European Commission

EU Health Programme
Selected projects

Edition 2014

Health and Consumers

Foreword

This publication puts together 31 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 2014 and the 7th Annual European Public Health Conference 2014.

The 2nd Health Programme came into force on 1 January 2008 and is implemented through various actions namely, projects, Joint Actions, operating grants, conferences, direct grants to International Organizations and service contracts. The total budget of the programme rises to € 321.5 million. 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 28 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 presented here cover a wide range of health themes, from health promotion to health security. They cover topics such as rare diseases, HIV/AIDS, good health in older age, antimicrobial resistance and organ donation to name a few. 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 which started in 2014 that continues 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
Consumers, Health and Food Executive Agency

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Health Promotion

Reducing health inequalities: preparation for action plans and structural funds projects

Tatjana Krajnc-Nikolić, Mateja Žajdela, National Institute of Public Health Slovenia

SUMMARY

ACTION-FOR-HEALTH project is aimed at improving health and lifestyle of EU citizens by means of health promotion. This is achieved through combination of interconnected approaches: (1) Capacity building of public health professionals at regional and local level in fields of health inequalities, health promotion and structural funds, (2) Raising awareness and making intersectoral partnerships on regional/local level and (3) Preparation of regional strategic action plans and implementation of one objective in 7 EU regions. The implementation of one strategic objective in each region is an evidence of effectiveness of the action plan to stakeholders as well as to target groups, since the implemented activities are mostly directed to promotion of healthy lifestyle among vulnerable groups. This bottom-up approach can be transferred horizontally from one region to another, as it was the case in Slovenia, and serving as an input for nation strategic action plan to reduce health inequalities.

INTRODUCTION AND OBJECTIVES

Although increasing, health inequalities are not very high on political agenda of EU states. EU has identified insufficient capacity at regional and local level as an important obstacle in approach to European funds. The objectives of the project are to increase capacity of public health professionals and stakeholders at regional and local level to tackle health inequalities by means of health promotion. This has been achieved through the preparation of strategic regional action plans and implementation of one objective. Regional stakeholders have been involved in the preparation of action plans enabling shared ownership of action plans, stronger commitment to its implementation and also increased comprehensiveness of strategic objectives.

METHODOLOGY

We have used health promotion as an overall approach. We have performed situation analysis by using all available data and information, needs assessment and priority identification. The training and summer school for public health professionals have increased the capacity in health inequalities, health promotion (theory and application), structural funds and strategic planning. In each of 7 EU regions the regional action plans have been prepared and one objective implemented. We have produced 5 project publications, where each project phase has been explained. We have prepared the distance learning tool with basic lectures on project topics and presentation of implementation of objectives. The distance learning tool is available on-line for free.

WP COORDINATION

There were 4 joint meetings of all partners, coupled with major events: kick-off meeting in Luxembourg coupled with 1st PSG meeting; training coupled with meeting of project partners, two-day summer school coupled with 2nd PSG meeting, and conference with final meeting of all partners. There were bilateral meetings of lead partner and partners from neighbouring countries. ICT channels were used (email, phone) on regular basis, in particular skype conferences.

WP DISSEMINATION

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

-The project website (visitors from 120 countries), leaflet, five project publications, training, summer school and reports. Public health professionals disseminated information in their broad environment to next target group (NGO's, stakeholders, decision makers, organizations etc.), using available and appropriate tools and channels. Academic community was reached by final conference and peer reviewed paper. Vulnerable target groups were reached using culturally adjusted and health promoting approach in 7 countries. Distance learning tool is available on project web site free of charge.

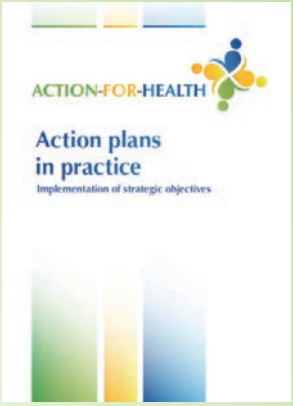
www.action-for-health.eu

WP EVALUATION

The internal evaluation was based on various qualitative and quantitative methods, evaluating the processes, outputs and immediate outcomes of the project. The project achieved all objectives, milestones, and deliverables, and went beyond what was required – added value.

RESULTS

The main results are: increased capacity on regional level in the fields of health promotion, health inequalities and structural funds; 7 regional strategic mid-term action plans; implemented objectives as evidence of effectiveness for stakeholders; reached end-users from identified vulnerable groups; 5 project publications and the distance learning tool, serving to other public health professionals as a useful guide and tool to implement this bottom-up approach.



THE PROJECT MANAGEMENT

The management structure is simple and transparent. Project coordinator was responsible for overall achievement of objectives, milestones and deliverables. WP leaders were responsible for achievement of WP deliverables and milestones, each partner for project management in its own country. Project steering group was responsible for scientific soundness and strategic consensus based decision making. Communication and dissemination plan have been prepared and implemented as planned. Project internal evaluation has been performed throughout the project, with periodical feedback to coordinator and all partners, interim and final evaluation report.

CONCLUSION

The ACTION-FOR-HEALTH project achieved all objectives. The bottom-up approach based on Slovenian good practice is transferrable to other environments. Unlike many other action plans, this one is not completely dependent on political will, actual policies and legal acts. The capacity of public health professionals and partners on regional level as well as the commitment is crucial for the success.

Project co-financed: EU Public Health Programme 2008-2013
Years of the Project: 2012-2014 (24 months)
Total cost: 988,420.32 €
Subsidy from the Commission: 588,862.96 €
Acknowledgments: We grateful to all persons who have generously supported the project activities in all 10 partner countries and to CHAFEA for their understanding and professional support.

Project coordinator: National Institute of Public Health, Organisational unit Murska Sobota, Slovenia
Partners: 1. University of Brighton, United Kingdom
2. Dutch Institute for Health Care Improvement (CBO), The Netherlands
3. University de La Laguna, Spain
4. Institute of Public Health County of Međimurje, Croatia
5. National Institute for Health Development, Hungary
6. National Center for Public Health and Analyses, Bulgaria
7. University of Trnava, Slovakia
8. Estonian-Swedish Mental Health and Suicidology Institute, Estonia
9. Institute of Hygiene, Lithuania

European Commission

BISTAIRS

Co-funded by the Health Programme of the European Union

Brief interventions in the treatment of alcohol use disorders in relevant settings

Prof. Dr. Jens Reimer, coordinator of BISTAIRS. Centre for Interdisciplinary Addiction Research (CIAR)

SUMMARY

A range of interventions exist for the prevention and treatment of alcohol-related risk and harm. In particular, screening and brief intervention for alcohol has emerged as a (cost-)effective preventative approach, which is relevant and practicable for delivery in primary health care, but has wider potential application beyond medical settings. BISTAIRS has: (1) produced evidence synthesise for SBI effectiveness in primary care, emergency care, workplace and social services; (2) outlined good practice for SBI implementation in each setting; and (3) developed and field-tested a set of tailored SBI concepts in primary care and beyond. Next, the project will develop recommendations and guidelines for tailored SBI approaches and will disseminate specific concepts to support a widespread implementation of SBI in medical/social primary care settings.

OBJECTIVES

BISTAIRS aims to foster the implementation of screening and brief interventions (SBI) for alcohol in a range of medical and social settings (Primary health care, accidental and emergency care, occupational health services, and social services/criminal justice systems) by identifying, systematizing and extending good practice of SBI across the European Union member states.

METHODOLOGY

BISTAIRS conducted systematic reviews and electronic surveys at regional, national and European level to determine SBI effectiveness and the status of implementation. Drawing on this evidence, setting-specific SBI concepts were developed for field-testing in five EU jurisdictions. Following the field-tests, recommendations and guidelines for the implementation of setting-specific SBI will be compiled and disseminated together with supporting material and toolkits to facilitate the widespread implementation of SBI in medical and social settings across the EU.

WP COORDINATION

Three annual scientific board meetings were held, supported by regular in-person / virtual work group meetings to support effective collaboration between partners and ensure that any arising issues were addressed promptly. Further, the coordinating partner, CIAR, ensures ongoing communication with partners through emails, regular bilateral teleconferences, and the website.

WP DISSEMINATION

The outputs of the project have been disseminated in a number of ways:

- The project website
- 6 International meetings and conferences at European level:
- 20 Presentations at local and national events and congresses
- 2 scientific articles published
- 5 scientific articles sent to journals or in preparation

WP EVALUATION

The BISTAIRS Evaluation Plan of the on-going project includes four dimensions for evaluation:

1. **Process evaluation**, assessing the level of fulfillment of the project objectives, milestones and deliverables
2. **Output evaluation**, examining the level of compliance and value of project milestones & deliverables
3. **Effect evaluation**, evaluating demonstrable effects on specifically defined outcomes
4. **Embedded field test work evaluation**, as a key part of developing and implementing tailored field tests of

Project financed: Health Programme of the European Union 2008-2013
Years of the Project: May 2012- April 2015
Total cost: € 556 837,-
Subsidy from the Commission: € 340 095,-
Acknowledgments: To all persons who have participated in the field tests and provided input to the project. To EU Commission for co-financing BISTAIRS.

PRELIMINARY RESULTS

For p**rimary health care a** robust and convincing evidence base for effectiveness of SBI was found. SBI is regularly implemented on regional but not national level. For **accident / emergency departments** the evidence for effectiveness is limited but promising, with SBI either not available or not regularly implemented. We found an inconsistent evidence for effectiveness in **occupational health services**, and SBI is not available or not regularly implemented. For **social service / criminal justice systems** there is a clear lack of evidence for effectiveness and SBI is not available in these settings.
On the basis of selected European and national SBI packages and in accordance with the WP5 good practice recommendations specific brief intervention concepts were developed and field tested in 5 jurisdictions. The field test outcomes will be integrated in a guideline development process.

CONCLUSION

BISTAIRS found a mixed evidence base for the effectiveness of SBI in different settings. In non-medical settings SBI is regularly not available in Europe but needs and opportunities identified should encourage further research. The integration of the outcomes of the on-going project will result in the development of tailored SBI implementation guidelines for different medical and non-medical primary care settings.

Project coordinator:
University Medical Center Hamburg-Eppendorf Centre for Interdisciplinary Addiction Research (CIAR), Germany
Partners:
- University of Newcastle upon Tyne (UNEW), United Kingdom.
- Fundacio Clinic per al la Recera Biomedica (FCRB), Spain
- Instituto Superiore Di Santa (ISS), Italy
- Generalität de Catalunya (GENCAT), Spain
- National Institute of Public Health (NIPH), Czech Republic. 6. Serviço de Intervenção nos
- Comportamentos Aditivos e nas Dependências (SICAD), Portugal

European Commission

CANCON Joint Action: European Guide on Quality Improvement in Comprehensive Cancer Control

T. Albreht, T. Lipušček, National Institute of Public Health Slovenia

SUMMARY

It is becoming clear that in many areas of medicine, integration of services is essential in order to ahcieve optimal results using available resources rationally. Several concepts shall be explored: the notion of a Comprehensive Cancer Care Network, improved community care for cancer patients with a greater focus on primary level care, organisational frameworks for survivorship, rehabilitation, re-integration and pallitave care and guidance on screening based on best available evidence. These activitites will be supplemented by discussions on cancer control topics at Member State level.

OBJECTIVES

The general objective of this Joint Action is to contribute to improvements in overall cancer control through quality-based cancer screening programmes, better integration of cancer care, community-based cancer care approaches and providing concerted efforts in all areas of survivorship, including palliative care.

These key elements will be combined with other relevant aspects of cancer control to form a **European Guide on Quality Improvement in Comprehensive Cancer Control.**

METHODOLOGY

The Guide will be developed through a common methodology, with the consultation process being managed, assuring the quality of the process and of the final output. All WPs will develop their own methodology for other outputs, for example, survey of existing Comprehensive Cancer Control Centers and development of distress thermometer and personalised rehab. & survivorship plans through consultation and expert workshops.

Project co-financed by the EU Public Health Programme 2008 – 2013

Starting date:24 February 2014, duration: 3 years

Total cost: 5,999,985 EUR

Subsidy from the Commission: 2,999,984 EUR

WP COORDINATION

Besides daily coordination and management of the Joint Action, the Coordination WP is responsible for the delivery of two Interim Reports and the Final Report to the European Commission.

A working group for external stakeholders, the **CANCON Stakeholder Forum**, has been set up for the cooperation of a wide range of cancer stakeholders, alongside a Joint Action management and meeting structure.

WP DISSEMINATION

A network analysis and dissemination strategy has been developed, elements of which include:

- Dedicated website, www.cancercontrol.eu

- Regular newsletters for partners and stakeholders
- Use of social media
- Wide mailing list of related stakeholders in the cancer control field, including journalists

Project coordinator: National Institute of Public Health, Slovenia

Contact Person: Tina Lipušček, Project Manager, cancer.control@nijz.si

Website: www.cancercontrol.eu

WP EVALUATION

Process, output and outcome indicators have been developed for all WPs. 2 Interim Evaluation Reports and 1 Final Evaluation Report will be prepared, with online questionnaires used to assess key meetings and events.

RESULTS

The main deliverable of the CANCON Joint Cation will be the European Guide on Quality Improvement in Comprehensive Cancer Control. Chapters in the Guide will address the topics of:

- Quality-based cancer screening programmes,
- Comprehensive Cancer Network organisation,
- Community-based cancer care,
- Survivorship and rehabilitation.

The Guide will be used by Member Stats and other governmental and non-governmental stakeholders in the cancer field.

CONCLUSION

The CANCON Joint Action aims to provide guidance to Member States on various aspects of improving cancer control through the development of a Guide.

Partners: Institut Scientifique de Sante Publique Belgium, Federal Public Service of Health, Food Chain Safety and Environment Belgium, Association of European Cancer Leagues, Croatian National Institute of Public Health, Deutsche Krebsgesellschaft, Cancer Society of Finland, Institut National du Cancer, Istituto Tumori Giovanni Paolo II (IRCCS-Bari), Fondazione IRCCS Istituto Nazionale dei Tumori, Regione Toscana – Istituto Toscano Tumori, Ministero della Salute Direzione Generale Della Prevenzione, Riga East University Hospital, Stichtung Nederlands Instituut Voor Onderzoek Van De Gezondheidszorg, Oncololgy Institute Prof. Dr. Ion Chiricuta Cluj, Institut Catala d'Oncologia, Norges Teknisk-Naturvitenskapelige Universitet, Ministry for Health Malta, Masarykova Univerzita, Oslo Universitetssykehus, Department of Health Ireland, Erasmus University Medical Center Rotterdam, Ministerio de Sanidad, Servicios Sociales e Igualdad Spain, Centro Superior de Investigacion en Salud Public Valencia, National Center of Public Health and Analyses Bulgaria, European CanCer Organisation, National Cancer Institute – Lithuania

Joint Action on Chronic Diseases and Promoting Health Ageing across the Life cycle

Juan E. Riese, Marie Roseline D. Bélizaire, Mercedes García

Institute of Health Carlos III (ISCIII), Spain

SUMMARY

Chronic diseases (CD) like diabetes, cardiovascular disease, stroke, affects 8 out of 10 people aged over 65 in Europe. Approximately 70% to 80% of health care budgets across the EU are spent on treating chronic diseases. There is a wealth of knowledge within EU Member States on effective and efficient ways to prevent and manage cardiovascular disease, stroke and diabetes type-2. This knowledge is however not readily accessible to public health authorities and other interested stakeholders across Europe. Joint Action on Chronic Diseases and Promoting Health Ageing across the Life cycle (JA-CHRODIS) is designed to utilize this potential.

OBJECTIVES

The general objective is to promote and facilitate the exchange and transfer of good practices between European countries and regions. The good practices address chronic conditions, with a specific focus on health promotion and prevention of chronic conditions, multimorbidity and diabetes.

METHODOLOGY

JA-CHRODIS includes four core work packages (WPs). Three are focused on the identification of good practices: WP5 Health Promotion and Chronic Disease Prevention, WP6 Multimorbidity and WP7 Diabetes. The fourth is cross-cutting: Platform for Knowledge Exchange (PKE). Criteria for assessment of good practices are being developed based on a Delphi consultation scheme in cooperation of all WPs. Once adopted, these criteria will be the basis for the creation of the PKE, with a help-desk and a clearinghouse. These criteria will then enable the identification of innovative experiences and potential candidates for "scaling up and transfer" from original settings to new ones. In addition, the WP of coordination includes a Forum for Representatives of Health Ministries.

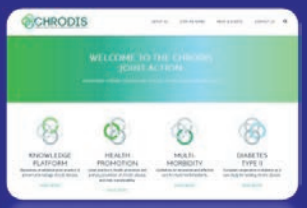
WP COORDINATION

All the Work-Package Leaders meet twice a year to review progress in all the work packages. All Partners, Associated Partners, Collaborating Partners, Advisory Board and Governing Board meet once every year during the project in General Assembly. The coordinating partner, ISCIII, maintains contact with partners mainly through emails, teleconferences and provides technical support to them for data collection and for the administrative management.

WP DISSEMINATION

The outputs of the project are being disseminated in a number of ways:

- The project website
- Stakeholders forum
- Presentations at local events and congresses
- Exhibition at national and international events
- Presentation at international meetings
- Distribution of materials
- Links with networks and other projects



WP EVALUATION

All the project aspects are being evaluated. Questionnaires are circulated after meetings in order to investigate the level of satisfaction of each partner. Final deliverables are evaluated by the Advisory Board before dissemination. The external impact of JA-CHRODIS will also be analysed.

RESULTS

1. A Platform for Knowledge Exchange, including a help-desk and a clearinghouse.
2. A methodology for scaling up and transferring good practices on health promotion and chronic diseases prevention.
3. A selection of most cost-effective practices to address multimorbid patients to be transferred to other settings.
4. A training programme for health professionals to address multimorbidity.
5. A set of best practices on primary prevention, early detection, secondary prevention, management of diabetes, and patient empowerment programmes, and the methods for transferring them.
6. A review of existing national programmes on diabetes.
7. A Forum of Representatives of Health Ministries to discuss the continuity of JA-CHRODIS after the end of this Joint Action.

