



EU Health Programme Selected projects

Edition 2012

*Health and
Consumers*

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Foreword

This publication puts together 27 projects which were funded under the 2nd Health Programme of the European Commission and are presented to the public in a scientific poster exhibition at the European Health Forum Gastein 2012 and the 5th Annual European Public Health Conference 2012.

The 2nd Health Programme came into force on 1 January 2008 and has since co-funded 115 projects with an amount of about € 75 million. The total budget of the programme rises to € 321.5 million euro. The programme aims at increasing solidarity and prosperity in the European Union by protecting and promoting health. The programme is intended to complement the national actions and policies of the 27 EU countries by adding a European layer. This means that they involve actors from different countries and that the project outcomes are beneficial for several countries and can be applied to other countries as well.

The projects in this booklet cover a wide range of health themes, from health information to health security. They cover topics such as alcohol commercials, fighting obesity, AIDS and organ donation.

Although progress has been made with the previous and the existing Health Programme, the work is not concluded yet - an ageing society needs to concentrate on improving the health and safety of its citizens consistently. This is why the European Commission has proposed a new Health Programme to start in 2014 which will continue the path we have taken with the first two Health Programmes and will help to face future health challenges all over Europe.

European Commission
Director-General for Health and Consumers

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1

Health Promotion



HANCPtool.org , a tool for small and medium sized companies to reformulate processed foods and meals. FOOD PRO-FIT

Beneficiary Regional Ministry of Health of the Balearic Islands , **Spain**

Associated partners • University of Vienna, **Austria** • Institute of European Initiatives, **Poland** • European Business Centre, **Germany** • Ministry of Health, **Cyprus** • Region of Crete, **Greece** • Agency for the Support of Regional Development, **Slovakia** • Hotel Faculty of the Balearic Islands, **Spain**

SUMMARY

The European FOOD PRO-FIT project contribute to the prevention of obesity and overweight problems by stimulating food innovation and reformulation among SMEs working in food service provision, thereby offering a wider choice of healthy food products to consumers and companies. Besides , it allowed users to make a better decision concerning their health

OBJETIVES

- Evaluating nutritional risk in Saturated Fatty Acids, Free Sugars and sodium
- Improving the nutritional profile of products and recipes
- Making easier the healthiest choices selection

METHODOLOGY

The project performed a study of consumer habits, awareness food production conditions and developed a computer tool based in the Hazard Analysis and Critical Control Points methodology applied to the nutrients qualitative and quantitative food composition

WP COORDINATION

- Mainly, these tasks were carried out :
- Guarantee the project objectives fulfilment.
 - Connexion among the partnership and the EAHC.
 - Leadership of partnership and pilot meetings.
 - Creation of the corporative image of the project
 - Creation of the project's website
 - Involvement in related events and other meetings of EU projects

WP DISSEMINATION

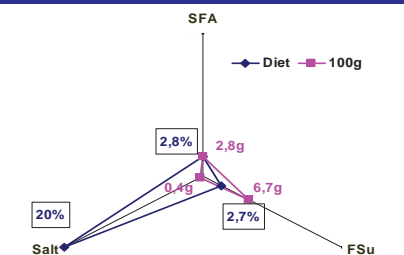
The Communication Strategy Plan, established the general parameters that guided the communication developed in the project. The main ideas were identified; this way, the mission, vision and values were defined together with the general and specific objectives

WP EVALUATION .

With more than 3.600 visits to the website and its tools, 2.000 recipes were added across the world from Dec. 2009 to Nov. 2010 showing that the implementation of the HANCP tool for SMEs was very successful is strengthening its importance as a tool to improve in the future the diet quality in Europe but with a new approach

RESULTS.

Reduction of nutritional risk by 100g of average recipe and diet



CONCLUSIONS

The European FOOD PRO-FIT project increased knowledge and awareness of healthier food by both enterprises and consumers.

<http://hancptool.org> Web2.0 tool empowers SME users to reformulate food, especially food delivered by mass caterers, supporting the characterization of the health effect in salt-reduction programs as well as fat tax initiatives

AKNOWLEDGEMENTS

Ingrid Keller & Antoinette Martiat
EAHC– DGSANCO Commission

Project co financed from the EU Public Health Programme 2006
Duration 38 months , Nov. 2007 to Dec 2010
Cost: 1,264,762€
60% Co-funding from the Commission

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Web site: www.foodprofit.org www.hancptool.org



ACTIVATE: capACity building and Training in HIV/AIDS Treatment and management across Europe

Summary: Despite major advances in knowledge and techniques in the area of HIV/AIDS, there is still a large knowledge and capacity need in HIV/AIDS treatment, especially in new Member States and Non-EU European states. Moreover, there is a lack of European standardisation in tailored HIV/AIDS training curricula. The coordinating centers of the four major European clinical HIV/AIDS networks PENTA, CASCADE, EuroSIDA and EuropeHIVResistance have joined forces to put their expertise, networks and experience in training healthcare professionals in the broad range of HIV/AIDS to the benefit of developing common training curricula and capacity building programmes in HIV/AIDS. The trainings will cover a broad range of relevant topics in HIV/AIDS treatment and management, combining on-site training with on-line distance learning methods. After piloting the curricula will be incorporated in the networks and disseminated to a broader stakeholder audience.

Objectives

1. Development of the content of training curricula based on the latest available knowledge and techniques - acquired within the affiliating networks - and tailored to the needs of target professionals dealing with PLWH.
2. To develop a combination of distance learning tools, classroom sessions and on-site practical training courses tailored to specific target groups to be adapted for different countries needs.
3. To assure that the project succeeds in capacity building of healthcare professionals within the specified target groups
4. To effectively disseminate the results of ACTIVATE within the four HIV/AIDS networks, to relevant stakeholders groups including the general public, national and international organisations active in HIV/AIDS, European educational institutions

Results & Conclusion

The direct results of this action will be the training curricula on HIV/AIDS treatment and management developed and piloted within the four European HIV networks. The results will be disseminated within and across the four HIV networks (inter)national stakeholders, including the general public. All modules and training courses developed will be piloted and evaluated at representative pilot-groups, after which they will be filed at EACCME for accreditation. The HIV clinical networks combined cover over 1,000 professionals at over 200 healthcare and research organisations in over 30 European countries. The training curricula developed will be incorporated within the regular training programmes between the four networks.

Work Packages and deliverables

WP1 Coordination of the project	Communication tools (e.g ACTIVATE website)
WP2: Dissemination	Stakeholder and target groups analysis of needs Trainings courses in Rome, Minsk, Glasgow, Stockholm for HCWs
WP3: Evaluation and quality indicators	Data collection and evaluation of knowledge and participants feedback
WP4: Content development	Development of training curricula according to the analysis of the needs and course participants feedback
WP5: Tools development	Distance learning materials

Partnership:

Penta Foundation – Italy (Coordinator)
Medical Research Council – United Kingdom
Hvidovre Hospital – Denmark
Universitair Medisch Centrum - Netherlands

Project cofinanced from the EU Public Health Programme 2003-2008

Starting date and duration of the project: 01/04/2007; 36 m.	Total cost: 597.488 €
Leader Organisation: FONDAZIONE PENTA ONLUS	Subsidy from the Commission: 356.056 €
Web site: http://www.eurocoord.net/CollaborativeProjects/ACTIVATE	Contact Person: Carlo GIAQUINTO, giaquinto@pediatria.unipd.it



European
Commission

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Main Beneficiary: Ethno-Medizinisches Zentrum e.V.

Management

Programme leader and director: Ramazan Salman

Summary

The AIDS&Mobility Europe project 2008-2011 (A&M) was cofunded by the Executive Agency for Health and Consumers (EAHC) at the European Commission, the State of Lower Saxony, the City and Region of Hanover as well as the Portuguese High Commissariat for Health. Associated project partners in six European cities worked with migrant communities using capacity building through transcultural mediators to reduce HIV infection risk. Each site convened a group of relevant local stakeholders to serve as a platform for recruiting mediator trainees and for ensuring that local efforts are well integrated into related local activities in the fields of health, social services and migration in general, and HIV and young migrant and mobile populations in particular.

The transcultural mediator approach aims to improve health literacy and HIV awareness by involving migrants themselves in undertaking research and delivering health promotion to their own communities. After participating in training and receiving their transcultural mediator's certificate, this group initiated, organized and conducted education sessions in twenty community languages overall, informing their communities about HIV/AIDS prevention and related topics. The Ethno-Medizinisches Zentrum e.V. (EMZ) centrally evaluated the training and the community education sessions using standardized questionnaires. Separate, overarching work packages on evaluation, networking, capacity building, dissemination and policy development support the model and continue the work of previous A&M projects.

Objectives

The objectives of the project focus on the steps required for testing the transferability of the transcultural mediator model to six different project sites in Europe. This approach is one important strategy to address HIV among migrants, ethnic minorities and mobile populations, as articulated by the overall goal of the project: The main aim of A&M is to reduce HIV vulnerability of migrant and mobile populations in Europe. The project's target group, according to the project plan, are migrants: this term is defined as people who experience language barriers in accessing health services because they belong to a minority ethnic group. The project has a particular focus on young people between the ages of 16 and 25 because they are particularly vulnerable to sexually transmitted infections (including HIV), and because they have a high capacity to adapt to change and to influence their social environment. Mediator training and community information sessions are implemented in Copenhagen, Hanover, Istanbul, Rome and Tallinn, supported and complemented by the overarching work packages. In Brussels the International Organization for Migration had Policy Development and the European AIDS Treatment Group the development of the Master Toolkit as work packages.

Methodology

Within the three-year project, the network adapted evidence-based transcultural mediator training on HIV to local circumstances and implemented it in six sites across the EU and Turkey. This process was then evaluated for its impact. Project partners adapted the initial model according to their strengths, needs and interests, collectively monitoring the process to ensure the preservation of the original method's core elements. Analysis was based on evaluation data, site visits, transcripts, presentations and minutes. To support sustainability, project work focused on capacity building, dissemination, policy development, producing the guiding Master Toolkit, evaluation and coordination.

Work Package Coordination

The EMZ had the overall coordination of the A&M work packages. The objective of the coordination was to provide and overall management to the project related activities of A&M, to establish the management framework and coordinate the work streams, to monitor compliance with guidelines, timeframe and reporting, to provide financial management, to report to the EAHC and to secure and enhance the sustainability of the network.



Work Package Dissemination

The project made significant efforts to publicize its intentions and activities in relevant circles at the local and at the European level. Project partners presented abstracts and reports on the project at a range of international and European conferences, meetings and through their own networks. The 12 issues of the A&M newsletter were not only distributed to the mailing list, which grew from 500 working email addresses at the beginning of the project to 1078 at the end of the funding period, but also at a wide range of relevant conferences and events, including the European AIDS conferences in Vilnius 2009 and Tallinn 2011 as well as the International AIDS Conference in Vienna in 2010, at the European HIV Think Tank and Civil Society Forum meetings and at the project's main policy event in the European Parliament in Brussels. Further the project was presented at the Correlation II Network final conference 2011 in Ljubljana and the EUPHA Conferences 2010 in Pecs and 2012 in Milan.

The project maintains its own website www.aidsmobility.org and has a permanent profile on AIDS Action Europe's website www.hivaidsclearinghouse.eu to complement its other dissemination strategies. Feedback from relevant networks and through discussions at the implementation, program and policy levels indicate that the project is well known and that policy makers and other stakeholders are taking the model into consideration.

Work Package Evaluation

The associated partners themselves, under the guidance and with the support of the EMZ, the National Institute for Health, Migration and Poverty (NIHMP) in Rome (WP leader), and supported by an independent consultant, evaluated the project on several levels. Firstly, NIHMP conducted a literature review of similar models and their effectiveness. Secondly, it produced a process evaluation of mediator training implementation including the quality of coordination, collaboration and communication among the partners.

Results

In Copenhagen, Hanover, Istanbul, London, Rome and Tallinn members of migrant, mobile population and ethnic minority populations from more than 140 countries responded to recruitment strategies. Mediator training promoted transcultural dialogue (one local coordinator stated: "We didn't know that these people would work with us"). The project trained over 100 mediators who in turn reached more than 3,000 migrants through over 200 local community education sessions. Certification and compensation of mediators ensured high professional standards. 50% of participants were between 19 and 25 years old. The sessions enabled self-reflection ("I have to reconsider my attitudes.") and internal evaluation shows that, despite low basic knowledge of sexual health, young migrants demonstrated high motivation to engage in further education. External evaluation recommends the methods to be used more widely as well as further research into its impact on behavior at the individual level. A Master Toolkit including a guidebook on HIV/AIDS in 16 languages was developed.

Conclusion

This systematic approach builds the capacities of individuals and organizations to meet HIV prevention challenges for migrants, mobile populations and ethnic minorities with professional methods in a wide range of settings. Effectively educating young migrants has the potential to lead to more sustained prevention. The A&M Master Toolkit provides all the necessary documents for local adaptation of the transcultural mediator approach and should be used strategically across the WHO-Europe Region. Increasing efforts in community-based HIV prevention can also serve to enable young migrants to commit to promoting health in a wider sense among their communities. The IOM (Policy Development WP leader) has developed recommendations for EU member states and for the EU as a whole stressing, among other things, the inclusion of ethnic minority communities, culturally sensitive communication on HIV, public funding and mainstreaming of peer to peer education approaches in health systems.

Acknowledgements

We thank the following organisations and individuals for their valuable work and contribution: AIDS & Mobility Europe associated project partners: European AIDS Treatment Group (Anna Lucia Cardoso, Anna Zakowicz, Ruben Alonso), Fondet til bekæmpelse af aids (Henrik Overballe), International Organization for Migration (Maria Jose Peiro, Roumyana Benedict), National Institute for Health, Migration and Poverty (Ilaria Uccella, Annalisa Rosso, Prof. Aldo Morrone), YeniDen Sağlık ve Eğitim Derneği (Romina Yorohan, Prof. Kültegin Ögel), AIDS-i Tugikeskus (Jury Kalikov), Naz Project London (Brian Teixeira), TAMPEP Project (European Network for HIV/STI Prevention and Health Promotion among Migrant Sex Workers), EAHC (Cynthia Marel Lemus), Henrique Barros (National HIV/AIDS Coordinator, Portugal), Jelantia Bilinska (Patients Safety Foundation, Poland), Mike Hiiza (African Eye Trust), Georg Bröring (NGZ), Iris Shripinda (SENSOA NL), Lisa Power (Terrence Higgins Trust), Eberhard Schatz and Katrin Schiffer (Foundation DE REGENBOOG GROEP), Ibiudun Fakoya (EuroCoord, WP 14), Paulo Jorge Vieira, Dynka Amorim dos Santos.

A&M associated partner:



Project co-funded by the European Union under the Programme of Community Action in the Field of Public Health 2005-2008/2008-2011
Start date and duration of project: July 2008 - July 2011 (36 months)
Total cost: (EUR) 832 249 84
Co-funding from the Commission: (EUR) 490 788 34
Leader Organisation: Ethno-Medizinisches Zentrum, Germany
Contact Person: Ramazan Salman (info@ethno-mz.de)

Web site: www.aidsmobility.org
National Institute for Health, Migration and Poverty - NIHMP (Italy), European AIDS Treatment Group-EATG (Germany), International Organization for Migration - IOM (Brussels), London (Turkey), AIDS Fondet (Denmark), AIDS-i Tugikeskus (Estonia), NAZ Project London (UK)
HIV Prevention with Migrants for Migrants
Practical Matters: Fore choice: A&M





EU Public Health Programme 2008-2013
 Start date: 1st June 2008
 Duration: 36 months
 Total cost: 1 393 256, 72 (EUR)
 Commission co-funding: 598 904, 89 (EUR)
 Main Coordinator: Protéines Paris

The EPODE EUROPEAN NETWORK (2008-2011): An integrated approach to prevent childhood obesity

Borys JM., Ruault du Plessis H., Waller L., Harper P., Le Bodo Y., Richard P., EPODE Coordination Team, Protéines, Paris
epode-european-network.com

With the support of



INTRODUCTION

EPODE is a **coordinated, capacity-building methodology for communities** to implement effective and sustainable strategies to **prevent childhood obesity**. In order to build up on EPODE experiences, Protéines has established the **EPODE EUROPEAN NETWORK (EEN)**, a structure for the **exchange of information and sharing of project engineering practices**.

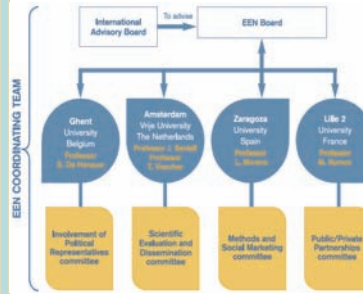
From 2008 to 2011, the aim of the EEN, supported by the European Commission (DG SANCO), was to **enrich existing methodologies¹** and deliver **concrete guidelines**, to be transferable to new countries willing to deploy an EPODE-similar programme. The EEN was a « think and do tank » gathering **key experts, political and institutional representatives**.

