based on a collaborative model for political, strategic and operational sustainability, the JA will support a new European eHealth Platform in order to establish a permanent network in an international context. It will be used to inform policy and health care decision makers in European countries.

The main outcome of the JA will be the consolidation of the permanent network for eHealth in Europe resulting for recognition of its added value. The commitment expressed by the Ministers of Health of 25 European countries (including both MS and States of the EEA/EFTA) to build a permanent network, with a coordinated MS approach, will be renewed and reinforced by assuring a long-term MS engagement in eHealth Governance Initiative together with the Commission. Additionally, countries not yet involved in the Network, recognise its advantages and join the Initiative while expressing their long-term commitment. At the end of the JA, sustainability of the Network is thus achieved provided by a collaborative platform assuring sustainable growth and employment, quality and continuity of care, etc.

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- Department of Health and Children, Ireland
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- European Health Management Association , Ireland
- European Health Telematic Association, Belgium
- European Hospital and Healthcare Federation, Belgium
- Gesundheit Oesterreich GmbH, Austria
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- Ministry of Health of the Republic of Slovenia, Slovenia
- National Health Information Center, Slovakia
- National Institute for Strategic Health Research, Hungary
- Pharmaceutical Group of the European Union, Belgium
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- Standing Committee of European Doctors, Belgium
- The Centre of Health Economics , Latvia

EC CONTRIBUTION:
EUR 1001894.49

DURATION:
36 month(s)

KEYWORDS:
- Health
- National Health Programs
- Health Policy
- Health Services
- Electronic Health Records

PROJECT NO 20101301

PROMOTING BETTER HEALTH FOR MOTHERS AND BABIES THROUGH ROUTINE EUROPEAN MONITORING OF PERINATAL HEALTH AND HEALTH CARE (EURO-PERISTAT ACTION)

Abstract

General objectives

The project's ultimate aim is to achieve better health for mothers and babies by building a European perinatal health surveillance system to provide evidence to policy makers, clinicians and users for informed decision-making. We aim to implement a financially sustainable approach to the production and use of perinatal health data in which (1) core EURO-PERISTAT indicators are included in routine statistical systems through EUROSTAT and ECHIM (European Community Health Indicators Monitoring) and (2) a European Network of experts from participating countries is created to monitor other EURO-PERISTAT indicators and to analyse trends and inequalities in health and care for dissemination to target audiences. The project has 5 specific objectives (1) Integrate EURO-PERISTAT perinatal health indicators into European statistical systems (2)Establish a European Perinatal Health Surveillance Network (3)Develop capacity for high quality health reporting (4)Monitor trends and inequalities in perinatal outcomes and care in Europe (5)Expand EURO-PERISTAT's geographical coverage.

Strategic relevance and contribution to the public health programme

This project addresses the third objective of the Health programme "to generate and disseminate health information and knowledge". All the priorities of 3.2.1 are covered by our aims (Integrate the perinatal health indicators into public health monitoring systems, develop capacity at the European level and at national levels in order to achieve high level reporting) It contributes to other work plan priorities by:

- Monitoring social and geographical inequalities in maternal-child health
- Building capacity for development and implementation of effective public health policies
- Exchanging knowledge and best practices among public health professionals;
- Engaging third countries, through outreach to applicant/candidate countries and exchange of information with researchers in the US, Canada and Australia.

Methods and means

METHODS: The project is based on the EURO-PERISTAT indicators, which were developed with rigorous scientific methods and tested twice (on 2000 and 2004 data). It mobilises the expertise and resources of EURO-PERISTAT's network of clinicians, epidemiologists and statisticians. It will:

- Establish working groups to execute WP objectives, including a technical working group with representatives from EUROSTAT and ECHIM, a network of legal officers, and thematic working groups on data quality, indicator development and social inequalities.
- Consult with external experts (legal specialists; authorities in perinatal health);
- Implement DELPHI consensus processes with the Scientific Committee (one representative per participating country) to update indicators and achieve agreement on the Surveillance Network's charter;
- Compile and analyse data to pretest quality improvement methods and to monitor indicators;
- Expand our existing contact base of over 500 perinatal health decision-makers and develop outreach to professional and user groups.

Expected outcomes

OUTCOMES: The principal outcome will be a high quality, innovative, internationally recognised and sustainable European perinatal health information system that compiles and analyses data on a regular basis. While transitioning to this system, the project will compile new data and produce analyses on patterns of perinatal health and care in Europe. These are eagerly awaited by perinatal health professionals who wish to monitor the wide inter-country variations in outcomes and care practices revealed by the first European Perinatal Health Report. By improving indicator quality and breadth and using data for scientific analysis, this project maintains the dynamism and relevance of routine reporting and the interest and involvement of our partners and stakeholders. Project deliverables, including a second European Perinatal Health Report on 2010 data, will be broadly disseminated through directed outreach activities and an integrated media strategy.

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- Terveyden ja hyvinvoinnin laitos, Finland
- The City University', United Kingdom
- Université libre de Bruxelles, Belgium

EC CONTRIBUTION:
EUR 607343.00

DURATION:
36 month(s)

KEYWORDS:

- perinatal mortality
- perinatal care
- Parturition
- Prenatal Care
- Socioeconomic Factors

CHAPTER 2

2.2. HEALTH INFORMATION CONFERENCES

PROJECT NO 20104304

5TH EUROPEAN PATIENTS' RIGHTS DAY: PUTTING CITIZENS AT THE CENTER OF EU HEALTH POLICY (EU PATIENTS' RIGHTS DAY 2011)

General objectives

The EU Patients Rights Day offers an excellent opportunity to highlight that citizens should be at the center of the health agenda.

The core values of EU health policy are ensuring citizens empowerment, reducing inequalities in health and using scientific evidence to drive policy. These values are also supported by EU health ministers, who agreed on a list of overarching values in EU healthcare systems in June 2006. These values encompass 11 of the 14 of the patients rights in the European Charter drafted by citizens demonstrating that Ministers of Health, citizens and EU institutions share the same vision of healthcare. Therefore, we should reflect even more on how these shared goals to promote patients rights are translated into action. The challenge is now turning this value-based vision of health policy and healthcare systems into a tangible reality.

As the former Health Commissioner Vassiliou mentioned in her speech during the 3rd EU Patients' Rights Day conference organized by ACN last year, we must do more than just set up principles we must also come up with concrete measures to make real improvements in practice. I agree on the importance of safeguarding patients' rights, despite the growing complexity of healthcare and we all have a role to play in this area. It is occasions such as EU Patients' Rights Day that remind us of this fact, and help us come together to help put words into action.

The main objectives

1. To bring together a wide range of stakeholders throughout Europe to reflect on what is currently being done regarding patients' rights and identify concrete EU actions that can be taken on by all stakeholders.
2. Increase awareness and information on the actual situation of patients' rights at EU and national level.
3. Collect and share good practices on the involvement of citizens and patients in health policy and the implementation of patients' rights.
4. Disseminate results of the EU conference with stakeholders at national level and propose concrete actions can then be evaluate in the next 6th EU Patients' Rights Day
5. Integrate the EU Patients' Rights Day in the context of the EU Year of Vountary activities.

Expected achievements

This is a multi-stakeholder conference though the main targets are European citizen & patient org. it is important to highlight the importance of the participation of medical profession representative and other health-care stakeholders.

Some of the expected participating speakers,and the members of the steering committee who will lead the different session of the conference should be:

- The representatives of the most important European Networks on Health: They will represent the people involved in the concrete implementation of patients' rights such as doctors, nurses, hospitals, associations, pharmacists, patients' organizations of course: the CPME (Steering Committee of European Doctors); EPF (European Patient Forum) PGEU(the Pharmaceutical Group of the European Union); the European Federation of Nurses Association EFN; HOPE the European Hospital and Healthcare Federation

- European Institutions:
  The opening remarks should be done by the European Commissioner, John Dalli who participated in the last EPRD. We are in contact with his Secretary and waiting for being confirmed is presence; Staffan Nilsson, the President of the EESC. The Members of the European Parliament (in particular the MEPs who promoted and actively participated in the last EPRDs)-Antonyia Parvanova (ALDE, BL)-Gianni Pittella,Vice-President European Parliament (S&D, IT) Françoise Grossetête (PPE, FR)-Corinne Lepage(ALDE, Roberta Angelilli, Vice-President European Parliament(PPE, IT)etc. The representative of the EC DG SANCO Andrzej Rys.
- National partners(as specified in target participants)

The number of participants expected in the European Conference will be around 200 from which 70% will come from 30 European countries (member states,candidate and associate) and 30% from EU Networks and other stakeholders directly in Brussels. Approximately 36,720 Euro of the budget under other costs is dedicated to the travel and accommodations for citizens and patient organizations from 30 European countries.

Over the past 4 years in the European events between 120 180 have participated therefore there should not be any difficulty in reaching our goal

in number as well as diversity of stakeholder. In addition to the European events there will be national dissemination events in most of the European Countries with approximately 30 to 50 participants with the potential to reach over 1000 participants Europe wide: the objective is to reach the diverse health-care stakeholders present in the national context.

The European conference target is the following:-A member of a citizen org. and a member of a patients org. from European countries (2 participants x 27 EU member states + Macedonia and Croatia) for a total of about 58 representatives from national citizen and patient organization. Their travel and accommodations will be covered by the conference budget in other costs (36,720)

- National authorities from each involved country -Industries (national and European)
- EU networks -Academics -Representatives from European Institutions.

Target audience

The conference is multi-stakeholder and it is importance to guarantee the participation of the various stakeholder groups at the EU as well as national level. The conference will be an occasion to inform, discuss and take commitments to empower citizens to actively participate in health policy and in doing so put citizens at the center of EU health policy.

For that reason even though this conference is directed to diverse stakeholders the main target will be citizen and patient organisations from the EU member states. Putting citizens in the center of EU health policy means listening to them and engaging with them together with health professionals (physicians, nurses, pharmacist), & national health authorities.

To guarantee the greatest diversity of stakeholders will we work in collaboration with other European Networks as in the past years. This has always been one of the main success factor regarding the previous EU Patients Rights Days. (for the details see the participants expected description).

The organizations currently involved (and that will also organize the dissemination events) are: Belgium: Vlaams Patienplatform vzw and Ligue des Usagers des Services de Sant; Bulgaria: Index Foundation; Croatia: Croatian Association for Patients'rights; Cyprus: Limassol District Committee for Examining Patients'Complaints and European Social Forum of Cyprus; Estonia: Estonian Patient Advocacy Association; Finland: Sosiaali-ja terveysj est jen yhteisty yhdistys YTY ry; France: CISS Collectif Interassociatif Sur la Sant and Assistance Publique Hopitaux de Paris; Germany: Deutsche Gesellschaft für Versicherte und Patienten e.V.; Greece: Europaiki Ekfrassi; Hungary: Hungarian Civil Liberties Union; Latvia: Patients Ombud Office; Lithuania: Council of Representatives of Patients Organizations of Lithuania; Macedonia: CRPRC 'Studiorum'; Malta: Malta Health Network; Poland: Foundation Institute for Patient's Rights & Health Education; Portugal: Associa PAR Respostas Sociais; Romania: Romanian Multiple Sclerosis Society; Slovak Republic: Združenie na ochranu práv spotrebiteľov v Poprade; Spain; Sociedad Espanola de Atencion al Usuario de la sanidad and Spanish Patient Forum; UK: Pelvic Pain Support Network.

Most of them was been already involved last year.

Target audience

In general the conference program content together with speakers need to be discussed with the Steering and Scientific Committee. This is the first step in the preparation phase. For this reason we can not provide at this moment a detailed program with the specific topic of each workshop or key speech.

However, based on our 8 yrs experience organizing European conferences we can provide the following basic outline regarding structure and time:

The Conference will be a day and half. The first day will include a morning session dedicated to general speakers providing the framework for the event, the presentation of a selected good practices and opening remarks from the Commissioner. Will be focused on reflecting on the actual situation of patients' rights also launching the final Report of the ACN's project on Assessing Patients' Rights in Europe.

The afternoon will be composed of breakout sessions - work groups (3) that will be based, as a start point and guide, on the last three Rights of

the European Charter of Patients' Rights: The Rights of Active Citizenship: the Right to perform general interest activities; the Right to perform advocacy activities; the Right to participate in policy-making in the area of health. The objective of these working groups are to propose concrete actions that can be taken at the European and national level by the various stakeholders present.

The first day will finish with a networking cocktail. In identifying the venue for the conference we will try to find a place the allows a space for organizations to have an exposition of their materials.

The second day morning session will be dedicated to the presentation of the proposed actions and discussion. This could also be an important moment for the European Institutions to comment on possible forms of collaboration. The output could be: steps or actions that can be taken to put citizens in the centre of EU Health Policy from now until the next European Patients' Rights Day.

What is important is that at the end there is a document and concrete actions that can then be evaluated at a later period and that in this document all stakeholder take responsibility to take action.

The second day will finish with lunch to give the opportunity for the majority of participants to travel back to their countries. To facilitate the travel for participants coming from member states as well as the participation of European institutions and European Networks the conference will be held in Brussels (we are waiting for two responses in relation to the room that we use for the conference. We asked the availability of a room both to the European Parliament, where we have already held two conferences for the European Patients' Rights Day in 2008 and 2010 and the Economic and Social Committee, where last year we held training for our partner associations).

The conference date will be the 11-12th of April 2011 (the date might be modified according to the Commissioner Dalli's agenda).

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EC CONTRIBUTION:
EUR 75125.00

DATE AND PLACE OF THE CONFERENCE:
2011/04/11 in Brussels

KEYWORDS:
- Health Determinants
- Civic participation
- Empowered users
- Correct and concrete information
- Common language and common awareness about patients' rights

PROJECT NO 20104302

CONTINUING CANCER CARE (CCC)

General objectives

Strategic objectives

1. To build public health capacity
2. To raise awareness, inform, initiate and/or continue to influence policy debates on five steps in the cancer patient's journey in order to advance the cancer part of the 2010 work plan
3. To strengthen networks and contacts between European cancer leagues and the European Institutions
4. To create channels through which the presence and influence of Association of European Cancer Leagues at European policy making levels is increased in order to advocate for better patient support in legislation.

Each conference topic has its own purpose for being presented which fit in with the overall objectives of the conference of networking, exchanging information and capacity building. These thematic objectives will not be monitored separately but within the context of the strategic objectives.