CONCLUSION

The results of this JA will be the basis for recommendations on the best analysed information necessary for the optimal care of the selected CD across the life cycle and will be available to policy makers, healthcare professionals and managers, elderly population and the society as the main recipient of healthcare. JA-CHRODIS aims to strongly contribute to reducing the burden of the referred CD and to promote healthy ageing in Europe by making use of the PKE for good practice.

AKNOWLEDGEMENTS

To all persons participating in the Joint Action and to EU Commission for co-financing it.

Project co-financed: EU Public Health Programme 2008-2013
Years of the Project: 2014-2017 (39 months)
Total cost: 9.213.152€
Subsidy from the Commission: 4.606.576 €
Project coordinator: Institute of Health Carlos III, Madrid, Spain
Contact persons: Juan E. Riese
Project website: www.chrodis.eu
Partners:
1: Spanish Foundation for International Cooperation, Health and Social Policy, Spain
2: EUROHEALTHNET, Belgium
3: European Health Management Association, Ireland
4: Aragon Health Sciences Institute, Spain
5: Federal Centre for Health Education, Germany
6: Italian Medicines Agency, Italy
7: National Institute of Health, Italy
8: Dresden University of Technology, Germany
9: Vilnius University Hospital Santariskiu Klinikos, Lithuania
10: National Institute of Public Health, Slovenia
11: National Center of Public Health and Analyses, Bulgaria
12: National Institute for Health and Welfare, Finland
13: Heinrich Heine University Düsseldorf, Germany
14: Ministry of Health, Italy
15: 1st Regional Health Authority of Attica, Greece
16: Health Service Executive, Ireland
17: Institute of Public Health, Ireland
18: Netherlands Institute for Health Services Research, Netherlands
19: Ministry of Health and Care Services, Norway
20: Directorate-General of Health, Portugal
21: National Health Institute Doutor Ricardo Jorge, Portugal
22: European Patients Forum, Belgium
23: National Institute for Health Development, Estonia
24: Health Education and Diseases Prevention Centre, Lithuania
25: Directorate of Health, Iceland
26: European Institute of Women Health, Ireland
27: National Institute for Public Health and the Environment, Netherlands
28: European Regional and Local Health Authorities, Belgium
29: Spanish Ministry of Health, Social Services and Equality, Spain
30: Andalusian Regional Ministry of Health, CSBSJA
31: Progress and Health Foundation, Spain
32: Basque Foundation for Health Innovation and Research, Spain
33: Galician Health Service, Spain
34: Foundation for Education and Health Research of Murcia, Spain
35: Aragon Foundation for Research and Development, Spain
36: University of Zaragoza, Spain

European Commission

EUCERD Joint Action: Working for Rare Diseases

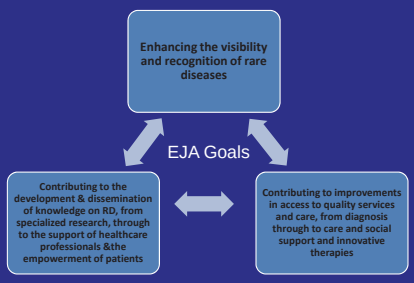
V. Hedley, S. Lynn, K, Bushby - Coordinator of EUCERD Joint Action, Institute of Genetic Medicine, Newcastle University, UK

SUMMARY

The challenges and specificities of rare diseases (RD) single them out as a unique domain of high added-value at the European level. Defined as conditions affecting no more than 5 per 10,000 citizens, patients with any single RD are, by definition, rare; however, the fact that there are 6-8,000 RD means that collectively around 30 million Europeans are directly afflicted. RD were a priority area for action in the Public Health Programme 2008-2013. A Communication of the European Commission (EC), entitled "Rare Diseases: Europe's challenge" was adopted on 11 November 2008, followed by a Recommendation from the Council to the MS and the Commission adopted on 9 June 2009. These texts identified key areas for collaborative action, and also proposed specific tools and instruments, further defined within a road map document. The EC was assisted in this work through the creation of an EU Committee of Experts on Rare Diseases (EUCERD) 2009-2013. In its place, the EC set-up an Expert Group on RD in 2013.

OBJECTIVES

The EUCERD Joint Action supports the mandate of EUCERD/ European Commission Expert Group on RD: to assist the EC in formulating and implementing the Community's activities in the RD field, and to foster exchanges of relevant experience, policies and practices between the MS and stakeholders.



COORDINATION

The EJA partners meet for annual partner meetings. In addition, the EUCERD/CEGRD meetings are often used as opportunities to consult with partners. Conference calls take place regularly. Technical and Financial management is ensured by two sets of internal reporting, to supplement the official Interim and Final reports. Regular communication is ensured with all WPs, to monitor progress and identify any difficulties

RESULTS AT M25

National Plans for RD: WP4 accelerates the development and implementation of National plans and Strategies (NP/NS) for RD, to provide support to EU MS.

EJA has:

- Engaged representatives of National MoH (and other competent national authorities) in the groundwork of the capacity-building process
- Organised 25 EUROPLAN National Conference to run between 2012 and 2015 and created a 'Tool-Kit' of resources
- Held 'debrief sessions' with competent authorities following the conferences, generated 'Proposals of Support'
- Drafted, revised and presented for adoption the ***EUCERD Recommendations on Core Indicators for RD National Plans/Strategies***

Coding and Classification: WP 5 is ensuring the comprehensive coding and classification of RD.to make RD traceable and more visible in health systems

EJA has:

- Organised workshop on cross-referencing of terminologies, and ensured continued interoperability between Orphacode, UMLS, HPO etc.
- Formed an agreement with SNOMED-CT to cross-reference coding terminologies
- Provided requisite input to ensure RD incorporation to the alpha and beta drafts of the ICD11.
- Guidance on use of OrphaCode in health information systems

Specialised Social Services: WP 6 demonstrates the need to develop adequate social services to support people living with RD, and to integrate RD with the social field.

EJA has:

- Produced a Guiding Principles document advising Social Services on how to integrate and support people with RD
- Produced advocacy document on the Training of Specialised Social Service providers
- Created an e-map to raise awareness of the Specialised Services which cater for RD patients across Europe, exploring case studies of best practice and attempting to define more clearly the various concepts of Specialised Social Services (crossing language boundaries)

Centres of Expertise (CEs): WP 7 is dedicated to identifying practices which could increase access to higher quality healthcare for RD patients across the EU.

EJA has:

- Conducted extensive ethnographic research to identify the key issues involved in the operation of Centres of Expertise (CEs) for RD
- Conducted in-depth qualitative interviews with various stakeholder representatives, on a cross-section of CEs
- Organised a workshop to present preliminary results and discuss good practices

Integration: WP 8 draws together various strands of RD activity, with a focus on integrating resources to ensure sustainability of RD initiatives

EJA has:

- Organised workshops on harmonising registry efforts and achieving interoperability of data
- ***EUCERD Recommendations on RD Patient Registration and Data Collection*** to support existing and new registries in the field
- Drafted a Thesaurus of registry terminology and minimum datasets for use by RD registries
- ***EUCERD Recommendations on RD ERNs***, to guide the field in terms of RD needs concerning ERNs
- Conducted a survey to explore the current extent of cross-border genetic testing for RD, and the challenges

DISSEMINATION

The outputs of the project are disseminated by several methods:

- **The project website - www.eucerd.eu**
- **OrphaNews Newsletter – 13,000+ registered readers**
- **Annual Report on the *State of the Art of Rare Disease Activities in Europe***
- **Presentations at conferences, meetings and workshops dedicated both to RD specifically and to public health more broadly (e.g. e-health events)**
- **Publications in appropriate journals**
- **Twitter (308 followers) and other social media**

METHODOLOGY

The project incorporates various methodologies to achieve the aims and objectives of each WP, including dedicated workshops (17 foreseen in total), national RD conferences (25), literature surveys, Delphi methods and questionnaires. Methodologies are tailored to each WP e.g. WP5 integrates with WHO procedures to develop an acceptable RD nomenclature and collect stakeholder feedback on implementation, whilst WP7 engages in hands-on ethnographic and qualitative research concerning centres of expertise and networking .

WP EVALUATION

The project has a dedicated Evaluation WP which compiles annual progress reports, assessing the project's achievements against the workplan and monitoring impact metrics.

CONCLUSION

The outputs of the project to-date have contributed significantly to the definition of collaborative European policy pertaining to rare diseases: the EJA has drafted and presented 3 sets of Recommendations to date. All WPs have made substantial progress in engaging broad stakeholder groups to ensure the relevance and impact of outputs

Project financed: EU Public Health Programme 2008-2013, contract 20112201
Years of the Project: 2012- 2015 (42 months, 36 funded and 6 unfunded)
Total cost:€5,508,946
EC (DG SANCO) co-funding – €2,994,162
Co-Funding from 7 MS – €2,514,784

Project coordinator: Newcastle University, UK
Partners: 1. Institut national de la santé et de la recherche médicale, France; 2. Istituto Superiore di Sanità, Italy; 3. EURORDIS (European Organisation for Rare Diseases); 4. CIBER, Spain; 5. Ministry of Social Affairs and Health, Finland; 6. Instituto Nacional de Saude Doutor Ricardo Jorge, Portugal; 7. Johan Wolfgang Goethe Universität Frankfurt am Main, Germany
Acknowledgments: to all partners, collaborators and additional individuals who have participated in the project and the EC for co-financing it.

European Commission

Equity Action – a European-wide Joint Action programme to address health inequalities

The Equity Action Team led by UKHF
http://www.equityaction-project.eu/

"Do something, do more, do better"

Michael Marmot - Equity Action Final Conference January 2014

Problem statement: *The Commission published a Communication on Health Inequalities "Solidarity in Health" which identified that avoidable inequalities in health exist in all countries of the European Union. Where these are avoidable by reasonable means, they are unfair and unjust. Equity Action aimed to assist Member States to move beyond analysis to take action on Health Inequalities. It is recognised that health inequalities are complex, persistent and pernicious, and require concerted effort across the whole of government to address their causes.*

Equity Action Programme

Equity Action was a Joint Action led by UK Health Forum and the Department of Health, England involving the ministries of health or their delegated partners from 15 Member States and Norway and 30 regions. It ran from February 2011 to February 2014 and with a budget of approximately €3 million. Its remit was to address health inequalities at EU, national, regional and local levels with a range of stakeholders across a range of policy areas. The focus of Equity Action was on developing evidence and knowledge to support practical action through four 'Work Packages':

Tools – promoting equity in cross-government policy by developing tools, providing training and encouraging creativity in their use:
- Health Impact Assessments (HIA)
- Health Equity in All Policies
- Health Inequalities Audit

Regions – using the EU's Structural Funds programme to support Regions to tackle health inequalities through meetings, the development of case studies and a Structural Fund Guidance Tool.

Knowledge – facilitating transfer of knowledge from scientists to policy makers through establishing a Scientific Reference Group and the commissioning of 10 literature reviews and policy briefs on topics including early years, employment and debt.

Stakeholders – developing stakeholder engagement between sectors through EU-wide stakeholder debates, national workshops and guides on inter-sectoral cooperation on education, built environment and welfare.

Quotes from policy leads:

"It's significantly helpful, just the feeling of being part of a big project and that you are not alone in the fight of tackling health inequalities. In this sense, the sharing of case-studies, methodologies, obstacles and challenges among Member States was really rewarding and useful."

"… Equity Action has contributed to a more sustainable field of expertise on how to improve public health and reduce social inequalities in health."

"… its legacy will be the visibility of health equity in the EU agenda, that will have an impact in the different Member States and the shared knowledge and networking in this area of work."

Member States and regions of Equity Action

Coordination and Dissemination of Equity Action

WP leads fed into a teleconference bi-weekly, where we agreed direction, assured quality and resolved issues. WP leads met with partners. Partners newsletters. Coordination meetings.

Dissemination was:
through partners to Ministries
By website: www.equityaction-project.eu/
By newsletter and attendance at key conferences
By high level conference with high-level EC and MS representation and 500+ delegates

Evaluation of Equity Action – Commissioned to PHAST

Phase 1: base-line study consulting WP leads, partners and EC
Phase 2: review of activities of Work Packages
Phase 3: surveys of policy leads and partners; conversations at final conference; review of objectives and outcomes; final report

- An action-research approach was adopted to ensure that what was learnt during the evaluation was fed back to the co-ordinating team to enhance programme development.

Emerging Issues

Impact:
- Working together – facilitating a co-operative process
- Sharing the vision - placing health inequalities on political agendas
- Building capacity - equipping partners with knowledge and skills
- Increasing visibility - through final conference, website and 'brand'
- Building a legacy- securing further funding for building on project
- Fulfilling outcomes - broad success

Lessons learned:
- Partners valued opportunities to learn from each other
- Value in learning about new approaches (including HIA)
- Importance of dialogue, cooperation
- Need to enhance allocation of Structural Funds
- Need to heighten visibility of health inequalities
- Value of practical resources to inform policy development

Messages to Member States and EU Commission:
- Take a strong lead on addressing health inequalities
- Build on the success of Equity Action
- Maintain a practical, strategic focus using HIA
- Support inter-sectoral co-operation
- Stimulate comparative research
- Foster education and dissemination good practice
- Maintain the network created by Equity Action
- Continue to provide financial support
- Reduce the bureaucracy associated with EU funding

SUCCESS

The efforts of Equity Action have not only enhanced the capacity of EU Member States and equipped them with resources to address health inequalities, but have also secured a commitment from the European Commission to invest new resources to support a successor programme across all Member States.

Equity Action received funding from the European Union in the framework of the health programme 2008-2013
The sole responsibility for this work lies with the author

Starting date and duration: February 2011 to February 2014 (36 months) Total Cost: €3 million
Lead Organisation: UK Health Forum on behalf of Dept. of Health, England chris.brookes@ukhealthforum.org.uk,
*Website: **HTTP://WWW.EQUITYACTION-PROJECT.EU/***

Other Partners: **European Network,** EuroHealthNet, **Belgium,** FPS, **Czech Republic,** SZU, **England,** Dept. of Health, **Finland,** THL, **France,** DG Santé, **Germany,** BZgA, **Greece,** Uni of Athens, **Hungary,** OEFI, **Ireland,** IPH, **Italy,** AOUIV, ASL TO3, Agenas, **Latvia,** CDPC, **Netherlands,** RIVM, **Norway** Directorate of Health, **Poland,** NIPH-NIH, **Scotland,** Scottish Executive, **Spain,** MSSSI, BIOEF, **Sweden,** SNIPH, Västra Gotaland, **Wales,** Welsh Government

With thanks to PHAST: http://www.phast.org.uk/ for the evaluation and assistance in producing this poster.

European Commission

European Haemophilia Network project EUHANET

E. Gilman, M. Makris, A. Bok, K. Fischer, A. Gatt, R. Hollingsworth, T. Lambert, R. Lassila, P. Mannuci, F. Peyvandi, J. Windyga

SUMMARY

EUHANET involves health professionals and patient organisations in Europe working together on a number of related projects to improve the care of European citizens with inherited bleeding disorders. It has 4 main areas of work: assessment and standardisation of the quality of care of haemophilia centres; Haemophilia Central website; European Haemophilia Safety Surveillance (EUHASS) adverse event reporting; and Rare Bleeding Disorders Database (RBDD). The project began in June 2012 and is co-funded by the European Commission until May 2015.

OBJECTIVES

The general objective of this project is to harmonise and improve the care received by European citizens with inherited bleeding disorders.

METHODOLOGY

Criteria were developed for the definition of levels of care provided by haemophilia centres. Centres were invited to apply for certification and are being assessed according to which criteria they satisfy.

The Haemophilia Central website is a public website providing a single location for key information on haemophilia and other rare bleeding disorders for patients, their carers and health professionals.

EUHASS (an adverse event reporting system monitoring the safety of treatments for people with haemophilia and other inherited bleeding disorders in Europe) was expanded to include reporting of adverse events in acquired haemophilia, acquired von Willebrand's disease and severe inherited platelet disorders.

The RBDD (a database of retrospective information on the non haemophilia rare bleeding disorders) was extended to collect prospective data on the bleeding and natural history of afibrinogenemia and factor XIII deficiency. Central specialised coagulation factor and genetic testing is offered and an external quality assessment scheme was established.

MANAGEMENT & CO-ORDINATION

EUHANET has 6 partners: the lead partner (University of Sheffield) and 5 associate partners. It also has many collaborating partners including 12 key institutions and 84 haemophilia centres across Europe. It is managed by a Steering Committee composed of representatives of all partners which meets every 6 months to review progress. The project is divided into 8 work packages (WPs) and partners meet and communicate as necessary relating to the WPs for which they are responsible. The lead partner also co-ordinates activities through email, telephone and teleconferences.

DISSEMINATION

Project outputs are disseminated by:

- project website
- annual meetings of project participants and stakeholders
- quarterly EUHASS adverse events reports and annual incidence reports
- presentations at local and international events and congresses
- publications in peer-reviewed journals

EVALUATION

Each project objective has a set of process, output and outcome indicators which are regularly reviewed by the project manager and the Steering Committee. Every 6 months questionnaires are sent to the associate partner leading each WP to collect information on progress. Responses are reported to the Steering Committee and used to monitor progress in achievement of project deliverables and objectives. Yearly reports are sent to the funding body. An independent external expert will provide an external evaluation report in November 2015.

RESULTS

1. Guidelines produced for designation of haemophilia centres as either European Haemophilia Comprehensive Care Centres (EHCCC) or European Haemophilia Treatment Centres (EHTC) and online application process up and running. – see screenshot

2. Haemophilia Central website live and under continuous development http://www.euhanet.org

3. EUHASS currently has 85 centres reporting events from 27 European countries caring for over 32,000 people with bleeding disorders (including Glanzmann Thrombasthenia, Bernard Soulier syndrome and platelet storage pool disease).

4. RBDD is collecting prospective data on patients with afibrinogenemia (85 patients) and factor XIII deficiency (110 patients) from 26 centres. External quality assessment scheme for FXIII screening/assay carried out and results being analysed from 21 centres. Central specialised genetic testing of patients with fibrinogen deficiency and with FXIII deficiency has begun.