Four committees – gathering universities and experts from different fields – were set up to document and conceptualize EPODE pillars :

- ✦ Involvement of local authorities
- ✦ Scientific evaluation
- ✦ Method and social marketing
- ✦ Public-private partnerships

The EEN provides a valuable opportunity and an efficient resource for any stakeholder willing to become involved in obesity prevention in a country.

METHODS



4 universities to better define the EPODE pillars by:

✓Bringing together the programmes directly concerned with EPODE throughout the world

✓List and evaluate the actions undertaken and/or planned in the field in Europe, and throughout the world, in cooperation with existing networks and institutions (IOTF, WHO, European Commission...)

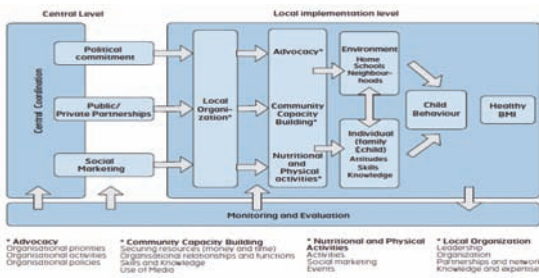
✓Conduct qualitative surveys the keys for the success and barriers (of the EPODE methodology)

✓Identify countries or institutions expressing a motivation towards the implementation of CBI

EPODE EUROPEAN NETWORK (EEN) MAIN RESULTS

1. SCIENTIFIC EVALUATION AND DISSEMINATION COMMITTEE

Chaired by Jaap Seidell, Vrije University, Amsterdam, The Netherlands



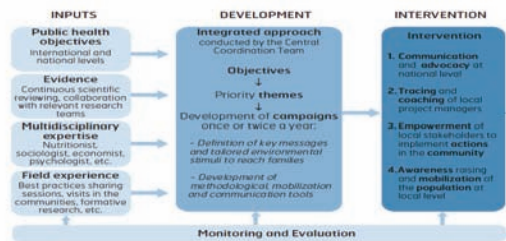
Recommendations to national or central EPODE coordination
 ✦ Create a "evaluation and monitoring" roadmap which describe each steps to be taken by central and local coordination
 ✦ Appoint an evaluation counsellor at central level
 ✦ Give advice to the communities on the common indicators to be measured

Recommendations to local organisations in EPODE communities
 ✦ Establish a local evaluation group responsible for the evaluation of the programme
 ✦ Involve key stakeholders in this group to secure sustainability
 ✦ Follow up the EPODE evaluation roadmap
 ✦ Be in continuous deliberation with EPODE coordination team and other EPODE cities on indicators and measurement of indicators

Both local coordination and central/national coordination should ask for statistics to support evaluation set up and in analysing the data. It appears that it is not possible to measure every data. As each community has its specificities, the evaluation plan should take these differences in consideration and be adapted to each community.

2. METHODS AND SOCIAL MARKETING COMMITTEE

Chaired by Luis Moreno, Zaragoza University, Spain



Priority topics for action should :
 ✦ match the **official recommendations**
 ✦ be **defined according to the needs of priority groups**.

Planning phase :
 ✦ is essential to define **long-term objectives**, a **strategy** and a **type of intervention framework**.
 ✦ is critical to build **valuable partnerships** for the interventions.

Strategies :
 ✦ **formative research** is of great value.
 ✦ **wide variety of data** collected that can be considered.
 ✦ **tailoring of action on the field** and an **healthy living brand** appears to be important for an effective campaign.

Interventions
 ✦ EPODE local project manager appears to be a cornerstone.
 ✦ Tailoring the intervention for priority groups is an important component of the intervention step, such as relying on **ambassadors** ("local leaders" or "local champion") to convey messages and stimuli.

Evaluation
 ✦ involve the local experts (e.g. university researchers)
 ✦ include as much as possible **"objective" data** from individuals and physical environment.

3. PUBLIC/PRIVATE PARTNERSHIP COMMITTEE

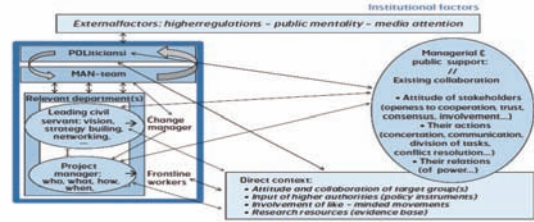
Chaired by Monique Romon, Lille 2 University, France

The PPP are ruled by transparency, openness and independence. All partners commit to transparency and accountability and respect EPODE the philosophy and commitments. Partnerships have to be long term commitment communities sustainability. The private partners have obligation : they must not intervene in the content of the programme or modify the communication tools. The committee recommends to set up communication rules for the PPP and to create an **independent steering committee** to guarantee representativeness and a strong governance for the protection of public interest, to monitor the implementation of the programme and to prevent & manage conflicts of interest.

DELIVERABLES

- The **EEN Book of Recommendations** including **key principles** to be observed by teams willing to set up and implement an EPODE-similar initiative
- From 3 to 6 countries implementing the Methodology across Europe
- Publications

4. INVOLVEMENT OF LOCAL AUTHORITIES



- ✦ Local governments must show **real leadership**.
- ✦ Need for local authorities to identify **requirements and priorities** of local stakeholders, evaluate actions currently in place and those implemented in the past.
- ✦ Local authorities are well positioned to **allocate specific budget for actions** and involve all sectors of the community.
- ✦ The research team recommends the development of **learning network** (e.g. Mayors' Club) to facilitate experience sharing opportunities and boost leadership strength.
- ✦ From a less coherent local obesity prevention policy and isolated projects, the EPODE approach can bring order and thematic coherence. The EPODE brand can also boost recognisability.

CONCLUSION

A fifth pillar could be added to these recommendations : **healthcare for children detected with overweight and obesity during programmes' follow-up**. This pillar is the next step for the EPODE methodology as healthcare and prevention should be interlinked in order to provide the necessary care for the children detected overweight or obese.

This pillar is already set up in some EPODE programmes, as the JOGG programme in the Netherlands and will be developed in other EPODE communities.

Following the success of the EEN, the non-profit international organization the **EPODE International Network** has been created on April, 2011, becoming the **world's largest network aimed at preventing obesity** and its related non communicable diseases. The EIN is aimed at supporting Community-Based Programmes (CBPs) through experience and best practice sharing for a continuous improvement. Its inaugural event, the **Global Obesity Forum**, was held on June 27th to 29th, 2012, in New York City.

KEEP IN TOUCH

For more information, please contact the EIN Coordinating Team:
EPODE INTERNATIONAL NETWORK COORDINATING TEAM - PROTÉINES :
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www.epode-european-network.com



A CAMPAIGN AGAINST OBESITY IN CHILDREN AND ADOLESCENTS

Univ.-Prof. Prim. Dr. Robert Birnbacher, MMag. Kathrin Brugger,
Sanicademia – International Training Academy for Health Professionals EEIG



Management

Leader Organisation: Sanicademia
Duration: 38 months (start date Oct. 2008)
Total cost: 1.054.317,79 EUR
Co-funding from EU: 582.159,30 EUR

Summary

The project "In Form – a campaign against obesity in children and adolescents", an interdisciplinary EU-funded project, aimed at finding ways to combat obesity in children and adolescents. In the course of the project a social marketing campaign was implemented and based on a manual for prevention, diagnosis and therapy an interdisciplinary obesity trainer course was developed and implemented, including the necessary training materials as well as a summer camp for children and parents.

WP-coordination

- 11 partners from 8 countries
- management structure:
 - project Executive Committee (PEC)
 - coordinator/project manager
 - workpackage leader
- management structure is based on:
 - fast, direct and open communication
 - mediation and consensus

Results

- prevention/diagnosis/ treatment manual
- network of competence centers
- obesity trainer course materials
- pilot obesity trainer course
- two week summer camp for families
- social marketing
 - social marketing website
 - project website
 - articles in local newspapers
 - pr-folder
 - cookery book in 4 languages
 - local prevention event
 - 2 international conventions



Objectives

The general objective is to develop integrated overweight/obesity prevention and treatment strategies for children and adolescents. Implemented beyond project time in the participating countries, these will contribute to combating the childhood obesity epidemic in Europe.

Specific objectives:

1. european interdisciplinary manual
2. european interdisciplinary training course
3. social marketing campaign at local levels
4. network of competence centres

WP-Dissemination

- project website containing
- general information about the project
- social marketing campaign
- project library for partners
- information packages

Making the project visible in the public and disseminating the results to stakeholders via:

- Articles
- Public conferences
- Information pack
- Educations
- Website



Conclusion

- common strategies for partner countries
- raise awareness about the importance of healthy lifestyle
- multidisciplinary nature
- intercultural team
- implementation of new media
- Innovative prevention materials
- **motivation for:**
 - intensive local work in future
 - building networks with
 - new local trainer courses planned
 - further prevention programs
 - further common projects

Methology

obesity trainer course



conferences



...and further more.

social marketing website



summer camp in UK



Evaluation

questionnaires and interviews with:

- network members
- children (participating summer camp)
- parents (participating summer camp)

physical evaluation of:

- children (participating summer camp)
- parents (participating summer camp)
- children and parents participating in the

The results were evaluated by Sanicademia and UMC and presented in the final report.

Contact

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* Project co financed from the EU Public Health Programm 2008-2013



Building Policy Capacities

for **Health Promotion** through **Physical Activity** among **Sedentary Older People**



The PASEO Project

Recent years have seen the development of many programs geared at promoting physical activity for older people – but by far not all of these programs get implemented. The EU-sponsored PASEO Project intends to improve the implementation of programs by helping build the necessary policy capacities. In 15 European nations, researchers and political institutions are teaming up to forge national alliances in order to improve capacities within and between relevant organizations.

The Framework

PASEO assumes that the implementation of physical activity programs can be improved by increasing the policy capacities of relevant organizations. The project focuses on strengthening capacities in two key areas:

Intersectoral Capacities

linking organizations across multiple policy sectors, e.g. health, social care, sport

Intra-Organizational Capacities

e.g. personnel, resources, co-operations within organizations

Capacity building involves the following steps:

Partnering: Researchers team up with a strong partner (e.g. a national ministry) to enhance prospects for the capacity building process

Assessment: Researchers assess existing capacities using the ADEPT framework, which conceptualizes capacities with four determinants: goals, obligations, resources, opportunities

Forging alliances: PASEO partners lobby relevant organizations in the field of physical activity promotion for older people to undertake a joint effort at capacity building

Cooperative planning: National alliances conduct a series of six pre-structured meetings to build capacities

Monitoring: Researchers continue to track the development of the alliances to ensure the sustained development of capacities

Select Results:

National or regional **alliances have been forged** in all 15 countries. **More than 130 organizations** and institutions from all relevant sectors are involved.

Ministries involved include the French Ministry of Health and Sport, Flemish Ministry of Sport, the Bavarian Ministry of Health, and the Regional Government of Extremadura. The alliances function as a platform for close **collaboration of various ministries** via the national alliances in Austria, Belgium, Finland, and Lithuania.

National alliances are linked to **national physical activity action plans** in Finland, France, Germany, the Netherlands, and Norway. The cooperative planning process underway in all countries, **national action plans** for all countries are expected by fall 2010.



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ISS
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and Sport



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European
Commission



A WORKPLACE HEALTH PROMOTION PROGRAMME

Fighting Obesity Through Offer And Demand

www.food-programme.eu

Nathalie RENAUDIN, Public Affairs Director, Edenred, coordinator of the FOOD project
Nolwenn BERTRAND, European Affairs Developer, Edenred, co-coordinator of the FOOD project

Eating at a restaurant can be compatible with a balanced diet within the context of professional life. The FOOD project aims at promoting healthy eating by influencing both offer and demand.

It was launched in 2009 in 6 member states: Belgium, the Czech Republic, France, Italy, Spain and Sweden.

THE OBJECTIVES:

1. To improve the **nutritional habits** of employees by raising their awareness on health issues
2. To improve the **nutritional quality** of the food offered in restaurants.

5 SUCCESSIVE AND MUTUALLY-REINFORCING STAGES TO MEET THESE OBJECTIVES:

- **Inventory** of the existing programmes and **2 types of surveys**
- Comparative analysis of the results and **specific recommendations** of the partners
- **Pilots** in restaurants and companies: development of simple **tools adapted** to each target
- **Evaluation** of the pilots
- New tools created and **dissemination** of best practices in Europe and beyond

Based on a public-private partnership, the richness of FOOD lies in the complementary skills and expertise of its participants. The consortium ended up with 36 partners whose contribution was essential in designing and implementing the project. An External Advisory Board of experts enabled a qualitative follow-up of the project.

The coordination of the project was built on simple yet efficient tools in order to foster exchanges such as a newsletter, Steering group meetings and a more sophisticated working platform where all preparatory documents are available as well as deliverables, progress reports and calendar of activities.
 Objective: make sure the results are reached and timetable respected.

The dissemination strategy was twofold:

- Visibility of the project through a complete website and participation in conferences (oral presentation + posters)
- Dissemination of the results and transfer of best practices in other countries.

Besides, strong press relations were built, participating to the dissemination of the project.

The project has been assessed following a complete evaluation plan. Management was followed-up thoroughly while special evaluation activities were executed:

- Questionnaires were sent to min. 52 000 employees and 5 000 restaurants
- 150 'mystery' site-visits in restaurants

The evaluation highlighted the necessity of such projects to connect the offer and demand sides.

RESULTS OF THE PROJECT:

- 102 communication tools in the 6 countries
- 1500 visitors in 7 days at the Road show in October 2009
- 320 articles (TV, radio, web, press)
- Targets reached
- 352,000 restaurants
- 4.2 million employees
- 185,000 companies
- Creation of a FOOD Network with 2200 restaurants (end of 2011)
- 36 partners at the end of the project
- FOOD was presented in 50 conferences and as a best practice at the XIXe World Congress on Safety and Health at Work
- A transition conference at the European Parliament in May 2011 attracted 160 participants and high level speakers from European and International organisations.

The partners have decided to continue developing and disseminating the project after the end of the funding period.

The methodology developed and the many deliverables act as an incentive to encourage new partners from other countries to join the consortium.

The 2 new countries that joined the FOOD programme are the Slovak Republic and Portugal.

Project co financed from the EU Public Health Programme 2008-2013
 Start date and duration of project: January 2009 for 28 months
 Total cost: 902 255.57€
 Co-funding from the Commission: 471 287.17€
 Leader Organisation : Edenred, France
 Contact Persons: Nathalie.renaudin@edenred.com
 and Nolwenn.bertrand@edenred.com

Web site: www.food-programme.eu

Other Partners: Information and Research Centre about Food Intolerances and Hygiene (Belgium), Public Health Ministry (Belgium), Stop Obesity (Czech Republic), Research Centre of Paul Bocuse Institute (France), University of Perugia (Italy), Agency of Food Security and Nutrition (Spain), Mediterranean Diet Foundation (Spain), Karolinska Institutet (Sweden)



European
Commission



POLICY HEALTH AND FAMILY LEARNING

POHEFA.EU

SUMMARY: IN ORDER TO ENSURE THAT HEALTH PROMOTING ACTIVITIES HAS A BETTER AND LONG LASTING EFFECT, THE POHEFA PROJECT SEEKS TO INCREASE THE AWARENESS ON HOW THE SOCIO-CULTURAL CONTEXT HAS AN EFFECT ON HEALTHY LIFESTYLE CHOICES AND THE HEALTH STATUS WITHIN FAMILIES.

Based on a close collaboration with academic partners and 12 pilot local authorities, The PoHeFa Method has been developed, tested and disseminated showing how to improve local health strategies, programmes and implementation practice.

- A conceptual paper, presenting the project strategy and a theoretical evidence base.
- A conceptual framework consisting of:
 - **Tools and methods** to assist local authorities to improve their health promoting activities.
 - **Practical examples and inspiration material** on how to work strategically with health pro-motion from the participating local authorities.
 - **Policy Recommendations and Key Messages.**

Please find all relevant material including the project evaluation at: www.pohefa.eu

AIMS AND OBJECTIVE: Reduction of social inequality in health may be one of the biggest challenges in the Western World.

Wishing to contribute to the reduction of social inequality, the general objective of the project is to increase the awareness on how the socio-cultural context has an effect on healthy lifestyle choices and the health status within families.

Three aims are set out:

- To make municipal health strategies more coherent and initiatives more efficient and effective.
- To create better coherence between projects and programming.
- To improve local implementation processes of practical health promoting initiatives.

METHODOLOGY: The process runs in 2 parallel phases.