Pyschosocial Screening

1. Development and implementation of psychosocial screening tools
2. Improvement of the accessibility of high quality psychosocial support for all cancer patients and their care givers/families
3. Inclusion of psychosocial aspects of cancer in medical guidelines and in the curriculum of all oncology health professionals

Palliative care

1. To address inequalities in palliative care concerning:
   a. Access
   b. Quality of care
   c. Pain control
   d. Economics
2. Capacity building for implementing standardised palliative care in Europe

Rehabiliation

1. Ensure that cancer rehabilitation is a part of national cancer control plans and EU (health) legislation
2. Prioritise data collection and research on rehabilitation to ensure the effectiveness of rehabilitation programmes
3. Ensure all cancer patients have a personalised cancer survivorship plan through cancer rehabilitation units/programmes at the hospitals and in the community

Access to Credit and Insurance

1. Raise awareness about life and health insurance and access to credit
2. Call for fair treatment of people with increased health risks due to cancer. We believe that:
   a. Insurance companies should be objective i.e. base their calculations on appropriate data
   b. People should have the right to independent re-evaluations
3. Identification of EU actions and players

Employment

Demonstrate ways to reduce the economic costs of cancer and minimise workforce loss via:

- Working with the 8 basic rights
- Focusing on how to get people back to work
- Working with trade unions/employers and other stakeholders

Expected achievements

ECL aims to invite around 600 participants to the conference, and hopes to get 150 maximum. Ideally a broad range of European Commission officers will attend to both give presentations and take part in round table discussions.

Participants from our leagues will come from Ireland, Iceland, Faroe Islands, Denmark, the UK, Belgium, Luxembourg, Turkey, Slovenia and others. Staff from WHO Geneva and IARC in France may also attend, and all Ministers of Health from EU member states will also be invited. MEPs in the MAC group, and those with a known interest in public health will be invited to participate and host sessions. Our colleagues in public health will pass on the invitations to members of the EPHA, ECCA, ESMO, ECPC and Europadonna networks for example.

From the private sector, employers associations based in Brussels who may have an interest in learning and/or contributing to the employment and insurance debates will also be invited. Trade Unions, insurance companies and creditors will also be made aware of the conference and invited.

We aim to have at least 150 participants over the 1.5 days from all member states, representing mainly cancer leagues and patient services but also including government staff, EU officers, health NGOs, and some private sector.

Target audience

European Institutions and Governments:

- European Commission officials from all relevant Directorates will be invited (DG SANCO, Agriculture, Trade, Internal Market, Taxation and Customs, Transport, Employment and Social Affairs, Education and Culture,)
- Members of the European Parliament, especially MEPs in the MAC group
- Health Ministry officials in all Member States
- Public health institutes in all Member States

Social Sector:

- National health services and pertinent clinical and social oncology regional offices in all member states
- University public health departments
- Social services in member states
- Government funded cancer centres for rehabiltiation, palliative care etc

Civil Society:

- European umbrella NGOs and their members; EPHA, ECCO, ECPC, ECCA, Europadonna, EHN, ENSP, Eurosafe, European Social Platform, Livestrong, American Cancer Society
- European umbrella organisations of employers and trade unions
- Members of the European Health Policy forum
- National health/cancer NGOs from all member states
- ECL Member leagues and associations and other cancer organisations acting at European and national levels.

Private sector:

- Representatives from insurance and re-insurance companies
- Relevant pharmaceutical companies (invitation only)
- Private service providers

In order to achieve the objectives of the workshop, it is essential that as many Commission staff, MEPs and members of ECL participate as possible. ECL has members in countries across Europe who will each bring their unique perspective and experience to the discussions and benefit from the cross-organisational learning environment the conference will create. In order to fulfill the potential for capacity building across a wide section of the public sectors, invitations will also be sent to cancer leagues who are outside of our membership network. The social sector such as national NGOs and health service providers will also be targeted for this purpose. Other pan-European cancer organisations, the WHO, IARC and public health professionals will also be invited in order to widen the scope of the discussions and increase potential for shared learning. Stakeholders with interests in European Health Policy such as faculty staff and consultants will also be invited.

Conference programme

The conference will cover 1.5 days of presentations, group discussions and networking opportunities. Guest speakers will be invited from DG SANCO, and other organisations to be selected by the Scientific Committee.

For each strand there will be one presentation from an ECL PSWG member and others from guest speakers. Group discussions will be focused around each topic and presentations back to the plenary will be focused on identifying similarities and differences in priorities for the organisations involved and potential ways forward in Europe on the topics concerned. Each topic will have its own chair.

There will be a conference dinner for participants, key speakers and chairs on the night of the 7th.

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EC CONTRIBUTION:
EUR 20845.00

DATE AND PLACE OF THE CONFERENCE:
2011/09/07 in Brussels

KEYWORDS:

- Cancer costs to individuals
- Health care provision
- Anti-discrimination Directive

PROJECT NO 20104303

FOURTH JOINT EUROPEAN PUBLIC HEALTH CONFERENCE (COPENHAGEN 2011)

EUROPEAN PUBLIC HEALTH CONFERENCE

General objectives

The general objective of the 2011 European Public Health Conference is to further the aims of the second European Community action in the field of health by building the capacity of public health and welfare experts, practitioners and policy makers through enhancing the European exchange of knowledge, policy and best practice.

More specifically, the 2011 European Public Health Conference aims to:

- offer a wide platform for exchanging knowledge, sharing research outcomes and discussing best practice in all fields of health and welfare and their interrelationship;
- provide a plenum for EU policies and projects with an audience of public health and welfare professionals;
- create, support and promote close and active collaboration links among European public health organisations and schools of public health;
- increase knowledge and skills among representatives of EUPHA and ASPHER member associations by the organisation of capacity building seminars.
- mobilise public and official bodies in the organising country and the Nordic countries for the promotion of public health.

The above general objective and aims are linked directly to the third objective of the second Health Programme (2008-2013) - to generate and disseminate information and knowledge.

The parallel scientific programme of the conference, which is based on submitted and ranked abstracts, covers the objectives and strands of the 2010 Work Plan. Workshops and presentations will focus on the various priority areas of the Work Plan such as quality of healthcare and patients' safety, sustainability of health systems in the face of challenges such as the ageing population and inequalities in health within and between EU Member States. EUPHA sections and ASPHER working groups cover priority issues such as mental health, communicable diseases and child and adolescent health in half-day or full-day pre-conferences.

The conference offers a meeting place for various projects funded by the second Health Programme and the 7th Research Framework Programme.

Expected achievements

Copenhagen 2011 is expected to be attended by 1 200 participants from over 50 countries worldwide. By inviting acknowledged experts from the welfare sector in Europe and abroad as keynote speakers, the conference will be able to attract a substantial number of welfare professionals.

Data from previous conferences in Lisbon (2008) and Lodz (2009) provides the following information on numbers and background of participants:

Lisbon 2008 was attended by 1 400 participants from 50 countries. 75% of all participants came from 27 EU Member States. The professional background of the 2008 participants included: university (42,5%), authorities (national level) (22,8%), practice (regional and local) (18,8%), NGOs (national and European) (10,7%).

Lodz 2009 was attended by 840 participants from 51 countries: 81.5% came from 24 EU Member States. 14 neighbouring countries attended the conference and 13 overseas countries. The professional background of the 2009 participants included: university (49,2%), authorities (21,5%), practice (9,3%), NGOs (10,7%). We observed an increase in international organisations and NGOs actively participating in the conference.

Data from Amsterdam 2010 is not available yet, but we expect an attendance of 1 200 participants with similar professional background. As of 15 September 2010, a total number of 891 persons have registered for the Conference already.

Target audience

The 2011 European Public Health Conference addresses public health and welfare professionals, researchers, education specialists, training professionals, students, policy makers and representatives from international and European networks and organisations.

Participants will come from all EU Member States, EU-neighbouring countries and countries outside the European region. Representatives from international organisations like the European Commission, WHO Europe and headquarters, ECDC, OECD and the European Observatory will attend the conference. European (public) health and welfare networks and organisations, such as EPHA, ESQH and ICSW will also actively participate.

By inviting acknowledged experts from the welfare sector in Europe and abroad as keynote speakers, the conference will be able to attract a substantial number of welfare professionals.

It is our goal to attract more public health experts from Northern America. Therefore, the partner organisations have intensified relations and exchange with the American Public Health Association and CDC (Atlanta, US), as well as with the Canadian Public Health Association.

Special efforts will be made to allow public health experts from low income countries and countries in Central and Eastern Europe to attend the conference.

The 2011 conference will focus particularly on young researchers and students. For this group, a special conference fee and specific competency workshops and networking possibilities are offered.

The choice for Copenhagen as a conference venue and the programming of workshops addressing specific regional issues will draw a substantial number of experts from the Nordic countries. The selection of the welfare theme is likely to attract higher participation from the welfare field of work.

The 2011 conference focuses deliberately on a broad target group. By offering 10 sub-themes or tracks, consisting of 70 parallel sessions and 20 pre-conferences, participants will find their own field of work represented in the conference programme. The broad programme and vast audience offer participants ample opportunities for increasing their knowledge and for networking for future collaboration.

Conference programme

The general framework of the conference programme consists of the following parts:

- Pre-conferences (20);
- Key-note lectures on the main theme of the conference (5 sessions);
- Planned workshops (40);
- Parallel sessions with oral presentations and discussion (30);
- Moderated poster sessions (12) with in total over 250 posters.

Special attention is given to the following topics related to the main theme, taking into account the priorities of the EC:

- European health and welfare systems and models: comparative analysis on the development and distribution of welfare.
- World economic crisis, European economic crisis and the health of the population; what do they have in common?
- Reducing inequalities in health: what is the European status, which actions have been taken?
- Focus on the aging population in Europe: the contribution of preventive and curative health services to the health, quality of life and welfare of the elderly population.
- Using individually linked population based registers for research and health information systems on the interrelationship between health and welfare: Scandinavian approaches and experience.
- The welfare orientation of public health education in Europe: status and perspectives for the planning of education.

Through the abstract submission procedure, the conference is open to presentations and discussions on all current and emerging issues in public health. This allows researchers and experts to introduce their work in areas related to the second Health Programme, such as quality of healthcare and patients' safety, sustainability of health systems, health inequalities in Europe.

In addition, several coordination meetings are organised, related to EUPHA and ASPHER, but also related to EU-funded projects. EUPHA will organise a skills development and capacity building seminar for its national member associations. ASPHER will organise its Young Researchers Forum for junior researchers.

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ASSOCIATED PARTNERS:
No Associated partners

EC CONTRIBUTION:
EUR 150000.00

DATE AND PLACE OF THE CONFERENCE:
2011/11/10 in Copenhagen

KEYWORDS:
- Public health
- WELFARE STATE

PROJECT NO 20104301

HIV IN EUROPEAN REGION – UNITY AND DIVERSITY (AIDS2011)

General objectives

The objectives of the European HIV/AIDS conference 2011 are:

- To contribute to the strengthening of capacity of governmental and community partners for designing health system interventions in the field of HIV and AIDS in the European region.
- To provide a forum in which HIV policies, key operational research, lessons learned and gaps in knowledge and successes, challenges, and innovations in HIV prevention are addressed.
- To provide PLHIV community and representatives of key populations a possibility to interact with public health stakeholders and researchers thus improving their involvement in policy development and decision-making process, including their participation in setting priorities for prevention and research.
- To strengthen collaboration between government and civil society partners and facilitate an increased participation of civil society and community-based organizations in the HIV response.
- To increase understanding of the contribution made by the HIV global response to broader social, economic and health issues.
- To create and strengthen links between EU Member States, European Neighbourhood Policy countries and Russian Federation, between old and new member states and countries acceding to membership of the European Union.
- To contribute to the Combatting HIV/AIDS in the European Union and neighboring countries.

Expected achievements

The conference will welcome attendees from the EU and across the WHO European Region. The expected number of participants is up to 750.

Fellowship will be considered and grants and scholarships will be given to attendees from:

- Eastern and Central European countries with low GDP;
- Countries that are applying for, are candidates for or are acceding to membership of the European Union;
- Countries to which the European Neighbourhood Policy applies;
- the Western Balkan countries included in the stabilization and association process
- representatives of civil society.

Representatives of the Estonian civil society organizations will be offered the possibility to participate in the preparation of the conference (preparation of the site-visits and other side-events) on voluntary basis, for these participants organizers will wave the registration fee.

To ensure the participation of national experts (civil servants) from ENP countries, information on applying for support through the TAIEX programme will be offered on the conference website.

Target audience

Target audience of the European HIV/AIDS conference 2011 includes:

- policy-makers and public health administrators (at national, regional and international level);
- representatives of the civil society and community based organizations;
- practitioners and researchers;
- representatives from international organizations and networks (e.g NDPHS, ECDC, EMCDDA, WHO regional Office for Europe, UNODC, Global Fund to Fight AIDS, Tuberculosis and Malaria, EATG, Civil Society Forum, EU HIV/AIDS Think Tank etc).

The conference will welcome attendees from the EU member states, countries that are applying for, are candidates for or are acceding to membership of the European Union, ENP countries and attendees across the WHO European Region.

To ensure the participation of experts from countries with low GDP and ENP countries organizers will consider the offer of a fellowship programme.

Conference programme

The special focus of the European HIV/AIDS conference 2011 is on such important cross-cutting themes as regional cooperation, quality of the public health services in the field of HIV and AIDS, health systems response to HIV and AIDS.
The conference programme will focus on following topics specific to European Region:

- HIV situation in European Region - key issues and main problems in epidemiologic situation with special focus on health systems approach to HIV prevention, treatment and care.
- Legal aspects of HIV. Why have we failed in reducing the stigma?
- Epidemiology of injecting drug use and related risk behaviors.
- Prevention of HIV among men who have sex with men. Is there a hidden HIV epidemic among MSM in Eastern Europe?
- Adaptation to living with HIV.
- Early diagnosis and uptake of HIV counseling and testing.
- Impact of the HIV epidemic on TB and MDR-TB situation in the region.
- Effective HIV prevention and care in prison setting.
- Quality of the public health services in the field of HIV and AIDS K how to measure and improve.
- Regional programs and policies. Is there enough cooperation and networking?

Conference format will include plenary sessions, parallel sessions each with 2 sub-session and at least one additional open session (moderated panel discussion), workshops and satellite events, poster sessions, site visits (to local health care and community based organizations).