CONCLUSION

EUHANET is making an important contribution to improving the care of European citizens with bleeding disorders.

Project co financed: EU Public Health Programme 2008-2013
Starting date and duration: June 2012 for 36 months
Total cost: 1,476,027 €
Co-funding from the Commission: 885,614 €
Leader Organisation: University of Sheffield, United Kingdom
Contact person: Prof. Mike Makris
Website: www.euhanet.org

Associate Partners: 1. European Association for Haemophilia and Allied Disorders, United Kingdom.
2. European Haemophilia Consortium, Belgium.
3. Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico, Italy.
4. University Medical Centre Utrecht, The Netherlands.
5. Medical Data Solutions and Services Ltd., United Kingdom.

Collaborating partners: 1.United Kingdom Haemophilia Centre Doctors' Organisation, UK. 2.Associazione Italiana Centri Emofilia, Italy. 3.World Federation of Hemophilia, Canada. 4.Centres de Référence Hémophilie et Déficits Hémorragiques rares associés, France. 5.Nederlandse Vereniging voor Hemofilie Behandelaren, Netherlands. 6.National External Quality Assessment Scheme, UK. 7.Federazione delle Associazioni Emofilici –FedEmo, Italy. 8.University College, London, UK. 9.HaemNet, UK. 10.Health Information Research Unit, McMaster University, Canada. 11.Centro Nazionale Sangue, Italy. 12.Serious Hazards of Transfusion (SHOT) + haemophilia centres across Europe.

European Commission

Joint Action Health Workforce Planning and Forecasting

Joint workforce planning and forecasting today for better healthcare of tomorrow.

JOINT ACTION ON HEALTH WORKFORCE

Michel Van Hoegaerden, programme manager
Federal Public Service, Belgium

SUMMARY

The Joint Action Health Workforce Planning and Forecasting is a 36 months project (from April 2013 to March 2016). A shortage of 1 million health workers is expected by 2020 in Europe. This Joint Action targets to support collaboration among Member States and tackle the challenges of understanding health workforce terminology, update information on mobility, estimate future skill mixes and needs and increase impact of planning on policy decision making.

OBJECTIVES

The general objective of this project is to provide a platform for collaboration and exchange between Member States to support them to prepare the future of the health workforce. This will increase Europe's capacity to take effective and sustainable measures. The project seeks to collect the essential data for health workforce planning, empower exchange of good practices in planning methodologies, support the use of horizon scanning and make sure that the results will be delivered to relevant target groups.

METHODOLOGY

Different methodologies were applied throughout the different work packages (WP). Common feature in methodology was literature reviews in each of the core WPs and conduction of surveys leading to better overview of existing situation in terms of data collection, planning methodologies and future needs.

COORDINATION

All of the project partners meet once a year at the Plenary Assembly meeting to review the progress of all work packages. So far there was one Plenary Assembly held in Bratislava and we are expecting to host two more. Besides this core WP leaders, under leadership of the coordinator, are organizing thematic workshops relevant to the work packages' work plans and deliverables. Invited WP partners and experts have the opportunity to discuss, exchange/share/gain knowledge and network intensely. Information on already conducted workshops held under Joint Action and workshops to come are fully available on our Joint Action website: http://euhwforce.weebly.com/events.html

DISSEMINATION

The outputs of the project are disseminated in various ways:

- The project website www.euhwforce.eu
- First JA Conference in Bratislava
- Upcoming JA Conferences in Rome and in Sofia
- Presentations on various national and international events
- Distribution of JA leaflet to partners
- Conduction of Stakeholder Analysis identifying various stakeholders at different levels of impact

EVALUATION

All the project's deliverables are being evaluated by team of experts using the process and outcome indicators. These were predefined for every WP individually.

RESULTS

1. Increased capacity in planning and forecasting by adopting fit-for-purpose models
2. Identifying Minimum data set for planning and forecasting models
3. Increased capacity in data collection and analysis
4. Improvements in the field of data understanding
5. Improved use of these models and data resulting in more evidence based health workforce planning
6. Implementation of WHO Code of Practice

ACKNOWLEDGEMENTS

The results of the project will be used for policy recommendations on European and regional level and decision making processes.

We thank the European Commission for providing financial support and all of the partners for their active and dedicated involvement.

www.euhwforce.eu

Project co-financed by the EU Public Health Programme 2008 – 2013
Starting date: April 2013
Total costs: 5 872 911, 34 €
Subsidy from the European Commission: 2 936 366 €
Currently we have 30 associated and 45 collaborating partners covering most of the European countries

Work package leaders:
WP1 – Federal Public Service of Health – Belgium
WP2 – Ministry of Health – Slovakia, EHMA
WP3 – Ministry of Social Affairs and Health – Finland
WP4 – Semmelweis University – Hungary
WP5 – Ministry of Health , AGENAS – Italy
WP6 – Centre for Workforce Intelligence – UK
WP7 – Medical University of Varna – Bulgaria

Project coordinator: Federal Public Service of Health, Belgium
Contact persons:
Michel Van Hoegaerden, programme manager,
Lieve Jorens, project manager
e-mail: EUHWForce@health.belgium.be
Project website: www.euhwforce.eu

European Commission

European Heart Health Strategy II

long-term prevention of cardiovascular diseases

SUMMARY

Aiming at addressing cardiovascular disease (CVD), *EuroHeart II* (European Heart Health Strategy II) analysed the latest figures and trends on CVD. It identified and shared the most effective ways and policies for preventing these diseases. It produced and published four reports, organised a high-level European conference, three regional conferences and seven national meetings. *EuroHeart II* completed this work in 36 months.

The broad partnership and wide-ranging impact of the project will ensure that it continues to influence policy making and prevention practice in Europe for many years to come.

KEY FINDINGS

- **CVD accounts for over 1.9 million deaths each year in the EU and the cost to the EU economy is more than €196 billion each year**
- **Previously falling CVD mortality rates are now plateauing in some age groups in some countries, and are even rising in young people in Greece and Lithuania**
- **The problem of CVD could worsen as a result of a growing incidence of high blood pressure and cholesterol levels, obesity and diabetes**
- **Policy interventions to decrease salt and saturated fat intakes are vital and could reduce CVD mortality by up to one third**

OBJECTIVES

EuroHeart II focused on six specific objectives identified in the European Heart Health Charter:

- Provide up-to-date data on CVD, establish mortality trends since 1985 and determine the costs of the disease
- Build capacity in the cardiovascular patients' community
- Evaluate existing guidelines on CVD prevention in diabetic patients
- Share knowledge on nutrition, physical activity and CVD prevention in Europe
- Identify the most effective and cost-effective CVD prevention policies – reviewing public health nutrition policies
- Predict future trends in coronary heart disease in Europe

METHODOLOGY

To achieve the specific objectives, *EuroHeart II* engaged with 30 partners from 17 countries. Partner organisations spanned academia, research centres, NGOs, patients' organisations and health professionals.

MANAGEMENT AND COORDINATION

Central management and coordination of *EuroHeart II* was undertaken by the main partner, the European Heart Network, assisted by the European Society of Cardiology, one of the work package leaders. The two partners were in contact on a weekly basis. Communication was through email and teleconferences.

The project was guided by a steering committee, consisting of all work package leaders and benefitted from input from an advisory board made up of representatives from the European Commission and the European regional office of the World Health Organization. The steering committee met six times during the project to review progress, adjust the schedule and elaborate on the dissemination plan.

DISSEMINATION

EuroHeart II has been and continues to be widely disseminated:

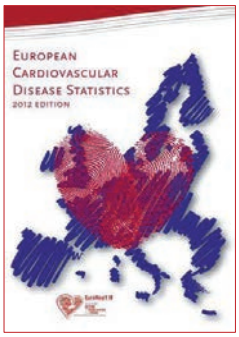
- Via dedicated webpages on the websites of the European Heart Network and the European Society of Cardiology
- Via European, regional and national conferences, meetings and workshops
- Via presentations at international and national conferences and seminars
- Via publications of articles in peer reviewed journals

EVALUATION

The main conclusions from the evaluation report were that the *EuroHeart II* project was extremely productive. The project partners produced literally hundreds of outputs (reports; papers; meetings) that helped to stimulate discussion on CVD prevention policy. *EuroHeart II* was very successful in building outstanding collaborations. It is highly likely that these collaborators will continue to work together. The actual impact of the outputs on the awareness and knowledge of stakeholders was extremely difficult to assess. The policymaker survey implied that there was little or no increase in stated awareness of project outputs among policymakers. However, it is important to note that the sample was very small and probably unrepresentative. It is also difficult to measure impact within the duration of the project. Many of the outputs have a shelf-life beyond it and will continue to influence the work of stakeholders and policymakers.

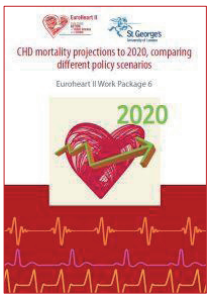
RESULTS

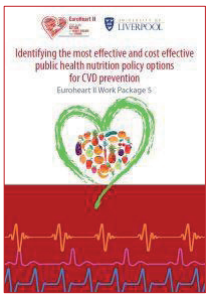
Significant reductions in CVD mortality have occurred over the last three decades, but **CVD remains the leading cause of death in Europe** – accounting for over 1.9 million deaths each year in the EU and over 4 million deaths in Europe. The cost to the EU economy is more than €196 billion each year.



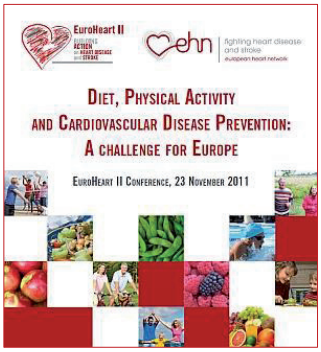
Substantial differences in mortality rates were found across EU Member States. Previously falling CVD mortality rates are now plateauing in some age groups in some countries, and are even rising in young people in Greece and Lithuania.

Interventions that address the whole population are the most cost effective and cost saving. Such policies, however, are not widely implemented across Europe. The problem of CVD could worsen as a result of a growing incidence of high blood pressure and cholesterol levels, obesity and diabetes. Policy interventions to decrease salt and saturated fat intakes are vital and could reduce CVD mortality by up to one third.





The latest evidence on food, nutrition and physical activity and their impact on preventing CVD were presented at a **European Conference on Diet, Physical Activity and Cardiovascular Disease Prevention**. The evidence was also presented at **regional conferences in Germany, Italy and Slovakia**. Additionally, at **seven national meetings**, evidence and policy recommendations were reviewed by more than 300 experts.



Over 97% of CVD patients' organisations, attending European seminars, reported that they had benefitted from the opportunity to share experiences with colleagues in Europe and that the information provided was useful for their everyday work.

An evaluation of the **impact of guidelines on the prevention of cardiovascular disease in diabetic patients** showed that around 90% of all doctors had copies of the guidelines at their practices. But doctors found that the guidelines were not always adapted to daily practice. Investigators, who worked on the evaluation, took account of these findings in their review of the ESC-EASD Guidelines that was published in 2013.

CONCLUSIONS AND RECOMMENDATIONS

- The project recommends investing in data collection systems in order to monitor trends in CVD risk factors, mortality rates and incidence
- Policymakers are also encouraged to adopt legislative measures to improve dietary standards and reduce smoking, while at the same time promoting greater physical activity
- Finally the project underlines the need for scientific and professional bodies to draw up effective strategies for implementing professional guidelines and overcoming barriers

ACKNOWLEDGEMENTS

The project partners are grateful to the European Union for the financial support received and for using the project's outputs to ensure a high level of cardiovascular health promotion and disease prevention in for its future policy making and initiatives.

The *EuroHeart II* Project ran from 1 March 2011 until 28 February 2014.
It benefitted from co funding under the EU public Health Programme 2008 – 2013.
The total cost of the programme was 1.563.118 Euro of which the Commission co-funded 58% (903.214 Euro).

More information: http://www.ehnheart.org/euroheart-ii.html or http://www.escardio.org/about/what/advocacy/EuroHeart/Pages/EHII.aspx

Partners in the project: Main partner: European Heart Network,
Associated Partners: Belgian Heart League, Dutch Heart Foundation, European Society of Cardiology, German Heart Foundation, Heart of Mersey Partnerships, Hungarian National Heart Foundation, Icelandic Heart Association, Institute for Clinical and Experimental Medicine (IKEM), Irish Heart Foundation, Italian Association against thrombosis and cardiovascular diseases; Italian Heart Foundation; Medical Research Council UK; Medical University of Gdansk – Poland; National Institute for Health and Welfare – Finland;

National Institute of Health – Italy; Portuguese Heart Foundation; Queen's University of Belfast – UK; Saint George's Hospital Medical School – UK; Slovak League for prevention and treatment of cardiovascular diseases; Slovenian Heart Foundation; Spanish Association for the development of clinical epidemiology; Spanish Heart Foundation; Thomayer University Hospital – Czech Republic; Trinity College of Dublin – Ireland; University of Gothenburg – Sweden; University of Liverpool – UK; University of Oxford – UK; UK Health Forum;

European Commission

HIV-COBATEST Project:
HIV COMMUNITY-BASED TESTING PRACTICES IN EUROPE (HIV-COBATEST)

J. Casabona, C. Agustí, L. Fernàndez, Centre for Epidemiological Studies on HIV/AIDS and STIs of Catalonia (CEEISCAT), Barcelona, Spain.

SUMMARY

Although some European countries have universal access to health care, many individual from most-at-risk groups face important barriers to HIV testing within the standard health care system.

Community-based voluntary counselling and testing (CBVCT) services are recognized to improve all aspects of HIV testing, including a better access to those vulnerable and hard-to-rich population.

The COBATEST project has obtained a deep understanding of these CBVCT across Europe, and contribute to standardise protocols and indicators to improve their implementation and evaluation.

OBJECTIVE

The general objective was to promote early diagnosis of HIV infection in Europe by **improving** the **implementation** and **evaluation** of CBVCT practices.

METHODOLOGY

Three of the core WP consisted in cross-sectional studies on :

- The implementation of CBVCT services in 22 countries (quantitative data, WP4),
- The good practices in CBVCT from 8 countries (qualitative data, WP5),
- The acceptability and feasibility of oral rapid HIV tests in CBVCT from 9 countries (quantitative data, WP8).

The others score WP consisted in:

- Identifying a core group indicators for monitoring and evaluating CBVCT activities (WP6),

- Formalizing a network of 59 CBVCT services in 16 countries, and building a common tool (questionnaire and data entry system) to collect standardized data in this network.

COORDINATION

Three face to face steering committees were held during the project, but also 4 general project meeting and 9 teleconferences.

Within each WP, periodical face-to-face meetings as well as teleconference have been organized between.

The coordinating partner, CEEISCAT, maintained contact with all partners mainly through emails and provided technical support to them for data collection and for the administrative management.

DISSEMINATION

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

- The project website
- The facebook page
- A brochure presented to stakeholders
- Dissemination of the main deliverables at country level (translated versions)
- Scientific presentations at local and international events and congresses
- Scientific publications (forthcoming)

EVALUATION

The majority of targets have been achieved, some to a larger extent than expected.

The project was evaluated with 13 process indicators, 11 output indicators and 11 outcome indicators.

Overall, only 5 indicators have not been validated: 1 of the process indicators, 3 of the output indicators, and 1 of the outcome indicators.

RESULTS

HIV-COBATEST has provided detailed information on how CBVCT programmes are being implemented in Europe, and has increased policy awareness on CBVCT by facilitating alliances between NGOs-GOs academic institutions.

<u>In particular, HIV COBATEST has</u>:

- Established a functional network of 59 CBVCT services in 16 European countries,

- Provided harmonized data collection instruments and indicators for monitoring the activity of these CBVCT,

- Introduced oral rapid test for the first time in countries where it was no accepted or allowed. Such testing offer was well accepted, but finger prick testing was preferred in many countries, particularly when concordant syphilis testing.

<u>The HIV-COBATEST project has also developed</u>:

- A guide to do it better in our CBVCT services,

- A core indicators and guidelines to monitor CBVCT,

- A standardized data collection form and a web-based data entry tool to monitor and evaluate HIV screening activity of the CBVCT services

CONCLUSION

The HIV-COBATEST project facilitated the emergence of a consensus around CBVCT services across Europe with the adoption of a common definition of what a CBVCT centre is.

HIV-COBATEST also impulse the creation of a network of CBVCT services across Europe, allowing collection of harmonized data in order to better monitor and evaluate their activity, and to bring actualized information to policy makers in various European countries.

NEXT STEPS: EUROPEAN HIV EARLY DIAGNOSIS AND ACCESS TO TREATMENT (EURO HIV-EDAT PROJECT)

Purpose: to generate operational knowledge to better understand the role and impact of Community Based Voluntary Counselling and Testing services (CBVCTs) across Europe, as well as to study the use of innovative strategies based on new technologies networks, to increase early HIV/STI diagnosis and treatment among the most vulnerable groups.