Phase 1: Based on a theoretical, cultural, structural and methodological framework a mapping of local programming procedures and implementation procedures are accomplished in 12 local authorities. 12 in depth analysis and recommendations for future policy-, strategy- and implementation practice are presented. Selected recommendations from the analysis are implemented and evaluated through a trial out period in 12 local authorities.

Phase 2: Tools and methods are developed and serve to advance and improve local processes. All material are conceptualised into the final conceptual framework. The project and its results are disseminated through a European web site.

DISSEMINATION: The project dissemination has been carried out through a number of different activities.

The main instruments for dissemination are:

- A project website to be found on www.pohefa.eu
- Promotional brochures and electronic newsletters.
- Articles in magazines with European relevance and in national and local press.
 - A national or regional conference promoting the project in each participating country.
 - A final European conference.
 - Presentation of the project and its results at national and international conferences, e.g. The 9th European IUHPE Health Promotion Conference in Tallinn.

RESULTS: The PoHeFa Project has contributed to initiate health promoting processes in the participating municipalities – processes that in the long term are expected to have a positive effect on citizen's health.

Through individual local policy analysis's, the needs of each local authority has been highlighted which has ensured that the PoHeFa-project has provided concrete results and benefits on local level.

"Because of the PoHeFa project, health has been integrated into the local re-generation project, as it has become a priority area for the city", Stefan Leyk, Stadt Lütjeburg, DE.

"The timing of the PoHeFa project is really good for us in the UK at it gives us some concrete instructions and directions on how the new structures can be formed and create strategies in a time where "localization" is on the political agenda", Mark Patterson, Department of Health, UK.

CONCLUDING REMARKS: The PoHeFa Method is not only relevant for the participating partners but has a high European transfer value.

Following a few examples of the recommendations that have been acquired through the project:

- Create a common understanding among local politicians and practitioners about the concept of health.
- Include staff and users more actively in development and implementation processes.
- Install a structured cross-organisational and cross-disciplinary approach, through a closer collaboration and dialogue between different groups of professional practitioners.

Project co financed from the EU Public Health Programme 2008 - 2013

Start date and duration of project: 15th of July 2009 - 15th of July 2012

Total cost: 949.840 EURO

Co-funding from the Commission: 500.000 EURO

Leader Organisation: University College South Denmark

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Other Partners:

Communication manager:

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Partners:

Langeland Municipality, Denmark

National Institute of Adult Continuing Education, UK

South West Strategic Health Authority, UK

Heinrich-Böll-Stiftung, Schleswig-Holstein, Germany

Landesvereinigung für Gesundheitsförderung e.V. in Schleswig-Holstein, Germany

JAMK University of Applied Sciences, Finland

University of Cyprus

Regione Abruzzo, Italy. ALBA Auxilia, Italy



European
Commission



EUREGIO III: lessons learned about improving investment in regional health systems using Structural Funds

Authors: Prof Jonathan Watson*,
Barrie Dowdeswell** and Edit Sebastyén*

Main beneficiary - Health ClusterNET* (United Kingdom)

Associate Partners - ECHAA** (Netherlands), EMK-SU (Hungary), U-Maastricht (Netherlands), U-Liverpool (United Kingdom), REGVEN (Italy)

Summary

The project was funded to explore and assess the use of Structural Funds for health investment in the 2000-2006 and 2007-2013 SF cycles. During the project all EU regional health systems were facing significant change: demographic, epidemiological, technological and economic. Project evidence identified important precedents and learning experience for the future. Specifically, driven by economic conditions and demands from the 'better informed' public – investment strategies must address at minimum:

- ☑ The rapidly changing demands on healthcare services in particular an ageing population (healthy ageing) and the rise in chronic illness are necessitating significant investment in changing the way services are delivered
- ☑ A slow down (and possible reduction) in new resource availability – likely to be particularly acute in the capital sector due to the problems arising from the credit crisis require major changes in the way we design and finance hospitals and other health facilities
- ☑ The EU Council Conclusions call for reform of health systems to move on from an unsustainable hospital-centric model towards more sustainable and effective integrated care systems
- ☑ The reinforcement coming from the new Cohesion Policy draft guidelines underpinned by EU2020 which in turn highlight specific areas of concern and opportunity e.g. innovation, healthy ageing, eHealth
- ☑ The need for health investment to make a greater economic related contribution to growth.

Unfortunately, our evidence indicates that the public (including SF) health sector is short of relevant capacity and structures to achieve these results. In contrast, the very few exemplars identified by EUREGIO III tend to have common characteristics:

- ☑ An understanding of how to assess and manage future risk
- ☑ Effective stakeholder accountability
- ☑ Economic and outcome related return on investment.

www.euregio3.eu

Objective

To contribute to improving the effectiveness of the SF process within the health sector through:

- ☑ A retrospective evidence based review of the SF programme cycles for 2000/6 & 2007/13 through:
 - ☑ Thematic analysis of representative case studies
 - ☑ Contribution from delegates attending EUREGIO III workshops and masterclasses
 - ☑ Desktop research (stakeholder analysis and capacity building audits) and other empirical evidence
- ☑ Recalibration of the project mid-term to recognise the extent to which pressures are building within health systems, in particular:
 - ☑ Ageing populations and the related rise in chronic disease
 - ☑ Costly technological advances
 - ☑ Patient demand driven by better information and by less healthy lifestyles
 - ☑ Legacy priorities and financing structures that are not suited to today's needs
- ☑ Anticipating the growing impact of a recessionary biased economic outlook, in particular public spending austerity and acute shortage of capital investment resources
- ☑ Provide policy briefings for relevant EU Directorates and MS that is useful in shaping future SF policy and strategy.

Methods and means

Several work packages informed an evidence-based & outcome related review (WP4-6 and 8-9). Selection and analysis of cross sectional representative case studies included non-SF projects that displayed smart innovation. The intention here was to benchmark SF investments against recognised good practice exemplars. There is a strong bias towards infrastructure and eHealth as critical factors in future reform-based investment (see Table 1).

Table 1: Relationship of case studies to new priority focus areas identified by EUREGIO III, EU Council Conclusions (6 June 2011) and draft Cohesion Policy 2014-2020

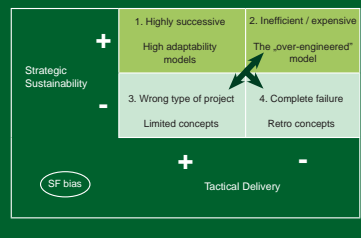
CASE STUDY	Healthcare reform and future planning	Integrated care	eHealth and technology innovation and integration	Healthy ageing	Hospital development/redevelopment
Hungary masterplanning	***	**			
Slovenia masterplanning	***				
Kymenlaakso, Finland masterplanning	***	***			
Biederburg, Germany Cardiovascular care	**	***	***		
Stony Health needs assessment, Technology assessment, Technology investment	*	*	***		
Norrbottenland, Sweden eHealth		***	***		
Greece, Cancer Centre					***
Slovenia, eHealth			***		
Poland, Hospital Investment			**		
Greece, Mental Health, Autism Services	***	**			

Analysis of evidence

Although the project involved a diverse range of case studies, thematic analysis demonstrated consistent themes:

- ☑ The SF structure and process tended to self limit the scope of projects, in particular a predisposition towards mono-focus stand alone investments often only loosely connected through overarching programmes
- ☑ This in turn limited the effectiveness of policy implementation in particular whole system reform
- ☑ Unresolved conflicts between tactical spending to resolve short-term problems and strategic investment aimed at change and sustainability, few projects bridged successfully between these needs
- ☑ Weakness in knowledge and capacity to plan, manage and implement complex large scale investments, in particular infrastructure and whole systems eHealth projects
- ☑ Weak or non-existent ex-ante evaluation, in particular relating to infrastructure and eHealth, focus tended to be on delivery on time and on cost as opposed to operational effectiveness and delivery
- ☑ Lack of relevant data and information about the relationships between inputs and outcomes mitigating against measuring results and value for money
- ☑ It did not prove possible to undertake meaningful comparative benchmarking between projects because of the weakness in data availability and ex-ante evaluation.

Figure 1: The CONCEPT model of analysis



Acknowledgements

This project could not have achieved its timely impact without the commitment, expertise, intelligence and insight provided by project partners, EC line Directorates (SANCO, REGIO & EMPLOY), and the full support and contribution of the regions/organisations responsible for the selected case studies. We also benefited from the thoughtful and stimulating work of the team at Imperial College London, Dr. Miklós Szócska, Hungarian Minister of State for Health, and ultimately EAHC Project Manager, Georgios Margetidis.

Collaborating partners:
 Ruppiner Kliniken GmbH – Brandenburg/UMC Potsdam
 Hungarian National Development Agency – Human Resource Development Programme
 Polish Ministry of Regional Development – Department for Coordination of Infrastructure Programmes
 Ministry of Health of the Slovak Republic – Unit for Structural Funds
 Ministry of Social Affairs of the Republic of Estonia, Ministry of Health of the Republic of Bulgaria
 Assembly of European Regions, European Investment Bank, EUREGHA
 EUREGHEALTHNET, European Association of Development Agencies
 European Health Management Association, Quarters en Crise – European Regeneration Areas Network
 Landesinstitut für Gesundheit und Arbeit (LIGA-NRW)

Findings

The results of the project demonstrate the need to improve substantially the effectiveness of structural fund investment in the health sector.

- ☑ SF investment is faced with hitting a fast moving target:
 - ☑ Overcoming severe and debilitating legacy problems resulting from previous underinvestment, in particular health infrastructure
 - ☑ Embedded health pressures: ageing, chronic illness, technology, workforce
 - ☑ Superimposed pressures: the economic crisis
- ☑ Future SF investment strategies will need to be:
 - ☑ More adaptable and dynamic to respond to the changing demands, priorities and resource outlook of a 21st century health system
 - ☑ More integrated to create the tipping point for structural reform and process change to improve affordability, quality, accessibility and sustainability
 - ☑ Incorporate smart innovation principles in particular relating to partnerships with the private sector and in contributing fully to economic growth – enacting the health is wealth ethos in more direct and measurable terms
 - ☑ More results orientated in terms of project delivery and performance. Greater rigour will be needed to meet the challenges set by strengthened conditionalities.

Impact

Project findings have informed the following:

- ☑ Interim findings were incorporated in the Hungarian Presidency programme for health and subsequently endorsed in the EU Council Conclusions (6 June 2011)
- ☑ A WHO/EU Equity project briefing – Opportunities for health systems to influence the use of Structural Funds to reduce health inequalities in the European Union
- ☑ Design and focus of the HealthEquity-2020 project (started July 2012) assisting EU10 member states/regions to develop evidence-based action plans on reducing health inequalities, which also informs use of structural funds
- ☑ An introductory guide for DG REGIO desk officers – Health infrastructure and health service priorities in the post 2013 programming period in convergence regions
- ☑ The final results of the study and accompanying case material is proving an important evidence base for the EU Council High Level Reflection Process sub-group charge with – ‘Defining success factors for the effective use of Structural Funds for health investments’
- ☑ Initial steps by the Task Force on European Pension Funds Investment in Common Good Innovation to assess the feasibility of long-term investment in regional health systems innovation plans.

Conclusions

SF Managing Authorities and intermediaries (such as MoH) should consider the following when preparing health investment priorities for partnership contracts and operational programmes during SF negotiations: realistic starting points, commitment to transformational change, affordable investment priorities, sustainable investment and address health inequalities.

Building on EUREGIO III evidence aligned to the draft Cohesion Guidelines and EU 2020 priorities, a strategic framework for health investment using structural funds should address the following:

- ☑ Understanding the context
 - ☑ The economic crisis and impact on growth and employment
 - ☑ Needs assessment and concept development
 - ☑ Undertake an assessment of adequacy and sustainability of social protection and pension systems, and identify ways to ensure better access to health care systems
- ☑ Strategic priorities - and policies
 - ☑ Social – Equality of Access and Quality – integrated models of care
 - ☑ Economic – Fiscal consolidation and long-term financial sustainability will need to go hand in hand with important structural reforms, in particular of health care
- ☑ Operational measures
 - ☑ Enhancing access to ICT – promoting online health
 - ☑ Healthy ageing programmes
 - ☑ Stimulating efficiency – effective innovation, technologies, service delivery models, infrastructure
 - ☑ Evaluation and accountability – an effective monitoring and review system.

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 Leader Organisation: Health ClusterNet (HCN), United Kingdom
 Contact Person: Professor Jonathan Watson, HCN
 (jonathan@healthcluster.net.eu, info@healthcluster.net.eu)



CompHP

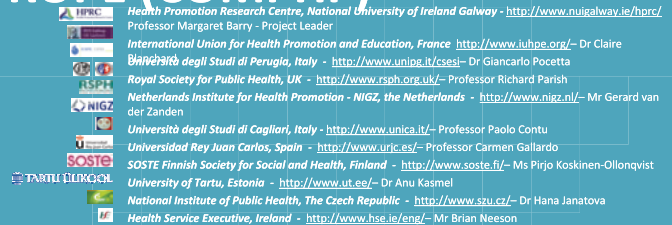
<http://www.iuhpe.org/index.html?page=614>

DEVELOPING COMPETENCIES AND PROFESSIONAL STANDARDS FOR HEALTH PROMOTION CAPACITY BUILDING IN EUROPE (COMPHP)

The CompHP Project aims to develop competencies, professionals standards and an accreditation framework for health promotion in Europe.



24 partners (11 actively involved in the project Workpackages and 13 as collaborating partners) representing 11 EU member states and two candidate countries.



Summary

The project engaged in consultation with Health Promotion practitioners, policymakers and education providers across Europe and beyond, to build a consensus on the core competencies and professional standards and an accreditation system for health promotion in Europe.

The project builds on European and international experience, including research undertaken by the International Union for Health Promotion and Education/European Region (IUHPE/EURO) on health promotion practice and training in Europe and on the feasibility of implementing a Pan European Accreditation Framework for health promotion.

Drivers for the development of CompHP included:

- quality assurance issues for practice, education and training identified within all health fields,
- freedom of employment policies highlighting the need for agreed standards to facilitate employment across the EU,
- the workforce capacity required for promoting health as identified in European Union (EU) health strategies.

Objectives

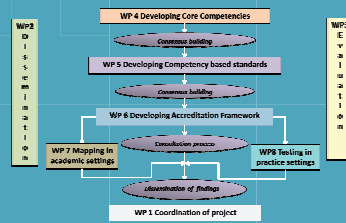
- to identify, agree and publish core competencies for health promotion practice, education and training in Europe.
- to develop and publish competency-based professional standards for health promotion.
- to promote quality assurance through the development of a Europe-wide accreditation system.
- to map competencies and standards in academic courses across Europe and link to accreditation for academic settings.
- to pilot competencies, standards and accreditation with practitioners in a range of settings across Europe.
- to engage in consultation with key stakeholders and disseminate information on the project outcomes throughout the 27 member states and all candidate countries.

Methodology

The Project uses a consensus building approach and works in collaboration with health promotion practitioners, policymakers and education providers across Europe. Methods used in the consultation processes include Delphi studies, online surveys, focus and discussion groups, in-depth testing in academic and practice settings. The Project also used social media as both research and consultations tools.

WP Coordination

The Project is structured into 8 interrelated Workpackages and is managed by a team comprising the Project Leader (Professor Margaret Barry, NUIG), Project Coordinator and Workpackages Leaders.



Achieved outcomes

- Wide ranging consultation with practitioners, policymakers, education providers and other key stakeholders across Europe and beyond
- Handbooks and reports which will inform capacity building for professional practice in health promotion across Europe including:
 - The **CompHP Core Competencies Framework for Health Promotion Handbook** (published March 2011)
 - The **CompHP Professional Standards for Health Promotion Handbook** (published February, 2012)
 - The **CompHP pan European Accreditation Framework for Health Promotion Handbook** (to be published in August 2012)
- Short versions of the Handbooks published in English, French and Spanish
- Literature reviews and reports on the development of the Handbooks

All Handbooks and reports are available on the project website <http://www.iuhpe.org/index.html?page=614>

Dissemination

- Stakeholders database for dissemination and consultations
- Communications plan, comprising a dissemination action plan, Publication Policy and Public Relations strategy
- Three CompHP newsletters
- CompHP web site
- CompHP poster, in different version and languages
- Announcements on publications and calls for participation in IUHPE family of journals
- Oral and poster presentations, workshops, including:
 - 20th IUHPE World Conference on Health Promotion (Geneva, CH, 2010)
 - EUPHA 4th European Conference in Public Health (Copenhagen, DK, 2011)
 - European Training Consortium in Public Health and Health (Zagreb, HR, 2011)
- Articles in Scientific Journals (e.g. La Santé de l'Homme-FR, La Salute Umana - IT)
- Translation and dissemination of publications
- Two Conferences (Galway, Ireland and Tallin, Estonia)

Evaluation

Process evaluation: Data collection included online surveys, participant observation at meetings, monitoring of monthly reports and qualitative approaches, including log books and interactive group work. Analysis includes assessing progress against targets, documentary analysis, qualitative analysis of log books, observation, group work.