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EC CONTRIBUTION:
EUR 100000.00

DATE AND PLACE OF THE CONFERENCE:
2011/05/25 in Tallinn

KEYWORDS:

- Acquired Immunodeficiency Syndrome
- HIV/AIDS
- Early Diagnosis
- Drug use
- Social stigma

PROJECT NO 20104305

MEN, MEN, SEX AND HIV 2011 – THE FUTURE OF EUROPEAN PREVENTION AMONG MSM (FEMP2011)

General objectives

The overall objective of the conference is to challenge and change the continuously increasing trends of HIV and other STIs among MSM. Innovative and evidence based methods are needed and the preventive interventions and programmes have to be scaled up to reduce transmission. The conference will also add to the ongoing development of Second Generation Surveillance.

The aim of the conference is limited to the European; the problem is not primarily lack of competence but rather deficiencies in the dissemination and sharing of existing experience or knowledge. Therefore the target participants are those working within the European Union and neighbouring eastern countries.

Expected achievements

The first two overall purposes of the conference, to connect the three main actors (four - when we include the private/commercial sector) in the MSM prevention field and connect the east (i.e. new member states and neighbouring eastern countries) with the western countries in the Union will manifest itself in the composition of the participants.

The immediate objective to formulate a Declaration of Purpose and Goals for the future HIV/STI prevention among MSM directed to policy makers and governmental agencies in the Member Countries and other participating countries, Non-Governmental Organisations and actors in the private sector will have be followed up in a long term perspective.

Target audience

One major purpose of the conference is to connect the three main actors in the prevention field targeting MSM with each other - organisations as well as individuals. We have also added a fourth actor group; the private/commercial sector of the gay/MSM scene.

Therefore the target participants for the conference and major stakeholders in the development on the future prevention are (the list not being comprehensive):

- Professionals and voluntary workers within non governmental organisations targeting varying MSM groups and populations. Outreach workers, advocacy and policy makers.
- The research community, both the institutions and faculties that have done and do specialist work in this field and various individual researchers.
- Several sectors of the public health system are (or should be) involved in the preventive efforts on a general population level. The healthcare system is a major actor here, both as care giver and partaker in prevention interventions (e.g. VCT). Governmental agencies for disease control and prevention and institutions for epidemiological surveillance are self evident actors in this field and should have and need specialist competence.
- Actors in the private and commercial sector

Participants are expected from at least 33 countries: Austria, Belgium, Bulgaria, Denmark, Croatia, Czech Republic, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Latvia, Lithuania, Moldova, The Netherlands, Norway, Former Yugoslavian Republic of Macedonia, Poland, Portugal, Romania, Russia, Serbia, Spain, Slovenia, Sweden, Switzerland, Turkey, Ukraine and The United Kingdom.

Conference programme

The conference will last two full days. As this is a conference mainly for dissemination of knowledge and best practices the format will be traditional conference, that is with plenary/policy sessions, presentations in various formats (e.g. seminars, workshops, oral presentations) and a poster exhibition. It should be noted that this proposal gives an indication and outline of the general contents.

The conference opening will be on a high level with political representation from Sweden and EU.

Suggested tracks (with matching plenary lectures/ policy sessions):

1. Key European Initiatives dissemination of results and evaluation: EMIS, EPAA, SIALON, EVERYWHERE , EUROSUPPORT 6 and ECDC tender for MSM prevention 2010 (this might expand to two or more tracks).
2. Epidemiology and Second Generation Surveillance/Monitoring of the MSM epidemic.
3. Academy and Practice: community based research and best practice, a mutual dependence.
4. Positive Prevention: the inclusion of men who have HIV as target group and agent in the prevention; sexual health of men with HIV.
5. East and West. Different human rights, same epidemic? (SRHR and prevention, under reporting MSM incidence).

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EC CONTRIBUTION:
EUR 100000.00

DATE AND PLACE OF THE CONFERENCE:
2011/11/10 in Stockholm

KEYWORDS:
- Sexual behavior
- Homosexuality
- HIV/AIDS
- Prevention And Control
- Surveillance

CHAPTER 3

Health Security

CHAPTER 3

3.1. HEALTH SECURITY PROJECTS

PROJECT NO 20101101

COST-EFFECTIVENESS ASSESSMENT OF EUROPEAN INFLUENZA HUMAN PANDEMIC ALERT AND RESPONSE STRATEGIES (FLURESP)

Abstract

General objectives

The objective of the FLURESP consortium is to redefine main human pandemic scenarios at the European level, describe and cluster possible response strategies and assess these response strategies in the frame of multi-criteria and cost-effectiveness analyses, taking into account lessons from the 2009 pandemic situation in Europe. Human pandemic scenarios and main related responses have never been assessed and ranked using both multi-criteria and cost-effectiveness approaches. It appears urgent to develop a strategy relying on assessment of lessons learnt with respect to improving intersectorial collaboration and cross-border coordination in responding to health emergencies. The integrated approach of Decision Making proposed by the FLURESP consortium would constitute a premiere at the European and global level, which would support member states to select the most appropriate and efficient public response to various scenarios of human pandemic.

Strategic relevance and contribution to the public health programme

The FLURESP consortium is composed by key European experts in Flu alert and response strategies, in Public Health and Health Economics advanced methodology. The added value of the FLURESP project in the frame of the second programme of Community action in the field of health is obvious, considering the important health threat of a potential viral mutation, leading to a human pandemic. The fact that the objective of the consortium is not only to describe pandemic and response scenarios, but also to assess the epidemiological and socio-economical performance of response strategies would allow European public authorities to improve their ability to better respond to various categories of threats.The proposed project would perfectly fall under the chapter 3.2.1 of the second health program dedicated to citizen protection against health threats, and particularly under action 3.2.1.2.

Methods and means

The first phase is dedicated to the creation of an expert panel, which defines possible human flu pandemic scenarios in Europe, describes and explains both possible pandemic scenarios in Europe and actual responses facing the emergence of H1N1.

The second phase focuses on response strategies at country and European level. Using existing sources, potential response strategies are selected for each pandemic scenario.

The third phase defines standardized criteria for each response strategy and performs multi-criteria analyses. This allows to cluster and rank response strategies according to performance and efficiency.

The fourth phase performs cost-effectiveness analyses on response strategies. Twenty simulation models are constructed to compare cost and performance of response strategies for each pandemic scenario.

The fifth phase proposes guidelines and recommendations for policy decision makers, based on ranking tables of performance, costs and cost-effectiveness ratios.

The outcome of the FLURESP project will provide an extensive assessment of human flu pandemic response strategies, which will lead to guidelines and recommendations for EU member states presenting and discussing most efficient response strategies for each pandemic scenario.

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- National Institue of Public Health - National Institute of Hygiene - NZIP, Poland
- Laurent Niddam Europai Közösségi Jogász Iroda - NECL, Hungary
- Open Rome - OPR, France
- Retroscreen Virology Ltd - RTS, United Kingdom
- Université Paris Descartes - UPD, France

EC CONTRIBUTION:
EUR 699220.00

DURATION:
36 month(s)

KEYWORDS:
- Cost-Effectiveness
- Human influenza
- Pandemic
- Modelling

tubidu

PROJECT NO 20101104

EMPOWERING CIVIL SOCIETY AND PUBLIC HEALTH SYSTEM TO FIGHT TUBERCULOSIS EPIDEMIC AMONG VULNERABLE GROUPS (TUBIDU)

Abstract

General objectives

The project TUBIDU objective is to contribute to the prevention of Intravenous Drug User (IDU) and HIV-related Tuberculosis (TB) epidemic through empowerment of health systems and civil society and to enhance collaboration of various stakeholders in the field in order to prevent TB. TUBIDU will develop and strengthen cross-border collaboration and partnerships on policy, services and community levels. It will improve horizontal collaboration between HIV, TB and other relevant sectors. It will empower civil society and address the social determinants of health which is crucial in order to tackle TB.

Strategic relevance and contribution to the public health programme

The project will contribute substantially to "Improve citizens' health security, protect citizens against health threats" and in particular by enhancing existing response capacity against biological agents of diseases". The project aims to better identify the health burdens related to TB, IDU and HIV in the project area and possible impact on EU in general. The project seeks the improvement of citizens' health security through developing strategies and mechanisms for preventing and exchanging information on and responding to health threats from communicable diseases such as TB and HIV with a special focus on vulnerable groups such as IDUs and People Living with HIV (PLHIV). The projects aims to improve partnerships, and develop networks between governmental structures and community based organizations both on national and international level. The project aims to promote health through identifying the causes of TB epidemic among IDUs and reducing health inequalities within and between the partner states.

Methods and means

Methods are chosen to develop health systems and community based organizations and to ensure sustainability of outcomes. They include transnational and national network meetings involving experts and stakeholders; information and experience exchange; development of training materials and organizing trainings for health and social care specialists; development of information materials about TB for vulnerable groups; research among IDUs and professionals to identify needs and gaps in services both on patient and provider level; development of guidelines for TB case finding and infection control in community based settings; elaboration of recommendations to national stakeholders in governmental organizations for provision of TB services in community based organizations working with vulnerable groups.

Expected outcomes

The main expected outcome is reduced burden of TB among IDUs and PLHIV throughout the project area. The specific outcomes include detailed description of the situation and scope of the problems in the project area which is necessary in order to plan future activities, to target the subgroups most in need, reduce the barriers to access to services, provide high-quality services, and to evaluate the process and outcomes of the national strategies. Project will also increase the capacity of the public health, health care and civil society professionals to work for TB/HIV/IDU prevention. Through developing guidelines and models for community based organizations working with vulnerable groups project adds to sustainable and high-quality provision of these services in the future. The involvement (including co-financing, from Estonian Ministry of Social Affairs) of the national HIV policy makers will contribute to the sustainable implementation of the outcomes.

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- Higienos institutas/Institute of Hygiene , Lithuania
- Latvijas Tuberkulozes Fonds/ Tuberculosis Foundation of Latvia, Latvia
- Сдружение "Доза обич"/ "Dose of love" Association , Bulgaria
- Finnish Lung Health Association, Finland

EC CONTRIBUTION:
EUR 694693.00

DURATION:
36 month(s)

KEYWORDS:
- injecting drug use
- HIV
- tuberculosis
- risk behaviour
- health policy

PROJECT NO 20102101

MUTUAL ORGAN DONATION AND TRANSPLANTATION EXCHANGES: IMPROVING AND DEVELOPING CADAVERIC ORGAN DONATION AND TRANSPLANTATION PROGRAMS (MODE)

Abstract

General objectives

Our main aim is to enhance the organization of transplantation systems through the exchange of best practices, complementing Member State policies in this field through cross-border cooperation. One interest area for each challenge field of the Commission Action Plan(increasing organ availability, enhancing efficiency and accessibility of transplant systems, improving quality and safety) will be selected and best-practice transfer will be implemented through two actions, exchange visits and specific training. The interest areas may be: HB/NHB/living donation, traceability systems, quality assurance programs including audit systems, lifesaving organ programs and urgencies, evaluation of transplant outcomes. Full benefit will be drawn from previous or ongoing projects(ALLIANCEO,DOPKI,COORENOR)

Since even European Union countries with well-developed services show differences in some organ donation and transplantation activity, the expected outcome is that all participating countries will benefit from full knowledge of the donation and transplant systems that achieved the best results.

Strategic relevance and contribution to the public health programme

The European Commission has adopted important safety and quality measures for organ donation and a 10 point action plan to work with EU Member States on strengthening organ donation and transplantation systems in Europe. For many patients, organ transplantation represents the only life saving treatment available. There are currently 56,000 patients waiting for a suitable organ donor in the EU. It is estimated that every day 12 people die while waiting for transplantation. This joint action will contribute to the Directive implementation and Action Plan allowing diffusion of best-practices in the three key challenge fields identified by the Commission, one for each challenge field. The consortium partnership, made of national organ Competent authorities or their appointees, delegated by their Member States, will also ensure a proper echo at the level of present policy makers, giving an added value to the action.

Methods and means

The project will foster the exchange of best-practice through exchange visits (up to five) followed by the provision of a set of specialized trainings.

Reciprocal onsite exchange visits will be planned and shaped after identifying a series of activities and/or programs, for which the beneficiary country has more interest or need.

The general methodology will be:

- Identification of areas of interest (one for each Action Plan challenge point) for transfer of best practices
- Organization of field visits in best-practice countries
- Field visits in beneficiary countries by joint expert commissions
- Production of short reports/guidelines for improvements
- Definition of training interests

On the basis of best-practice exchange/identified training needs, two kinds of courses (short term/medium term) will be developed, whose contents will be tailored upon needs highlighted during the exchange visits. The courses will be addressed to the health-care staff of organ coordinating and transplantation centers. Through these courses a further transfer of best practices will be performed.

Expected outcomes

The mail goal of our action is fostering the transfer of best-practices in the field of organ donation and transplantation and investigating its feasibility. The forthcoming implementation of the European Directive identifies a series of actions to be taken, that each country has to prioritize according to its own organization and existing system.

With the help of this legislative tool, each country would be able to find organizational solutions for bettering sectors where its own donation/transplant network has room for improvement. Long-term sustainability would be ensured by the quality of partnership and the support of MS to joint action. An external evaluation would also be performed at international level through indicators that are presently being defined by the European Union.

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- Department of Health of Malta, Malta
- Institute for Transplantation of organs and tissues of the Republic of Slovenia - Slovenija Transplant, Slovenia
- Koordinaní stedisko transplantací, Czech Republic
- National Transplant Bureau, Lithuania
- Organisacion Nacional de Trasplantes, Spain
- Országos Vérellátó Szolgálat, Hungary
- Pauls Stradins Clinical University Hospital, Latvia
- Tartu University Hospital, Estonia

EC CONTRIBUTION:
EUR 284591.30

DURATION:
18 month(s)

KEYWORDS:
- organ transplant
- organ donation
- best practices transfer

HProImmune
Promotion of Immunization for Health Professionals in Europe

PROJECT NO 20101102

PROMOTION OF IMMUNIZATION FOR HEALTH PROFESSIONALS IN EUROPE (HPROIMMUNE)

Abstract

General objectives

(1)Increase awareness about the most important vaccine preventable diseases which pose a particular risk to EU HCW (2)Increase awareness about Immunizations among Health Care Workers through a database comprising vaccination specific information from across the EU (3)Provide new knowledge about vaccination behaviors and barriers among HCWs(4)Widely disseminate information on best practices for promoting HCWs immunization in different health care settings(5)Provide new knowledge on how to communicate and promote immunizations among HCWs by piloting a purpose and tailor-made Immunization Toolkit (6)Increase awareness and promote HCWs immunizations through a widely disseminated and pilot tested HCW Immunization Promotion ToolKit comprising recommendations, communication guidelines, tools and fact sheets

Strategic relevance and contribution to the public health programme

The 2009 Health Council Recommendation considers HCW a major risk group calling for "education, training, and information exchange on seasonal influenza and vaccination by organising:(i) information action for healthcare workers" According to the same rcommendations a new seasonal influenza vaccination target has been set to reach a vaccination coverage of 75% for the older age groups and people with chronic diseases as well as other high risk groups including HCWs.