Specific objectives :

1.To monitor and evaluate CBVCT services in Europe; 2.To identify determinants for HIV test seeking behaviour and seroconversion in Europe; 3.To describe and improve approaches of point of care and linkage to health services for HIV/STI among MSM in Europe; 4.To improve the implementation of CBVCT services specifically addressed to MSM in Europe; 5.To describe HIV testing patterns and identify barriers to testing and care among migrant populations in Europe; 6. To assess acceptability and feasibility of innovative strategies and interventions aimed at increasing HIV counseling and testing

Project financed: EU Public Health Programme 2008-2013
Years of the Project: 2010-2013 (37 months)
Total cost: 749,500.00 €
Subsidy from the Commission: 449,663.00€
Acknowledgments: to all persons who have been involved in the project , and to EU Commission for co-financing it.
Project coordinator: CEEISCAT, Barcelona, Spain
Contact person: Jordi Casabona, Cristina Agustí
Web site: www.cobatest.org (https://eurohivedat.eu)

Associated Partners: 1 – Projecte dels Noms-Hispanosida (Spain); 2 – Regional Centre for Health Promotion Veneto (Italy); 3 – Association AIDES (France); 4 – STOP AIDS - Gay Men´s HIV-Organization (Denmark); 5 – Institute of Sexology, Medical Faculty, Charles University (Czech Republic); 6 – Institute of Public Health of the Republic of Slovenia (Slovenia); 8 – National AIDS Centre (Poland); 8 – AIDS-Hilfe NRW e.V. (Germany).
Collaborating Partners: Arcigay (Italy); 2-SkUC (Slovenia); 3-Laboratory for Molecular Microbiology and Slovenian HIV/AIDS Reference Centre (Slovenia); 4-Ceska spolecnost AIDS pomoc (Czech Republic); 5-Romanian Monitoring Center for Drugs and Drug Addiction National Antidrug Agency (Romania); 6-Karolinska University Hospital (Sweden); 7-Institute of Public Health of Montenegro (Montenegro); 8-PROLEPSIS (Greece); 9-Sexual Health Promotion & Evaluation Department HIV/STI Centre for Infections Health Protection Agency (UK); 10-Public Health Agency of Latvia (Latvia); 11-Programa per a la prevenció y assistència de la Sida, Generalitat de Catalunya (Spain); 12-G.A.T. Grupo de Activistas VIH/SIDA (Portugal); 13-National AIDS Commission (Portugal); 14-LEGEBITRA (Solvenia); 15-Aidsberodung Croix-Rouge (Luxemburg); 16-Deutsche AIDS-Hilfe e.V. (Germany); 17-Institute of Tropical Medicine (Belgium); 18-Estonian Network of People Living with HIV (Estonia); 19-Safe Pulse of Youth (Serbia); 20-ARAS (Romania); 21-ISPUD (Portugal).

European Commission

Joint Action on Monitoring Injuries in Europe (JAMIE)

Wim Rogmans, coordinator of JAMIE. European association for Injury Prevention and Safety Promotion (EuroSafe), Amsterdam

Why focus on injuries?

Injuries due to accidents or violence constitute a major public health problem also within the European Region.

In spite of the magnitude and the severity of the problem, injury surveillance systems are not yet sufficiently well developed to accurately quantify the burden of injuries on individuals, health services and society in Europe.

Objectives

The JAMIE project aimed at having by 2014 common hospital-based injury surveillance systems in at least 24 EU/EFTA member states, reporting on external causes of injuries due to accidents and violence for upload in the EU-Injury Data Base (IDB).

These national systems should also produce reliable national incidence estimates.

Source

Emergency departments (EDs) at hospitals served as the preferred source for gathering data on injuries.

The JAMIE approach allowed participating countries to deliver ED injury data at two levels of detail:

- records collected in a representative sample of ED's containing limited information on the injury circumstances, but sufficient for developing the accurate estimates of population incidence; AND
- records containing greater detail as for the circumstances of the injury event, allowing these to be collected in a relatively small number of hospitals. These dat should provide information for a wide range of policy makers and health, transportation and consumer protection authorities.

Methods

Originally 24 countries signed up for a joint action which started in April 2011. In the course of the project two new countries joined the action. The project ended on 31 July 2014.

The project partners started to define the best achievable level of quality of data collection process and quality control in accordance with EuroStat (ESS) criteria. This was done also in consultation with an international scientific advisory group for injuries and EuroStat experts in public health statistics.
It resulted in the publication of the JAMIE Manual for collecting data as part of the EU-Injury Data Base (IDB).

Country specific work plans were developed by each of the partner countries and executed over 2012-2014.
All partners received bi-lateral support in the process of implementing an appropriate infrastructure for injury data collection at national or regional level. Counselling was provided on implementation challenges and technical issues.

Two joint training seminars were organised for National injury Data Administrators (NDAs) and four meetings of the JAMIE-associated partners with a view to:

- enhance competencies of NDA's and partners in establishing and operating hospital-based injury monitoring systems;
- ensure continuous development of methods and tools for injury data gathering; and to
- help partners in raising support for their injury surveillance efforts from stakeholders at national and local level.

In the course of the project two bi-annual reports were produced, presenting data collected over the years 2008-2010 and 2010-2013 respectively, featuring the core data that has been collected in the countries that participated in JAMIE

Results

26 participating countries (see figure) developed and implemented a national action plan, documenting the initial situation and targeted efforts to implement JAMIE/IDB standards and to meet the objectives of JAMIE at national level.

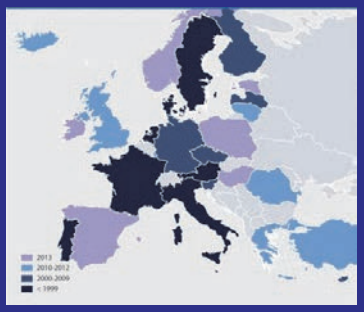


Figure: Map of the 26 injury data reporting countries and approximate starting date of data collection.

While at the start of JAMIE only 13 countries provided injury data to the IDB today *26 countries* provide such data at least at MDS-level and 17 counties do so also at FDS-level. A total number of over 1.3 million injury reports were collected over the year 2013 at MDS level, of which 340.000 reports contain also FDS-level detailed information about the circumstances and causes of these injury events.

The way ahead

In June 2014 the Commission announced a new action from 2015 onwards to make health information capacity and resources within the EU, including those in the field of injury surveillance, more sustainable.
As for the use of injury data for consumer product safety policy purposes, the Commission is currently also examining the feasibility of a public Consumer Product Safety Information Database, which could include a platform for the exchange of data on product related injuries.

Project financed:
EU Public Health Programme 2008-2013
Years of the Project:
2011-2014 (40 months)
Total cost: 1.581.283,16 € (EC: 781.098,39 €)
Project coordination:
European association for Injury Prevention and Safety Promotion, Amsterdam - NL

JAMIE-partner countries:

Austria, Cyprus, Czech Republic, Denmark, Estonia, Finland, Germany, Greece, Hungary, Ireland, Iceland, Italy, Lithuania, Latvia, Luxembourg, Malta, the Netherlands, Norway, Portugal, Poland, Romania, Sweden, Slovenia, Spain, Turkey, and the United Kingdom,

More information:

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European Commission

www.mentalhealthpromotion.net

The MHP-HANDS project

Dr. Richard Wynne, Work Research Centre Dublin, Ireland.

Partners: Work Research Centre, Ireland; Forschungsinstitut des Roten Kreuzes (FRK), Austria; The Estonian-Swedish Mental Health and Suicidology Institute (ERSI), Estonia; EWORX S.A. ; Greece; Bundesanstalt fuer Arbeitsschutz und Arbeitsmedizin (BAuA), Germany; National Institute for Health and Welfare (THL), Finland; Nofer Institute of Occupational Medicine, Poland, Romtens Foundation, Romania.

SUMMARY

MHP-HANDS (**Mental Health Promotion Handbooks**) is a recently completed 36 months project (from March 2010 – to February 2013). **The project is concerned with the promotion of mental health and wellbeing in 3 settings**: **schools; workplaces and older people's residences**. MHP-HANDS has produced Handbooks and related materials for people wishing to promote wellbeing in each of these settings.

OBJECTIVES

The project had a number of specific objectives. The main ones were:

- Development of MHP implementation Handbooks
- Improving access to appropriate MHP tools
- Testing and evaluating the Handbooks
- Disseminating as widely as possible the Handbooks and related materials

METHODOLOGY

The Handbooks were targeted for use by people who work regularly in the 3 settings of interest, e.g. teachers, health and safety staff, carers rather than at professionals in mental health. The design of the methodology reflected these target groups – the needs analysis concentrated on potential users and the methods used were interactive, while evaluation by the target groups was a key part in developing the Handbooks.

The main methodological steps were:

- A multi-method needs analysis survey in 6 countries with 65 expert users to assess the kinds of needs that practitioners and stakeholders might have in relation to implementing MHP.
- Literature reviewing
- Development of the 2nd version of the Handbooks and associated training and materials
- Field evaluation with user experts
- Development of the final version of the Handbooks and training

Quality was maintained via internal and external evaluation of the developing Handbooks.

MANAGEMENT

WP CO-ORDINATION

The project was led by WRC and all partners met every 6 months during the project. Project management was aided by an external advisory group and by a an external evaluator. Workpackage leaders took a major role in quality management and all partners actively participated in all management activities.

WP DISSEMINATION

Dissemination is of major concern to the project and is being achieved in a number of ways:

- Developing the project website through the European Network for Mental Promotion (ENMHP) Portal
- Dissemination through European networks such as ENMHP and the European Network for Workplace Health Promotion and through national networks
- Presentations at national and international conferences
- Presentations to policy makers
- Publications
- Brochures and promotional material

WP EVALUATION

Evaluation played a central role in the project, both from the perspective of ensuring the highest possible technical and scientific standards, but also in order to ensure the usability and utility of the Handbooks.

Evaluation activities involved:

- Expert workshops
- Field trials of the developing Handbooks
- Internal evaluation by project partners
- External evaluation by an MHP expert
- Inputs from an external Advisory Committee

RESULTS

The main results from the project were:

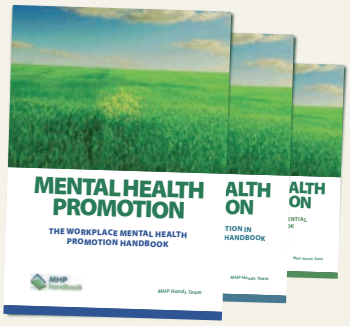
- Development of 3 highly usable and validated Handbooks for mental health promotion in schools, workplaces and older people's residences
- Development of an integrated project website
- Integrated of project outputs with related tools for training and MHP tools
- Widespread dissemination through European and National Networks

CONCLUSIONS

Though not primarily a research project, many conclusions can be drawn. These include:

- The concepts of mental health promotion and mental illness prevention are not clearly understood
  Confirmation of the need for settings specific tools to support MHP
- There are significant differences between the settings
- The Handbooks need to be backed up by training for users in most instances

There also appears to be significant demand for the Handbooks from users – since the Handbooks have been made available through the website, there have been significant numbers of requests for downloads of the Handbooks.



ACKNOWLEDGEMENTS

The Project partners wish to acknowledge the kind support of the European Commission in enabling this project.
We would also wish to acknowledge the **35 project team members and the external support** received throughout the project.

This handbook was funded by the EU Health Programme 2008-2013
Agreements Number: 2009 12 13

Starting date and duration of project:
Total cost:
Co-funding from the Commission:

Leader Organisation: (Name, Country)
Contact Person:
Web site: www.mentalhealthpromotion.net

Other Partners: (Name, Country)

European Commission

NEWIP | NIGHTLIFE EMPOWERMENT & WELL-BEING IMPLEMENTATION PROJECT

Funded by the Health Programme of the European Union

THE NIGHTLIFE EMPOWERMENT & WELL-BEING IMPLEMENTATION PROJECT(NEWIP) | 2011-2013

Authors: the NEWIP SC members | www.SaferNightlife.org

SUMMARY

Recreational settings are privileged spaces to reach synthetic drugs users. The project proposed answers to new challenges in the field of harm reduction to synthetic drugs usage, such as partygoers' mobility (party tourism), new youth cultures and drug uses'trends, necessity of improving nightlife community empowerment as well as filling the gap in terms of geographic coverage.

OBJECTIVES

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

METHODOLOGY

- The "Party+" workgroup promoted safer clubbing labels in new cities. More info on www.partyplus.eu

-The Field Intervention workgroup organised common interventions in big music festivals.

- The Trans European Drug Information (TEDI) workgroup set up a database of synthetic drug checking results, as well as reports on new trends, to improve rapidity of responses.
More info on www.tediproject.org

- The Emerging Media workgroup developed individual harm reduction strategies through the use of interactive technology tools and the development of a serious game (What the dope!).

- The Good Practice and Standard Integration workgroup collected, adapted and supported the implementation of good practice standards and guidelines, improving interventions.

- The Training and Exchange workgroup organised training sessions and study visits in order to improve existing interventions, involving nightlife professionals and participants from new member states.

MANAGEMENT & COORDINATION

The responsibility to reach the objectives was shared and defined clearly between the associated partners from the start of the project. The steering committee members were each WP managers. Other experts such as the Networking consultant, the external evaluator, a TEDI expert and an expert from the EMCDDA also took part to the SC meetings.
The Coordination was managed by ABD (ES), the Dissemination was managed by ABD and UNIPD for the final Conference, the Evaluation was managed by APDES (PT) and the specific workgroups by MODUS VIVENDI (BE), JELLINEK (NL), DRUGSCOUTS (DE), UNIPD (IT), TECHNO PLUS (FR) and ABD-Energy Control (ES).

DISSEMINATION

The external communication was managed by the WP Dissemination with the collaboration of all partners and the subcontractor for external cooperation and networking development.
It was structured in different subtasks:
1 - Project Websites and Newsletters
2 - The European Party Friends Night: www.partyfriendsnight.eu
3 - Scientific dissemination.
4 - The final Conference (NIGHTS 2013)
5 - Paper and audiovisual materials production and integration
6 - Networking (Partners, Conferences, Networks, NGOs, Administrations, clubs syndicates, Media, Tourism agencies)

In December 2013, the NEWIP network had a total of 90 collaborating partners.

EVALUATION

All the evaluation design is detailed in the project evaluation plan, which gathers the project database and the different evaluation designs for each of the WP and defines the methodology, procedures, timetable and the responsible of each evaluation activity.

The level of achievement of the NEWIP objectives was high and all the objectives of the project were accomplished.

However, this type of changes in behaviour and knowledge, as well as the promotion of empowerment in vulnerable communities, needs time to solidify. It is therefore very important to continue the investment in this type of projects and services that approach public health in a more holistic way and prioritize the promotion of healthy lifestyles towards young people, in particular within new member states.

RESULTS

- 4 good practice standards were produced (Peer Education, Labels and Charters, Serious games and Drug Checking) as well as Training guidelines and Safer Party guidelines for party organizers.

- The International Conference "Nights 2013" with 161 participants and all WP's had coordination meetings that allowed good practice sharing. The Party+ workgroup has carried 10 expert visits and their seminar and info sessions were attended by 465 participants. The Good Practice & Standard seminars had 42 participants. The Exchange and Training workgroup organized 4 training sessions with over 100 applicants and the different guidelines produced will be extremely useful for new projects.

- The Party+ network improved health settings and harm reduction in EU clubs and Nightlife events. 171 stakeholders were involved in labelling processes and summer festivals. A total number of 220 nightclubs from 65 cities and 16 European countries are part of a safer party label offering different health services to 7.771.733 partygoers every year. Since 2011, 1.376 workers of nightclubs were trained, 91% of the staff trained claims to have acquired useful information to respond to a health related crisis.

- 7 field interventions took place in 5 different European countries (Germany, Romania, Hungary, Croatia and Portugal) together with several New Media interventions in Italy, reaching 43.913 partygoers via info stand and 6.919 partygoers with new media contents. The results show that 74% partygoers declare positive behavioural intentions.

- The interactive game called "What the dope" was translated in 5 different languages (English, Italian, French, German and Spanish). 51 volunteers and social workers were trained in New Media as well as 18 nightlife professionals. Since the game was launched in the field, 6,919 (1,033 active players and 5,886 passive players) partygoers were reached by new media contents.

- The TEDI workgroup involves 12 projects, 4 trends reports/newsletters were distributed. 193 persons receive each newsletter and trend report directly and 1785 downloads were operated of the 4 newsletters. 2873 people visited the TEDI website. 7 contributions were made to the early warning system.

- NEWIP is now represented at the EU Civil Society Forum on Drugs (CSF), through ABD's representative, and has also actively contributed to the OPINION of the European Economic and Social Committee on the Proposal for a Regulation of the European Parliament and of the Council on NPS.

CONCLUSION

The project has shown the growing interest of various types of stakeholders and the results demonstrate the importance to keep on developing health promotion and harm reduction-based approaches and interventions within nightlife settings:
i.e. by disseminating existing tools, supporting new innovative projects and sustaining networks based on "Good Practice sharing".

Project co financed from the EU Public Health Programme / Starting date and duration of project: January 2011 - 36 month
Total cost: 1.485.399 euros / Co-funding from the Commission: 845.530 euros
Leader Organisation: ABD - Spain / Contact Person: Stéphane Leclercq / Website: www.safernightlife.org

European Commission

PaSQ European Union Network for Patient Safety and Quality of Care

Jean Bacou Coordinator, Haute Autorité de Santé, France

SUMMARY

PaSQ Joint Action is co-funded and supported by the European Commission within the Public Health Programme. Its focus is to improve **Patient Safety and Quality of Care** through **sharing** of information, experience, and the implementation of **good practices**. 28 EU Member States plus Norway are involved around **PaSQ National Contact Points (NCPs)**, who are also the contact persons for PaSQ matters in their respective countries.

OBJECTIVES

The main objective of PaSQ is **to support** the implementation of the Council Recommendation on Patient Safety. PaSQ **unites** representatives of the European medical community, and the institutional partners involved in Patient Safety and Quality of Care in the Member States of the European Union

PaSQ TOOLS

Mutual learning web platform: www.PaSQ.eu

Exchange mechanisms in Member States: national and cross national exchange of knowledge and experiences through
European conferences, on-line courses, workshops, site visits
National network building,

Patient Safety good practices implementation (18 MS)

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WP COORDINATION

Five coordination meetings have been organised and the Executive Board (work packages leaders plus EC and CHAFEA) met every month by teleconference

Work Plan:
literature review: April – Oct. 2012
Data collection: Nov. 2012 – Feb 2013
Implementation: Jul. 2013 – Sept. 2014
Analysis: Oct. 2014 – Jan. 2015
Recommendations: Feb – March 2015

WP DISSEMINATION

The outputs of the project will be disseminated in a number of ways:

- PaSQ website www.pasq.eu
- Dissemination of 8 Newsletters to 400 EU stakeholders
- Presentation of interim and final reports
- Presentations at local and international events (i.e. International forum on Quality and Safety in Health Care)
- 3 open coordination meetings (500 invitations sent for each meeting)
- A publication in preparation

WP EVALUATION

The 6 PaSQ specific objectives will be evaluated through 8 process indicators, 10 output indicators and 12 outcomes indicators.