Evaluation of the effect of the CompHP Project included online surveys to partners and stakeholders, interviews with key stakeholders. Data collected is analysed using quantitative and qualitative methods.

Conclusion

The work of CompHP creates a new dimension in European health promotion by establishing the means and methods by which agreed core competencies and quality standards can be implemented across Europe to stimulate innovation and best practice. The development of a Europe-wide system of competency-based standards in health promotion provides a basis for building a competent and effective health promotion workforce capable of putting into action the key priorities identified in recent European health strategies. While the CompHP Project ends in October 2012, the Project Partners are actively exploring the sustainability of its work and products at Global, European, nation and local levels.

Acknowledgements

We acknowledge the support of the CompHP project partners, collaborating partners, International Expert Advisory Group and project stakeholders who have contributed to the development of the Project and the European Commission who provided the funding for the CompHP Project.

For more information please visit the CompHP Project Website <http://www.iuhpe.org/index.html?page=614> or contact the Project Coordinator, Barbara Battel- Kirk, email: bbkconsultancy@eircom.net

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Co-funding from the Commission: (EUR) 659.540,00

Leader Organisation: Health Promotion Research Centre, National University of Ireland Galway – Ireland

Contact Person: Professor Margaret Barry - Project Leader

Web site: <http://www.iuhpe.org/index.html?page=614>

Partners: Health Promotion Research Centre, National University of Ireland Galway; International Union for Health Promotion and Education (France); Università degli Studi di Perugia (Italy); Royal Society for Public Health (UK); The Netherlands Institute for Health Promotion; Università degli Studi di Cagliari (Italy); Universidad Rey Juan Carlos (Spain); Finnish Society for Social and Health; University of Tartu (Estonia); National Institute of Public Health (Czech Republic); Health Service Executive (Ireland).



Funded by
the Health Programme
of the European Union



European
Commission

The reference portal for information on rare diseases, expert services and orphan drugs in 38 countries

An inventory of rare diseases and an encyclopaedia

- Classifications of rare diseases
- Cross-referencing with genes and other databases
- Epidemiological data
- Clinical description and search by clinical signs
- Encyclopaedia for professionals & patients
- Bi-monthly newsletter: latest political and scientific news on rare diseases
- Thematic studies and reports of the "Orphanet Report Series"
- Orphanet Journal of Rare Diseases www.ojrd.com (IF=5.07)

A collection of reports and articles

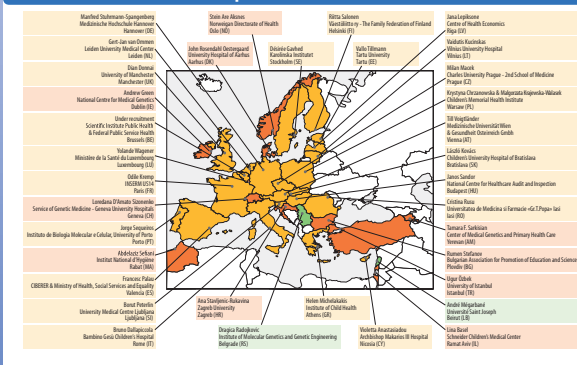
A directory of expert services in Europe and beyond

- Disease-related healthcare resources
- Disease-related research activities
- Patient organisations
- Links to additional sources of expert-authored information
- Orphan drugs on the market and in development
- Clinical trials
- An inventory of orphan drug R&D

Free-access web service to download data: www.orphadata.org



Orphanet teams present in 38 countries to collect information on expert services and R&D



20,000 users per day from over 200 countries



Project co-financed from the EU Public Health Programme 2008-2013

Start date and duration of project: 01/04/2011; 36 months
 Total cost: 7,229,749.00 €
 Co-funding from the Commission: 3,295,857.00 €

Leader organisation: INSERM (Institut National de la Santé et de la Recherche Médicale)
 Contact person: Ségolène AYME, segolene.ayme@inserm.fr
 Web site: www.orpha.net



Building consensus and synergies for the registration of rare diseases patients in Europe: the EPIRARE project

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National Centre for rare Diseases, Italian National Institute of Health, Rome, Italy ; 2) EURORDIS; 3) Instituto de Salud Carlos III, Spain; 4) Consiglio nazionale delle Ricerche, Italy; 5) University of Maastricht, Netherlands; 6) Bulgarian Association for Promotion of Education and Sciences, Bulgaria.

SUMMARY: EPIRARE identifies the regulatory, ethical and technical solutions and the agreements necessary to promote the registration of rare diseases (RD) patients and to establish a European platform for RD registries.

OBJECTIVES:

- **Assess the organizational features of EU rare disease registries:** scope and type of data collected; compliance with legal and ethical requirements; quality assurance; IT measures; human and financial resources.
- **Prepare a proposal for a legal basis to allow data sources integration and RD patient data sharing at the Community level.**
- **Elaborate guidance documents for quality control and agree on a minimum Common Data Set** to conduct epidemiological research at the EU level.
- **Identify scope and mechanism of governance and long-term sustainability of a platform for RD registries.**

METHODOLOGY

EPIRARE has carried out a survey (online questionnaire) on the activities and needs of existing RD registries in Europe (n=220).

Starting from survey results and from the available literature, EPIRARE will propose common standard of quality for the registration of RD patients, a common data set, a legal basis and a governance framework in Europe to regulate registration activities for RD patients.

COORDINATION AND MANAGEMENT

EPIRARE is coordinated by the National Centre for Rare Diseases of the Italian National Health Institute.

The Advisory Board is composed by Members of Institutions from Italy, Belgium, Bulgaria, France, Germany, Greece, Hungary, Netherlands, Spain and UK, EURORDIS.

DISSEMINATION

EPIRARE launched an open network for the consultation of all stakeholders to build consensus on the project proposals and results. EPIRARE is strongly connected with EUCERD to ensure that the health authorities of EU countries are prepared to consider the implementation of the project proposals. The public is informed of the project activities and results with a brochure and a website (www.epirare.eu).

EVALUATION

The achievements of the project will be evaluated by process, outcome and impact indicators. The satisfaction of the intended stakeholders for the project deliverables will be assessed.

www.epirare.eu

RESULTS

- 1) A survey of organizational features of RD Registries has been carried out. Data have been collected between October 2011 and January 2012 and 220 "active registries" (collecting data) replied to at least the first 20 questions. Survey results show a general lack of standardization in registries activities, in technical issues and in legal and ethical practices.
- 2) A position paper is being prepared on the revision of the personal data protection directive and the needs of RD patients and care.
- 3) A document analyzing the stakeholders' interests and proposing services and outputs of the EU platform of RD registries is being prepared.
- 4) An International Workshop is scheduled at the Istituto Superiore di Sanità (Rome, Italy) on October 8-9, 2012 to discuss the draft documents.
- 5) EPIRARE supports the exchange of information among the authorities currently planning national initiatives for the registration of RD patients.

CONCLUSION

Considerable work has to be done to promote standardisation in RD registration activities. The platform to be developed by EPIRARE will consider the interests of different stakeholders and offer tools and services to help data sharing and exchange.

Health and Consumers

Project co-funded by the EU Public Health Programme 2008-2013

Start date and duration of project: April 15, 2011, duration 30 month

Total cost: 1.102.717 EUR; Co-funding by the EU Commission: 661.402 EUR

Leader Organisation: Istituto Superiore di Sanità, Italy Contact Person: Dr Domenica Taruscio (domenica.taruscio@iss.it)



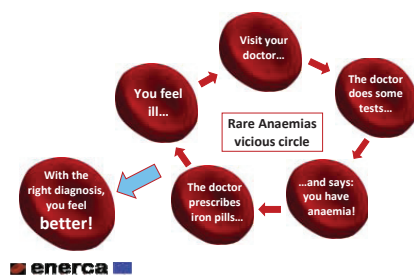
European
Commission



Coordinated by:
CLÍNIC
 BARCELONA
 Hospital Universitari

European Network for Rare and Congenital Anaemias

www.enerca.org



Objectives

- Creation of a **European Reference Network (ERN) of Expert Centres in Rare Anaemias**
- **Harmonization** of procedures & **Epidemiological surveillance**
- Continuous **medical education & public awareness**
- Promotion of relationships with **patients' associations**
- Promotion of experts **research and cooperation**
- Consolidation of the **ENERCA web site** services

Methodology

Core Work Package

- WP1** Networking of expert centers
- WP2** Quality of patient care
- WP3** Education and training

Public health issues / management of patients with:

- WP4** Sickle Cell Disorders
- WP5** Thalassaemia
- WP6** Very Rare Anaemias

Horizontal Work Package

- WP7** Project Evaluation
- WP8** Project Dissemination
- WP9** Project Coordination



Acknowledgements

Project co financed from the EU Public Health Programme 2008-2013
Start date and duration of the project: June 1st 2009 – 3 years
Total Cost: 2.022.625 €
Co-Funding from the Commission: 1.193.800 €
Leader Organization: Hospital Clínic de Barcelona
Contact person: Prof. J.L Vives Corrons
Website: www.enerca.org
Other Partners: 24 associated partners and 24 collaborating partners

Summary

ENERCA started back in 2002 with the purpose of offering an improved health service for patients with rare anaemia. ENERCA 3 (2009-2012) aims to create a **European Reference Network of Expert Centres on Rare Anaemias** and provides both **information and services** in every aspect of rare anaemia to health professionals, patients, citizens, authorities and pharmaceutical industry managers.

Management



WP Coordination

- Project **management, quality** assurance and assessment of **progress and results**.
- To guarantee the compliance with the **work plan** and to achieve the real coordination.

WP Dissemination

- To get the critical mass of **interest** necessary for the project success.
- To organize two **European Symposiums** on Rare Anaemias.
- Promotion of **ENERCA website** services.

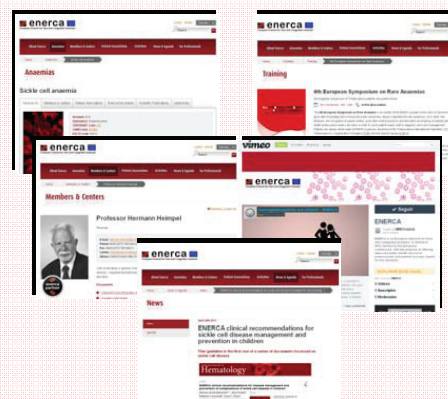
WP Evaluation

- **Monitoring** the general Project's management and evaluating its progress.
- **Evaluation programme** for detecting partial progress failures or weak points in order to implement corrective measures.

The achievement of objectives, outcomes and impact of the project is very satisfactory.

Results

- Publication of a **White Book** for the recognition of centres of expertise and creation of a ERN on rare anaemias
- Production of a catalogue for **External Quality Assessment** schemes available in Europe and implementation of new ones
- Contribution with the **ICD-11** classification of rare anaemias
- Creation of up to **62 rare anaemias' card** including definition, diagnosis, treatment and inheritance in seven languages, ORPHA, MIM and ICD codes.
- Inventory of **centres, health professionals and patients' associations** through Europe
- Publication of **ENERCA recommendations** on diagnosis and/or therapeutic procedures in rare anaemias
- Organization of three **European** and two **national training courses** on specific rare anaemias diagnosis and management.
- Celebration of two **European symposium** on rare anaemias co-organized with national patients' associations (Spain and Bulgaria)
- Creation of **educational material**: video on haemoglobinopathies, comics
- Creation of a Intranet with **collaborative diagnostic tools** for the project partners



Conclusion

The **consolidation of a ERN** of Experts Centres in Rare Anaemias is a crucial step to improve the services for clinical management of these diseases. The opportunities to undertake innovative and useful actions based on the ERN are enormous. After 10 years of work, **ENERCA offers a solid platform to develop multidisciplinary initiatives for tackling rare anaemias.**



SOCIAL-ECONOMIC BURDEN AND HEALTH-RELATED QUALITY OF LIFE IN PATIENTS WITH RARE DISEASES IN EUROPE (BURQOL-RD)

Julio López-Bastida^(1,13), Pedro Serrano-Aguilar⁽¹⁾, Renata Linertová⁽¹⁾, Panos Kanavos⁽²⁾, Johann-Matthias Graf von der Schulenburg⁽³⁾, Ulf Persson⁽⁴⁾, Giovanni Fattore⁽⁵⁾, Karine Chevreul⁽⁶⁾, Rumen Stefanov⁽⁷⁾, László Gulácsi⁽⁸⁾, Manuel Posada⁽⁹⁾, Arrigo Schieppati⁽¹⁰⁾, Domenica Taruscio⁽¹¹⁾, Claudia Delgado⁽¹²⁾
BURQOL-RD Group*

INTRODUCTION

BURQOL-RD is a 3 year project under the Second Programme of Community Action in the field of Public Health, promoted by DG Sanco in Europe that started in April 2010. The main aim is to generate a model to quantify the socio-economic costs and Health-related Quality of Life (HRQOL), of both patients and carers, for 10 rare diseases (RD) in 8 European countries (Spain, France, UK, Italy, Sweden, Germany, Hungary and Bulgaria).

SPECIFIC OBJECTIVES

- To generate a framework to measure the socio-economic burden and the HRQOL of RD.
- To develop unified instruments to gather information on the socio-economic burden and HRQOL of RD throughout Europe.
- To perform a pilot study measuring the socio-economic burden and HRQOL for selected RD.
- To refine and package the tools for the continued study of the costs and HRQOL of RD.

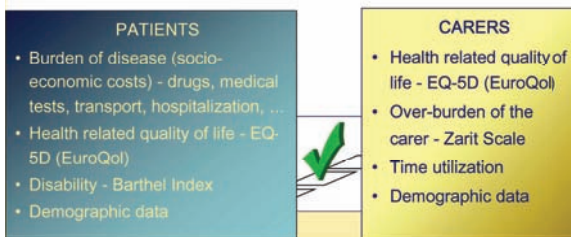
METHODS: Survey

Questionnaires for patients and their carers were developed for measuring the direct and indirect costs and HRQOL. The survey has been launched in all countries between September 2011 and July 2012.

Main features: anonymity, on-line form (and traditional form if necessary).

The collaboration of national patients' associations and federations for the specific rare diseases is fundamental to ensure that all the objectives are successfully reached.

The survey in all 8 countries is expected to finish in October 2012.



Project co financed from the EU Public Health Programme 2008-2013

Start date and duration of project: 20/04/2010, 3 years

Total cost: 1,175,044.00 €

Co-funding from the Commission: 705,026.40 €

Leader Organisation: Fundación Canaria de Investigación y Salud (FUNCIS), Spain

Contact Person: Renata Linertová (renata.linertova@sescs.es)

Web site: www.burqol-rd.eu

Other Partners: *BURQOL-RD Group: (1) Fundación Canaria de Investigación y Salud (Spain); (2) London School of Economics and Political Science (UK); (3) Leibniz University Hannover (Germany); (4) The Swedish Institute for Health Economics (Sweden); (5) Università Commerciale "Luigi Bocconi" (Italy); (6) University Paris Est (France); (7) Bulgarian Association for Promotion of Education and Science (Bulgaria); (8) Centre for Public Affairs Studies Foundation (Hungary) (9) Instituto de Salud Carlos III, Research Institute for Rare Diseases (Spain); (10) Mario Negri Institute for Pharmacological Research (Italy); (11) Istituto Superiore di Sanità (Italy); (12) Federación Española de Enfermedades Raras (Spain).
Collaborating partners: Rare Diseases Europe – EURORDIS; Euro-Histo-Net; Rare Diseases UK-Genetic Interest Group (United Kingdom); Hungarian Federation of People with Rare and Congenital Diseases-Rare Diseases Hungary (Hungary); National Alliance of people with rare diseases (Bulgaria); Consulta Nazionale delle Malattie Rare (Italy); Federazione Italiana Malattie Rare

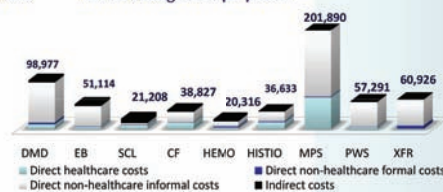
The project is divided in different workpackages with responsables from 8 European countries. The first work was related to the selection of the 10 rare diseases targeted in the pilot study:

<i>Cystic Fibrosis</i>	<i>Histiocytosis</i>
<i>Duchenne Muscular Dystrophy</i>	<i>Juvenile Idiopathic Arthritis</i>
<i>Epidermolysis Bullosa</i>	<i>Mucopolysaccharidosis</i>
<i>Fragile X Syndrome</i>	<i>Prader-Willi Syndrome</i>
<i>Hemophilia</i>	<i>Scleroderma</i>

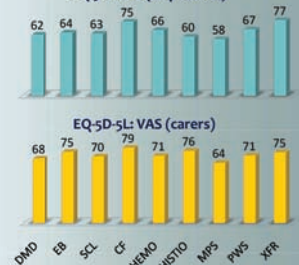
FIRST RESULTS IN SPAIN

567 responses were received. Annual average socioeconomic costs for each patient were calculated. Costs were divided in 4 categories: direct healthcare costs, direct non-healthcare formal costs (professional carers, social services), direct non-healthcare informal costs (unpaid carers), indirect costs (productivity loss). Both patients and their carers completed a generic scale to measure HRQOL with the EQ-5D questionnaire.