HProImmune is strategically relevant in terms of this recommendation as it offers practical and methodological knowledge about immunizations that can contribute to the development of national immunization action plans. The new methods and tools developed will contribute to the protection of EU HCW adding significant value to the overall emergency response policy of EU. HProImmune addresses strategic objectives of the 2008-2013 WP in particular by "developing prevention and control of existing or emerging communicable diseases" (3.2.1.1., WP 2010) and by providing knowledge and tools for promoting vaccination among HCW.

Methods and means

1. Critical analysis and review of existing knowledge (peer reviewed literature, national recommendations, policies and legislation, databases, web sites), will lead to the identification of a short list of vaccine preventable diseases of particular threat to HCW. The review will yield the information used to populate the database which will also be presented in the form of a report
2. Direct communication with health authorities
3. Qualitative analysis through focus groups and quantitative analysis through an on line questionnaire will lead to the identification of barriers of vaccination among HCW
4. Best practice identification through the use of a purpose designed scoring system. Best practice will be verified through an expert workshop that will also lead to the development of recommendations for HCW Immunization Record and registries
5. Development and piloting of a comprehensive Immunization tool for the Promotion of immunization
6. Comprehensive dissemination strategy including workshops, info days, a project dedicated website, newsletters and press releases

Expected outcomes

A list of vaccine preventable diseases posing major threat to the health of HCW will be the first major achievement of the project.

A comprehensive Toolkit for the promotion of immunization among HCW in Europe will be developed. Through the toolkit higher vaccine coverage rates and improvement of resilience and response capacity of the European health sector will be achieved. Increased awareness through training and knowledge provision is expected to enable HCW to better protect their health and act as role models for their workplace and community.

An immunization knowledge library will be available through a database that will provide a comprehensive picture of the status of immunizations among European HCW. HProImmune will also provide important insight into the barriers of immunization among HCW and based on best practice evaluation offer recommendations for immunization of HCW.

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EC CONTRIBUTION:
EUR 603900.00

DURATION:
36 month(s)

KEYWORDS:
- Immunizations
- Health Care Workers
- Vaccine Preventable Diseases
- Communication tool
- Vaccination coverage

PROJECT NO 20101103

PUBLIC HEALTH ADAPTATION STRATEGIES TO EXTREME WEATHER EVENT (PHASE)

Abstract

General objectives

The project will provide a framework of tools for the preparedness and response to extreme weather events (heat waves, cold spells) and their environmental consequences (floods, wildfires, air pollution) to reduce their impact on health. A specific contribution of the project will be to apply new methodologies to improve knowledge on health effects of extreme weather events (EWE), and to identify individual risk factors. The vulnerable subgroups to specific EWE will be identified to target prevention activities and optimize resources. Prevention plans will be evaluated to identify a set of efficient measures. The collaboration between different sectors (public health, environmental,civil protection, policy makers,etc) will be strengthened to improve preparedness and response to health emergencies and support adaptation to EWE. A link with ongoing EU projects on climate/ health will be established to optimize resources. Results of the project will be contextualized taking into account different environmental, socioeconomic and political conditions throughout Europe.

Strategic relevance and contribution to the public health programme

PHASE will build on findings from previous EU projects filling the knowledge gaps with innovative research methodologies. A synergy between the epidemiological evidence and public health measures will be created to improve preparedness and response actions. The project is innovative in that it identifies population subgroups vulnerable to each specific EWE and by tailoring prevention activities towards these will guarantee a more efficient use of public health resources. The project will help improve existing response to extreme weather events, that constitute serious health threats for the European populations. Prevention measures will be especially targeted to low socio-economic groups and this will help reduce health inequalities within the EU and improve citizens health standards and quality of life.This project addresses cross-border health threats and collaboration between the partners will set the foundations for the development of a network between local and international institutions for reducing the impact on health of future climate change.

Methods and means

For each EWE considered, a review of the scientific literature will be carried out to identify gaps in knowledge. Effect estimates will be performed through a time-series approach on different EWE exposures taking into account potential confounders/effect modifiers. Spatial analysis using Geographic Information System (GIS) will be performed to identify high risk areas. Dispersion modelling will be used to estimate population exposure. Performance of warning systems and effectiveness of the prevention activities will be evaluated in case studies and an overview of prevention guidelines performed. Shared methodologies for the selection of vulnerable population subgroups will be defined on the basis of epidemiological evidence and based on city-specific cohorts enrolled and followed up from administrative databases. Case studies of risk and health impact assessment and prevention plans will be developed as worked examples. A framework of tools will be defined to improve preparedness and help mitigate the impact of EWE's on health.

Expected outcomes

The project has the aim of bridging the gaps and increasing knowledge on: the health effects of extreme weather events and their environmental consequences; indicators to monitor the impact on health of extreme events; determinants of vulnerability to specific extreme events; performance and effectiveness of warning systems and prevention activities; Synergies between air pollution, extreme weather events, and wild fires. The project is finalized to the development of evidence-based guidelines to implement prevention plans tailored to vulnerable population subgroups (children,elderly,people with chronic disease and socially/economically disadvantaged individuals) The project will increase awareness and improve evidence-based prevention policies.Furthermore it will promote and enforce local/international networks including epidemiologists, public health professionals, health authorities, WHO Euro, international and national Institutions and Services. In the long term the project will provide tools for the mitigation of expected EWE health impacts also due to future climate change.

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EC CONTRIBUTION:
EUR 744037.82

DURATION:
36 month(s)

KEYWORDS:
- Climate change
- Risk factors
- Environmental Exposure
- Public health
- Guideline
- Vulnerable Population
- Extreme weather events

PROJECT NO 20102102

QUALITY ASSURANCE EXERCISES AND NETWORKING ON THE DETECTION OF HIGHLY INFECTIOUS PATHOGENS (QUANDHIP)

Abstract

General objectives

The Joint Action (JA) aims to link and consolidate the objectives of two existing networks dealing with highly infectious bacteria and viruses that emerged from the EU funded project EQADeBa, coordinated by the Robert Koch-Institut (RKI), Germany (EAHC n° 007 204) and the ENP4-Lab project, coordinated by L.Spallanzani National Institute for Infectious Diseases (INMI), Italy (EAHC n° 006 208). The primary objective of the current application is to stabilise both network activities that link 33 partners from 21 European countries highly specialised and advanced laboratories. This will ensure the universal exchange of best diagnostic strategies able to support a European response strategy to outbreaks of highly pathogenic infectious agents plus generating a biodiverse repository of reference materials. The JA will provide a supportive European infrastructure and strategy for external quality assurance exercises (EQAE, bacterial antibiotic susceptibility testing, training, and biosafety and biosecurity review of current practices).

Strategic relevance and contribution to the public health programme

The project is directed at ensuring and improving citizens´ health security and bridging Security and Health by improving the laboratory diagnostic capabilities of appointed European laboratories to detect high consequence pathogens in situations arising from natural outbreaks and deliberate or accidental release. These outbreaks would not respect national borders. A closely aligned European specialised laboratory network will ensure the universal ability to respond with rapid diagnostics of highly pathogenic bacteria or viruses in support of clinical and public health outbreak management. Moreover, the network has the ability to enhance the support of other agencies (veterinary, forensic) dealing with suspected or confirmed bioterrorist incidents. Participants of the JA will evaluate and develop rapid diagnostic tools that will provide the necessary infrastructure to support the effectiveness of mobile “field” diagnostics. This would also contribute to enhance the global health security capacity and address the requirements of the International Health Regulations (2005).

The project will be open for other laboratories not yet considered as Associated partners. There will be the opportunity to join the project as Collaborating partner as it was offered to the Hungarian P4 laboratory funded under the PHARE twining programme. There are more initiatives at the European level dealing with the management of biological threats like EURINHA project funded by DG RTD/ENTR or ENIVD supported by ECDC. QUANDHIP will provide a unique quality assurance schemes for high risk bacteria and the majority of European P4 laboratories will assess and improve the diagnostics for risk group 4 viruses. In a unique matter a bacterial and viral network of high threat agents will be linked together. Furthermore, biosafety and biosecurity issues from the laboratory perspective will be evaluated and recommendations drawn.

Methods and means

SO1 External Quality Assurance Exercises - Different EQAEs are planned for bacteria and viruses. Reference material will be quality assured in terms of agent characterisation, homogeneity, storage stability and suitability for different analytical approaches. Various formulations of reference material like dried samples will be checked for applicability. Protocols of EQAEs will be analysed and best practices identified.

SO2 Setting up of a repository for reference materials - The existing repository for bacteria is to be extended with additional strains provided by partners. Where possible, the bacterial and viral isolates will be characterized by all applicable means of phenotypic, molecular and immunological characterization. Viral reference material will be stored at recognised national laboratories and exchanged between appointed laboratories in inactivated form according to European Biosafety and Biosecurity Guidelines.

SO3 Training on best diagnostic practices and biosafety/biosecurity - Partners of the JA with a proven track record in the delivery of effective training and exchange programmes covering best microbiological, biosafety and biosecurity practices will be identified and listed. The training will consider actual biological events and possibilities to share laboratory capacities and capabilities.

SO4 Further improvement and application of checklists for evaluation of Biosafety and Biosecurity laboratory management - A common checklist for laboratory infrastructure, containment, and operational biosafety and biosecurity for European BSL3 and BSL4 will be evaluated and further improved by all partners.

SO5 Support to laboratory outbreak response coordination - Recommendations on laboratory management of biological events will be developed by a Working Group addressing issues like providing laboratory support for risk assessment in case of cross-border highly infectious pathogens. A final workshop will be used to present and discuss the project achievements to invited first responders and representatives from EU institutions and initiatives supported by the EU like DG Home, Europol, DG RTD ENTR, ECDC, beyond DEVCO and DG Sanco.

Expected outcomes

Once the objectives are reached, an improvement of the laboratory capabilities to detect and identify high threat pathogens and of the technical skills as well as more harmonised approaches on biosafety and biosecurity will be expected. The repository of reference material set up in the previous EQADeBa project will be extended and scientifically characterised reference material will be made available for quality assurance exercises and validation of methods and instruments. The reference material collected and characterised in the framework of the previous ENP4 project will be further extended and characterised. Data from three rounds of EQAEs, separately carried out for representative high-threat inactivated and native bacteria and viruses will be acquired. Recommendations for a “Gold Standard” in the diagnostics of high threat pathogens will be further developed and optimized.

The project will further strengthen the network among relevant laboratories appointed for the detection of high threat infectious pathogens throughout Europe. This network will contribute to the long-term monitoring of bacterial and viral zoonoses occurring naturally in Europe or being imported from other parts of the world. The Joint Action will contribute to training and to the improvement of biosafety and biosecurity skills for the handling of high threat pathogens through the dissemination of best practices. Information will be collected on the capabilities and the degree of European preparedness to detect highly infectious pathogens. Stakeholders will have the opportunity to evaluate their national needs for further support of individual reference laboratories appointed for recognition of high threat pathogens, including recognised bioterrorism agents.

In the framework of the project, a Working Group will be set up aiming to produce recommendations and guidelines from the laboratory perspective to manage biological events.

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- Philipps Universität Marburg, Germany
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- Terviseamet (Health Board), Estonia
- Veterinary & Agro-chemical Research Institute, Belgium
- State Agency "Infectology center of Latvia", Latvia

EC CONTRIBUTION:
EUR 3315981.96

DURATION:
36 month(s)

PROJECT NO 20101105

SCREENING FOR HEPATITIS B AND C AMONG MIGRANTS IN THE EUROPEAN UNION (EU-HEP-SCREEN)

Abstract

General objectives

Chronic viral hepatitis B and C is a major health problem in many European countries. Migrants from endemic areas in particular, are the most affected and underserved population groups. The general objective of this project is to assess, describe and communicate to public health professionals the tools and conditions necessary for implementing successful screening programmes for hepatitis B and C among migrants in the European Union.

Strategic relevance and contribution to the public health programme

Screening programmes for hepatitis B and C in European countries target blood donors, pregnant women and behavioural high-risk groups. The purpose of these programmes is primary prevention - for hepatitis B through vaccination- rather than detection of chronically infected individuals. Recent advancements in treatment for chronic hepatitis B and C have made secondary prevention possible and there is an urgent need to identify patients who qualify for treatment. Migrants from endemic countries are at risk but are currently not targeted in screening programmes. The European added value is ensured as lessons learned from screening specific migrant groups in specific countries, and the assessment of the evidence base for screening, will be translated into an array of communication materials, methods, recommendations and information that will be widely applicable and available to public health professionals in the EU and that can be adapted to local circumstances and specific target groups. The project also fits into current health policies to connect prevention and curation.

Methods and means

Central in the project are four pilot studies using different screening strategies: 1) information and outreaching, combined with testing through local general practitioners; 2) combined information and testing on location; 3) opportunistic and systematic case finding in general practice; and 4) case finding through existing screening programs. Depending on the contents of the respective work packages, different methods and means will be used to achieve the general objective. Methods include literature review and surveys with structured questionnaires to obtain additional information from experts. Communication materials will be collected and a module in the project website will be developed to facilitate information and communication exchange with health care professionals. The main product of the project is a tool kit for policy makers and public health professionals containing recommendations, information and materials on implementing a screening program.

Expected outcomes

The project will lay the foundation for the expansion of nationwide screening and prevention programmes for hepatitis B and C among migrants in the EU. This will be achieved through a sequence of outcomes of the project resulting in a comprehensive overview and analysis of knowledge on the clinical management of hepatitis B and C in migrants, an appraisal of alternative screening strategies, and methods for effective communication to the target population. Based on the integration of the outcomes, best practices for screening will be defined and a tool kit will be developed, which gives instruments and information on the practical aspects of implementing a screening programme, together with the recommendations and materials collected and developed in the project. A tool kit will enhance the capacity of public health professionals by allowing them to design an effective screening programme for their country or region, targeted at specific migrant groups.