RESULTS

Implementation in 18 countries (**211 HCOs**).

Surgical Safety:	77 HCOs
Medication Rec:	102 HCOs
Hand Hygiene:	73 HCOs
PEWS:	34 HCOs

Exchange of good practices in Patient Safety and Quality of care

400 good practices available in the PaSQ website with relevant contact details

35 events (international meetings, workshops, webinars, study tours) organised in the EU MS to:

-exchange information regarding selected clinical and organisational good practices

-build relationship between experts and practitioners and decision makers to promote the implementation of good practices in different settings

CONCLUSION

The results of this project have been used to make a proposal for a permanent network patient safety and quality of care in the EU focusing on:

patient involvement/empowerment

reporting and learning / rapid alert systems

quality improvement systems: peer review

implementation of good clinical practices

Project financed: EU Public Health Programme
Years of the Project: 2012-2015 (36 months)
Total cost: 5 850 148 €
Subsidy from the Commission: 3 496 164€
Acknowledgments: to all persons who have participated in the project and have given information. To EU Commission for co-financing it.

Project coordinator: HAS, **France**
Communication, dissemination: AQAH, **Croatia**
Evaluation: NKUA, **Greece**
Patient Safety Good Clinical Practices: DSPS, **Denmark**
Patient Safety Initiatives Implementation: AQuMed, **Germany**
EU collaboration for healthcare management systems: MSSSI, **Spain**
Sustainability: SKMOH, **Slovakia**

57 Partners:
44 institutions (mainly Ministries of Health) from 29 Member States
10 EU stakeholders representing health care professionals, patients, health care organisations
3 International organisation

European Commission

RARECAREnet project
Information network on rare cancers

Gemma Gatta, PI and Annalisa Trama coordinator of RARECAREnet.
Fondazione IRCCS Istituto Nazionale dei Tumori, Milano (Italy)

SUMMARY

RARECARE (Surveillance of rare cancers in Europe) data provided a first indication of the size of a public health problem. Due to their low frequency, rare cancers pose particular challenges such as late or incorrect diagnosis, lack of access to appropriate therapies, dearth of clinical trials. Against this background, a key goal is to build on a network of cooperating organizations collaborating in research, promotion and implementation of appropriate solutions to address rare cancers challenges. RARECAREnet aims at building an information network to provide comprehensive information on rare cancers to the community at large (oncologists, general practitioners, researchers, health authorities, patients).

OUR MAIN OBJECTIVE

1. to collect and disseminate information on **updated epidemiological indicators** (2007) on the basis of 139 population-based Cancer Registries.
2. to describe the **healthcare pathways** for rare cancers.
3. to develop a **clinical database on very rare cancers**.
4. to propose quality criteria for **centres of expertise** for rare cancers.
5. to list **centres of treatment** for rare cancers in Europe.
6. to support the identification of **European Refrence Networks**.
7. to spread knowledge and good practice **guidelines** on rare cancers.
8. to increase **awareness** amongst general practitioners and pathologists about rare cancers.
9. to **disseminate information** tailored to the needs of patients and of all concerned stakeholders.
10. to **support patient associations** to build the capacity of patient groups, to make a change for patients and to make sure they are recognised as stakeholders.
11. to continue to encourage initiatives to **put rare cancers on the map**.

HOW?

Updated incidence, prevalence and survival figures for Europe will be provided using the most recent EUROCARE database. Information on the hospital of treatment will be collected by cancer registries (CRs) in a subset of countries. The association between outcome and hospital case volume will be analyzed. The quality criteria to identify centres of expertise for rare cancers, in accordance with the European Reference Network on all rare diseases, will be defined by a specific working group including all concerned stakeholders. For a subset of rare cancers, the criteria identified will be tested collecting relevant information in collaboration with CRs. From the identified criteria, a list of centres of expertise will be developed by the European Cancer Patient Coalition (ECPC) conducting a survey among members. Information on diagnosis and treatment of rare cancers will be developed by the project State-of-the-Art Oncology in Europe (START).New knowledge on very rare cancers will be produced developing a prospective clinical database.

COORDINATION

The project is oversee by the Steering Committee (SC) which includes all work packages (WP) leaders. The SC meets every year to discuss WP progresses. The coordinator, INT, maintains contact with partners mainly through emails, conference call and ad hoc meetings. INT provides scientific and administrative support to all partners.

DISSEMINATION

The results of the project are and will be disseminated in different ways:
The project web-site www.rarecerenet.eu
Publication in major public health and clinical journals
Presentation at conferences of major scientific societies (ESMO, ESSO, ESTRO)
Reports at the meetings of the EC Expert Group on Rare Diseases
Major newsletters (OrphaNews Europe, ECPC newsletter),
European Parliament Cancer Patient Interest Group
European School of Oncology educational instruments (e-Grand Round, Cancer world magazine)
Policy brief
EU Joint Action on Cancer Control (CANCON) meetings
Information will be developed in formats adapted to the needs of professionals and of patient groups.

EVALUATION

An internal evaluation is performed by the coordinator and the SC.
In addition, an external evaluation, is asked to the Advisory Board (AB). The AB has developed an evaluation plan with process, output and outcome indicators that are annually discussed with the coordinator.

RESULTS

The list of rare cancers was revised by the experts and defined a list of 196 rare cancers.

The information on incidence, prevalence, survival and trends for all the 196 rare cancers were estimated and will be available on the project web-site for on-line analyses by November 2014.

Clinical information on rare cancers for professionals and for patients are available on the project web-site. New chapters of the clinical management for rare cancers have been produced (n=3) and additional chapters will be produced by the end of the project.

A list of patients associations per each rare cancer and per EU country was developed and is available on the project web-site.

A repository of information for patients already available was developed and will be accessible on the project web-site by the end of October 2014.

New information on rare cancers of common sites (such as rare cancers of bladder, kidney) will be produced by the end of 2014.

A list of quality criteria for centres of expertise for rare cancers will be provided together with a list of centres for rare cancer treatment.

EXPECTED OUTCOMES

The proposed network is expected to contribute to:
- promote better classification of rare cancers complementing the EU dynamic inventory of rare diseases developed by the portal for rare disease Orphanet
- produce and disseminate information material about rare cancers building a knowledge system involving all concerned stakeholders
- ameliorate diagnosis, treatment and referral of patients with rare cancers to appropriate centres of expertise
- promote international collaborative groups to foster research on very rare cancers
- identify determinants of variations in survival across Europe
- empower patients

Project co financed from the EU Public Health Programme 2003-2008
Starting date and duration of project: 1 May, 2012 (36 months)
Total cost: 1.705.007,70
Co-funding from the Commission: 1.000.630,70
Leader Organisation: Fondazione IRCCS, Istituto Nazionale dei Tumori, Milano (Italy)
Contact Person: Gemma Gatta, Annalisa Trama (gemma.gatta@istitutotumori.mi.it; annalisa.trama@istitutotumori.mi.it)
Web site: www.rarecarenet.eu

European Commission

Sialon II

Azienda Ospedaliera Universitaria Integrata Verona

SIALON II – Capacity building in combining targeted prevention with meaningful HIV surveillance among MSM

Massimo Mirandola, Coordinator of the SIALON II Project – AOUI-Verona University Hospital, Veneto Region, Italy

SUMMARY

HIV infection remains an important public health issue in Europe, with evidence of continuing transmission in many countries. Men who have sex with men (MSM) continue to represent a population at higher risk of HIV infection.

In this context, HIV diagnosis has become a key surveillance activity for monitoring the HIV epidemic especially in hard-to-reach MSM.

Few studies have targeted MSM using outreach methods collecting behavioural and biological data in line with Second Generation Surveillance System (SGSS) criteria and Global AIDS Response Progress Reporting (GARPR) indicators.

OBJECTIVES

To carry out and promote combined and targeted prevention complemented by a meaningful surveillance among MSM and develop capacity building and know how through both training and coaching under the active supervision and in collaboration with UNAIDS/WHO on:

- Prevention needs assessment and prevention actions among MSM
- Innovative surveillance methodologies for HIV-STI (Time-Location Sampling, Respondent-Driven Sampling, HIV-STI testing methods)

METHODOLOGY

The project is implemented in 13 EU countries using the same methodologies (protocols, UNGASS/ECDC indicators, algorithms) and prevention strategies.

- **Formative research** was carried out in order to choose the most fitting method for data collection among MSM according to local contexts and for prevention needs assessment.
- The **Time-Location Sampling** method was adopted in 9 countries, whilst the **Respondent-Driven Sampling** method was used in 4 countries. The sample size is of 400 MSM in each participating city. Behavioural (questionnaire) and biological samples (oral or blood samples) are collected in line with the Second Generation Surveillance System.
- **HIV/STI prevention activities** and testing promotion directly on the field was carried out parallel to the data collection, in line with a specific SIALON 2 prevention campaign framework differentiated according to the two data collection methods.
- An aliquot of HIV positive serum samples are sent to a specialised laboratory for the calculation of **HIV antibodies' Avidity Index** and incidence estimation (STARHS).

SIALON II protocols were finally approved by the WHO **Research Ethics Review Committee** in February 2013.

EXPECTED OUTCOMES

- Evidence for MSM prevention campaigns and for effective epidemiological surveillance
- Increased comparability of data in E.U. and neighbouring countries
- Implementation of effective public health strategies and policies
- Strengthening of a wide network (including WHO, UNAIDS, ECDC)
- Development of culturally sensitive HIV/STI prevention policies

WP EVALUATION

Process, output and outcome indicators were assessed for each specific objective according to an Evaluation Logical Framework. Two progress reports were drafted and a final report is foreseen. One of the components of the SIALON II evaluation consists of a small evaluation study aimed to assess the experience and impact of conducting bio-behavioural surveys in commercial gay venues and the quality of the process of data collection in SIALON II studies.

WP DISSEMINATION

Results will be disseminated at International, European and at national/regional level to healthcare and social professionals, decision makers, public health professionals, epidemiologists, HIV and gay communities, through institutional website (www.sialon.eu), gay magazines and websites, international conferences, press releases and final conference.
Key documents to be disseminated will be the "Prevention needs assessment report" developed for prevention action and a public version of the "Final report" on bio-behavioural survey and related prevention strategy.

WP COORDINATION

All project partners met twice during the project and two last meetings are foreseen. The coordinating partner maintained contact with all WP leaders and all the partners through emails, telephone conferences and site visits (when needed), and provided technical support to them for data collection and for the administrative management using also a specific Web-based Monitoring Tool.

Partners of Sialon II project:

Project financed: EU Public Health Programme 2008-2013
Years of the Project: 2011-2014 (36 months)
Total cost: 1.650.415,915,24 €
Subsidy from the Commission: 989.960 €
Acknowledgments: to all persons who have participated in the project. To EU Commission for co-financing it.

Project coordinator: AOUI-Verona University Hospital, Veneto Region, Italy
Associated partners: 1. Prins Leopold Instituut voor Tropische Geneeskunde, Belgium; 2. National Centre of Infectious and Parasitic Diseases, Bulgaria; 3. Robert Koch-Institut, Germany; 4. Istituto Superiore di Sanità, Italy; 5. National Institute of Public Health - National Institute of Hygiene, Poland;
6. Instituto de Higiene e Medicina Tropical, Portugal; 7. Institutul National De Boli Infectioase Prof. Dr. Matei Balș, Romania; 8. National Institute of Public Health, Slovenia; 9. Fundació Institut d'Investigació en Ciències de la Salut Germans Trias i Pujol, Spain; 10. University of Brighton, United Kingdom; 11. Smittskyddinstitutet, Sweden; 12. Slovak Medical University, Slovakia; 13. Centre for Communicable Diseases and AIDS, Lithuania

European Commission

An initiative of RutgersWPF

y-sav Youth Sexual Aggression & Victimization

Tackling youth sexual aggression
Observations of the Y-SAV project

Contact person: Prof. dr. Ine Vanwesenbeeck, Rutgers WPF, Utrecht, the Netherlands

1 SUMMARY

The Youth Sexual Aggression and Victimization (Y-SAV) project was formulated based on evidence that youth sexual violence is highly prevalent in many European countries, and that young people's sexual health is strongly endangered by it. The project has contributed to expand and harmonise the knowledge base on sexual health and enhance multi-country and multidisciplinary dialogue, and encouraged member states to learn from each other and develop, joint strategies towards context-sensitive responses to youth sexual violence.

2 OBJECTIVES

The general objective of the project is to promote sexual health among young people across Europe. The following specific objectives were identified:

- To establish an extended multi-country, multi-disciplinary expert network on sexual aggression among young people;
- To develop a research instrument for (future) research and monitoring of youth sexual aggression;
- To establish a state-of-the-art comprehensive knowledge base on youth sexual aggression;
- To develop an Action Plan addressing youth sexual aggression to mobilize policy and responses across Europe.

3 METHODOLOGY

The project:

- identified experts in 27 EU countries and engaged them in dialogue and research;
- mapped the prevalence, risks and responses in each country using existing;
- developed and pre-tested tools and guidelines to conduct research across Europe;
- undertook extensive stakeholder consultations in nine countries (to provide recommendations for policy and practice).

4 MANAGEMENT AND COORDINATION

The coordinating partner, Rutgers WPF (Utrecht, The Netherlands), maintained contact with partners and network members through emails and provided technical support if required. All project partners reported on a 6 monthly basis. Annual steering board meetings were conducted.

DISSEMINATION

Krahé, B., Tomaszewska-Jedrysiak, P., Kuyper, L. and Vanwesenbeeck, I. (2014). Prevalence of Sexual Aggression among Young People in Europe: A Review of the Evidence from 27 EU Countries. *Aggression and Violent Behaviour*. Volume 19, Issue 5, pp. 545-558. Elsevier.

Diesen, C., Lainpelto, K. and Vanwesenbeeck, I. (2014). Youth sexual aggression and victimization. A European agenda? In: *Michael Harry Pearson (Ed.) Crime: International Perspectives, Socioeconomic Factors and Psychological Implications*. Chapter 5, pp. 141-159. Hauppauge, New York: Nova Science Publishers. ISBN: 978-1-62948-657-4.

Krahé, B., Berger, A., Vanwesenbeeck, I., et al. (in press). Sexual Aggression and Victimization in Young Men and Women from 10 European Countries: A Multi-Level Analysis. *Culture, Health and Sexuality*.

Reports:

Krahé, B., & Vanwesenbeeck, I. (2014). A Research Framework for Studying Youth Sexual Aggression in Europe: Assessment, Principles of Good Practice, and Indicators of Risk and Vulnerability.

Parren, F., Murauskiene, L., Papadakaki, M. (2013). Combatting youth sexual aggression and victimization in the European Union. Stakeholder perspectives and recommendations. Utrecht: Rutgers WPF.

EVALUATION

The project was evaluated through an internet-survey. 68 respondents from 17 countries filled in the questionnaire. Important results from the network evaluation are that 82% of the respondents have improved their knowledge on Y-SAV and also 82% feels motivated to act against Y-SAV. The Y-SAV project was rated 4.1 on a scale from 1 (poor) to 5 (excellent).

5 RESULTS

By the end of 2013, the Y-SAV project has achieved the following main results:

- An expert network of more than 130 professionals, researchers and policy makers and concerned agencies has been established;
- 27 country reports were compiled. The reports outline government policy, legislation, services and the agencies providing them, prevalence research, risk factors and any evidence-based interventions;
- Development of a research framework that measures self-reported sexual aggression and victimization, aiming to strike a balance between the need for harmonisation of methods and findings on the one hand and adaptability to specific cultural contexts and research questions on the other;
- Recommendations for policy and practice. The consultations produced recommendations to improve responses to youth sexual aggression at both the EU level and the level of individual member states.

6 CONCLUSIONS

Combatting Y-SAV across the European Union requires a comprehensive approach with cross cutting issues of continuous research & monitoring and ensuring meaningful youth participation. Within the Y-SAV project the following elements have been identified:

- Adapt policy and frameworks;
- Improve prevention programmes;
- Offer care and support for young victims;
- Employ campaigns and awareness raising;
- Realize treatment of perpetrators.

Project financed: EU Public Health Programme 2008-2013
Years of the Project: 2010-2013 (42 months)
Total cost: €1.157.158
Subsidy from the Commission: € 649.424
Acknowledgements: To all Y-SAV network members who, often voluntarily, contributed their time and expertise to the project. To EU Commission and ZonMw for financing the project.

Lead partner: Rutgers WPF, Utrecht, The Netherlands (Prof. dr. Ine Vanwesenbeeck, Nathalie Kollmann, Franny Parren)
Associated partners: Department of Psychology, University of Potsdam, Germany (Prof. dr. Barbara Krahé, Paulina Tomaszewska-Jedrysiak); Faculty of Law, Stockholm University, Sweden (Prof. dr. Christian Diesen, Katrin Lainpelto); MTVC - Training, Research and Development Centre, Lithuania (Dr. Liubove Murauskiene, Dr. Marija Veniute); Department of Social Work of the Technological Educational Institute of Crete, Greece (Prof. Joannes Chliaoutakis, Maria Papadakaki)

www.rutgerswpf.org/ysav

European Commission

Health Information

Advancing Care Coordination & Telehealth Deployment (ACT)

Cristina Bescos, coordinator of ACT programme
Philips Healthcare, Hospital to Home, Germany

Background and Motivation

Telehealth potentially brings

- 15% reduction A&E visit reduction
- 20% emergency admission reduction
- 14% elective admissions reduction
- 14% bed days reduction
- 8% tariff cost reduction
- 45% mortality reduction

Why is CC&TH not fully implemented yet?