Annual average costs per patient

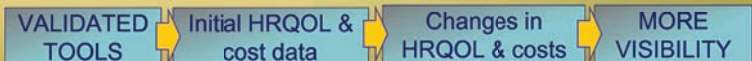


EQ-5D: VAS (all patients)



EXPECTED OUTCOMES

The expected outcomes of BURQOL-RD are an integrated and harmonized set of instruments to assess socio-economic burden and health-related quality of life of patients affected by rare diseases and their caregivers. The tools developed by BURQOL-RD will build on the EUROPLAN project and will also improve Rare Diseases awareness and literacy among European citizens.



www.burqol-rd.eu



European
Commission

2

Health Information



Introduction

- The European Surveillance of Congenital Anomalies (EUROCAT)
- In existence since 1979
- Funded by the European Commission
- Network comprising almost all population-based congenital anomaly registries in Europe

The EUROCAT Joint Action aims to facilitate the reduction of the public health burden of congenital anomalies by epidemiological surveillance through the EUROCAT network of population-based congenital anomaly registries.

Project Aims and Objectives

- Evaluation of the public health impact of congenital anomalies, enabled by accessible/updated epidemiological information on the EUROCAT website
- Detection, investigation and reporting of clusters/trends in congenital anomalies, improved capacity for rapid response and establishment of a new Task Force for Evaluation of Clusters
- Assessment of teratogenic impact of new/changing environmental exposures
- Evaluation of potential linkage of databases and electronic exposure information to enable surveillance/etiological analyses of congenital anomaly risk
- To establish a strategy on primary prevention of congenital anomalies implemented in national plans for rare diseases
- Evaluation of progress in preventing neural tube defects by raising periconceptional folic acid status in women of childbearing age
- Evaluation of the impact of delayed childbearing, changes in prenatal screening, and policy on Down Syndrome
- To contribute to development of a pharmacovigilance system
- Improved coding and classification of congenital anomalies (training/revision of International Classification of Disease)
- To establish new registries - provide guidelines/software
- Organisation of European Symposia to share results

Methodology

- EUROCAT currently surveys more than 1.7 million births per year in Europe, covered by 39 registries in 21 countries
- Cases of all major structural congenital and chromosomal anomalies among livebirths, stillbirths and terminations of pregnancy following prenatal diagnosis of a fetal anomaly, are registered using multiple sources of information
- Using common software, each member registry transmits a standard dataset to a central database at EUROCAT Central Registry, where further quality validation and annual statistical monitoring are undertaken
- EUROCAT also provides a framework whereby data can be accessed upon request to conduct collaborative specific/ad hoc research in relation to congenital anomalies



26th Registry Leaders Meeting/EUROCAT Symposium, Belgium, 2011

*Project co financed from the EU Public Health Programme 2008-2013

Start date: 1st January 2011

Duration: 36 months

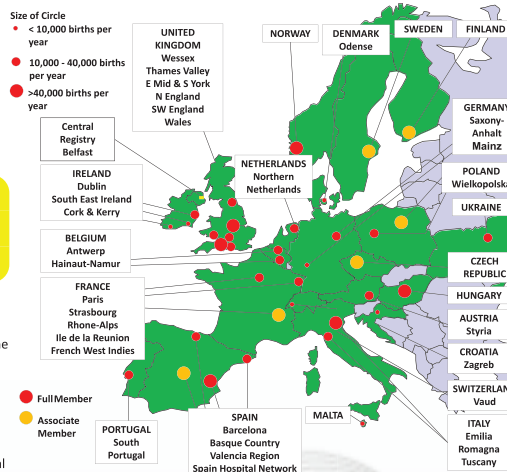
Total cost: 3,360,210.89 (EUR)

Co-funding from the Commission: 1,106,302 (EUR)

Leader Organisation: Prof. Helen Dolk, University of Ulster, U.K.

Contact Person: Dr. Rhonda Curran (Project Manager)
rcurran1@ulster.ac.uk

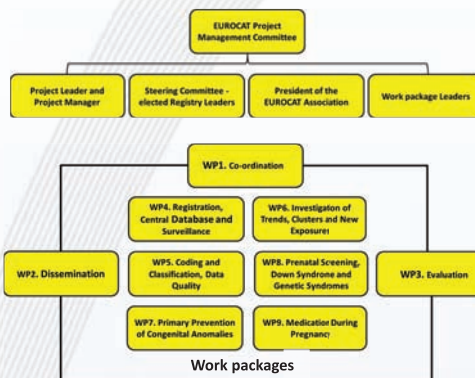
Web site: www.eurocat-network.eu



Map of EUROCAT Full and Associate Member Registries

Co-ordination

- The EUROCAT Association is the association of member EUROCAT registries, which is legally constituted and independent of funding modes. The EUROCAT Association elects a President and Steering Committee members



Dissemination

Purpose – to raise awareness of the importance of registries and databases on congenital anomalies, coordinated at European level

Liaison – EUCERD, EUROPLAN, EURORDIS, EUROPERISTAT, ICBCDSR

Target Groups

- Health professionals** – e.g. paediatricians, obstetricians, paediatric pathologists, medical geneticists, genetic counsellors, midwives
- Public health professionals/health service planners** - e.g. regional/national, EU,
- Governmental/public regulation agencies** – e.g. industry, air quality, environmental protections, food, medication
- Scientific research community** – e.g. epidemiology, public health, clinical genetics
- Politicians and policy makers**
- Community**

Results

To view all EUROCAT publications, please visit <http://www.eurocat-network.eu/aboutus/publications/publications>

A publication entitled "Recent decrease in the prevalence of congenital heart defects in Europe" has been accepted (June 2012) for publication in the Journal of Pediatrics

"Rare chromosome abnormalities, prevalence and prenatal diagnosis rates from population based congenital anomaly registers in Europe" has now been published in the European Journal of Human Genetics. This paper, using data from 16 EUROCAT registries, is one of the first to offer epidemiological data on the full range of rare chromosome abnormalities. These data provide the only baseline prevalence figures currently available for health service planning for the management and care of people with a rare chromosome abnormality. The live birth prevalence rate of 3.7/10 000 births of long-term survivors with a rare chromosomal abnormality is significant and may be used to guide long-term healthcare for affected individuals.

To view all EUROCAT reports, please visit at <http://www.eurocat-network.eu/aboutus/publications/eurocatspecialreports>

EUROCAT prevalence data (including data up to 2010) are available via interactive tables at <http://www.eurocat-network.eu/accessprevalencedata/prevalencetables>

EUROCAT prenatal detection data are available at <http://www.eurocat-network.eu/prenatalscreeninganddiagnosis/prenataldetectionrates>

As part of the Joint Action 2011-2013, EUROCAT systematically monitors the rates of birth defects over time to detect signals of new or increasing teratogenic exposures requiring public health action. EUROCAT statistical monitoring results (including data up to 2009) are available at <http://www.eurocat-network.eu/clustersand trends/statisticalmonitoring/statisticalmonitoringintroduction>

Key findings from pan-European (all EUROCAT registries combined) analysis were:

- The number of babies born with birth defects (major congenital anomalies) across Europe has fallen (2000-2009).
- The overall occurrence of spina bifida and heart defects have declined by 10% and 14% respectively (2000-2009).
- The proportion of pregnancies affected by Down syndrome has increased by 5%, now occurring in almost 22 out of every 10,000 pregnancies. Analysis has shown that the increase in Down syndrome is a consequence of the trend in Europe for women to delay childbirth until later in life. Older maternal age is a known risk factor for Down syndrome.
- The proportion of pregnancies affected by gastroschisis - an abdominal wall defect that requires babies to have corrective surgery - is also continuing to rise, going up by 29 per cent over the decade to 3 per 10,000 pregnancies.

Also as part of the Joint Action, the **EUROCAT Coding and Classification Committee** have been actively involved in the development of the **malformation chapter for the International Coding and Classification System for Diseases (ICD11)**.

Primary prevention is a main goal of the EUROCAT Joint Action (2011-2013). WP7 is collecting data on current policies in the European Union Member States (EU-MS) for primary prevention of congenital anomalies and proactively liaising with EUROPLAN to indicate the areas that Member States could target develop in their strategies for Primary Prevention of congenital anomalies.

*Associate Partners:

- Forschungsverein zur Registrierung Steirischer Geburtsfehlbildungen, Austria
- Provinciaal Instituut voor Hygiene, Belgium
- Institut de Recherche Scientifique en Pathologie et en Genetique, Belgium
- Klinika za dječje bolesti Zagreb, Medicinski fakultet Sveučilista u Zagrebu, Croatia
- Region Syddanmark, Denmark
- National Institute for Welfare and Health, Finland
- Paris Registry of Congenital Malformations, INSERM, France
- Université de Strasbourg, France
- University medical Centre of the Johannes Gutenberg University Mainz, Germany
- Otto-von-Guericke University Magdeburg, Germany
- National Centre for Healthcare Audit and Inspection, Hungary
- Health Service Executive, Ireland
- Azienda Ospedaliero Rilevato Nazionale, Italy
- Azienda Ospedaliero Universitaria di Ferrara, Italy
- Istituto Superiore di Sanita, Italy
- Istituto di Fisiologia Clinica del consiglio Nazionale delle Ricerche, Italy
- Children's University Hospital, Latvia
- The National Health Service, Latvia
- Malta Congenital Anomalies Register, Malta
- Academisch Ziekenhuis Groningen, Netherlands
- University of Groningen, Netherlands
- Norwegian Institute of Public Health, Norway
- Poznan University of Medical Sciences, Poland

- Instituto Nacional de Saude Dr Ricardo Jorge, Portugal
- University Medical Centre, Ljubljana, Slovenia
- Agencia de Salut Publica de Barcelona, Spain
- Fundacion Vasca de Inovacion e Investigacion Sanitarias, Spain
- Fundacion Centre de Recerca en Epidemiologia Ambiental, Spain
- Asociacion Espanola para el Registro y Estudio de las Malformaciones Congenitas, Spain
- Centre Superior de Investigacion en Salud Publica, Spain
- University of Leicester, UK
- University of Newcastle upon Tyne, UK
- Queen Mary University of London, UK
- The Chancellor, Masters & Scholars of the University of Oxford, UK
- Public Health Wales, Wales
- Southampton University Hospitals Trust, UK

*Collaborating Partners:

- Belarus Research and Clinical Center "Mother and Child", Belaru
- Clinical Genetics Department, Archbishop Makarios III Hospital, Cyprus
- Department of Medical Genetics - Thomayer University Hospital, Czech Republic
- Research Institute of Pediatrics and Child Surgery, Russia
- Slovak Medical University in Bratislava, Slovakia
- University Clinical Centre Maribor, Slovenia
- Service de Genetique Medicale, Switzerland
- University of Glasgow, Scotland
- OMNI-NET Centre, Ukraine



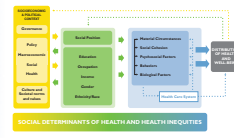
DETERMINE HEALTH INEQUALITIES

An EU Consortium for Action on Socio-economic Determinants of Health

The project has received funding from the European Commission.

DETERMINE builds on and stimulates action on the social determinants of health and on health inequalities in the EU and its Member States, by bringing together a Consortium of over fifty bodies within the EU. The Consortium advances EU work on Health Equity and on Health in All Policies (HiAP).

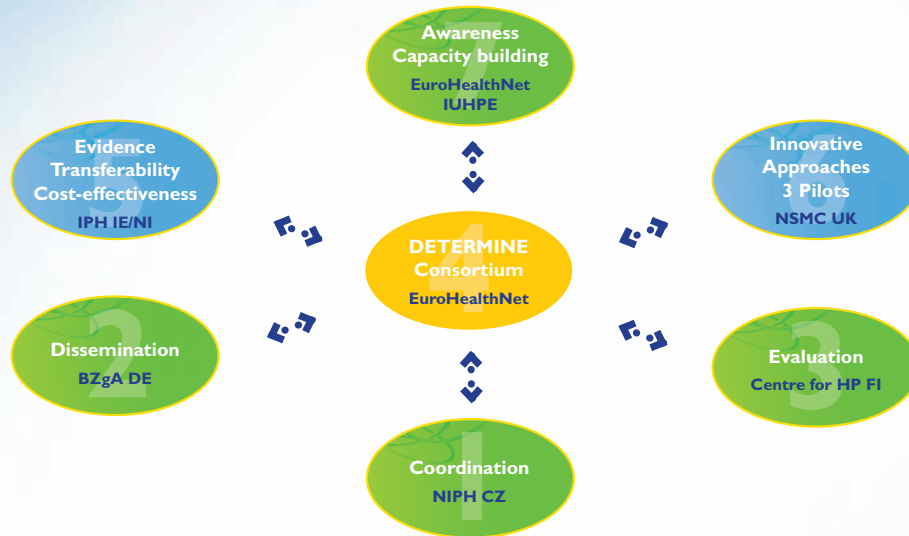
In all EU countries with available data, differences in life expectancy typically amount to five years or more and differences in healthy life expectancy to ten years or more between people with higher and lower educational, occupational or income levels. (EuroThine, 2007). In addition, a systematic correlation between health status and social class has been identified in all European countries with available data.
This means that even in relatively wealthy EU countries, a large portion of society does not enjoy the right to the highest attainable standard of physical and mental health.



Summary pathway and mechanisms of social determinants of health inequalities. Developed by WHO Commission on the Social Determinants of Health

The conditions in which people live and work can help to create or destroy their health – lack of income, inappropriate housing, unsafe workplaces and lack of access to health systems are some of the main social determinants of health leading to inequalities within and between countries. (WHO Commission on the Social Determinants of Health, 2006.)
All policy areas, not just the health sector, are responsible for health and health equity. This calls for a collaborative approach.

The Consortium's activities are undertaken in the context of seven work packages (WP), led by different organisations. Overall work is coordinated by EuroHealthNet and the Czech National Institute of Public Health (contract holder), in collaboration with an executive group of WP leaders.



DETERMINE Consortium - WP 4

OBJECTIVES

- To establish a Consortium comprised of governments, health bodies, organisations and institutions from 25 countries, to gather evidence and apply what works to improve health through a SDH approach.

OUTCOMES

- The DETERMINE Consortium: a sustainable, multi stakeholder partnership that has met three times in EU Presidency countries, and an annual report series on "Addressing socio-economic determinants of health in the EU".

Evidence Transferability and Cost Effectiveness - WPs

OBJECTIVES

- To develop the current evidence-base on policies which address the socio-economic determinants of health inequalities, by drawing on expertise of the Consortium partners.

OUTCOMES

- A working document on EU governments' experiences with cross-sectoral collaboration to address the social determinants of health inequalities.
- A working document on economic arguments that have been used in the EU to incorporate a socio-economic determinants of health perspective

Innovative Approaches - WP 6

OBJECTIVES

- To identify innovative approaches to change health-related behaviours amongst socio-economically vulnerable groups, involving social marketing and public-private partnerships.
- To promote and reward innovative cross-sector approaches by supporting three small-scale pilot projects that take them forward.

OUTCOMES

- A working document on social marketing, private/public partnerships and other innovative approaches that address the socio-economic determinants for health.
- Three innovative pilot actions with potential transferable benefits.

Dissemination - WP 2

OBJECTIVES

- To further develop a web-based resource of knowledge and tools in the EU context on the wider health determinants that will support policy making in public health and other policy sectors.

OUTCOMES

- www.health-inequalities.eu
- Widespread dissemination of Consortium outcomes in appropriate media and at relevant events.

Awareness and Capacity Building - WP 7

OBJECTIVES

- To advocate and raise awareness of approaches that address socio-economic determinants in health and other relevant policy sectors at the local, national, EU and global level and to build the capacity of Consortium members and other stakeholders to take action in this field.

OUTCOMES

- An analysis of target audiences based on interviews with policy makers.
- Capacity building and awareness raising activities in participating countries integrating the project outcomes.
- A Final Conference in Brussels (March 2010), bringing together Consortium partners and wider stakeholders from various policy sectors.