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- Queen Mary's University London, United Kingdom
- The Hepatitis C Trust, United Kingdom
- University of Florence, Italy
- University of Las Palmas de Gran Canaria, Spain

EC CONTRIBUTION:
EUR 792816.00

DURATION:
36 month(s)

KEYWORDS:
- Migrants
- Screening
- hepatitis, chronic
- Liver disease
- Hepatitis screening

CHAPTER 4

Operating Grants

PROJECT NO 20103209

AP-HP_PORPHYRIA_FY2011 (AP-HP_FY2011)

Mission and vision of the operating grant holder

Our mission is to improve the lives of porphyria patients by improving the diagnosis and treatment of these rare conditions. EPNET has been funded by the EU Commission (DG SANCO, PHEA programme). The objective is to provide an effective network of specialist porphyria centres in each country. EPNET contains 28 EU specialist centres that work together to develop an up-to-date approach to the management of patients and families with porphyria that conforms to uniform standards. EPNET focuses on: provision of information to patients (in their own languages) and healthcare professionals (HCPs); collection of information on safety of drugs; use of external quality assessment to develop quality standards for diagnosis and clinical advice; a web-based registry to collect data about the porphyrias to inform clinical practice and healthcare planning. Progress is communicated to partners through regular meetings and reports. Information on the porphyrias and drug selection is made available to patients, public health authorities and HCP's at www.porphyria-europe.org; www.drugs-porphyria.org.

Strategic objectives and specific activities for 2011

Porphyrias are uncommon diseases for which diagnosis and treatment varies within the EU. The overall aim of EPNET is therefore to improve the clinical management of porphyria patients.

The general objectives are to:

- increase accuracy of diagnosis; reduce delay in diagnosis and to expand specialist diagnostic and clinical centres in the EU, each of which conforms to agreed quality criteria
- improve knowledge and understanding of porphyrias by providing continually updated information to patients in their own languages, and to HCPs, on a dedicated porphyria website
- provide continuously improving, evidence-based information about selection of drugs for use in patients with acute porphyria
- improve collective knowledge of clinical manifestations and phenotypic variability of porphyrias and their complications through collection of epidemiological data to inform Public Health Authorities
- promote and facilitate research into the porphyrias through EU collaboration

Therefore the main activities are:

- Coordinate the European Porphyria Network
- Host and manage the European Porphyria Network website to ensure regular updating of information for patients and healthcare professionals
- Offer training opportunities to clinicians and clinical scientists through 4-6 week attachment to an acknowledged specialist centre
- Develop and disseminate evidence-based best practice guidelines for diagnosis and treatment of porphyria
- Provide remedial support to under performing specialist laboratories identified through the External Quality Assurance Scheme to improve diagnostic testing quality
- Co-ordinate collection, update and maintenance of a searchable, evidence based database for selecting drugs for acute porphyria patients
- Expand registry database to collect and analyse clinical data regarding clinical manifestations and phenotypic variability
- Disseminate information to EPNET members, patient support groups and the wider clinical community
- Identify opportunities to contribute to related European organisations and initiatives in rare disease such as Orphanet, EuroGentest and others

Expected outcomes

Objective 1: to extend EPNET to all European countries

Activities and Methods: Representatives in countries where there is still not a porphyria centre will be approached through personal contacts, internet browsing or national Presidents of Associations for Clinical Chemistry affiliated to the EU federation of clinical chemistry. Potential specialist centres will be asked to fill in the application form developed during the first part of this project. This form gives minimum criteria for being a specialist porphyria centre. All the existing participants in EPNET will also be asked to complete a similar annual activity report. In countries without a specialist centre, the project will try to encourage such centres to be established.

Expected outcomes: An overview of the status of laboratory-based porphyria services in all European countries. Where services exist, each will have a feedback activity report comparing their activity to the others (as for EPNET members in the first part of the project). Where requirements for being a specialist centre are not met, advice on how to move further to obtain the status will be given. All will be expected to join the EQAS for porphyria.

Objective 2: to improve diagnostic and analytical quality of specialist Porphyria centres in Europe
Activities and Methods: To establish target values for the EQAS and quality specifications (QS) for acceptable analytical and clinical quality. We will do this by assessing the literature and having discussions about what quality is necessary for diagnosis and monitoring of porphyrias. Target values and QS will be implemented in the EQAS; advice will be offered to participants not meeting the criteria.

Expected outcome: Improved performance by Specialist Laboratories, measured by recording the number of laboratories meeting QS in the EQAS, with reduction in diagnostic errors.

Objective 3: to expand the European porphyria registry.
Activities and methods. From 2007, the registry has been collecting incidence data and complications. In 2011 we will expand the registry (i) The minimum prevalences of each inherited porphyria in participating countries will be estimated from data held by specialist porphyria centres participating in EPNET. Each centre will return to a single centre (Bergen) only the total number of patients (not lists of individual patients) with each porphyria known to their centre. These lists will be mainly derived from laboratory records; duplication between centres will be controlled by comparing dates of birth at local/national level. (ii) The Paris database will be modified, in collaboration with MediFirst, to allow collection of additional clinical information on patients newly presenting with an attack of acute porphyria. The extended database will be validated by input of data from pilot centres (Sweden, France).

Expected outcomes: (i) Determination of the minimum prevalences of inherited porphyrias in selected countries. (ii) Expansion of database for prospective collection of clinical information about the clinical pattern of acute porphyrias.

Objective 4: to continue to improve the clinical evidence for selection of drugs for patients with acute porphyria
Activities and methods: A simplified reporting system will be used to collect information about drug usage from patients in as many EU countries as possible. A steering group for the drug database, composed of four members from different EU countries, will continually review the drug data, draft SOP and guidelines. Generic drug information will be disseminated on the Drug Database for Acute Porphyria (drugs-porphyria.org)

Expected outcome: Additional clinical evidence to strengthen the drug data base.

EPNET target groups are patients, their families and relevant healthcare professionals in the Europe. Sylvie le Moal from the French porphyria patient association will participate to network meetings and work with the EG and network manager. Sylvie will liaise with Eurordis and with the network centres to identify patient groups in each country. A survey will be sent to patients to understand their expectations of the network.

Appropriate ethical approvals have been obtained.

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ASSOCIATED PARTNERS:
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EC CONTRIBUTION:
EUR 99250.00

DURATION:
12 month(s)

KEYWORDS:
- Porphyria
- European Reference Network
- Registry
- Rare Disease
- Consensus Care Guidelines

PROJECT NO 20103208

ALZHEIMER EUROPE - AE FY 2011 (AE _FY2011)

Mission and vision of the operating grant holder

Alzheimer Europe defines its mission as "changing perceptions, practice and policy in order to improve the access of people with dementia and their carers to treatment options and care services".

To achieve its mission, Alzheimer Europe has defined the following six objectives in its strategic plan which covers the period of 2006-2010:

1. Representing the interests of people with dementia and their carers,
2. Involving and supporting national Alzheimer associations,
3. Improving the information exchange between AE, its members and other stakeholders,
4. Promoting best practice through the development of comparative surveys,
5. Jointly developing policy with its member organisations,
6. Developing strategic partnerships with other actors in the field.

On the basis of these strategic objectives, Alzheimer Europe develops annual work plans outlining the priority areas and projects of the organisation. The development of a new strategic plan for 2011-2015 forms part of the 2010 operating grant.

Strategic objectives and specific activities for 2011

In line with the strategic objectives of the organisation, AE carried out a number of key initiatives in the past years. AE:

1. developed close ties with the different European institutions and created a European Alzheimer's Alliance comprised of Members of the European Parliament and actively participated in the preparations of the Commission Mental Health Conference and the French Presidency Conference on Alzheimer's disease,
2. contributed to European policy discussions such as information to patients, cross-border health care, the Commission Transparency Initiative and other consultations,
3. jointly developed with its member organisations the Paris Declaration which outlines the political priorities of the European Alzheimer movement,
4. organised annual conferences which were attended by between 300 and 600 participants from different professional backgrounds and countries,
5. actively communicated with its membership, European institutions and interested parties (~3,700 contacts on AE mailing list) on its activities, European and national policy developments and scientific news through its monthly e-mail newsletter and its Dementia in Europe magazine,
6. promoted a rights based approach to the care of people with dementia through projects focused on the legal rights of people with dementia and in depth coverage of such issues as the use of advance directives by people with dementia or end-of-life care.

From 2006-2008, AE also coordinated a three year Commission financed project entitled "European Collaboration on Dementia - EuroCoDe" which resulted in reports on the socio-economic impact of dementia, psycho-social interventions, risk factors and prevention, the prevalence of dementia, the diagnosis and treatment of dementia and the provision of social support to people with dementia and their carers.

For its 2010 activities, the organisation received an operating grant and inter alia was able to/will work on the development of a European Dementia Ethics Network, carry out an inventory of guardianship legislation and organise its 20th Annual Conference in Luxembourg.

Expected outcomes

Alzheimer Europe identified five key activities and projects for its 2011 work programme which will build on the expected results of its successful 2010 operating grant. These activities are geared towards a collaboration with and support of other European initiatives, such as the Joint Action and Joint Programming on Alzheimer's disease. In particular, the organisation will carry out the following main activities:

1. The ethics of dementia research

The work on dementia ethics started in 2009 had the aim of collecting and disseminating ethical positions and recommendations, to provide in-depth coverage of specific ethical dilemmas, to develop, where possible consensual positions and recommendations and to collect requests of individual carers and health care professionals and provide guidance where possible. Building on the work carried out in 2010, the focus will be on developing a report on the ethical issues of dementia research (informed consent, representation of people unable to consent, placebo research, genetic testing) whilst at the same time starting a detailed literature review on ethical dilemmas faced by informal carers at home and highlighting the ethical dimension of some of the experiences that carers encounter in their daily lives.

2. Legal Rights Project

Based on the previous European Commission financed project Lawnet and the work carried out in 2009 and 2010 on healthcare decision making and guardianship systems, Alzheimer Europe will update the national reports on the legislation surrounding restrictions of freedom and coercive measures of the previously studied 15 Member States of the European Union and develop reports for those countries not previously studied (10 new Member States and Croatia, Iceland, Norway, Switzerland and Turkey). These comparative reports will be published with the 2011 Dementia in Europe Yearbook.

3. Dissemination of European and national information on dementia

Alzheimer Europe will continue to gather and disseminate all information on dementia at both a European and national level and will collaborate closely with the Joint Action and Joint Programming on Alzheimer's disease. A focus of the dissemination work will also be on policy developments and the development and implementation of national dementia strategies and Alzheimer's plans. Scientific developments with regard to new treatments and new care approaches will also be highlighted in AE's dissemination tools (extensive website and monthly newsletter).

4. Annual General Meeting

The Annual General Meeting of Alzheimer Europe will take place in Warsaw on 6 October 2011. A focus of the meeting will be on the involvement of people with dementia in the activities of Alzheimer associations on a European and national level, as well as outreach activities of interest to emerging associations in Central and Eastern Europe. The Annual General Meeting will take place in conjunction with the 21st Alzheimer Europe Conference to allow participants from member organisations and people with dementia to participate in the two day event.

5. Organisational issues

A number of organisational issues will also be addressed in the 2011 Work Plan to improve the organisation's activities in the future, in particular the outreach to other organisations active in the field, as well as the implementation of the new strategic plan and financial diversification strategy developed under the 2010 operating grant. The involvement of people with dementia has been identified as a key objective for the organisation and a mechanism for establishing an advisory board consisting of people with dementia will be developed in 2011. Particular attention will need to be paid on how best to support people with dementia to attend working groups set up in the framework of the operating grant and to contribute to the discussion with members at the Annual General Meeting.

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EC CONTRIBUTION:
EUR 200000.00

DURATION:
12 month(s)

KEYWORDS:
- Dementia
- Alzheimer
- Legal rights

PROJECT NO 20103201

ASSISTANCE PUBLIQUE HÔPITAUX DE PARIS (AP-HP-WILSON FY2011)

Mission and vision of the operating grant holder

EuroWilsoN (EW) mission is to improve quality of care and access to multi-disciplinary expertise for EU patients with Wilson's disease (WD). From 2004-2008 EW (LSHM CT2004 503430), has achieved:

- An active patient registry
- Interaction between clinicians and an expert validation committee
- External molecular quality network
- A DVD in the neurological evaluation
- Transferring knowledge by contribution to the public consultation papers and participation in policy conferences
- organisation of a European patient meeting during the Eurordis conference

EW's goals include maintaining and enhancing this network; the French centre for WD serves as a network model. The network will include all stakeholders involved in patient care: medical, scientific para-medical, EU authorities and patients' associations. EW will:

- Promote exchange between participants
- Provide up-to-date disease information on its website (eurowilson.org) and Orphanet
- Develop and publish evidence based clinical guidelines
- Enhance the registry to provide epidemiological data, outcome indicators, country comparisons and to facilitate collaborative research and public health projects
- Support patients and patient associations in the EU

Strategic objectives and specific activities for 2011

The general objective of EW is to develop the EU WD multi-disciplinary network and its registry and ultimately to provide EU patients and their families with up-to-date information, optimised management and equal access to expert advice, diagnosis and care.

Objective 1: improve information and services to patients, health professionals and general public

- Development and dissemination online of up-to-date information and educational documents for patients and families in their own language, information for health professionals including social workers and nurses
- Develop a "bibliographic journal watch" with two levels of information: interpretation for the lay public and patients and interpretation for scientific audience
- Help set up EU patient meetings, on average once every two years with the aim to transfer experience between different national associations. Torben Gronnebaek and Eurordis will have a strong role in this activity

Objective 2: Increase knowledge of the disease

- Continue information sharing between different WD expertise. Since its beginning, EW has successfully produced a neurology scoring system, a hepatic scoring system, a laboratory external quality assessment programme, several publications and information for children, parents and adult patients in patients own language
- Continue the annual network meetings
- Continue to enter newly diagnosed patients in countries that have resources to do so and follow-up into the registry, analysis of indicators to show evolution of care and impact of rare disease plans. The feasibility of this has been determined by the success of the French contribution to the EW database which currently has a cohort of 285 patients.