- From pilots to implementation
- Barriers in translating telehealth into routine care

Telehealth needs to be integrated into a local care delivery process

- Re-structuring towards care coordination
- Promoting education of care providers
- Tailoring to disease state and acuity level
- Engaging patient self-care and adherence

Organisational & structural changes are needed

Source: Whole System Demonstrator Programme, Headline Findings – December 2011

Objective

"Identify 'best practice' **organisational and structural processes** supporting integration and implementation of telehealth in a care coordination context for routine management of chronic patients"

Outcomes

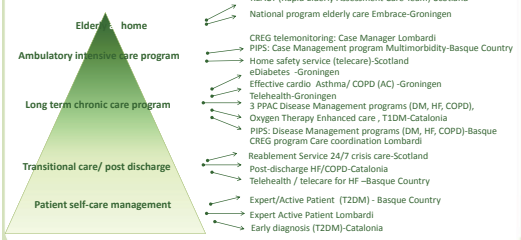
The main outcome of ACT is the ***evaluation of key drivers and indicators*** of effective deployment at scale of CC&TH services in the five participating regions.

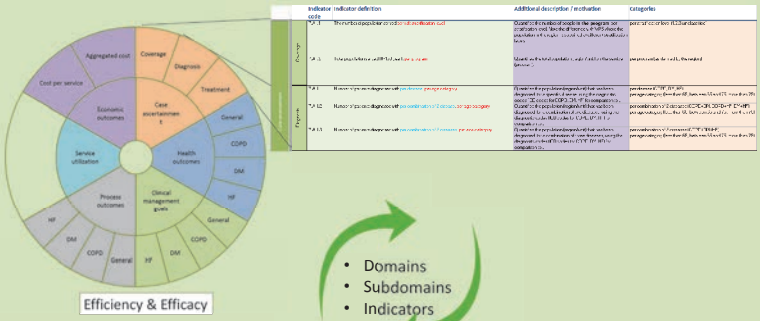
These results will be published in a ***best practice Cookbook*** specifying how these insights can be leveraged to expedite deployment of CC&TH in other European healthcare regions.

Methodology

- Gather data and good practices from different regions (Catalonia, Basque Country, Lombardy, Groningen and Scotland) and affiliate collaborators.
- Determine a baseline for how care coordination and telehealth works in these regions
- Conduct an iterative evaluation of care structures and procedures
- Select best practices
- Disseminate findings to ensure transferability to other regions

ACT Regions and Programmes





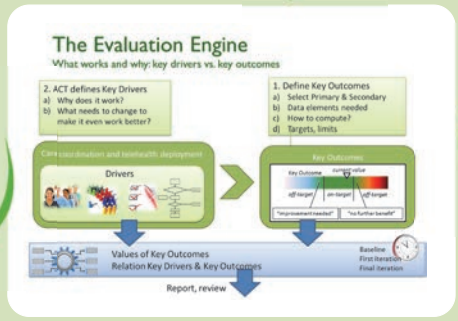
- Domains
- Subdomains
- Indicators

Become an Affiliate Member !

If you are an European Healthcare region and interested in our activities, we would like to welcome you as an Affiliate Member of the programme

What are the benefits ?

*Engagement as **Observer** :*	*Engagement as **Evaluation Site** :*
* Access to ACT results and participation in project meetings * Learn from the others' good practice and experiences * Provide opportunities for collaboration leading to efficiently (re-)design and validate innovative care services and expand the services to larger population * Enlarge your visibility at international level * Enable local industry to see a larger market, beyond region * Engage political/industrial support	In addition, * Access to the ACT evaluation engine and fully participate in the evaluation process and best practice selection * Get evidence and benchmarking of your solution under the review of the key international experts * Combine evidence with all the evaluation sites



- Data
- Surveys
- On-line questionnaires

- Literature
- Clinical experts
- Regional experts

Project financed: EU Public Health Programme.
Grant Agreement: 0121209
EC Funding: 1,6 M Euros
Budget: 2,7 M Euros
Start: 15 Feb 2013
Duration: 32 Months
Coordinator: Philips Healthcare Boeblingen
Web site: www.act-programme.eu

For more information, contact Cristina Bescos, Philips Healthcare: Cristina.Bescos@philips.com

The program is fully aligned with the European Innovation Partnership on Active and Healthy Aging (EIP on AHA) objectives to deploy integrated care for chronically ill patients.
ACT is an active member of the B3 Group on Integrated Care.

We acknowledge the contribution of the following researchers participating in ACT:
C. Westerteicher (**Philips Healthcare**); S. Pauws, H. Schonenberg (**Philips Research**); P. Natsiavas, D. Filos, C. Maramis, I. Chouvarda, N. Maglaveras (**Aristotle University Thessaloniki**); S. Newman, R. Davidson (**City University London**); J. Roca (**IDIBAPS**); J. Escarrabill, M. Moharra (**AQuAS**); J. Cleland (**Imperial College**); D. Barrett, J. Hatfield, S. Nabb (**University of Hull**); N. Hart (**Guy's and St Thomas' NHS Trust**); M.David, J. Mora, E. de Manuel (**Kronikgune**); E. Buskens, M. Lahr (**UMCG**); M. Romano, M. Nalin, I. Baroni (**Telbios**); J. Rasmussen, A. Pavlickova (**NHS 24/SCTT**); S. Störk, C. Wahl (**University of Würzburg**).

European Commission

Evaluation of population newborn screening practices for rare disorders in Member States of the European Union

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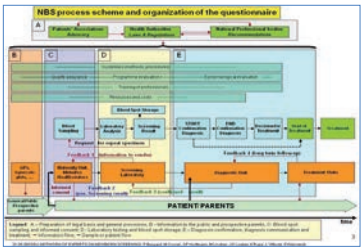
[1] National Centre for Rare Diseases, National Institute of Health - Rome (IT); [2] Department of Pediatrics , University Hospital - Heidelberg (DE); [3] VU University Medical Centre - Amsterdam (NL); [4] RIVM - Bilthoven (NL)

Introduction

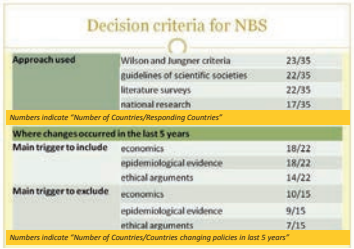
Neonatal screening has been extended in many European countries to a variety of neonatal screening programs after the introduction of tandem mass spectrometry technique.
With the aim of informing national and EU policy-makers on the status of neonatal screening, this work provides the first comprehensive overview of the NBS process in Europe, spanning from the supporting legislation to confirmation diagnostics and start of treatment. For each step it addressed existing guidelines, actual practices, quality assurance and training schemes. Ethical aspects and the systematic evaluation of the screening programs have also been investigated.



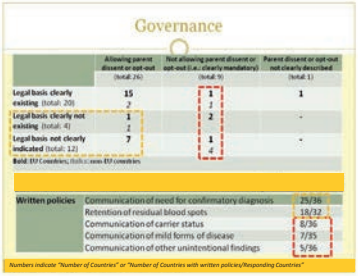
Methods

The process steps of a complete NBS program were investigated with a web-based questionnaire organized in 5 modules (A, B, C, D, and E) as shown in the Figure on the left. As the different modules required different expertise, respondents for each module were identified in each EU Member States, Candidate, Potential Candidate and EFTA Countries and contacted via the corresponding European professional organisations and national health authorities. Final approval of the national data sets was achieved during a conference of EUNENBS members held in Luxembourg on 20-21 June 2011.

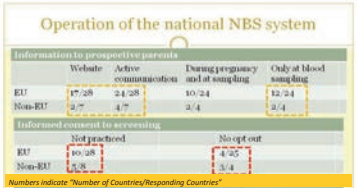
Results



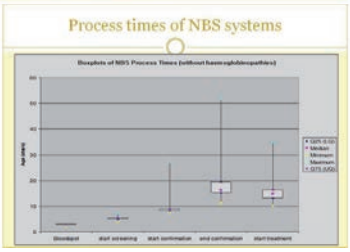
In spite of the wide variety of screening panels adopted in the EU Countries, there is a remarkable uniformity in the approaches used to make decisions.



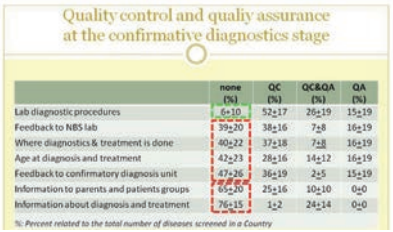
About half the jurisdictions surveyed (17 of 35) reported to have laws or regulations mandating participation in newborn screening. Most jurisdictions (26 of 36) allow for opting-out or dissent, but in 9 of them it is not or not clear whether this is legally regulated. Written policies are limited where ethical aspects are more important.



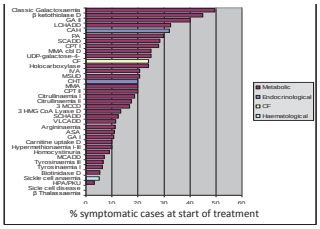
The patterns of communications on neonatal screening are rather different among countries. The practice of informed consent and opting-out is not uniformly applied.



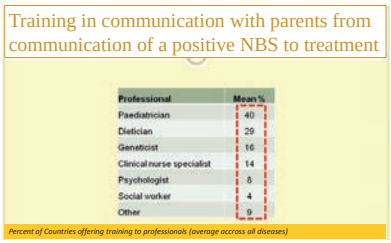
The initial steps of NBS have a very similar timetable across countries, whereas confirmatory investigations and treatments in some countries start rather late, compared with the other countries.



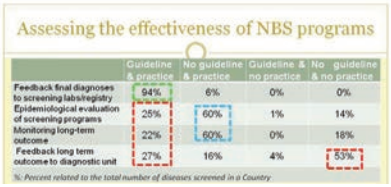
Quality control and quality assurance schemes are applied satisfactorily at the laboratory test stage, whereas subsequent steps of the process draw lesser attention and therefore their performance relies essentially on the general quality control systems operated locally.



Based on estimates of the responders, the fraction of symptomatic cases at the start of treatment is rather significant for some diseases.



Training of professionals in communication with parents varies across diseases. Training for psychologists and social workers are rare. Training is most often offered for cystic fibrosis (25%), followed by metabolic (20%) and endocrinological (17%) disorders . For haemoglobinopathies, training is offered only for the clinical nurse specialist and the geneticist.



But for the feedback of confirmed diagnoses to the screening laboratory, other activities of use to assess the effectiveness of NBS programs are losely regulated. It is remarkable that epidemiological evaluations and the monitoring of long term outcomes of many screened diseases are carried out as spontaneous initiatives.

Conclusions

This work highlighted that:
- Proximal steps of the programs (information of parents and laboratory procedures) are better regulated than distal steps (epidemiological evaluation by registries and evaluation of the outcome of treatment).
- Training of professional groups involved in NBS programs is poorly developed and offers opportunity for substantial improvement especially regarding the communication with parents.
- The systematic assessment of the procedural and clinical aspects as well as the cost-effectiveness of neonatal screening programs would benefit from the development of systems coordinating the collection and exchange of data (e.g. registries).

For more information: *http://www.iss.it/cnmr/prog/cont.php?id=1621&lang=1&tipo=64*

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- Cornel M.C., Rigter T., Weinreich S.S., Burgard P., Hoffmann G.F., Lindner M., Loeber J.G., Rupp K., Taruscio D. and Vittozzi L. (2013) A framework to start the debate on neonatal screening policies in the EU: an Expert Opinion Document. European Journal of Human Genetics (2013), May 8, 1–6. DOI: 10.1038/ejhg.2013.90.

European Commission

Public Health Genomics
European Network

2012 DECLARATION OF ROME

European Best Practice Guidelines for Quality Assurance, Provision and Use of Genome-based Information and Technologies

Angela Brand* and Jonathan A. Lal* for the Public Health Genomics European Network (PHGEN II)

* Institute for Public Health Genomics, Cluster of Genetics and Cell Biology, School for Oncology and Developmental Biology (GROW), Faculty of Health Medicine and Life Sciences, Maastricht University, The Netherlands.

Summary

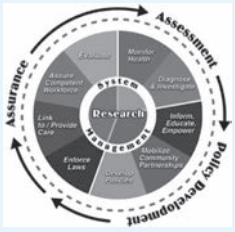
The EC asked to develop "European Best Practice Guidelines for Quality Assurance, Provision and Use of Genome-based Information and Technologies" to support Member States, Applicant and EFTA-EEA countries to more efficiently and effectively work together at a European level in addressing the challenges deriving from emerging genome-based information and technologies (GBITs) and to prepare for the paradigm shift of personalized healthcare in time, which requires modifications of public health and health governance systems on all levels. PHGEN II fulfills this task, which recently produced the first edition of these European best practice Guidelines. The guidelines will assist all stakeholders with evidence-based guidance on the timely and responsible integration of GBITs into healthcare systems for the benefit of population health. They build on the extensive work of PHGEN I (DG SANCO 2006–2008) which identified the need for European best practice guidelines (mapping exercise). These European best practice guidelines used the concept of "genome-based information and technologies" (Bellagio-Model). In this concept, genome-based information is very holistic, which means includes not only all "omics" data but also environmental, socioeconomic and lifestyle factors, as well as information on health systems. On 19 and 20 April 2012, experts from across the field of public health genomics representing key European and national organizations and institutions from policy making, academia and private sector came together at the final PHGEN II meeting in Rome to endorse the Declaration of Rome on 19 April 2012, a summary of the "European Best Practice Guidelines for Quality Assurance, Provision and Use of Genome-based Information and Technologies".

Introduction

Genomics is a highly dynamic field and, as such, represents a moving target for public health. Public health is shifting from a focus on the population towards an emphasis of the individual as a means of supporting the well being of the population. In particular, we are entering the era of predictive, personalized, preemptive and participatory (P4) medicine supported by advanced technological infrastructure. These changes represent a paradigm shift in our approach to healthcare and will go hand-in-hand with a major reclassification of diseases. The challenge now is to understand how all of these changes will impact public health and how to ensure that they are translated effectively into benefits for individual citizens and society as a whole. Thus, there is a need to develop guidelines aiming not to close doors. Instead, the goal is to create a vision that allows for flexibility and adaptability in their implementation in order to have a maximum impact on health, the healthcare infrastructure, health technologies and economic growth in the health sector.

Method

This meta-level guidance was achieved by ensuring that the 10 essential public health tasks, as described within the public health wheel over the domains of assessment, policy development, assurance can be adequately fulfilled in each jurisdiction on the basis of a common understanding of best practice guidelines for each task. Within these best practice guidelines, translational research considerations had been combined with system management under the holistic concept of public health genomics.

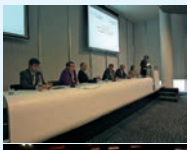


Management

The project was divided into 9 work packages (WP) with 12 deliverables divided among them to handle both content, management & dissemination of different aspects of the project. Each pillar met once every 3 months via Skype or face to face. Core management tasks for the three pillars Quality Assurance, Provision and Use had been handled by a group of 5 Associate Partners (APs) and the Main Partner. For each WP the project had appointed 2 APs ensuring a constant work flow. The management followed content responsibility. Due to the communication and dissemination structure the project was always open and transparent to input from external experts and stakeholders via a Wiki page, which was publicly accessible, and website. An external steering was updated every 6 months, and the Steering Committee met once a year to assess the progress/steer accordingly. There were 5 consortium meetings among the partners, in which to all the EC was invited, and the final PHGEN II conference in Rome in April 2012 for the endorsement of the guidelines by the key stakeholders. Over the project duration publications, workshops, posters and presentations were given at various international conferences on the progress and results of PHGEN II.

Results

PHGEN II produced over 50 publications in international scientific journals and disseminated the results in over 100 international conferences and policy meetings. Several key European policy papers, organizations and institutions such as the Irish EU Presidency report, the EC DG SANCO Success Stories, the ESF Forward Look on Personalized Medicine, the EAPM Manifesto, the iNNOVAHEALTH report, the Hipocrate journal, the WHO Europe Policy Framework, the ECDC, the EHFG, Statements regarding the Data Protection Directive, EUPHA among others have taken up the PHGEN best practice guidelines.



PHGEN II also coordinated with several other projects like HTAi, ITFoM, P3G, GRaPH-Int, BBMRI, EUnetHTA, EuroGenTest2, MUTANOM, OncoTrack, Epirare, RareBestpractices, PerMed, Orphanet among others.

The developed guidelines addressed current problems on a truly European level and were endorsed by over 100 key European stakeholders. They answered perfectly the need of DG SANCO for a "new overarching, strategic framework".

Conclusion

The proposed list of best practice guidelines under the Declaration of Rome (DoR) is crucial for the implementation of GBIT amongst European Member States in order to improve public and personal health. Future PHGEN activities will continue to build on previous work to provide a platform for the developments indicated in these guidelines. We therefore strongly recommend that PHGEN activities continue to be supported on European, national and regional levels within the applicable healthcare framework. Thus, as the next step a Joint Action "Public Health Genomics and Personalized Healthcare: Implementing the European Best Practice Guidelines for Quality Assurance, Provision and Use of Genome-based Information and Technologies in rare diseases and cancer" is planned to achieve inclusive growth by guiding the transition to personalized healthcare in all EU Member States. Many of the EU Member States expressed already their interest and support.

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

Starting date and duration of project: June 2009 to November 2012

Total cost: € 2,194,382

Co-funding from the Commission: € 1,301,693

Leader Organization:

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Katholieke Universiteit Leuven – Belgium

Fondazione IRCCS Ca' Granda Ospedale Maggiore Policlinico – Italy

University of Debrecen, Medical and Health Science Centre – Hungary

Osteba, Basque Office for HTA, Department of Health, Basque Country - Spain

Vrije Universiteit Amsterdam – Netherlands

University of Vienna – Austria

Medical University of Varna, Faculty of Public Health – Bulgaria

University of Twente – Netherlands

Friedrich-Alxeander-Universität Erlangen-Nürnberg – Germany

Ruhr-Universität Bochum – Germany

Philipps-Universität Marburg – Germany

BioGlobe GmbH – Germany

Max Planck Institute for Molecular Genetics – Germany

Universita' Cattolica del Sacro Cuore – Italy

Norwegian Group on Inherited Cancer – Norway

National Institute of Public Health-National Institute of Hygiene – Poland

Instituto Nacional de Saude Dr Ricardo Jorge – Portugal

Fundación Centro Nacional de Investigaciones Oncológicas Carlos III – Spain

Genetic Alliance UK – United Kingdom

Collaborating Partners:

University of Malta, CHESS Sweden, Erasmus Medical Center Netherlands

Observers:

RIVM Netherlands, DMDI Germany, CNMR Italy

Drug Metabolism and Drug Interactions 2012, 27(3):177-182

European Commission

EISAH project

Cooperation between the EC and WHO Regional Office for Europe on further development of joint data gathering and common knowledge base relating to the alcohol situation and alcohol policies in EU Member States

L Møller, J Brummer, WHO Regional Office for Europe

SUMMARY

The general objective of this project was to further develop joint work by the EC and WHO to monitor alcohol-related trends and developments in Member States. The project also aimed to update the knowledge base relating to information needs identified in the EU alcohol strategy, including the health, social and economic impacts of alcohol, in order to underpin the development of effective policies to curb alcohol-related harm to individuals, communities and the society.