Evaluation WP 3

OBJECTIVES and OUTCOMES

- Ongoing process evaluation of the Consortium's work, using the principles of Action Research (participation in all activities and continuous feedback).
- Output evaluation to assess the added value of the Consortium, and the uptake of DETERMINE's outcomes.

DETERMINE Consortium Members

Interested in learning more about DETERMINE and its outcomes? See:

The WHO Commission on Social Determinants of Health (2005-2008) brings together evidence on policies that improve health by addressing the social conditions in which people live and work. It is chaired by Sir Michael Marmot and is comprised of twenty leading scientists and practitioners throughout the world. Amongst the goals of the CSDH is to help build a sustainable global movement for action on health equity and social determinants.

This project is co financed by the EU Public Health Programme 2003-2008 • 01/06/2007 – 31/05/2010 • Total cost: 1.680.720.000 • Subsidy from the Commission: 907.359.00
Leader Organisation: EuroHealthNet and NIPH-CZ • Contact Persons: Ingrid Stegeman (i.stegeman@eurohealthnet.eu) and Dr. Hana Janatova (janatova@szu.cz)

www.health-inequalities.eu

Self-regulation is not the answer

Conclusion of the AMMIE research project:

“Self-regulation codes are not able to protect young people from exposure to large volumes of alcohol marketing.”



To appeal or not to appeal The result of independent monitoring in Bulgaria, Denmark, Germany and the Netherlands (2009-2011)

Project Organization:

Coordinator: Dutch Institute for Alcohol Policy (STAP).
Project leader: Wim van Dalen (STAP)

Partners:

-Alcohol & Society Denmark
-German Centre for Addiction Issues (DHS), Germany
-Foundation 'Horizonti 21', Bulgaria
-Eurocare Italia, Italy
-Eurocare, Belgium

Objectives:

The AMMIE project aimed to monitor alcohol marketing practices in Europe by bodies independent from the commercial interest.

It also evaluates the effectiveness of existing marketing regulation in Bulgaria, Denmark, Germany, Italy and The Netherlands.

It will allow the European Commission and the Member States to formulate advices in order to improve the existing regulations of alcohol marketing on MS and EU level.

Summerized results:

1. The project shows innovative ways of alcohol producers to circumvent existing alcohol marketing regulations, especially self-regulation.
2. Hard exposure data show that especially vulnerable young people between 13-15 years of age are expressly targeted by alcohol commercials compared to adults.
3. Television time bans on alcohol marketing have limited protective power for young people
4. Especially top clubs in football are often sponsored by alcohol producers. Alcohol brands attempt to be associated with sport, the sport club, its sportive success, the loyalty of its fans.
5. Differences in opinion between youth opinion panels and the decisions of the Advertising Code Committees illustrate the incompetence of Advertising Committees to prohibit alcohol marketing practices that are appealing to minors.

Conclusion:

Data collection within the AMMIE project shows that existing self-regulation codes are not able to protect young people from exposure to large volumes of alcohol marketing practices and appealing alcohol advertising. Alcohol marketing is recommended to be monitored systematically by independent monitoring bodies.

Methodology:

Five independent national NGOs monitored alcohol marketing practices in a comparable and systematic way based on the experience of the Dutch Institute for alcohol policy. The content of the alcohol marketing practices were recorded and analysed. Questionable ads were put into the jurisdiction systems of the national advertising bodies. The same ads were rated by national youth panels. National statistics were gathered in order to define the percentage of young people in the specific countries that are exposed by alcohol marketing practices in order to compare these figures with the relevant regulations in the national self regulation systems.

Acknowledgements:

The project was evaluated by Prof. Hastings of the University of Sterling (Scotland); the final deliverables were also disseminated by EUROCARE towards all relevant NGOs and to the commercial and political stakeholders.

How to get the AMMIE reports? The results of AMMIE are described in 2 European and 20 national reports. These reports can be found on the website of the European Centre for Monitoring Alcohol Marketing (EUCAM): www.eucam.info/AMMIE

Project co financed from the EU Public Health Program 2008-2013. Start date and duration of the project: 01-08-2009- 31-08-2011. Total costs: € 425.251,- Co-funding from the Commission: € 255.151,- Leader organisation: Dutch Institute for Alcohol Policy (The Netherlands) Contact Person: Wim van Dalen. Website: www.eucam.info/AMMIE



European
Commission




The European Health Literacy Project 2009-2012

1. Summary

The HLS-EU project aimed to **estimate the state of the art of health literacy in Europe** and to establish a sustainable approach to the advancement of health literacy in the region.

The outcomes include:

- the European Health Literacy Survey (HLS-EU)
- the network 'Health Literacy Europe'
- national advisory boards in Austria, Bulgaria, Germany, Greece, Ireland, Netherlands, Poland and Spain.

The outcome of the HLS-EU project provide **new grounds** for innovation in research and practice to develop people's health literacy and meet the needs for new solutions in healthcare.

2. Introduction

Health literacy is identified as a critical empowerment strategy, which constitutes the **ability to make sound health decisions** in the context of everyday life. According to the HLS-EU consortium: *Health literacy is linked to literacy and entails people's knowledge, motivation and confidence to access, understand, appraise and apply health information to make judgments and take decisions in everyday life in terms of healthcare, disease prevention and health promotion to promote and maintain quality of life during the life course.*

People with limited health literacy are in risk of having less health knowledge, lower health status, higher utilization of health services, and higher health care costs. For the first time the **HLS-EU survey provides a trans-national overview** of the situation in Europe.

3. Methods

The HLS-EU survey applied the conceptually based **HLS-EU-Q** measurement tool designed by the HLS-EU consortium. It contains **47 items covering 12 sub-dimensions of health literacy**. The tool was pre-tested in focus groups in three countries and field tested using face to face interviews in two countries.

The survey was conducted with face to face interviews in summer 2011 according to Eurobarometer standards. It included a total of **8000 participants in eight countries**: Austria, Bulgaria, Germany, Greece, Ireland, Netherlands, Poland and Spain.

The results refers to a **four level health literacy index** indicating health literacy to be: **Excellent, sufficient, problematic or inadequate.**

4. Results

The survey has provided **crucial information** in terms of health literacy related to healthcare, disease prevention and health promotion.

The results show that **47% on average have risk of limited health literacy**, and that there is a social gradient, which need to be addressed.

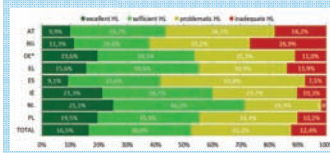
Vulnerable groups are identified and include people with no or low education, socio-economic deprived and people with self-reported ill health.

The cross-national comparison shows that **health literacy levels differ substantially across the eight countries** (Figure 1). The Netherlands provides the best national results.

Figure 1:

Figure 1 shows the four level health literacy index results for the eight participating countries in the HLS-EU survey.

An expression of **'limited health literacy'** is seen when combining the red 'inadequate level' with the yellow 'problematic level' of health literacy.



5. Conclusion

The HLS-EU project has **contributed to the field of health literacy** with a new definition and concept of health literacy accompanied by a tool to measure health literacy in populations. It has generated first time data on health literacy (n=8000) for comparative analysis across eight European countries and built up eight national advisory groups and an international network with European and global representation to secure valorisation of the results.

The HLS-EU consortium recommends on basis of the survey results and the profound review of global research, health literacy to be a **public health issue**, which need to be treated in its own rights by decision-makers in healthcare and educational sectors.

6. The HLS-EU consortium

- Maastricht University (NL)
- Ludwig Boltzman Institute for Health Promotion (AT)
- Faculty of Medicine, Sofia (BG)
- National Centre for Health, NRW (DE)
- National School of Public Health (GR)
- University College Dublin (IE)
- National Institute for Health and Environment (NL)
- Institute of Cardiology, Warsaw (PL)
- University of Murcia (ES)

7. Project details and contact

The HLS-EU Project was co-financed from the EU Public Health Programme 2003-2008, grant 2007-113. It took place from 1 January 2009 – 29 February 2012.

The total costs were approximately 1.1 million Euros, and 40% was co-funded by the European Commission.

The HLS-EU consortium was lead by Maastricht University/CAPHRI.

For more information please contact the HLS-EU project coordinator: Kristine Sørensen: K.Sorensen@maastrichtuniversity.nl or link to www.health-literacy.eu

Sørensen K. et al. 2012. Health literacy and public health: A systematic review and integration of definitions and models. BMC Public Health 12(1):80. (<http://www.biomedcentral.com/1471-2458/12/80>)



Joint Action for Piloting the European Health Examination Survey



<http://www.ehes.info>



Introduction

Representative and valid population level health information is needed for the evidence based health policies, planning and evaluation of health prevention programs and health services. For many health indicators reliable information can be obtained only by health examination surveys (HES). National HESs have been carried out at regular intervals only in a few European countries. Comparability between these surveys is limited due to lack of joint standardization.



EHES

The European Health Examination Survey (EHES) is a collaboration to collect nationally representative, high quality health data which are comparable between countries and over time. EHES consists of national HESs and activities of the EHES Reference Centre (RC). EHES RC is responsible for the European level coordination, development and maintenance of the standards, training, evaluation and reporting. EHES Pilot Project in 2009-2012 focused on the measurement of the important modifiable risk factors of major chronic diseases in the adult population.



EHES Joint Action

The EHES Joint Action (JA), as a part of the EHES Pilot Project, focused on the national activities needed to build the capacity in each of the country. It aimed

1. to test the EHES standards in different countries and survey settings, and
2. to plan and prepare for a full-size HES in these countries, including the fieldwork of a pilot survey.



Results

Twelve countries prepared for and planned all aspects of national HESs and completed the national HES pilot fieldwork. Standardization of the measurements was successful. Standardization of the questionnaire items turned out to be more difficult. The biggest challenge in all countries was achieving a high participation rate, which is a prerequisite for accurate population estimates of the health indicators.



Conclusions

The EHES Joint Action demonstrated that health examination surveys which follow the EHES standards can be adapted to countries with different cultural settings and economic status. It was possible to maintain the comparability with previous surveys and hence to follow trends in countries with existing survey systems.



The EHES Pilot Project has created a structure for the European Health Examination Survey. The structure is supported by the interest and need indicated by potential survey organizers in most of the EEA countries. A prerequisite for the sustainability of EHES is the European level coordination, support to countries in planning the national HES, sampling design, training, external quality assessment and reporting.

Project co financed from the EU Health Programme 2009-2013

Starting date and duration of the project: 1 January 2010, 24 months

Total cost: 1.683.681,59 €

Leader Organisation: National Institute for Health and Welfare (THL), Finland

Other Partners: National Institute of Public Health, Czech Republic; Robert Koch Institute, Germany; Hellenic Health Foundation, Greece; Hellenic Center for Disease Control and Prevention, Greece; Istituto Superiore di Sanità, Italy; Department of Health Information & Research, Malta; Rijksinstituut voor Volksgezondheid en Milieu, the Netherlands, Norwegian Public Health Institute, Norway; The Cardinal Stefan Wyszyński Institute of Cardiology, Poland; Instituto Nacional de Saúde Dr. Ricardo Jorge, I.P., Portugal; Regional Public Health Authority, Slovakia, Prestacions d'assistència Mèdica, Spain; University College London, UK

Web site: <http://www.ehes.info>

Co-funding from the Commission: 841.837,08 €

Contact Person: Project Leader, Kari Kuulasmaa (kari.kuulasmaa@thl.fi)



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3

Health Safety

EUROPEAN LIVING DONOR PSYCHOSOCIAL FOLLOW-UP ELIPSY PROJECT

Manyalich, M.; Menjivar, A.; Yucetin, L.; Dias, L.; Legendre, C.; Hiesse, C.; Papachristou, C.;
Fehrman-Ekholm, I.; Kvarnström, N.; Ballesté, C.; Paredes, D.; Revuelta, I.; Diekmann, F.;
Peri, J.M.; Torres, X.; Rimola, A.; Fondevila, C.

INTRODUCTION

ELIPSY is a project co-funded by EU Public Health Programme which aim is to contribute guaranteeing high quality of living organ donation programs by creating an assessment model for the Living donor's (LD) psychosocial well-being and quality of life, including the impact of the recipient's outcome on the donor and the donor's perception of the process.



OBJECTIVES

To contribute guaranteeing a high quality of living organ donation programs by creating an assessment/follow-up model for the LD's psychosocial well-being and quality of life, including the impact of the recipient's outcome on the donor and the donor's perception of the process.

METHODS

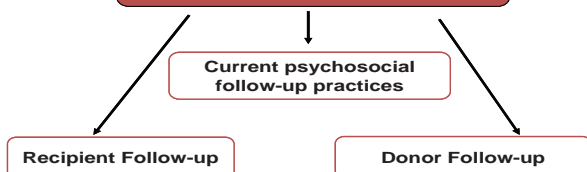
Prospective study

- Compare the **psychosocial well-being and quality of life** of the donors **before and 1 year after donation**.
- The **impact of donation**, including the impact of the **recipient's outcome** on the living donor well-being.

Retrospective study

- Assessing the **long-term impact of donation** and the impact of the recipient's outcome on the donor.
- Psychosocial well-being, quality of life and impact of recipient's outcome** data will be collected to the donors who donated **one, three and five years ago**.

METHODOLOGY OF THE WORK



WP COORDINACION

Regular communication with the partners
Build up working plans and define deadline
Organize meetings

WP DISSEMINATION

DIRECTED TO MEDICAL AND SCIENTIFIC COMMUNITY
 OPEN PUBLIC AND MASS MEDIA

DISSEMINATION MEANS: International Congress
International Journals
Web page
Mass Media activities

WP EVALUATION

Manual/Guide for the internal evaluation

Evaluation criteria : Efficacy
Impact
Transferability
Lessons learned
Conclusions and recommendations

RESULTS

- Design and creation of the tools
 - Survey about current psychosocial assessment practices
 - Questionnaire for the preoperative psychosocial assessment
 - Questionnaire for the post-operative psychosocial follow-up
 - Survey of recipient follow-up to correlate the recipients outcome with the psychosocial wellbeing of the donor
- Development and standardization of the methodology to be used for the e LD psychosocial follow-up

CONCLUSION

The harmonisation of LD psychosocial follow-up among Europe will guarantee a high quality model for living donation programs.



PARTNERS AND INSTITUTIONS OF REFERENCE

Hospital Clinic of Barcelona, Spain; Centro Hospitalar do Porto, Portugal; Hôpital Necker Enfants Malades, Paris, France; Charité University Hospital Berlin, Germany; Sahlgrenska University Hospital, Göteborg, Sweden.

Collaborative partner: Medical Park Antalya Hospital Complex, Turkey;

Project co financed from the EU Public Health Programme 2008-2013. Starting date December, 2009. Duration of the project 30 months.

Total cost : € 498.835,00. Co-funding from the Commission € 299.188,00.

Lider organization: Hospital Clinic of Barcelona, Spain. Contact person: Marti Manyalich.

Website: www.eulivingdonor.eu



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Comparing and recommending good donor management practice

W.L.A.M. de Kort, I.J.T. Veldhuizen, E.T. Wagenmans

European project

DOMAINE is a European project, focusing on good blood donor management. It is carried out by blood establishments from 18 European countries, the Thalassaemia International Federation and the South-eastern European Health Network and is coordinated by Sanquin Blood Bank South East Region in the Netherlands.

The most efficient and secure way of creating a safe and sufficient donor population is the development and adoption of European good practice and cooperation between blood establishments and professionals at European level. DOMAINE aims to achieve good practice in donor management.

Rationale

- European population is ageing
- Demand for blood products is growing
- Number of potential donors is decreasing
- Large group of multi-gallon recipients
- Need for adequate blood donor management

Every year in Europe

- For 509,000,000 inhabitants
- 3,800,000 patients requiring blood products
 - 10,700,000 blood donors
 - 19,000,000 blood donations



Method

- Performing a **Survey** on current practice in European blood establishments, including practices geared to promoting voluntary unpaid donations
- Developing a **Donor Management Manual** in several European languages, identifying and recommending good European practice for donor management with respect to:
 1. donor recruitment
 2. donor retention
 3. donation procedures, including deferral policy
 4. patients requiring long-term transfusion therapy
- Developing a **Training Programme** which will assist blood establishments within each EU member state to implement Good Donor Management

Current project phase: Final Reporting

The Donor Management Manual was published in June 2010. It was launched during the XXXIst International Congress of the International Society of Blood Transfusion in Berlin on June 26th. It is available on the DOMAINE website (www.domaine-europe.eu).

The project is at its final stage. A training programme that will disseminate the manual's information to professionals in blood establishments throughout Europe has been developed. This training programme (TP) aims at executive staff in donor management. The first TP has been very successfully presented at the XXIst Regional ISBT Congress 2011 in Lisbon (P). More TPs have been scheduled already and will be scheduled on a regular basis.