Objective 3: Improve access to diagnosis, treatment and high-quality health care

- Encourage new labs to participate to EMQN mutation quality assay
- Develop European guidelines on the management of the disease
- Evaluate current status of the availability of WD diagnostic tests and expert clinical care in Europe
- Work with the MS national plans or strategies for rare disease with the objective to work with one database on WD which provides policy makers with information necessary in resource decisions. Long-term sustainability is one of our aims within these national plans

Expected outcomes

Objectives and methods:

Objective 1: improve information and services to patients, and HCP's; The lead of activities related to objective 1 is T.Gronnebaek, patient rep & director of Eurordis

- Provide information on EU centres with expertise in WD on www.eurowilson.org
- Determine needs and expectations of patients, families and associations through a survey in collaboration with Eurordis
- Disseminate to patient organisations
- Develop and disseminate educational documents adapted to the needs of psychologists, social workers, physiotherapist, speech therapists and nurses.
- Learn from the Danish patient association and their role when new diagnosis are announced to patients or parents

Objective 2: continue to collect data in the registry and increase knowledge

- The EW database will be maintained and enhanced by inclusion of new cases and collection of follow-up data
- The interface between the EU database and the French CNR has been successful; its applicability will be explored in other countries i.e. developing multi-disciplinary teams working with the database
- Registry data will be produced on: treatments being used and different clinical scenarios; doses used; changes of Rx and reasons for change; outcomes will provide data on drug efficacy, side effects and compliance
- Quality issues to be examined are: completeness of family screening; indicators of quality diagnosis (symptom-diagnosis interval), treatment (adherence to guidelines) and outcome.

Objective 3: improve patient access to diagnosis, treatment and high-quality care

- A yearly network meeting to improve awareness, knowledge and quality of care
- Recruitment of clinicians from under-represented countries,
- encourage the involvement of professionals allied to medicine and patient representatives
- Review of difficult cases eg by transmission of MRI images, liver biopsy slides, or neurological video
- encourage participation to the WD EMQN scheme
- Survey to establish the availability of different diagnostic tests and clinical care in Europe: he-

patic copper assay, mutation and access to multidisciplinary care and treatment

Objective 4: develop guidelines

- Guidelines on the investigation and management of WD patients including psychological and social aspects. They will be based on a critical review of the literature and expert opinion. An expert group will share and translate national protocols already used and validated.

Objective 5: develop a journal watch

- A review of recent publications relevant to WD will be produced thrice yearly. Sub-editors will be asked to review their fields. Two levels will be developed: one professional and one easy to understand for lay people and patients. The reviews will be emailed and produced on-line.

EB Members lead the different tasks. A part-time registry manager will work with Prof Tanner to validate new cases, give feed-back, analyse data and produce reports. The programme manager based in Lariboisiere will have responsibility for day-to-day running in collaboration with the CNR Wilson for writing the reports

Expected outcomes: Knowledge will be improved concerning current care protocols, services provided and outcomes. Recommendations will be given to optimise patient care. Patients and healthcare professionals will get access to up-to-date information on WD in their own language. Qol of patients and families should be improved as they have more efficient diagnosis, care and information.

Target groups: Experts will be able to exchange information, have access to a registry for patient follow-up, patients will benefit from access to improved care, healthcare professionals will have access to information and guidelines and could share their experiences. Health authorities will be aware of the availability of the access to diagnostic test and to expert clinical care in Europe.

The registry has ethical approval. Network members are involved with their national patient organisations. EW will apply with the Eurordis guidelines for collaboration with European Reference Networks.

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ASSOCIATED PARTNERS:
No Associated partners

EC CONTRIBUTION:
EUR 167160.00

DURATION:
12 month(s)

KEYWORDS:
- Guidelines
- Wilson's disease
- European Reference Network
- Registry

PROJECT NO 20103207

DE STICHTING AIDS - SOA AIDS NETHERLANDS (SANL_FY2011)

Mission and vision of the operating grant holder

Soa Aids Nederland (SANL) is host organisation of the network AIDS Action Europe (AAE). AAE's mission: unite civil society to work towards a more effective response to the HIV epidemic in Europe and Central Asia. We strive for better protection of human rights and universal access to prevention, treatment, care and support and work towards a reduction of health inequalities focussing on most at risk populations in Central and Eastern Europe and Central Asia.

Strategic objectives and specific activities for 2011

AAE's general objectives in Europe and Central Asia: Strengthen civil society is contribution to a more effective response to the HIV epidemic by:

- Making an effective and meaningful contribution to regional and national policies related to HIV and AIDS;
- Facilitating continuous exchange among NGOs on good practices and lessons learned related to HIV and AIDS;
- Developing a stronger, more effective organization and network.

AAEs core activities focus around advocacy and linking & learning. We focus on most at risk populations such as men having sex with men, people using drugs and migrants as well as on strengthening civil society's response in Eastern Europe and Central Asia. We are however an inclusive network, facilitating learning, exchange and cooperation among NGOs in the wider European and Central Asian region.

AAE undertakes advocacy on global, European and national level. Since 2005 AAE is co-chair of the HIV/AIDS Civil Society Forum (CSF). Together with EATG, we prepare, organise and chair the CSF meetings. AAE also acts as rapporteur of the CSF meetings and ensures follow-up communications. AAE is also member of the HIV/AIDS Think Tank (TT). This facilitates AAE's pro-active involvement in development and implementation of European HIV/AIDS policies. In 2009 we played a key role in the development of the EU HIV/AIDS Communication 2009-2013. In 2011 AAE will strengthen involvement of civil society in implementation, monitoring and evaluation of this Communication and will coordinate a ECDC survey among CSF members. As regional network of ICASO AAE contributes to a more effective response to the global HIV epidemic.

Our Clearinghouse is the online database on HIV and AIDS for Europe and Central Asia- facilitates interactive exchange of good practices. Maintenance and promotion of the use of the clearinghouse has evolved into one of AAE's core activities.

From 2011 onwards AAE will also engage in social media communications as part a renewed cross-media communications strategy. Social media are more and more developing into departure points for online browsing and for gathering of communities. They provide perfect tools for new and deeper ways of involvement. Social media are often described using the 4 Cs: Content, Collaboration, Community and Collective intelligence. These 4 Cs are fully in line with the work and mission of AAE.

In fact, the 4 Cs can be matched one on one with our strategic objectives:

- Strengthen civil society's contribution to a more effective response to the HIV epidemic; (Content)
- Make an effective and meaningful contribution to regional and national policies related to HIV and AIDS; (Collaboration)
- Facilitate continuous exchange among NGOs on good practices and lessons learned related to HIV and AIDS; (Collective intelligence)
- Develop a stronger, more effective organization and network (Community)

AAE is currently developing a cross media strategy which will include the use of social media taking full advantage of their potential to reach our objectives. It will be implemented in phases, starting in 2010 (Focus), continuing in 2011 (Integration and Interaction) on to 2012 (Expansion).

AAE also coordinates the project ROST 2010-2012(Responding to HIV through Organisational Support and Technical Cooperation in EECA) through partner organisation AFEW.

Expected outcomes

Strengthen civil society's contribution to regional and national HIV/AIDS policies and programmes

- NGOs and relevant stakeholders are well-informed about relevant policy developments
- CSF is involved in implementation/monitoring of Communication
- Civil society concerns are advocated for at European and International policy/advocacy opportunities

Increase collaboration, linking & learning, and good practice exchange among NGOs, networks, policy makers and other stakeholders in Europe and Central Asia

- NGOs, networks, projects, policy makers and other stakeholders are better informed about and make more use of the clearinghouse (indicators: 20% increase in up and downloads;15% increase in account holders);
- Strengthened networking and collaboration between AAE and stakeholders (indicators: minimum 300 members; 1375 monthly web visits and 25% of members/partners connected via social media)

Manage internal processes to successfully implement the work plan

- Work programme 2011 implemented as planned (indicator: 2 SC meeting reports; minutes 8 TCs;90% work plan implemented;2010 annual report online; staff progress reports)

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ASSOCIATED PARTNERS:
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EC CONTRIBUTION:
EUR 250000.00

DURATION:
12 month(s)

KEYWORDS:

- Acquired Immunodeficiency Syndrome
- HIV/AIDS
- Learning
- Policy Making
- Communication

PROJECT NO 20103204

EUROPEAN ALCOHOL POLICY ALIANCE (EUROCARE_FY2011)

Mission and vision of the operating grant holder

Eurocare's vision is a Europe where alcohol related harm is no longer one of the leading risk factors for ill-health, early death, violence and disability, where innocent third parties no longer suffer from the drinking of others and where the EU and its Member States recognise the harm done by alcohol and implement effective and comprehensive policies to tackle it.

Eurocare is recognized as the leading independent NGO on alcohol policies. Eurocare is unique in its role as the sole non-governmental organization specialised on alcohol policy working at European level.

The mission of Eurocare is to promote policies that prevent and reduce alcohol-related harm, through advocacy in the EU and WHO EURO.

Our message in regards to alcohol consumption is that "less is better".

To achieve its mission Eurocare seeks to influence policy makers, advocate effective and evidence based alcohol policies, monitor initiatives, monitor marketing practices of the alcohol industry, disseminate information and knowledge, publish reports and position papers.

Strategic objectives and specific activities for 2011

Eurocare works with its members to influence the European Institutions and Member States to recognise and challenge the harm caused by alcohol with the aim of reducing the total alcohol consumption in Europe by 20% by 2020.

We envisage a Europe where children and young people are less affected by the harm done by alcohol, the minimum age for purchasing alcoholic beverages is 18 year, there is no marketing of alcoholic beverages targeting young people, blood alcohol level (BAL) for driving is 0,2 and it is properly enforced.

The following strategic objectives are needed to meet the above mentioned challenge:

1. To advocate towards the EU institutions for change.
   - promote the recognition of the causality between the availability of alcohol and the levels of harm in society;
   - Promote legislative and regulatory measures to prevent alcohol related harm;
   - Raise awareness for a balanced and integrated strategy which combines information and education with alcohol control policies
   - Facilitate the collection, collation, analysis, dissemination and utilization of data on alcohol consumption and related harm within the EU and other countries;
   - Promote the development of alcohol prevention and rehabilitation strategies and programs appropriate to the needs of individuals and their environment;
   - Promote a wide range of alcohol education and training programs for special target areas such as the workplace, schools and social and health care organizations;
2. To create an NGO network to influence the political processes at EU level
   - Provide a forum for non - governmental organizations and institutions working in the field of preventing and reducing alcohol related harm;
   - To create a platform for discussions and exchange of best practice;
   - Establish, where possible, common ground and purpose;
   - Provide a regular exchange of information;
   - Seek co-operation with appropriate stakeholders and international agencies.
3. To attract member organizations and to support and inform existing members
   - Foster among its members an understanding of social, cultural, economic and political responses to the use of alcohol throughout Europe;

3. Expected outcomes

Eurocare s membership is the foundation of its existence, credibility and legitimacy. Maintenance, development, service and support to members are main-streamed into all activities. In order to perform its essential functions it is necessary for Eurocare to be adequately balanced and representative of the different strands of alcohol work and Member States. One of the main objectives is to build capacity to enable members to engage in decision making processes and increase the advocacy of evidence based policy at all levels, to actively foster cooperation and exchange of knowledge among members (and other NGOs).

A plan for expanding membership will be developed by the end of 2010. In 2011 an advocacy course will be held for members in Brussels and a plan for

expanding this will be discussed with the members. Dissemination of information is one of Eurocare's core activities. The secretariat will provide timely, accurate and useful information that supports the work of the members and facilitates the sharing of good practice. The main information tools are the website and the newsletter (see www.eurocare.org). Planning and preparations for including a database on the web site with good practice and literature database will be developed in 2011. The newsletter is bimonthly and includes information on EU policies/activities, updates from MS, the Secretariat and members etc). Policy briefings and reports are provided at the request of the board or the members (who are always consulted).

In 2011 advertising and marketing will be a key issue (including digital media). A major conference at the European Parliament is being planned together with the Irish MEP M Harkinn. Eurocare is also planning a mapping exercise of people's exposure to alcohol marketing. The objective of the study is to do a snapshot of people's experiences of alcohol marketing and see if there is a difference between age groups.

Eurocare will organize follow up activities of the Policy statement on alcohol accidents and injuries signed by 14 EU NGOs (Nov 2009) as particularly young men are in danger for accidents and violence and young women for sexual abuse. It is also estimated that 1 of 4 of all road traffic deaths involve alcohol.

The forthcoming 4th European Alcohol Policy conference will produce a number of protocols of action in different areas. The knowledge gathered needs to be fed into the relevant policy making processes, especially the forthcoming EU Alcohol Strategy from 2012.

Eurocare wishes to influence key decision makers in the EU, within both the MS and the EU Institutions, especially focusing on health in all policies, reminding policy makers of the harm done by alcohol and the need to put the health of citizens before the economic interests of a few. There are several issues that need continued attention; food information - labelling of alcoholic beverages (ingredient listing and kcal), health and safety warning labels on alcoholic beverages (no alcohol during pregnancy, no drink and drive,can be addictive, liver cirrhosis etc), volume of alcohol advertising and marketing, enforcement of age limits, availability and affordability, enforcement of BAL for drivers, taxation and price, improving health systems, getting good data from both MS/ industry, supporting a global strategy.

Continued support from the secretariat is needed to engage and coordinate members' input into the activities of the EU Alcohol and Health Forum and the EU Health Policy forum.

The media play a key role at national and EU level in raising awareness of key public health issues. Eurocare needs to further engage with the media to raise the profile of the organization and its concerns. The majority of these activities will be taken by the Secretariat and the staff needs to be strengthened in order to follow this up.

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EC CONTRIBUTION:
EUR 99000.00

DURATION:
12 month(s)

KEYWORDS:
- Alcohol Drinking
- Capacity building
- Alcohol policy
- Prevent and reduce alcohol related harm
- Control policies
- Networking and advocacy

PROJECT NO 20103205

EUROPEAN ORGANISATION FOR RARE DISEASES (EURORDIS_FY2011)

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). It represents the voice of an estimated 29 million citizens in the EU.

EURORDIS mission is to build a strong pan-European community of Patient Organisations and people living with RD, to be their voice at the European level and to fight against the impact of RD on their lives.

To this end, EURORDIS undertakes activities on behalf of its members:

- Empowering RD patient groups
- Advocating RD as a public health priority
- Raising public awareness on RD
- Improving access to information, treatment, care and support for people living with RD
- Improving quality of life
- Encouraging good practices in relation to these issues
- Promoting scientific and clinical research on RD
- Developing treatments and drugs for people with RD

EURORDIS plays a pivotal role in the implementation of the EU strategy on RD (EC Communication, Dec.2008 and Council Recommendations, June 2009), in the EU Committee of Experts on RD and in the elaboration of National Plans or Strategies on RD.