OBJECTIVES

The specific objectives were to develop a functional and sustainable system for monitoring trends in alcohol consumption, harm and policies across the EU and Europe by developing survey instruments and performing surveys among Member States. A further objective was to continue the development of the European Information System on Alcohol and Health (EISAH) and parallel European Union Information System on Alcohol and Health (EUSAH) and to enhance the capacity of national focal points to contribute to and make use of alcohol information systems.

METHODOLOGY

The project involved collaborative work between WHO headquarters, WHO Regional Office for Europe, the EC, external experts and consultants to conduct surveys among Member States to monitor alcohol consumption, harm and policies; update and further develop EISAH/EUSAH; conduct meetings among focal points; and produce reports featuring collected data and analysis.

Project co financed from the EU Public Health Programme 2008–2013
Years of the Project: 2011–2013 (36 months)
Total cost: 1.017.600,00 €
Co-funding from the Commission: 600.000 €
Leader Organization: WHO Regional Office for Europe
Contact Person: Lars Møller
Websites: http://www.euro.who.int/alcohol
http://who.int/gho/eisah
http://who.int/gho/eusah
Acknowledgements: This project was made possible thanks to the financial assistance of the EU.

MANAGEMENT & COORDINATION

The project was coordinated by WHO Regional Office for Europe in collaboration with WHO headquarters. WHO recruited expert authors for the reports, conducted surveys, updated the databases, and organized launch/ distribution events and yearly focal point meetings. WHO Regional Office for Europe worked in close collaboration with the EC in developing the surveys to secure that that survey instruments could be used to evaluate the EU alcohol strategy.

DISSEMINATION

The outputs of the project were disseminated through the WHO Alcohol programme website; reports and launch events; presentations at focal point meetings and WHO events; email notifications; flyers; press releases; and social media.

EVALUATION

The project was evaluated using process, output and outcomes indicators that included satisfaction survey ratings, meeting attendance, and Member State participation in major surveys,

CONCLUSION

There is a growing demand for effective monitoring of alcohol-related trends, with cross-national strategies requiring comparable and reliable data across Member States to evaluate progress and for comparative analysis between countries. To address this need, projects supporting close collaboration between WHO Regional Office for Europe and the EC in the administration of surveys and analysis and presentation of data must be maintained. Such joint actions are necessary to provide a sustainable system for monitoring progress in reducing the harmful consequences of alcohol use, as well as to minimise overlap and thereby ease the burden of reporting for Member States.

RESULTS

The first report, *Alcohol in the European Union. Consumption, harm and policy approaches* (Fig. 1), presented results of the 2011 survey and summarized recent research related to the health, social and economic impact of alcohol in the EU and the impact and effectiveness of alcohol policy measures. The second report, *Status report on alcohol and health in 35 European countries* (Fig. 1), presented results of the 2012 survey and included alcohol policy timelines for each Member State.

Fig. 1. Reports presenting results of the EU Survey on Alcohol and Health and updating the wider knowledge base

EISAH and EUSAH are databases that provide easy and rapid access to a wide range of country-level alcohol-related health statistics, including levels and patterns of consumption, harms and consequences and policies (Fig. 2). Data are based on passive epidemiological surveillance, joint EC/WHO surveys of Member States, and other sources. In collaboration with WHO headquarters, a number of improvements were made to the functionalities of EISAH/ EUSAH.

Fig. 2. EUSAH (http://who.int/gho/eusah)

European Commission

Health Security

The ARPEC project
Antibiotic Resistance and Prescribing in European Children

M. Sharland, J. Bielicki, H. Bird, T. Munera, ARPEC project team

Summary

ARPEC is a 40-month project (from September 2010 to December 2013) with the overall aim to improve surveillance of antibiotic use and antimicrobial resistance in the European childhood population. This is achieved by building on existing relevant European networks and bringing together key partners from across European Member States.

Core objectives were to

1) develop and validate surveillance methods for childhood antibiotic prescribing,
2) adapt and validate surveillance methods for antimicrobial resistance to children,
3) collect and evaluate existing treatment guidelines across European Member States,
4) develop a dedicated training programme to improve antibiotic use in neonates and children.

Methodology

The project identified, adapted and validated approaches to the surveillance of antibiotic consumption and antimicrobial resistance in children. The findings and recommendations are communicated to relevant authorities and will be fed into an educational tool.

Management & Coordination

The partners of the project met face-to-face annually. The coordinating partner, SGUL, was in regular contact by email and telephone to provide support for the administration of budgets and reporting. Technical support for individual WPs was provided by the WP leads.

Dissemination

The outputs of the project are disseminated through:

- A dedicated project website
- Presentations at international and national meetings as well as local events
- Regular communications with key European agencies such as ECDC
- Peer reviewed publications.

Results

1) Overview of European outpatient and inpatient childhood antibiotic consumption.
2) Overview of antimicrobial resistance patterns in key bloodstream isolates from neonates and children in Europe.
3) Summary of the current landscape of guidelines for the use of antibiotics in neonates and children.
4) Educational tool to improve antibiotic prescribing.

Evaluation

The project undergoes formal evaluation twice with a detailed report. Feedback was gathered continuously through face-to-face meetings, email and phone contact to improve the implementation of the project.

Conclusion

ARPEC successfully built on existing networks in Europe to develop a unique alliance to tackle antibiotic use and antimicrobial resistance in European children. Partners from within the ARPEC network have gone on to successfully develop further European projects to improve the knowledge of treating infections in children.

Acknowledgements

The project partners would like to thank the commission for their financial support and all participants for engaging with the project.

Project co-financed from the EU Public Health Programme 2003-2008
Start date and duration: 01/09/2010 (40 mths)
Total cost: 1,142,114.00 Euros
Co-funding from the commission: 683,048.74 Euros

Lead partner:
St George's University, London, UK

Contact persons:
Mike Sharland, Julia Bielicki, Helen Bird

Project website: www.arpecproject.eu

University of Antwerp, BE
University Medical Centre Freiburg, DE
University of Tartu, EE
Fundacion para la Investigacion Biomedica del Hospital Gregorio Maranon & SERMAS, ES
National & Kapodistrian University of Athens, GR
Universita Degli Studi di Milano, Consorzio per le Valutazioni Biologiche e Farmacologiche, IT
Fondazione PENTA for the Treatment and Care of Children with HIV ONLUS & PEDIANET, IT
Vilnius University Children Hospital , LT
Erasmus University Medical Center Rotterdam, NL
Associacao de Saude Infantil de Coimbra, PT
University Medical Centre Ljubljana, SI

European Commission

EpiSouth Network for the Control of Public Health Threats in the Mediterranean Region and South East Europe

The EpiSouth Plus Project: strengthening the control of public health threats through a Mediterranean and South-East European network

Dente MG , Riccardo F, Fabiani M, Alfonsi V, Nacca G, Ranghiasci A, Meduri F, Tancredi P and Declich S on behalf of the EpiSouth Network*

Italian National Institute of Health (ISS), Rome, Italy

* ALBANIA, Tirana (Institute of Public Health); ALGERIA, Alger (National Institute of Public Health); BOSNIA & HERZEGOVINA (Ministry of Civil Affairs, Sarajevo; Ministry of Health and Social Welfare, Banja Luka, Republic of Srpska; Public Health Institute, Mostar, Federation of B&H); BULGARIA, Sofia (National Center of Infectious and Parasitic Diseases; Ministry of Health); CROATIA, Zagreb (Croatian National Institute of Public Health); CYPRUS, Nicosia (Ministry of Health); EGYPT, Cairo (Ministry Of Health and Population); FYROM–Former Yugoslav Republic of Macedonia, Skopje (Institute for Health Protection; Clinic of Infectious Diseases); FRANCE (Institute for Public Health Surveillance, Saint Maurice Cedex; Institute Pasteur, Paris); GREECE, Athens (Hellenic Center for Diseases Control and Prevention); ISRAEL (Center for Disease Control, Tel Hashomer; Ministry of Health, Jerusalem); ITALY (National Institute of Health, Rome; Teaching Hospital, Padua; National Institute for Infectious Diseases "Lazzaro Spallanzani", Rome; Intrauniversity Consortium CINECA, Casalecchio di Reno; Local Health Unit of Turin, Turin); JORDAN, Amman (Ministry of Health); KOSOVO UNSCR 1244, Prishtina (National Institute of Public Health); LEBANON, Beirut (Ministry of Public Health); LIBYA, Tripoli (National Center for Infectious Disease Prevention and Control); MALTA, Msida (Ministry of Health, Elderly and Community Care); MECIDS Middle East Consortium on Infectious Disease Surveillance; MONTENEGRO, Podgorica (Institute of Public Health); MOROCCO, Rabat (Ministry of Health); PALESTINE, Ramallah (Ministry of Health); ROMANIA, Bucharest (Institute of Public Health); SERBIA, Belgrade (Institute of Public Health); SLOVENIA, Ljubljana (Institute for Public Health); SPAIN, Madrid (Carlos III Health Institute); SYRIA, Damascus (Ministry of Health); TUNISIA, Tunis (Ministry of Health); TURKEY, Ankara (Ministry of Health; Refik Saydam National Hygiene Centre); WHO-IHR International Health Regulations Coordination, Lyon, France

Summary

With 27 participating countries, the EpiSouth Network was the biggest inter-country collaborative effort in the Mediterranean Region. Following the successful implementation of the EpiSouth Project (2006-2010), which focussed on communicable diseases, surveillance and training, the network implemented the EpiSouth Plus Project (2010-2014) with a focus on strengthening preparedness to common health threats and bio-security risks. Thanks to the EpiSouth Plus Project, a Mediterranean Regional Laboratories Network was established, a capacity building process on preparedness to common health threats was set up, the creation of a "*culture of epidemic intelligence*" was supported and facilitation of IHR implementation with a special focus on coordination of surveillance between Points of Entry was promoted.

Background and Aim

Countries around the Mediterranean Sea share epidemiological characteristics and public health problems.
In order to share knowledge and develop joint activities, in 2006 a Mediterranean collaborating framework, called the EpiSouth Network, was established.

The EpiSouth Network progressively expanded from including 9 EU MS to 27 countries of which 10 EU MS and 17 Non-EU MS from South Europe, the Balkans, North Africa and the Middle-East. It was therefore the biggest inter-country collaborative effort in the Mediterranean Region.

In order to increase health security in the Mediterranean Area and Balkans, it is necessary to enhance preparedness, detection and response capacity at national/regional levels to face threats to public health. The framework of the International Health Regulations (IHR) is particularly useful in this effect because it is not only legally binding for all EpiSouth partners but it also declines a set of capacities to be met, detailing a mechanism for information exchange and response collaboration under the umbrella of WHO.

Between 2010 and 2014, the network implemented the EpiSouth Plus Project with the aim to increase the health security in the Mediterranean area and South East Europe by enhancing and strengthening preparedness to common health threats and bio-security risks at national and regional levels and in the framework of the WHO-IHR.

EpiSouth Plus activities

In addition to WP1-Coordination; WP2-Dissemination; WP3-Evaluation, EpiSouth Plus activities were articulated in four WPs: WP4-Establishing a Mediterranean Regional Laboratories Network; WP5 - Promoting common procedures in Generic Preparedness and Risk Management Plans; WP6-Enhancing Mediterranean Early Warning Systems (EWS) and cross-border Epidemic Intelligence, and WP7- Facilitating IHR implementation.

Management

The Project was led by the Italian National Institute of Health (ISS) and counselled by an Advisory Board composed by EC, ECDC, WHO and other international experts. Each country participating in the EpiSouth Network was represented by two national EpiSouth Focal Points (FPs). Each FP was a public health officer working in the country's MoH or IPH officially selected among those involved in preparedness and risk management of Communicable Diseases and other Public Health threats. Most FP were also WHO International Health Regulations (IHR) and/or EU Early Warning and Response System (EWRS) Focal Points. Participation to the Network activities was on a voluntary basis. Staff from participating countries were not paid for their contribution, however all costs related to their involvement in the Network activities were covered by the projects. Each EpiSouth Plus WP, with the exception of WP3 evaluation, was led by two co-leaders (one from an EU and one from a non-EU Country/International Organization). In order to facilitate countries' participation and WPs activities implementation, Steering Teams (WPSTs) were established for each WP to identify the countries' needs, develop the tools and the conducive project environment in accordance with the specific objective and requirements of the related WP. The project activities and achievements were disseminated through a multilingual website and quarterly bulletins. EpiSouth Plus underwent both an internal and external evaluation.

Results

A Mediterranean Regional Laboratories Network was established to facilitate common threat detection and build regional capacity on the diagnosis of Dengue, West Nile Viruses and on Biosecurity. This network was consolidated through trainings, site visits and an External Quality Assessment (EQA). A capacity building process on preparedness to common health threats was set up with training modules and workshops culminating in the implementation of the Nautilus Simulation Exercise and the preparation of the EPREP Tool (Emergency Preparedness Planning) aimed at supporting EpiSouth Countries in setting up their Preparedness Plans. The focus of EpiSouth Plus epidemic intelligence (EI) activities has been on sharing information, the publication of bulletins and thematic notes and residential stages on EI/Event Based Surveillance. In order to facilitate information sharing, the EpiSouth Network set up and facilitated a dedicated secure platform. Since late 2012, to ensure its sustainability after the end of EpiSouth Plus and interoperability, this secure platform is hosted and managed by the European Centre for Disease Prevention and Control (ECDC). In the framework of facilitating IHR implementation, EpiSouth Plus countries highlighted the need to enhance the coordination of surveillance between Points of Entry, (i.e. ports, airports and ground crossings), and the National Health Systems in the Mediterranean Region. EpiSouth Plus contributed to the development of knowledge in this area, by conducting in four countries of the Network the EpiSouth Plus National Situation Analysis on coordination of surveillance between PoE and NHS (ENSA). This study included site visits in each participating country involving both the Ministries of Health and PoEs.
The EpiSouth Plus capacity building events/activities have involved more than 200 people and include two project meetings, two workshops/trainings on preparedness, two trainings on applied epidemiology, one simulation exercise, one lab training on Dengue, one lab training on WNV, EQA for Dengue and WNV, lab experts site visits, three residential stages on Early Warning and Epidemic Intelligence and four site visits carried out in the framework of the WP7 ENSA. The main final Outcomes/Deliverables have been three Strategic Documents: the EPREP Tool; Recommendations for the Institutions and consolidation of relevant lab networks and their capacity building process; and the Report on Coordination of Epidemiological Surveillance between PoE and the National Health System in the Episouth Region, co-authored by WHO.

The EpiSouth Network website

Conclusions

EpiSouth-Plus was unique for its focus on the Mediterranean region as a whole, including non-UE countries and all three WHO Regional Offices that cover the Mediterranean. In addition to facilitating epidemiological communication and practical training, this regional approach strengthened solidarity and cohesion within the European Community and between EU and non-EU countries. It also enabled information sharing on cross-border public health threats and contributed to facilitating the implementation of IHR. Ultimately, EpiSouth-Plus contributed to the stability of the region as well as to improve public health protection.

The EpiSouth Plus Project was co-funded by the European Union DG-SANCO/EAHC and EuropeAid together with the participating national partner Institutions. The financial support of the Italian Ministry of Health and ECDC is also acknowledged.

Starting date -duration	October 2010 - 39 months
Leader Organization	The Project is led by the Italian National Institute of Health (ISS) and counselled by an Advisory Board composed by EC, ECDC, WHO and other international experts.
Contact/WebSite	EpiSouth Dissemination Team: episouth@iss.it www.episouthnetwork.org

European Commission

This project is receiving co-funding from the European Union in the framework of the EU Health Programme 2005-2008

Euro Living Donor EULID

CLÍNIC BARCELONA Hospital Universitari

EULID

European Living Donation and Public Health

Protection, information, registry and satisfaction in living donation

Hospital Clínic de Barcelona (Spain)
Hospital Geral de Santo Antonio (Portugal)
Paraskevaidion Surgical and Transplant Center (Cyprus)
Assistance Publique Hôpitaux de Paris–Hôpital Necker (France)
POLTRANSPLANT (Poland)
Rikshospitalet – Radiumhospitalet Medical Centre (Norway)
CNT ISS-Centro Nazionali Trapianti (Italy)
Slovenija Transplant (Slovenia)
Sahlgrenska University Hospital (Sweden)
NHS Blood and Transplant – UK Transplant (UK)
ANT Fundatia Petnru Transplant (Romania)
Institute for LifeLong Learning - IL3 (Spain)

Contribute to consensus and establish recommendations to ensure the health and safety of the living donor among European countries

Consensus	Tools
Legal aspects	Informative leaflet
Ethical dilemmas	On-line data base
Protection practices	Satisfaction survey
Registry model	

Tools Developed

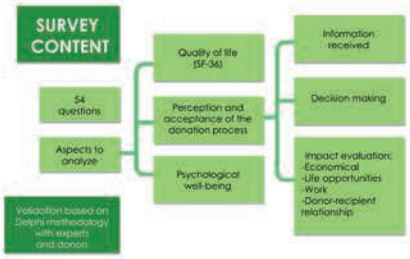
INFORMATION - INFORMATIVE LEAFLET

Translated in **12 languages**, 2 different parts according to **each organ** (kidney and liver) about: options to become a donor, donor selection, surgical approach and long-term follow-up.