* Austria, Belgium, Cyprus, England, Estonia, Finland, France, Germany, Hungary, Ireland, Malta, the Netherlands, Northern Ireland, Portugal, Scotland, Slovenia, Switzerland, Wales ** Thalassaemia International Federation

Project co financed by the EU Public Health Programme 2003-2008

Starting date and duration of project: March 1st 2008, 36 months
 Total cost: € 862,073
 Subsidy from the Commission: € 500,000

Leader organisation: Sanquin Blood Supply Foundation
 Contact Person: e.wagenmans@sanquin.nl
 Web site: www.domaine-europe.eu



The COORENOR project Coordinating a European initiative among National Organizations for ORgan Transplantation

C. Carella, P. Di Ciaccio, A. Nanni Costa, Italian National Transplant Centre, Italy

SUMMARY

COORENOR is a 30 months project (from June 2010 – to December 2012). The general aim of this project is to establish a coordinated network between national programmes existing in the participating European Member States in the field of organ transplantation, taking into account some major issues such as cadaveric donation, living donation and cross border organ exchange.

OBJECTIVES

The project is coordinating the efforts of organizations based in countries which joined the European Union during the last ten years with those of organ donation and transplantation bodies that have a consolidated experience in cooperating together in this specific field. A main objective is the definition of shared and feasible best practices and guidelines in the field of organ transplantation. In countries in which organ transplantation is already a well-established and organized activity, the identification of best possible strategies will have a positive effect on quality and coordination, whereas for those where some programmes are not yet fully developed the project served as catalyzer of existing positive synergies.

METHODOLOGY

An overview of existing situations was performed under different WPs: legal and clinical conditions for death diagnosis and organ donation, parameters for clinical evaluation of living donors and existence of follow-up registries, current volumes of cross border organ exchanges. Recommendations have been drafted on each single topic, whereas a country profile was drawn up under the WP on existing transplant programs.

MANAGEMENT & COORDINATION

All the Associated partners met every 4 months to review progress in all of the work packages. The coordinating partner, CNT, maintained contact with partners mainly through emails and provided technical support to all work packages for the circulation of the surveys through the 27 European Competent Authorities for organ and for the administrative management of their budgets and reporting requirements.

DISSEMINATION

The outputs of the project were disseminated in a number of ways:

- The project website
- Presentation at international meetings
- Distribution of the project brochure to all EU Competent Authorities for organs
- Presentations at local events and congresses



EVALUATION

All the project aspects were evaluated. Questionnaire were also circulated during the meeting by the evaluating partner in order to investigate the level of satisfaction of each partner. Draft version of final deliverables were provided to the evaluators who gave suggestions during each meeting. Final deliverables will be evaluated by the advisory board and shared through the scientific community.

RESULTS

1. Overview of supranational/ national/ regional/ local transplant programmes in EU and analysis of organisational systems: recommendations on further initiatives and future work.
2. Overview on the deceased donation and public campaigns within the EU member states.
3. Common strategy for enhancing Living Kidney Donation within the EU member states.
4. Setting up of an IT web portal for the cross border organ exchange.

CONCLUSION

The history of cooperation among the EU member states goes back to European Transplant Network activities and ALLIANCE-O projects.

Starting from the membership of these previous projects, COORENOR enlarged its border establishing not only a network between National transplant Organization but becoming itself a bridge between the past experiences and the future networking of Competent Authorities in the Joint Action.

ACKNOWLEDGEMENTS

The Project partners are very grateful to the European Commission for providing financial support and for using the project outputs as the basis for developing further initiatives.

Project co-financed by the EU Public Health Programme 2008 - 2013
Starting date: June 2010. Duration 30 months.
Total costs: 1.424.215,95
Subsidy from the Commission: 799.145,08

Leader organization: Italian National Transplant Centre – Italian National Institute of Health (CNT-ISS), Italy
Contact persons: Alessandro Nanni Costa, Paola Di Ciaccio

Other partners:
 Országos Vértáplató Szolgálat - Hungary
 Agence de la Biomédecine - France
 Medical University of Warsaw - Poland
 Koordinacni Stredisko Transplantaci - Czech Republic
 Poltransplant - Poland
 Eurotransplant

Pauls Stradins Clinical University Hospital, Latvia
 Transplantation Center - Latvia
 Lithuanian National Transplant Bureau - Lithuania
 Fundeni Clinical Institute - Romania
 Univerzitna Nemocnica Martin - Slovakia



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Improving Vigilance of Tissues and Cells applied to Patients in the European Union : the SOHO V&S Project

Summary

The EU funded project 'Vigilance and Surveillance of Substances of Human Origin (SOHO V&S)' was launched in March 2010 and will finish at the end of February 2014. Co-ordinated by the Italian National Transplant Centre, it is supporting EU Member States in the development of vigilance systems for tissues and cells that are applied to humans in a wide range of treatments. The scope includes transplanted bone marrow and cord blood, skin and bone used in burns treatment and orthopaedic surgery, gametes and embryos used in the treatment of infertility and corneas, heart valves and vessels used in transplantation. It has surveyed the situation regarding vigilance in this field in the EU and has developed specific guidance for the field of assisted reproduction and suspected illegal activity. Guidance documents on vigilance investigation are under development. Training courses are being provided to EU tissue and cell Vigilance Officers.

Objectives

The key objective is to develop a shared view of how serious adverse events and reactions associated with tissue and cell donation or human application should be reported, evaluated and investigated within the EU. A series of work packages address specific areas of concern: vigilance in assisted reproduction, vigilance for living donors, how investigation of adverse incidents such as suspected virus or malignancy transmissions should be carried out, how best to encourage clinical users to notify adverse outcomes that might be associated with the quality or safety of the tissues or cells and how regulators should detect and prevent illegal and fraudulent activity in the field. The project aims to facilitate harmonisation of terminology and documentation and consensus on how information should be exchanged between EU Member States, the European Commission and third countries.

Phase I: Exploration

WP 4 Survey of EU MS

A survey was conducted by the Spanish National Transplant Organisation in all EU MS and showed that vigilance systems for tissues and cells in the European Union are generally at an early stage of development. There was a need for guidance and training of Competent Authority personnel, particularly in the investigation of serious adverse events and reactions. Many MS required reporting of adverse incidents that gone beyond the requirements of the Directives particularly in relation to donor reactions that do not influence the quality and safety of the procured tissues or cells.

WP5 Vigilance of Gametes and Embryos

Gametes and embryos are within the scope of the EU tissue and cell legislation but vigilance issues can be quite different compared with other fields of tissue and cells. An exploratory workshop with participants from Competent Authorities the European Society for Human Reproduction and Embryology identified the key issues for vigilance in this field. A working group then developed a guidance document that explores the topics of adverse reactions and events that should be reported and investigated. The most important ones are mix-ups of gametes or embryos (among embryos implanted, oocytes fertilized with sperm from a different couple, etc.), events involving loss of embryos due to equipment failure or media defects, genetic transmissions by gamete donation and reactions associated with oocyte donation. This work was led by the Biomedicine Agency in France.

WP 5 Adverse Reactions in Donors

There are different practices in place regarding the notification of adverse reactions in living donors of tissues and cells, with some following the Directives very precisely and requiring donor reactions to be reported only where quality or safety of procured tissues has been influenced and others requiring, or at least accepting, reports of any donor reactions, regardless of whether tissue or cell quality or safety was impacted. This report summarises the situation and makes recommendations for a common approach to this issue.

WP 6: Detection and Management of Illegal and Fraudulent Activity

Up to now, most EU Competent Authorities for tissues and cells have focused their efforts on putting in place systems and procedures to implement the regulatory functions that are required by the tissues and cells Directives, notably inspection, authorisation and vigilance. Many however, lack experience and training, as well as procedures to follow, for the investigation of cases where illegal or fraudulent activity is suspected. A SOHO V&S work package led by the French Agency for the Safety of Health Products gathered information from MS on cases that have been investigated and concluded, in some cases with enforcement action. The work package has developed guidance, including tools and recommendations, to support all Member States in this particular area of work.

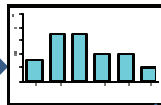
WP 7: Investigating Serious Adverse Events and Reactions

In 2010, WP7 joined forces with the World Health Organization (WHO) and the Italian National Transplant Centre (INT) to organise a major global initiative aimed at raising the profile of V&S of substances of human origin: the initiative was called Project NOTIFY. Ten international expert groups worked collaboratively on a Google site where over 100 participants (regulators, clinicians, professional society representatives, scientific experts) reported and reviewed documented cases of reactions and events across the scope of the substances under consideration, using published articles and vigilance system reports as their sources. Over 1,500 published references were inserted on the site. The cases were used as the basis for developing draft guidance on detection and confirmation of reactions and events, with an emphasis on the role of the treating physician. Key elements of this guidance are incorporated in the Deliverable 8 of this project.

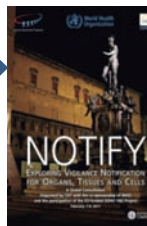
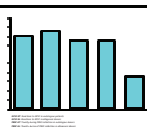
WP 9: Engaging Clinical Users

This work package, led by the Irish partner, addresses the critical role of the clinical user of tissues and cells in ensuring traceability at the hospital level and in the detection and investigation of suspected adverse reactions. The 4 major professional societies in the field are collaborating with the project partners to develop this guidance which will be released at the end of the project.

Phase II: Reports and Guidance



Length of time that EU V&S Systems for Tissues and Cells have been in place



Chapters on:
 • Detection and Reporting of Serious Adverse Events and Reactions
 • Investigation of Serious Adverse Events and Reactions
 • Communication of Serious Adverse Events and Reactions
 Incorporating guidance from other work packages

Consultation ongoing with EU Competent Authorities during Summer of 2012

This document will be provided to MS for translation and distribution to their hospitals as they wish.

Phase III: Dissemination and Training

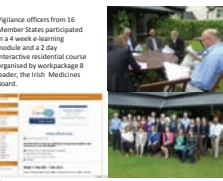


The project has been presented at professional conferences and described in many publications in Europe and the USA



www.eurovet.eu has been developed to make information on tissue and cell vigilance more easily available to the public.

Training Course 1: Ireland June 2012



Vigilance Officers from 16 Member States participated in a 4 week e-learning module and a 2 day interactive residential course organised by workpackage 8 leader, the Irish Medicines Board.

The training course will be repeated in October 2012 in Italy for a second set of vigilance officers

Final Conference

The Human Tissue Authority in the UK will host a global vigilance conference in the last month of the project where the project outputs will be presented and future priorities for maintaining and improving vigilance will be discussed.

Evaluation

All project deliverables have been reviewed and evaluated by an internal evaluation committee composed of individuals who are not directly involved in the work of the project. Events and training courses are evaluated by the participants. Two external peer reviewers also review and evaluate each deliverable. Structured questionnaires are used for all evaluation activities and the results are analysed and reported by the work package leader, Donor Action.

Conclusions

The application of human tissues and cells in transplantation and assisted reproduction brings enormous benefits to patients across the EU. Adverse reactions and events are rare but they need to be detected, investigated and reported so that patients can be protected and repetition can be avoided. This project is supporting MS in the development of their vigilance systems, drawing on existing experience and agreeing common principles of best practice.

Project co-financed from the EU Public Health Programme 2000-2006
 Start date and duration of project: 1 March 2010 3 years
 Total cost: Euro 1 524 100 Co-funding from the Commission: Euro 754 500
 Leader Organisation: National Transplant Centre, Italy
 Contact Person: Alessandra Iannicelli

Website: www.sohovets.org
 Other Partners:
 Donor Action Foundation, Belgium
 Irish Medicines Board, Ireland
 National Transplant Organisation Spain
 Biomedicine Agency, France

French Agency for the Safety of Health Products, France
 National Centre for Tissue and Cell Doping, Poland
 Human Fertilisation and Embryology Authority, UK
 Human Tissue Authority, UK
 World Health Organisation, Switzerland

4

Health Threats



EU SHIPSAN TRAINET Project

European Union Ship Sanitation Training Network Project

<http://www.shipsan.eu>



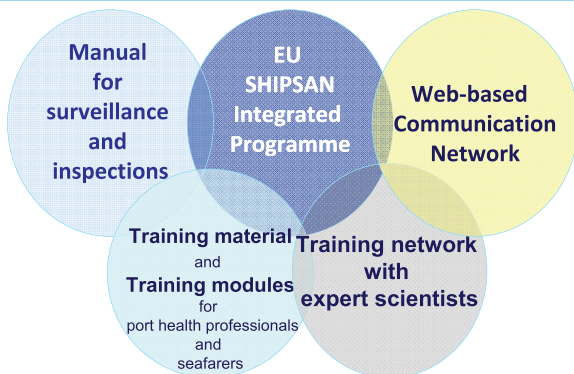
The **overall aim** of the project was to develop an integrated programme on sanitation and control of communicable diseases on passenger ships including a training programme and communication network. Moreover, the project aimed to facilitate the practical implementation of the International Health Regulations (IHR).

The partnership

Associated partners: **14** Collaborating partners: **24**
 EU geographical coverage: **9 EU MS, 2 EFTA,**
9 EuroMed countries participated in the training courses
 Cruise companies: **16**
 International & EU Organisations:
 CDC-VSP, CLIA, IMO, WHO, ECDC, ECC

Objectives

Common standards Common training Communication



Evaluation

Internal and external evaluation, questionnaires, SWOT analysis (strength and weakness analysis, opportunities and threats analysis)



Dissemination

- Publications (6 articles)
- Web-portal (>18,000 visits)
- Newsletters (16 issues, 3 editors in rotation)

Conclusions

- Better prevention and management of the communicable diseases aboard ships and transnational transmission.
- Common inspection process in EU
- Promoted coordination and exchange of ship inspection results under IHR 2005

Results

Communication network platform <https://www.shipsan.eu/comnet/>

- used to follow up 3 real events, 2 pilot exercises in 2011
- 20 port health authorities and 10 countries participated



European Manual for Hygiene Standards and Communicable Diseases Surveillance on passenger ships

Part A includes 10 chapters: 1: Medical facilities - 2: Communicable diseases surveillance aboard ships - 3: Food safety - 4: Potable water safety - 5: Recreational water safety - 6: Pest management - 7: Housekeeping and facilities - 8: Hazardous substances - 9: Waste management - 10: Ballast water management

Part B includes guidelines for the prevention of influenza-like illness, of gastroenteritis and of legionellosis on passenger ships

A total of **101 experts** contributed to the development of the manual.

Pilot Inspection Programme

- 42 pilot inspections on passenger ships during summer 2011
- 62 inspectors, 7 trainers, 16 ports from 9 countries, 31 cruise ship and 7 ferries participated in the pilot phase

www.shipsan.eu/down/manual_october2011/Manual_October_2011.pdf

Training

- **Pool of trainers:** 35 experts
- **Training material:** 21 presentations, 6 case studies, 2 CD-ROM, e-learning platform <http://elearning.shipsan.eu/>
- **Training courses:** 2 train the trainers courses, 1 for seafarers (59 trainees) and 1 for port health officers (50 trainees)



European information database system of International Health Regulations Ship Sanitation Certificates (IHR SSC)

<http://ssc.shipsan.eu>

- Currently used by **102 inspectors** in 10 EU countries
- **301 inspections** have been recorded

Project co-financed from the EU Public Health Programme 2003-2008

Starting date and duration of project: November 2008 – October 2011 (35 months)

Leader Organisation: University of Thessaly (UTH), Greece

Contact Person: Prof. Christos Hadjichristodoulou (chhatzi@med.uth.gr), Project Leader, UTH, Greece

Total cost: 1,421,125.51 €

Co-funding from the Commission: 799,984.23 €



European
Commission

EuroNHID



National Institute for Infectious
Diseases
IRCCS Lazzaro Spallanzani
Rome – Italy

Project Contacts

giuseppe.ippolito@inmi.it
francescomaria.fusco@inmi.it

European Network for Highly Infectious Diseases

EuroNHID project - Summary

The European Network for Highly Infectious Disease (EuroNHID) is a network of European experts in the management of patients with Highly Infectious Diseases.

The main aims of EuroNHID are to enhance and maintain co-operation, communication, and exchange of data and good practices on highly infectious diseases (HIDs) among infectious disease clinicians, epidemiologists and public health experts, and to enhance preparedness and response within Europe to these health threats.

HIDs are transmissible from person to person, cause life-threatening illness, and represent a serious hazard in health care setting and in the community, requiring specific control measures. These diseases/agents are: human to human transmissible Viral Haemorrhagic Fevers (Marburg, Ebola, Crimean Congo, Lassa and South American Haemorrhagic fever); SARS Co-V; Emerging highly pathogenic strains of influenza virus; Smallpox and other orthopox infections (eg monkeypox); XDR-Tuberculosis; other emerging highly pathogenic agents, including agents of deliberate release (eg pneumonic plague).