Strategic objectives and specific activities for 2011

1. Consolidate the EU RD patients community & voice
   - Promote RD as a public health priority at national European & global levels
   - Be the voice of all RD patients, genetic or not,incl.ultra RDs and rare cancers
   - Raise public awareness on RD,incl. Rare Disease Day
   - Organise the ECRD every 2 years
   - Focus on key EU policy issues relevant to people living with RD
2. Facilitate the implementation of EU regulations/ strategies
   - Support effective implementation of EC Communication & Council Recos on RD
   - Promote RD national plans
   - Evaluate impact of regulations&strategies on RD patients
   - Participate in EU CERD & related WGs
   - Support therapeutic development/access to OD, paediatrics & ATMPs
   - Participate in EMA committees & WPs, bring in patient expertise
   - Inform & involve more members/volunteers in therapeutic activities
   - Facilitate dialogue between patient groups, experts, companies regulators, NCA & HTA
   - Support the development of EU/national integrative healthcare policies
   - Promote EU Ref Networks of Centres of Expertise and patient registries
   - Participate in activities on screening & gene testing
   - Support a better research policy framework
   - Promote the development of EU research networks and infrastructures
   - Support the participation of patients in researchðics committee
   - Support development&access to information & social specialised services
   - Consolidate national Help Lines & EU Networking
   - Produce validated information on respite centres & therapeutic recreation programmes
   - Generate/share patient-based knowledge
3. Build capacities & empower members and volunteers
   - Maintain high level of legitimacy and professionalism within the membership
   - Organise the annual Membership Meeting
   - Broaden the patient group membership base &focus on Central&Eastern Europe
   - Identify, involve and support volunteers in more activities
   - Intensify networking & collaborative process with/between National alliances and RD specific Federations
   - Share good practices & organise training for patient reps
4. Sustain human, financial & organisational resources
   - Good governance & financial transparency
   - Web communications in work process
   - Integrative IT infrastructures
   - Diversify resources and increase public funding
   - Increase in-kind resources

Expected outcomes

A. Communication to POs, stakeholders and the public:

a) EURORDIS Website & Electronic newsletter;6 languages
b) Preparation of the ECRD 2012 Brussels: Programme Committee, announcement,selection of Conference venue, hotels and providers
c) Update of fact sheets
d) RDD 2011 on 28/02 and Media Monitoring Services; Rare Disease Day 2012 preparation
e) Awareness raising through patient stories,

video & photo
f) Maintenance of EURORDIS RD community databases: 1400 POs, 406 members, 150 volunteers
g) International dialogue with NORD, CORD, ICORD, DIA, etc.
h) Promoting RD as an international priority

B. Capacity building for patient representatives:

1. Health Policy, POs networking and empowerment:
   a) Outreach to POs and members, dissemination of information, consultation of members
   b) Strengthen focus on new MS, Eastern & Central Europe; fellowships
   c) Support the EU Network of National Alliances; organisation of 2 Workshops of the Council of National Alliances(CNA); involvement in public awareness (RD Day) and empowerment on the development of strategies for RD at national level
   d) Support the EU Network of RD specific Federations through dissemination and sharing of good practices; involvement in public awareness and empowerment on EU policies(CoE,ERN); organisation of 2 Workshops for the Council of European Federations(CEF)
   e) Support to volunteers representing EURORDIS in EU committees
   f) Fact sheets for capacity-building purposes on RD policy aspects
2. Research and Therapeutics Development:
   a) Patient involvement in EMA activities:
      - Support the participation of patient representatives in the EMA Committees (COMP, PDCO, CAT) and Working Parties (Patients & Consumers,Protocol Assistance and Pharmacovigilance)
      - Support the EURORDIS Therapeutic Action Group(TAG)composed of all RD patient representatives at the EMA to exchange information and coordinate actions
      - Monthly report compiling feedback from each committee and WP
   b) Review and validate public information on RD therapies disseminated by the EMA at the time of designation (PSOs) and marketing authorisation (EPARs, Package Leaflet)
   c) Support involvement of more RD patient representatives in the OD,PD, ATMP policies and in drug development through information dissemination and capacity building activities on clinical trials and EU regulatory affairs, using the following means:
      - Support EURORDIS Task Forces on Orphan Drugs, Pediatrics, Drug Information,Transparency & Access (DITA), each involving 10-15 trained volunteers
      - Summer School 2011, based on experience exchange & case studies; 40 new participants
      - e-Learning on specific and advanced aspects of drug development, clinical trials and regulatory affairs
   d) Support capacity building activities of patient advocates in HTA and access to medicines, through a section on the website, dissemination of information
   e) Support good practice relations between POs & Sponsors on RD Clinical Trials (CT)based on EURORDIS Charter on Clinical Trials (CCT): promote signature by pharmaceutical Cies, and provide adequate staff and advisors to support the collaboration on specific CTs

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EC CONTRIBUTION:
EUR 580000.00

DURATION:
12 month(s)

KEYWORDS:
- Rare diseases
- Capacity building
- Patient organisations
- Advocacy
- Networking

PROJECT NO 20103203

EUROPEAN PUBLIC HEALTH ALLIANCE (EPHA_FY2011)

Mission and vision of the operating grant holder

EPHA is a change agent – Europe's leading NGO advocating for better health. Our mission is to bring together the public health community to provide thought leadership and facilitate change; to build public health capacity to deliver equitable solutions to European public health challenges, to improve health and reduce health inequalities. Our vision is of a Europe with universal good health and well-being, where all those living within our borders have access to a sustainable and high quality health system: A Europe whose policies and practices contribute to health, both within and beyond its borders. Our values are: Equity, Solidarity, Sustainability, Universality, Diversity, Good Governance EPHA's work within the political and economic environment of the European Union is unique - bringing the voice of public health and the public interest into the policy-making arena, contributing to the delivery of the Health Strategy and advocating for citizens' health across policy areas in the Commission adds value to the institutional agenda and facilitates the decision-making process.

Strategic objectives and specific activities for 2011

EPHA's overarching objective for 2011-2015 is „to promote good health and well-being, to reduce disease and health inequalities" with general objectives:

1. To improve overall population health and healthy life years
2. To increase equity and access in health and reduce health inequalities
3. To support a health-promoting European institutional and policy framework

We have a fourth horizontal objective:

4. To strengthen and increase effective public health capacity

These general objectives and actions are identified as multi-annual with annual priorities set by the General Assembly.

Our activities are pan-European and include supporting public health capacity and cooperation in the geographic areas of greatest need, as well as underrepresented groups, particularly vulnerable groups or those suffering discrimination. EPHA s main activities are:

1. Advocating and building cooperation and partnerships in public health policy:
   a. Networking - supporting of networks and networking of public health academics and practitioners
   b. Cooperation - encouraging increased cooperation amongst national public health NGOs and actors
   c. Advocacy - supporting advocacy on issues affecting public health
2. Disseminating information and improving communication:
   a. Information relay - regular EU information to members and stakeholders through alerts, press releases, newsletters, adding European value to those working at national and local level
   b. Dissemination - sharing policy positions and briefings to support our stakeholders and partners in participating in EU policy discussions
   c. Sharing best practice - providing regular news on the activities of members and more broadly to our partners via our mailing lists (4,700 experts and NGOs across the European region)
3. Supporting capacity in under-represented regions and sectors for health advocacy:
   a. Trainer - developing and providing advocacy training and knowledge development in EU and health issues
   b. Forum - providing a space for an exchange of knowledge and best practice in the field of public health, EU issues and public health advocacy
   c. Thought leader - supporting the generation of evidence-based reports and policy recommendations, and participating in policy exchanges and stakeholder dialogue
4. Strengthening EPHAs functioning and governance:
   a. Financial sustainability - increasing EPHAs diversification in funding and financial independence
   b. Staff recruitment and retention - improving EPHA as an employer
   c. Membership and governance - supporting good governance and providing added value for members

Expected outcomes

EPHAs policy work is structured according to three core areas: equity and access to health, population health and the European institutional and policy framework. EPHA has a horizontal work strand to strengthen public health capacity. In 2011, each of the thematic areas has a specific focus and emphasis which is consistent with the priorities of WP 2010 (Point 3.1, Issues of strategic importance) and the

criteria of exceptional utility. As the leading advocate and platform for health in Europe, EPHA reaches out beyond the health sector to collaborate with philanthropic foundations, local and regional authorities, researchers and stakeholders working on development cooperation, transparency and good governance, environment, urban planning and transport.

1. Improving population health and increasing healthy life years: Disease prevention especially cancer and cardiovascular disease will be addressed through specific actions on the key causal factors of diet, alcohol consumption, physical activity and smoking. Building on the work of its members that specialise on each topic, EPHA will bring evidence for action and policy recommendations to decision-makers at EU/national level on how they can contribute to cancer and chronic disease prevention. EPHA will continue to make commitments for action on nutrition through the EU Diet Platform and at the EU Alcohol and Health Forum.
2. Increasing equity and access to health and reducing health inequalities: EPHAs work in this strand tracks EU initiatives on the health workforce, discussing issues of patient and professional mobility, patient-centric care. EPHA will continue work with MEPs and Member States to assess the potential impact on health inequalities and the sustainability of healthcare by monitoring the legislative passage of the Directive on Cross-Border Healthcare & the former Pharmaceuticals Package. EPHA will continue to cooperate with development NGOs on its campaign for global health. EPHA will also monitor EU initiatives on eHealth and medical devices. Health inequalities across the EU and within regions is a central theme for EPHA. Supporting NGOs representing under-represented groups/regions, EPHA will provide training and guidance. EPHA will participate in health inequality events of the Presidencies.
3. Supporting a health-promoting European institutional and policy framework: EPHA will focus on raising the profile of health in areas such as climate change, agriculture, transport, taxation, development and trade. EPHA will continue to work on impact assessment and better regulation. In the EU 2020 Strategy, more priority and resources are needed for public health and social protection. EPHA will also work on issues of transparency in policy-making processes, and dialogue between civil society and policy-makers.
4. Strengthening and increasing effective public health advocacy: EPHA will continue its work to raise awareness and interest amongst public health actors and the public of the legislative policy and processes and their impact on population health. In 2011 EPHA will continue to increase the impact of its communication, to strengthen and develop public health capacity and advocacy at national level, to increase the representation of geographic areas and vulnerable groups - building on its 2009 & 2010 work to identify lessons learned from capacity building in CEE countries, and to implement the learnings from this work. EPHA will continue to demonstrate its example of good governance and financial sustainability as a model for its members and other civil society actors.

The work carried out by EPHA within these strands is implemented via workshops, meetings and study visits; elaboration of briefings, policy dossiers, reports and articles for the newsletter; and advocacy campaigns. The implementation of the work is undertaken by the EPHA secretariat, in close cooperation with members and partners.

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EC CONTRIBUTION:
EUR 549364.00

DURATION:
12 month(s)

KEYWORDS:
- Advocacy
- Public health capacity
- Health NGO's
- Networking of Public Health

PROJECT NO 20103206

STICHTING HEALTH ACTION INTERNATIONAL (HAI_FY2011)

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.HAI Europe's mission and goals follow the overarching global work programme set every 5 years.HAI Europe devises plans and strategies for medicines' policy issues in Europe and acts as a regional centre.

HAI Europe's mission is:

- to increase access to essential medicines = medicines for priority health needs are available, accessible and affordable for all;
- to improve the rational use of medicines = citizens receive medication appropriate to their clinical needs, in tailored doses, for an adequate period of time,at the lowest cost to them and their community.

HAI works to achieve these goals through research excellence and evidence-based advocacy.

Vision: Poverty and social injustice represent the greatest barriers to sustainable health and development. HAI works for just and equitable societies where people can participate in decisions affecting their health and well being, including the allocation of resources.

Strategic objectives and specific activities for 2011

HAI's goal is to increase access to essential medicines and improve their rational use through research excellence and evidence-based advocacy.

In order to improve access to essential medicines, HAI encourages medical innovation that meets real therapeutic needs (including neglected and rare diseases); advocates for EU competition policies driven by health outcomes, making generic medicines available and affordable to European citizens; monitors European trade agreements that adversely affect access to essential medicines in third (often low and middle income) countries; formulates evidence-based policy advice and shares expertise to build the capacity of civil society organisations(CSOs).

To encourage the rational use of medicines, HAI promotes the use of medicines that have tangible therapeutic advantages; are acceptably safe and cost-effective. HAI educates civil society about antimicrobial resistance, the unethical promotion of medicines and encourages health literacy by promoting access to independent medicines information. HAI improves European patient safety by supporting effective and robust medicines regulation. HAI encourages direct reporting of adverse reactions by patients to enhance health security.

In order to advance democracy and good governance in medicines policy decision making, HAI works to reduce industry secrecy and control over important clinical data; promotes the inclusion of CSOs in the medicines policy process; advocates for engagement between the public and stakeholders to exchange knowledge on health policy; works to assess the correlation between corporate-funded interest representatives and their political messages at European level.

HAI Europe's advantage lies in our widely recognised expertise and credibility, and our ability to draw on input from staff, members and partners across Europe and beyond. HAI Europe's role is to trigger action, to serve as a multiplier, and to mobilise and coordinate, which is realised through research, policy analysis, information sharing, capacity-building, and by acting as a watchdog, monitoring governments, the European Commission, European agencies and intergovernmental organisations involved in medicines policy.

Expected outcomes

HAI's work programme is drafted every 5 years in consultation with the HAI network, advisory board and project staff. This programme informs the strategic plan, which is approved by the Global Secretariat and Foundation Board and implemented through sequential annual plans.

Objectives

1. To increase Access to Essential Medicines

1.1 Improve EU trade policy coherence with EU commitments on health and development.
Activities: Establish an observatory to monitor the impact of EU trade agreements with third parties on access to medicines (such as India and regional communities in Asia and Latin American); awareness campaign on the intellectual property (IP) enforcement agenda and its impact into public health
Methods and means: Literature review and data collection; if appropriate, apply research methodology; impact assessment of IP provisions; develop briefing papers; public event.

1.2 Promote EU competition policies that support equitable access to medicines.
Activities: Awareness campaign on competition and the accessibility and affordability of generic

medicines at national and EU levels; highlight the link between competition policy and medicines policy innovation,regulation,drug promotion.
Methods and means: Develop briefing papers, statements; meet with policy-makers; generate media coverage.

1.3 Advance medical innovation policy to meet public health needs.
Activities: Promote alternative mechanisms for pharmaceutical innovation that separate research and development costs from costs to the consumer.
Methods and means: Identify expertise; collect and collate information; formulate a blueprint, develop briefing papers.