Objectives of the project

The main aim of the project is to conduct an on-the-field assessment of current capabilities in isolation, infection control and HCWs safety in the hospitals designed, in participating countries, to give care to HID patients.

Specific Objectives:

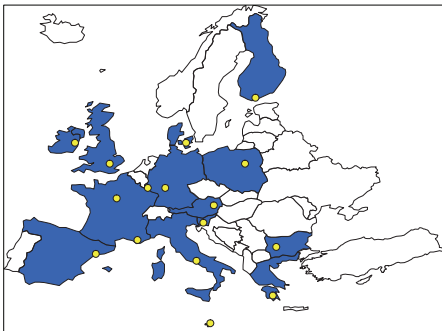
- Development of specifically-designed checklists for hospital assessment in participating countries;
- Checklist-based survey of capabilities and policy in participating countries. Only High Level Isolation Units/Referral Centres identified/designed for HID management have been surveyed;
- Identification and assessment of critical points as emerged from the survey and proposal for affordable improvements

Methodology

During the 42 months, many methodologies have been used in order to achieve the deliverables of the project.

EuroNHID included 15 EU countries, plus Norway who participated to the activities of the last year (see map)

For all objectives and activities, a networking approach has been used. The Coordination Team, helped by a Steering Committee including partners from 4 countries, developed drafts and proposals, that were disseminated to and discussed with all project partners. Final agreements on all issues were reached during extensive discussions at the general meetings



Countries participating in the EuroNHID project

Coordination Team

The Coordination Team is based in Rome, Italy, at the National Institute for Infectious Diseases "Lazzaro Spallanzani", the Italian national referral centre for infectious disease emergencies and bioterrorism-related pathogens. The Coordination team was helped by a Steering Committee, nominated at the beginning of the project, including project partners from France, Germany, Greece and UK, selected on the basis of their experience in the management of HIDs and/or high-level isolation units

Dissemination of the project results

The EuroNHID consortium:

- published 7 articles on scientific, peer-reviewed journals, while other papers are currently in preparations;
- presented 11 oral communications and 9 posters at national and international congresses and meetings;
- disseminated the results through the project web-site (www.eunid.eu, see "Documents", registration required)



Project evaluation

The final project results comply with all indicators developed at the beginning of the project

Main project results

During the first year of project activities, three specific checklists (about hospital resources, infection control procedures and HCWs' safety) have been developed as shared and standardized tools for the assessment of hospital capabilities in dealing with HIDs.

During the second year, the surveys have been performed in the selected isolation units/referral centres. Totally, 47 facilities have been selected. Data are available from all facilities, 44 of them have been personally visited by the Project Coordinator, in order to collect standardized data. From 3 facilities, only self-fulfilled checklists are available.

During the third and last year a specific feedback has been developed and sent to each surveyed facilities, in order to identify strengths and weaknesses of each one, to disseminate good practices, and to suggest affordable solutions for the improvement of the facility.

Moreover, a general Manual on the good management of infection control and HCWs safety in case of HIDs has been produced, starting from partners' experiences and expertise and from data emerged during the surveys. This Manual presents the current European situation and provide expert recommendations for a safe and appropriate management of these patients in isolation settings

Conclusion

The project gives, for the first time, an on-the-field evaluation of European resources and capabilities in the management of HIDs patients. The project identified the main existing gaps, also.

Imported cases of HIDs are considered very rare events. Several specific aspects, such as the management of clinical waste or the policies for hygiene and disinfection are very rarely described in the scientific papers. For this reason, a network is essential for the sharing of experiences and the dissemination of good practices about the management of HID patients.

The EuroNHID Manual, in our intention, wants to fill an existing gap in scientific literature. Indeed, some clinical guidelines for the management of HIDs exist, but few of them specifically face the isolation, infection control, and HCWs safety issues. A set of recommendations, based on the large experience gathered during the survey, on these issues are still lacking, and thus EuroNHID Manual may become an important tool for the safe and appropriate management of these patients.

Project co financed from the EU Public Health Programme 2008-2013

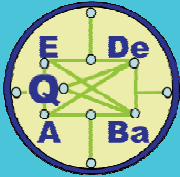
Start date: July 01, 2007
Duration of project: 42 months
Total cost: 622.093,00 EUR
Co-funding from the Commission: 361.970,16 EUR (58%)
Leader Organisation: National Institute for Infectious Diseases "L. Spallanzani", Rome, Italy
Contact Person: Giuseppe Ippolito, MD
Web site: www.eunid.eu
Other Partners:
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European
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Establishment of Quality Assurances for Detection of Highly Pathogenic Bacteria of Potential Bioterrorism Risk (EQADeBa)

Ursula Sauer, Daniela Jacob, Anna-Maria Rohleder and Roland Grunow



Management:
 Coordinator: Robert Koch-Institut
 Advisory Board = Steering Committee

Summary:
 EQADeBa was a project funded by the European Commission on the topic of "Establishment of Quality Assurances for Detection of Highly Pathogenic Bacteria of Potential Bioterrorism Risk", coordinated by the Robert Koch-Institut (RKI), Germany, and carried out in cooperation with, originally, 23 partners from 21 European countries. The project started in May 2008 and ran for 36 months (+3 months prolongation).
 External Quality Assurance Exercises (EOAEs) turned out to be an essential tool of any quality management ensuring external quality control beyond the internal quality control of each laboratory. They revealed not only the state of knowledge and weak points in diagnostics but also directed improvement wherever needed or confirmed an existing high quality standard.
 In this context, a supportive European Network for Highly Pathogenic Bacteria (ENHPB), capable of identifying very rapidly potential natural or bioterrorism threats, has been established.

Growth variation in mixed cultures (Examples of the second exercise)

- Some grow very close together
- some do not disturb each other

Burkholderia mallei (blue dart, non-haemolytic growth) and *Streptococcus equi zooepidemicus*

Brucella melitensis and *Aeromonas hydrophila*

WP Coordination:
 The management structure and responsibilities were agreed in a **Consortium Agreement**. The **General Assembly** was the decision-making body of the Consortium and consisted of one representative of each partner:

- Germany: RKI
- Austria: AGES
- Belgium: VAR
- France: FLI
- Italy: ISS
- Netherlands: SMI
- Sweden: HPA
- United Kingdom: TFL
- Finland: NKUA
- Greece: NCEBACT
- Hungary: NPHSL
- Lithuania: LNS
- Luxembourg: LNPH
- Norway: PZH
- Poland: BIOEF
- Spain: RIVM
- The Netherlands: IZSPB
- Italy: NCIPD
- Bulgaria: IMBBW
- Germany: INSA
- Portugal: SUJCHBO
- Czech Republic: SUJCHBO

Results:

- A clear improvement of correct positive and correct negative results could be observed over the course of the project.
- The speed of diagnostics during the three exercises could considerably be improved.
- The major impact, however, has been given by personal troubleshooting tailored to the partners' results. Further important factors were the exchange of best practices and approaches among the partner institutes and training offered and made use of within the network whenever appropriate.
- Development of a common detection strategy as a "Gold Standard" for the identification of high threat bacteria.
- Proficiency tests for diagnostics of highly pathogenic bacteria were recommended as a continuous process.

Objectives
 The general objective of the project was to provide the infrastructure for networking and to design, organize and manage three External Quality Assurance Exercises (EOAEs) for high pathogenic bacteria.
 Several meetings mostly combined with scientific workshops, training offers between network partners, the set up of a repository and of working groups on relevant topics served as further tools to strengthen the network.

some prevent others from growing

Francisella tularensis ssp. *holarctica* (LVS) and *Escherichia coli* (+metabolites of toxic concern preventing LVS from growing)



WP Dissemination:
 The following dissemination means were used:

- Interim and final report to EAHC
- Presentations on scientific conferences
- Publications in scientific journals
- Website with public and restricted domains "RKI EQADeBa"
- Implementation of the EOAE experiences into national laboratory networks in various countries

Improvement of partners' performances in the course of the 3 exercises

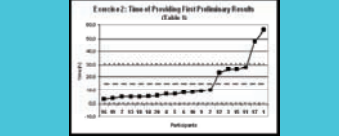
Lab	1st exercise		2nd exercise		3rd exercise	
	Correct positive	Correct negative	Correct positive	Correct negative	Correct positive	Correct negative
1	100%	100%	100%	100%	100%	100%
2	100%	100%	100%	100%	100%	100%
3	100%	100%	100%	100%	100%	100%
4	100%	100%	100%	100%	100%	100%
5	100%	100%	100%	100%	100%	100%
6	100%	100%	100%	100%	100%	100%
7	100%	100%	100%	100%	100%	100%
8	100%	100%	100%	100%	100%	100%
9	100%	100%	100%	100%	100%	100%
10	100%	100%	100%	100%	100%	100%
11	100%	100%	100%	100%	100%	100%
12	100%	100%	100%	100%	100%	100%
13	100%	100%	100%	100%	100%	100%
14	100%	100%	100%	100%	100%	100%
15	100%	100%	100%	100%	100%	100%
16	100%	100%	100%	100%	100%	100%
17	100%	100%	100%	100%	100%	100%
18	100%	100%	100%	100%	100%	100%
19	100%	100%	100%	100%	100%	100%
20	100%	100%	100%	100%	100%	100%
21	100%	100%	100%	100%	100%	100%
22	100%	100%	100%	100%	100%	100%
23	100%	100%	100%	100%	100%	100%
24	100%	100%	100%	100%	100%	100%
25	100%	100%	100%	100%	100%	100%
26	100%	100%	100%	100%	100%	100%

Methodology
 The detection range of high threat bacteria included

- Bacillus anthracis*
- Yersinia pestis*
- Francisella tularensis* ssp. *tularensis*
- Francisella tularensis* ssp. *holarctica*
- Burkholderia mallei*
- Burkholderia pseudomallei*
- Brucella melitensis*
- Brucella abortus*
- Coxiella burnetii*

Three EOAEs were performed with increasing level of difficulty and in a way to identify improvements.
 Results of the EOAEs were analysed with regard to

- speed,
- sensitivity and
- specificity of applied methods.



WP Evaluation:
 The process was continuously evaluated by achievements of milestones, performance of meetings including agreed protocols, performance of EOAEs and training.
 Results of 3 EOAEs helped to assess the current laboratory capabilities. More detailed analyses and trouble shooting revealed the baseline for individual recommendations, correct positive and negative results and the speed of diagnostics. These data of the exercises were compared to evaluate improvement and best practices.

Conclusions:

- The project has collected experiences on biosafety, biosecurity, and transportation issues throughout Europe.
- A repository for reference material of highly pathogenic bacteria has been set up and should be maintained on a long-term basis.
- A network of laboratories responsible for the diagnostic of highly pathogenic bacteria is required in the long run as these bacteria also occur naturally with often unknown and/or underestimated prevalence.
- The network should also be linked with other networks, e.g. on viruses and toxins.
- The impact of the project in the participating countries sets out the future prospects for European Reference Laboratories which organize and perform quality assurance exercises regularly and provide appropriate reference materials for validation of diagnostic methods and instruments.

Acknowledgements
 We would especially like to thank the EAHC for funding and thus realizing EQADeBa, but also all partners for their cooperation and for the external support of the project by ECDC, SANCO C3, DG ENTR, WHO and EUROPOL.

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 Website: www.rki.de/EN/Content/Prevention/EQADeBa/EQADeBa_node.html

Total cost: 1.999.747,60 €
 EC co-funding: 1.199.848,51 € (60%)
 (originally calculated budget)

Start date: 1st May 2008
 Duration of project: 3 years (-3 months)
 Leader Organization: Robert Koch-Institut, Germany





React Project

Response to Emerging infectious disease: Assessment and development of Core capacities and Tools

The REACT project has been created to provide evidence and tools for an improved and better coordinated response to the outbreak of infectious diseases within the European Union.

In order to use the available expertise in all areas of interest four European public health institutions from Poland, UK, Norway and Germany took over responsibility each for one area of response.

The project focussed on four areas of generic response which are crucial for the international cooperation on prevention and harmonized action:

1. Contact tracing in ground transport
2. Implementation of International Health Regulations (IHR)
3. Enhanced surveillance during mass gathering events
4. Surveillance in Health Care Workers (HCW)

The choice of the four areas of interest was inspired by the observation that in these areas little is known or done and that existing international regulations for surveillance urgently need reinforcement for effective implementation.

REACT PRODUCTS AND TOOLS

Contact Tracing in ground transport

1. A risk assessment tool – the pictorial profiles “CT-RAP” – to support evidence based decision making on contact tracing exemplified for the following infectious diseases:

- a. Tuberculosis,
- b. Measles
- c. Meningococcal Disease

2. Disease specific fact sheets to support decision making

The tools developed

- are innovative, scientifically well founded
- apply to a variety of contact tracing decisions
- support evidence based decisions
- protect from unnecessary contact tracing
- help training epidemiologists in sound decision making

Implementation of International Health Regulations

1. A toolkit for National Focal Points that includes

- a. a guidance document and
- b. adaptable templates to improve event reporting by clinicians and laboratories.

The toolkit

- aims of making first line health care workers think in terms of public health
- encourages reporting of events that may not meet notifiable criteria but deserve immediate public health attention

Enhanced surveillance during mass gathering events

1. Tool box of core surveillance capacities for mass gatherings
2. Training module “Surveillance of infectious diseases at mass gatherings”

Both tools have been tested during a pilot training in Poland in December 2010 and were applied during the UEFA Euro 2012.

Surveillance in Health Care Workers

1. Conceptual framework model for HCW surveillance
2. Template for pre-exposure training and education material
3. Template for a data collection tool with a data analysis guide
4. Template for a standardised hospital outbreak investigation protocol

As shown in the testing phase the tools are useful and user friendly.

HCW are a powerful cohort for surveillance because

- the population is well known (clear denominator),
- they are a healthy population,
- they are able to report symptoms more accurately.

CONCLUSION

In all four areas all planned products and tools – training modules, education and information material, guidelines and protocols - have been elaborated and tested.

The React tools are presented for dissemination and application on the REACT Web site:
http://www.rki.de/EN/Content/Prevention/React/react_node.html

Three years of work experience in these areas have revealed that the gaps are to some extent due to the difficulty or impossibility of effective routine contact tracing and public health action: anonymous ground travel – although very relevant in size – does hardly allow contact tracing and surveillance of health care workers is difficult, costly and in some countries even impossible due to the legal set up.

Project Publications:

1. Askar M, Mohr O, Eckmanns T, Krause G, Poggensee G. Quantitative assessment of passenger flows in Europe and its implications for tracing contacts of infectious passengers. Euro Surveill. 2012;17(24): pii=20195. Available online: <http://www.eurosurveillance.org/ViewArticle.aspx?ArticleId=20195>.
2. MacDonald E, Aavitsland P, Bitar D and Borgen K. Detection of events of public health importance under the international health regulations: a toolkit to improve reporting of unusual events by frontline healthcare workers. BMC Public Health 2011, 11:713. Available online: <http://www.biomedcentral.com/1471-2458/11/713>
3. Aghaizu A, Elam G, Ncube F, Thomson G, Szilágyi E, Eckmanns T, Poulakou G and Catchpole M. Preventing the next ‘SARS’ - European healthcare workers’ attitudes towards monitoring their health for the surveillance of newly emerging infections: qualitative study. BMC Public Health 2011, 11:541. Available online: <http://www.biomedcentral.com/1471-2458/11/541>

Project co financed from the EU Public Health Programme 2008-2013

Start date and duration of project: August 2008 - January 2011 (30 months) **Total cost:** 1.342.233,45 Euro
Co-funding from the Commission: (51%) **Leader Organisation:** RKI (Robert Koch-Institute), Berlin, Germany
Contact: REACT@rki.de **Web site:** http://www.rki.de/EN/Content/Prevention/React/react_node.html
Other Partners:
GIZ (Gesellschaft für Internationale Zusammenarbeit), Eschborn, Germany
PZH (National Hygiene Institute Polen), Warsaw, Poland
HPA-CfI (Health Protection Agency, Centre for Infections), London, United Kingdom
NIPH (Norwegian Institute of Public Health), Oslo, Norway



European
Commission

More information:

European Commission – Public Health website
http://ec.europa.eu/health/index_en.htm

Health-EU Portal
http://ec.europa.eu/health-eu/index_en.htm

Health-EU Newsletter
http://ec.europa.eu/health-eu/newsletter_en.htm

Executive Agency for Health and Consumers – Project database
<http://ec.europa.eu/eahc/projects/database.html>

Library publications public health
http://ec.europa.eu/health/publications/index_en.htm

European anti-tobacco campaign – Ex-smokers are unstoppable
<http://www.exsmokers.eu/>

EU Health Prize for Journalists
http://ec.europa.eu/health-eu/europe_for_patients/prize/index_en.htm