2. To encourage Rational Use of Medicines

2.1 Improve health and treatment literacy by promoting access to relevant medicines information among consumers and health professionals.
Activities: Scoping exercise to map independent sources of medicines information; promote independent medicines information; improve European Medicines Agency (EMA) documents aimed at the public.
Methods & means: Literature review and methodology development; design data collection tool;draft briefing papers with key partners; appraise EPAR summaries and package leaflets; attend and contribute to EMA Patients and Consumers Working Party meetings.

2.2 Empower citizens by advocating for direct patient reporting of Adverse Drug Reactions (ADRs).
Activities: Collate and disseminate information on spontaneous ADR reporting by patients and consumers.
Methods & means: Publish of briefing papers.

2.3 Foster evidence-based policy by providing high-level technical advice on medicine issues to policy-makers.
Activities: Produce a report on key issues in medicines policy, potential aspects to be included: innovation, regulation, competition, promotion, pharmacovigilance and transparency.
Methods & means: Publish report; deliver policy recommendations; meet with relevant stakeholders.

3. To support Democratisation of Medicines Policy

3.1 Empower independent citizen voices
Activities: One-day seminar „Resolving Conflict of Interest(s) in Medicine & Science"; increase civil society involvement in monitoring and evaluation
Methods & means: Publish event memo; develop advocacy materials; facilitate local CSO membership of HAI for national advocacy and awareness-raising.

3.2 Promote transparency and impartiality as key principles of democratic decision making in health policy.
Activities: Collate and disseminate information about the EU Health Policy Forum as a case study; advocate for impartiality in co-operation with CSOs; monitor the impact of HAI'scorporate sponsorship research on patient and consumer perspectives at the EMA PCWP.
Methods & means: Collect data and publish report; develop factsheets; publish statements and open letters
For a detailed list of EXPECTED OUTCOMES,see page 27 of the work plan for 2011.
Ethical aspects: HAI's programme applies and promotes ethical principles, and human rights,dignity and fundamental freedoms. HAI sources data from the public domain.

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ASSOCIATED PARTNERS:
No Associated partners

EC CONTRIBUTION:
EUR 218000.00

DURATION:
12 month(s)

KEYWORDS:
- Access to essential medicines
- Rational use of medicines
- Research excellence
- Evidence-based advocacy

PROJECT NO 20103202

THE ASSOCIATION OF SCHOOLS OF PUBLIC HEALTH IN THE EUROPEAN REGION (ASPHER_FY2011)

Mission and vision of the operating grant holder

Founded in 1966, ASPHER is the key independent organisation in Europe dedicated to strengthening the role of public health (PH) by improving the education and training (E&T) of PH professionals for practice and research. It represents the scientific and academic components of the PH workforce education and advanced training.
[ref.p.11 Track 1]

ASPHER members are collectively committed to PH capacity building. Whilst respecting the European diversity of national and regional contexts in which each school of PH operates, ASPHER promotes structured processes of sharing evidence-based PH, models of innovation and good practice, and mobilizing schools of PH to be pro-active in shaping the PH core competencies.
[ref.p.11 Track 2]

ASPHER's strategic vision includes the promotion of the highest standards of E&T for practice increasingly involving cross-sectoral intervention and global as much as EU wide and national issues. A key role for advocacy and communication to promote and incorporate European values into the wider PH movement is also assumed by ASPHER.
[ref.p.11 Track 3, H-Track]

Strategic objectives and specific activities for 2011

The ASPHER 2015 strategic planning initiative identified a clear strategic direction for the association, manifested in the work plans of the seven workforces which were set up based on top priorities emerging from the consultation process [see: Annex 1. ASPHER 2015: From priority setting to implementation of strategy for the European Association of Schools of PH]. The general objectives of each workforce are outlined below.

1) Global Health: To create a single forum for interested academic institutions with involvement in Global Health to exchange views and ideas, so as to develop a European voice on Global Health issues and influence relevant policies;
2) Doctoral Programmes and Research Capacities: To define the models and formulate recommendations re: European standards for PhD in PH, leading to organisation of a common European PhD training programme in PH;
3) Innovation and Good Practice in PH Education: To propose PH performance standards (related to European PH competencies) and to translate them into teaching/training modules for undergraduate, graduate and postgraduate education in PH;
4) PH Core Competencies: To develop and to refine a European system of competencies to support both PH education and PH practice, appropriate to the population health challenges and PH systems across Europe;
5) Accreditation for PH Education: To develop the standardisation and quality criteria with respect to PH education leading to the establishment of a European Accreditation Agency for PH Education;
6) PH Advocacy and Communication: To motivate schools of PH to promote academic and advanced training programmes based on evidence and research related to PH advocacy and communication topics including health literacy and interventions to change behaviors;
7) Ethics and Values in PH: to devise an ethical framework for PH teaching/practice and promote its adoption;

Other activities > ASPHER Forums:

- Annual Conference (European Public Health Conference),

- Deans' and Directors' Retreat,
- Summer Schools (support role only),
- Young Researchers' Forum,
- Public Health Reviews Journal,
- Members' Blog,
- Public Health Employment Portal.

3. Expected outcomes

ASPHER WP 2011 includes 3 tracks of activities and 1 horizontal stream of actions:

TRACK 1. CAPACITY BUILDING: PH WORKFORCE PLANNING AND DEVELOPMENT, PH PROFESSIONALISATION

A. Development of the coordinating structures: (i) to launch the accreditation system for PH education, and (ii) to oversee and validate the process of developing and refining a European system of PH core competencies; in collaboration with other key PH organisations, mainly EUPHA; [ref.p.17 EUPHA]
B. Workshops with PH workforce: to identify, validate and refine competencies with local PH workforces and schools of PH. 4 such workshops will be organised in 2011 (1 in SE, 1 in SW, 1 in NE, and 1 in NW Europe); [ref.p.17 EuroHealthNet, EHMA]
C. Masterclasses for senior decision-makers: to engage senior representatives of health ministries and PH service employers to strengthen the relevance and utility of PH competencies. In 2011 there will be 1 masterclass organised; [ref.p.17 EPHA]
D. Conference (pre-conference event to European PH Conference 2011):
'Introducing a Competencies-based Accreditation System for PH Education in Europe'.

ASPHER Workforces in lead of this track:
PH Core Competencies
Accreditation for PH Education

TRACK 2. CAPACITY BULDING: MOBILISING SCHOOLS OF PH, INNOVATION AND GOOD-PRACTICE

A. Seminars with schools of PH and their local PH service provider organisations, including the use of webcast to connect with national/European decision-makers and other schools; networking exercise/best practice sharing; lifelong learning/continuous education. 2 such seminars will take place in 2011; these will also serve the need of track 1 activities.
B. Survey among PH service institutions on the draft performance standards (PS) and a series of interviews with key resource persons in Europe: to propose PH PS (related to PH competencies) and to translate them into PH curricula

at all 3 Bologna levels paying attention to the principles of interdisciplinarity and multiprofessionality.

C. Young Researchers Forum (pre-conference event to European PH Conference 2011).

ASPHER Workforces in lead of this track:
Innovation and Good-practice in PH Education
Doctoral Programmes and Research Capacities

TRACK 3. WIDER PUBLIC HEALTH MOVEMENT IN EUROPE AND BEYOND

A. Developing Statement on PH Ethics (to be adopted by ASPHER and EUPHA), as well as a core curriculum on PH Ethics for MPH courses. The group will meet once in 2011.
B. Fostering exchange of ideas and collaboration between European global health institutions on research, teaching, and capacity building. The group will meet once in 2011. It will also organise 2 seminars in Brussels with the involvement of EU policy-makers on selected global health issues.

ASPHER Workforces in lead of this track:
Ethics and Values in PH
Global Health

H-TRACK. HORIZONTAL STREAM OF ACTIVITIES

A. On-line resource centre for PH education and training (E&T): resource centre for PH E&T will be a unique initiative of that kind in Europe; linked with the ASPHER website it will allow the creation of an online community of PH experts and greater collection of PH E&T materials. It will incorporate a multidimensional search facility and a networking mode allowing members to categorise themselves into institutions, countries, projects, and to create, invite and participate in a group/event initiatives, etc; to increase understanding, dialogue and cooperation. After the initial investment, the resource centre will be self-susitainable based on the ASPHER organisational capacity.
B. PH Reviews Journal: to develop the special issue on PH Training and Education.
C. To develop policy brief on PH Workforce and Skills Development; [ref.p.17 Observatory]

ASPHER Workforce in lead of this track:
PH Advocacy and Communication

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ASSOCIATED PARTNERS:
No Associated partners

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EUR 160000.00

DURATION:
12 month(s)

KEYWORDS:
- Capacity building
- Education / Training
- Public health professionals
- Academia

Main beneficiaries by country of establishment

Austria

Bundesministerium für Gesundheit
Joint Action eHealth Governance Initiative (JA-EHGov)

Medizinische Universitaet Wien
CHILD - Combating Health Inequalities in Life-threatening Diseases (Bridges for CHILD)

Belgium

The Association of European Cancer Leagues
Continuing Cancer Care (CCC)

European Council on alcohol rehabilitation research and education
European Alcohol Policy Aliance (Eurocare FY2011)

European Public Health Alliance
Project No 20103203: EPHA FY2011

European Multiple Sclerosis Platform
European Register for Multiple Sclerosis - A tool to assess, compare and enhance the status of People with MS throughout the EU (EUReMS)

FPS Health, Food Chain Safety and Environment
Innovative approaches for chronic illness in Public health and healthcare systems
(Chronic diseases)

Prevent, Institute for Occupation Health & Safety
Promoting Healthy Work for Employees with Chronic Illness - Public Health and Work (PHWork)

The Association of Schools of Public Health in the European Region
Project No 20103202: ASPHER FY2011

Estonia

National Institute for Health Development
HIV in European Region - Unity and Diversity (AIDS2011)
Project No 20104301

Tervise Arengu Instituut/National Institute for Health Development
EMPOWERING CIVIL SOCIETY AND PUBLIC HEALTH SYSTEM TO FIGHT TUBERCULOSIS EPIDEMIC AMONG VULNERABLE GROUPS (TUBIDU)

France

Assistance Publique -Hôpitaux de Paris
Project No 20103209: AP-HP_Porphyria_FY2011 (AP-HP FY2011)

Assistance Publique Hôpitaux de Paris
Project No 20103201: EuroWilsoN (EW)

European Organisation for Rare Diseases
Project No 20103205: EURORDIS FY2011

Institut National de la Santé et de la Recherche Médicale
Development of the European portal of rare diseases and orphan drugs

Institut National de la Santé et de la Recherche Médicale
European Health and Life Expectancy Information System (EHLEIS)

Université Claude Bernard Lyon 1 - UCBL
Cost-effectiveness assessment of European influenza human pandemic alert and response strategies (FLURESP)

Germany

Robert Koch-Institut
Quality Assurance Exercises and Network-
ing on the Detection of Highly Infectious Pathogens (QUANDHIP)

Universitätsklinikum Heidelberg
European registry and network for Intoxication type Metabolic Diseases (E-IMD)

University of Leipzig
Preventing Depression and Improving Awareness through Networking in the EU (PREDI-NU)

Greece

Institute of Preventive Medicine Environmental and Occupational Health - PROLEPSIS
Promotion of Immunization for Health Professionals in Europe (HProImmune)

Hungary

National Institute for Food and Nutrition Science
Action for Prevention (PREVACT)

Italy

Azienda Ospedaliera Universitaria Integrata Verona
Capacity Building in Combined Targeted Prevention with Meaningful HIV Surveillance among MSM (SIALON II)

Azienda Ospedaliera Universitaria Integrata Verona
EUROPEAN REGIONS ENFORCING ACTIONS AGAINST SUICIDE (EUREGENAS)

Azienda Sanitaria Locale Roma E- Regional Department of Epidemiology - ASLRME.DE
Public Health Adaptation Strategies to Extreme Weather Event (PHASE)

Centro Nazionale Trapianti, Istituto Superiore di Sanità
Mutual Organ Donation and transplantation Exchanges: Improving and developing cadaveric organ donation and transplantation programs (MODE)

CITTADINANZATTIVA ONLUS
5th European Patients' Rights Day:Putting Citizens at the Center of EU Health Policy (EU Patients' Rights Day 2011)

Istituto Superiore di Sanità
Building Consensus and Synergies for the EU Registration of Rare Disease Patients (EPIRARE)

Tecnogranda SpA - TECNOGRANDA
A EUROPEAN NETWORK TO FOLLOW-UP THE REFORMULATION OF FOOD; IDENTIFICATION AND EXCHANGE OF GOOD PRACTICES FOR SMEs AND CONSUMERS (SALUS)

Luxembourg

Alzheimer Europe
Alzheimer Europe (AE FY2011)

The Netherlands

De Stichting Aids - Soa Aids Nederlands
Soa Aids Netherlands (SANL FY2011)

Erasmus University Medical Center Rotterdam
Screening for Hepatitis B and C among migrants in the European Union (EU-HEP-SCREEN)

European Association for Injury Prevention and Safety Promotion - EUROSAFE
Joint Action on Monitoring Injuries in Europe (JAMIE)

European Association for Injury Prevention and Safety Promotion - EUROPSAFE
Tackling the challenges of implementing good practices in safety promotion (InjuryConf-2011)

European Public Health Association
European Heart Health Strategy II (EuroHeart II)

European Public Health Association
Fourth Joint European Public Health Conference (Copenhagen 2011)

Netherlands Institute for Health Promotion
ALzheimer COoperative Valuation in Europe (ALCOVE)

Stichting Health Action International
Project No 20103206: HAI FY2011

Stichting Volksgezondheid of Roken, voor een rookvrije toekomst
European Conference on Tobacco or Health 2011 (ECToH2011)

Slovenia

Inštitut za varovanje zdravja Republike Slovenije / National Institute of Public Health
European Partnership for Action Against Cancer (EPAAC)

Spain

Asociación Bienestar y Desarrollo
Nightlife Empowerment and Well-being Implementation project (NEW Implementation)

Sweden

Swedish Institute for Infectious Disease Control
Men, Men, Sex and HIV 2011 - The Future of European Prevention among MSM (FEMP2011)

United Kingdom

National Heart Forum, Health Action Partnership International
Joint Action on Health Inequalities (Equity Action)

Royal Society for the Prevention of Accidents
Tools to Address Childhood Trauma, Injury and Children's Safety (TACTICS)

University of Birmingham C/O Diabetes Unit
An EU Rare Diseases Registry for Wolfram Syndrome, Alstrom Syndrome and Bardet Biedl Syndrome (EURO-WABB)

University of Ulster
European Surveillance of Congenital Anomalies (EUROCAT)

Index

1. Project List

2. Keyword list

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