REGISTRY - MODEL DATA

On-line login module was **created**; in use for research project activity

SATISFACTION - LIVING DONOR SATISFACTION SURVEY



Dissemination

MINI-CD OF THE PROJECT

Information and deliverables, are widely spread in several international meetings

WEBSITE

It is active and updated; actually in use for further research projects

LIVING DONOR REGISTRY

Currently there are **1550** registered Living Donors with mandatory data; from 19 centres in 12 EU countries

Conclusions

- The project contributes to a European consensus on legal and ethical issues that could lead to best practices.
- The protection of living donors should be done through laws and regulations as well as giving information and performing a follow-up.
- The consensus on common registries and the recommendation for their application are important improvements to be implemented.

Expert involved: M. Manyalich

www.eulivingdonor.eu

European Commission

Cost effectiveness of public health responses against human influenzae pandemic in Europe

Project leader: A. Beresniak, Paris Descartes University, France

SUMMARY

BACKGROUND

The constant threat of emerging subtipes influenza viruses with pandemic potential imposes to European countries to prepare efficient responses adapted to pandemic planning.

Most of the European countries had pandemic preparedness plans in place when the Pandemic H1N1 (2009) strain emerged in april 2009. These plans need to be revised to take into account the lessons learned form the 2009 pandemic. The objective of the FLURESP project is to assess performance and socio-economical impact of response strategies in order to improve European public authorities ability to better respond to various categories of threats thru better preparedness plannings.

METHOD

After clustering pandemic scenarios, 18 public health responses have been selected and assessed according to 15 criteria. Data collection has been carried out in France, Italy, Romania and Poland.

Multi-criteria analyses using outranking methods have been performed to compare the performance of the response strategies in four health system (France, Italy, Romania, Poland).

Cost-Effectiveness ratios have been calculated for each response strategies according to the 6 pandemic categories and two effectiveness criteria (achieving mortality reduction by 40% or achieving morbidity reduction by 30%)

Then recommendations have been proposed for public health decision making .

RESULTS

A new typology of pandemic scenarios has been clustered in 6 levels (A-B-C-D-E-F) from seasonal-like scenario (A) to severe pandemic (F).

Multi-criteria analyses suggested that mass vaccination outranked other interventions.

Cost-effectiveness analyses established that using morbidity effectiveness criteria, mass vaccination using usual organizations is the most cost-effective response.. Concerning antiviral therapies, curative strategies appear more cost-effective than prophylactic distribution.

CONCLUSION

FLURESP is the only program developing a methodology able to assess main public health interventions according to multiple endpoints, and to compare their cost-effectiveness for public health decision making.. Tested in four European health systems, this approach should be implemented in the other member states for efficient preparedness.

PROJECT MANAGEMENT

WP1 : MANAGEMENT

The management of the FLURESP project implies the coordination of 12 partners located in 10 countries.

The actions undertaken to manage the FLURESP project are the following : - Ensure the general project management, - Assist and control each WPs management, - Be the interface between the project administration and the administrative structure EAHC.

WP2 : DISSEMINATION

WP2 includes external communication actions ensuring that the results and deliverables of the FLURESP project will be made available to the stakeholders and a wider audience.

The general public will be reached through stakeholders and policy makers : -International stakeholders will be contacted through relevant institutions and international organizations.

National bodies in charge of flu control and epidemiology from the 27 member states will be involved in the dissemination to policy makers. Flyers, posters and congress communications have been edited to promote the project.

In particular, a **special FLURESP conference** has been organized in Luxemburg in March 2014 to present the preliminary results of the FLURESP project to an audience composed by European stakeholders.

In addition a **FLURESP dedicated symposium and a booth** has been presented in the frame of the fifth ESWI influenza conference organized in Riga in September 2014.

Finally derived scientific manuscripts will be submitted to peer reviewed scientific journal ensureing the sustainability of the FLURESP project final outcomes.

WP3 : EVALUATION

WP3 has organized a systematic appraisal of the quality of the FLURESP project and has monitored whether the project achieved its objectives, based on measurable performance indicators (Timelines, objectives reached, resource management, etc.).

METHODOLOGY

The first phase of the FLURESP was an **extensive literature review** in order to define pandemic scenarios in Europe.

On the second phase, **18 key public health interventions** have been selected and defined according to **15 criteria** including costs, performance, ethical, legal and inter-sectoral impact.

Pilot data collection has been carried out in four countries: **France, Italy, Poland and Romania.**

Then **multicriteria analyses** have been carried out using outranking approaches.

The third phase of the methodology was devoted **to cost-effectiveness analyses** comparing the 18 interventions according to the six defined pandemic scenarios and two effectiveness criteria (achieving morbidity reduction by 30% and achieving mortality reduction by 40%).

RESULTS

The following recommendations were derived from the FLURESP results:

1. **An appropriate data collection should be organized through a robust information system to better assess interventions against human influenza threats**
2. **Cost-Effectiveness of public health interventions should be expressed using meaningful criteria such as costs per success**
3. **Using existing vaccination centers and primary care services appears more cost-effective for implementing vaccination programs**
4. **Targeting the general population appears more cost-effective for implementing vaccination programs whatever the level of severity of the outbreak**
5. **Curative distribution of Antivirals appears more cost-effective than prophylaxis distribution**
6. **Guidelines for antibiotic therapy appears to be a cost-effective measure to reduce mortality**
7. **Development of referral centres with extracorporeal membrane oxygenation (ECMO) capability appears to be a cost-effective measure to reduce mortality**
8. **Screening interventions and individual prevention measures are more cost-effective when implemented in addition to other interventions**

CONCLUSION

The integrated approach of Decision Making proposed by the FLURESP consortium constitutes a premiere at the European and global level, which would support European member states to select the most appropriate and efficient public response to various scenarios of human pandemic. The FLURESP project will contribute to the European Union initiatives on Health Security, in the area of preparedness and management of Human influenza pandemics .

Project co-financed by the EU Public Health Programme 2008-2013
Starting date: April 2011, Duration 42 months
Total costs: 1'108'787 €
Subsidy from the Commission: 699'977 €

Leader organization: Paris-Descartes University, Paris, France
Administrative entity: Claude-Bernard Lyon 1 University, Lyon, France
Contact person: Ariel Beresniak
aberesniak@datamining-international.com
Project website: www.fluresp.eu

Partners

Paris Descartes University, LIRAES, France; Neiker Tecnalia, Animal Health Department, Spain; WHO, Global Influenza Programme, Switzerland; Openrome, France,; Ministry of Health, Public Health Regulation Division, Malta; National Institute of Hygiene, Poland; University of Crete, Greece; Niddam European Community Lawyer; Hungary; Retroscreen Virology ltd, Virology, UK; National Center for Epidemiology, Surveillance and Health promotion, Italy; Claude Bernard University, ERIC, France

European Commission

Joint Action QUANDHIP
Quality Assurance Exercises and Networking on the Detection of Highly Infectious Pathogens

R. Grunow[1] (Coordinator), D. Jacob[1], U. Sauer[1], B. Arnold[1], A. Rohleder[1], A. Di Caro[2], R. Iacovino[2], G. Ippolito[2] (Co-Coordinator), on behalf of QUANDHIP partners

[1]Robert Koch-Institut, Centre for Biological Threats and Special Pathogens (ZBS 2), Berlin, Germany, [2]National Institute for Infectious Diseases "L. Spallanzani", Virology Department, Rome, Italy

Summary

QUANDHIP is a Joint Action initiative set up in 2011 that has successfully unified the primary objectives of the "European Network of P4 Laboratories" (ENP4Lab) and the "European Network on Highly Pathogenic Bacteria" (ENHPB) both of which aimed to improve the efficiency, effectiveness and response capabilities of laboratories directed at protecting the health of European citizens against high consequence bacteria and viruses of significant public health concern. Both networks have integrated a wide collaborative consortium of currently 37 partners. The infectious agents in focus of the activities comprise B. anthracis, F. tularensis, Y. pestis, B. mallei, B. pseudomallei, Brucella species, C. burnetii as well as Filoviruses, Arenaviruses, Bunyaviruses, Orthopoxviruses, Paramyxoviruses, and recently discovered viruses.

Methodology

External Quality Assurance Exercises (EQAEs):
Exchanging experiences regarding laboratory preparedness and response capabilities by performing 6 rounds of EQAEs (bacterial and viral) and 6 meetings (separate and joint for partners working on bacteria and viruses).

- to test and improve the network's capacity for diagnostic preparedness
- to develop „Gold Standard(s)": Standardised European laboratory diagnostic strategies and reference material
- to establish data on antimicrobial susceptibility of high threat bacteria in connection with EUCAST
- to test spectroscopic, rapid, and alternative diagnostic methods

Repository:
Providing relevant characterized isolates, clinical and environmental samples, for quality control and for validation in the diagnostic process of highly infectious agents.

- to extend the bacterial repository at the RKI
- to develop a list of key reference strains of all BSL 4 agents and their location to promote the exchange of all reference strains of all BSL 4 viruses
- to develop and verify quantitative standards for the comparison of different methods and instruments
- to transfer material assuring security and traceability

Training:
Exchange of practical laboratory based training between the JA Partners with regard to best practice including essential elements of biosafety and biosecurity.

- to exchange expertise on high threat bacteria and viruses
- to identify best practices in diagnostics, biosafety and biosecurity, management of biological events and risk assessment
- to extend the existing training list by developing further training programmes
- to involve experiences of other networks, such as ETIDE and EURONHID

Biosafety and Biosecurity:
Improvement and dissemination of prepared checklists outlining engineering, primary and secondary containment strategies, building design and infrastructure, integrated specialized equipment, disinfection, biosafety and biosecurity issues for risk group 3 and 4 pathogens.

- to include cross-disciplinary input from other organizations: ECDC, Biosafety Europe, European Biosafety Association and WHO
- to support the setting up or re-evaluation of BSL 3 and 4 laboratories
- to cooperate with security agencies in order to bridge Health and Security

Working Group (WG):
Providing recommendations and support with regard to cross-border events with highly infectious pathogens.

- to develop collaboration models between highly specialized and routine laboratories, emergency services, clinical settings, Public Health officials, CBRN investigation and forensic operations (SOP: running a BT-sample)
- to promote interactions between the bacterial and viral networks
- to organise transport for sample sharing
- to assess existing mobile laboratories and their deployment during outbreak response
- to bridge CBRN investigation and forensic laboratory operations

Coordination

Actions undertaken to manage the project and to ensure that it is implemented as planned

- Technical coordination and management is carried out for each network separately by RKI and INMI.
- The two networks on viruses and bacteria are linked for a close collaboration in case of unknown biological threats.

Dissemination

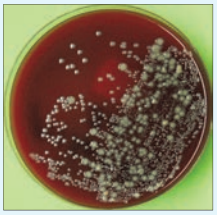
Ensure information flow and access to various prepared documents for partners and public

- Development of recommendations, a website, an internal workspace, publications, leaflets, presentations, meetings.
- The primary target groups will be laboratory workers dealing with the diagnostics of high threat pathogens, biosafety experts, first responders, clinical staff and security forces. The targeted stakeholders will be the EU Commission, national MOH including National (Microbiology) Focal Points (N(M)FP), GHSAG, WHO, ECDC.

Evaluation

A continuous evaluation process performed by Advisory Board, Steering Committee, Coordinators and WP leaders

- The Advisory Board comprises representatives from different organizations: ECDC, SANCO C3, GHSAG-LN and WHO.



Mixed bacterial culture containing *Yersinia pestis*

Filovirus (Ebolavirus)

Objectives

- to link and consolidate the objectives of two existing European networks, dealing with highly pathogenic bacteria (ENHPB) and viruses (ENP4Lab) that emerged from the EU funded project EQADeBa, coordinated by the Robert Koch-Institut (RKI), Germany, and the ENP4Lab project, coordinated by the National Institute for Infectious Diseases "L. Spallanzani" (INMI), Italy
- to ensure the exchange of best diagnostic strategies to support a European response strategy in case of outbreaks of highly pathogenic infectious agents
- to provide a supportive European infrastructure and strategy for external quality assurance exercises (EQAEs)
- to generate a biodiverse repository of reference materials

Results

- to protect and improve citizens' health and to bridge Security and Health by enhancing and optimizing the laboratory capabilities for diagnostics of high threat bacteria and viruses
- to provide sustainability for European capacity and capability building in the field of detection and identification of highly infectious pathogens based on national and international cooperation
- to ensure European laboratory preparedness for the management of natural and intentional outbreaks of high consequence pathogens
- to provide the necessary early response capabilities to support public health authorities, control measures, clinical patient management, and epidemiological and forensic investigations
- to further improve the laboratory preparedness for the diagnostics of highly pathogenic agents of risk groups 3 and 4
- to support the coordination of laboratory response to cross-border events dealing with highly infectious pathogens

ROBERT KOCH INSTITUT

Istituto Nazionale per le Malattie Infettive
I.R.C.C.S. "LAZZARO SPALLANZANI"

Partners

Main Partner / Coordinator: RKI, Germany
Co-Coordinator: INMI, Italy

26 Associated ENHPB partners:

AGES	Austria	RIVM	The Netherlands
VAR	Belgium	IZSPB	Italy
FLI	Germany	NCIPD	Bulgaria
ISS	Italy	IMBBw	Germany
FoHM	Sweden	INSA	Portugal
PHE	UK	SUJCHBO	Czech Republic
THL	Finland	IZSLER	Italy
NKUA	Greece	ISC III	Spain
NCE	Hungary	DGA	France
NPHSL	Lithuania	NVRI	Poland
NIPH	Norway	DTU	Denmark
PZH	Poland	TA	Estonia
BIOEF	Spain	LIC	Latvia

5 Associated ENP4Lab partners:

BNI	Germany	FoHM	Sweden
PHE	UK	INSERM	France
PUM	Germany		

2 Collaborating ENHPB partners:

FOCP	Switzerland
NVI	Norway

2 Collaborating ENP4Lab partners:

FOCP	Switzerland
NCE	Hungary

Acknowledgements

We would like to thank the CHAFEA for funding and thus realizing QUANDHIP, but also all project partners for their cooperation and for the external support provided by ECDC, SANCO C3, GHSAG-LN and WHO.

Project co-financed by the EU Public Health Programme 2008-2013
Starting date: 1st August 2011
Duration: 42 months
Total costs: 6.631.963 €
Subsidy from the Commission: 3.315.982 €

Coordinator: RKI
Co-coordinator: INMI
Contact person: Prof. Dr. Roland Grunow
E-mail: GrunowR@rki.de
http://www.quandhip.info

European Commission

EU SHIPSAN ACT Joint Action

The impact on maritime transport of health threats due to biological, chemical and radiological agents, including communicable diseases

EU SHIPSAN ACT Coordination Team: *Prof. Christos Hadjichristodoulou (University of Thessaly, Greece), Dr Barbara Mouchtouri (University of Thessaly, Greece), Mr Mauro Dionisio (Ministry of Health, Italy), Dr Carman Varela Martinez (National Centre of Epidemiology, Spain), Prof. Raquel Duarte Davidson (Public Health England), Dr Peter Otorepec (National Institute of Public Health, Slovenia), Dr Thomas von Münster (Institute for Occupational and Maritime Medicine, ZfAM, Hamburg State Department for Health and Consumer Protection, Hamburg, Germany), Dr Martin Dirksen-Fischer (Institute for Occupational and Maritime Medicine, ZfAM, Hamburg State Department for Health and Consumer Protection, Hamburg, Germany), the SHIPSAN ACT partnership*

SUMMARY

Ships sail from country to country where different hygiene standards and rules for controlling diseases exist. This Joint Action aims to (i) produce a state of the art report, (ii) develop guidance on risk assessment and response to chemical and radiological events on ships, (iii) develop an outline of a risk assessment tool for occupational health risks per cargo ship type, (iv) increase port health staff and crew competencies, (v) improve quality of inspections and bring a consistent/ proportionate approach to inspection of all ship types, (vi) maintain and update SHIPSAN ACT information tools.

OBJECTIVES

The general objective of this action is to strengthen an integrated strategy and sustainable mechanisms at EU level for safeguarding the health of travelers and crew of passenger and cargo ships and prevent the cross-border spread of diseases.

METHODOLOGY

Methods for completing the specific objectives include:

- literature review
- table top and operational exercises
- surveys and questionnaires
- site visits
- training
- inspections
- working group meetings
- development of guidance documents

WP COORDINATION

The Joint Action has a three level organization structure:

- **strategic level** (general assembly and the advisory board)
- **executive level** (coordination and evaluation teams, and the coordinator)
- **management and implementation level** (work package leaders and teams)

WP DISSEMINATION

- **National Dissemination Plans** implemented by partners
- **Web-portal** www.shipsan.eu
  - 9,502 visits (August 2013 – August 2014)
- **Bimonthly e-newsletter**
  - 9 issues, >1500 readers
- **Leaflets**
- **Presentation of SHIPSAN ACT in Events:**
  - national conferences in EUMS
  - Events in Non-EU countries
  - European conferences/meetings (EC, ECDC)
  - International conferences (WHO, ANVISA)
- **Exit/Sustainability Plan**

WP EVALUATION

Evaluation is ongoing and throughout the Joint Action.

- **Indicators** are used to evaluate the progress and impact of the Joint Action.
- **Internal and external evaluation** involving
  - (a) interviews
  - (b) questionnaire
  - (c) SWOT analysis (strength, weakness, opportunities, threats)
- **Timely feedback of evaluation results**

RESULTS

RESEARCH

A five part State of the Art report consisting of:

Part A	Part B	Part C	Part D	Part E
• Literature review on **infectious diseases** on all types of ships.	• Literature review and survey on **chemical and radiological incidents** in maritime transport.	• Survey on hygiene inspection practices on **fishing vessels** in EU.	• Survey on training needs related to **core capacities at points of entry-ports** in EU.	• Survey on practices & responsibilities of port health authorities along **inland waterways** in EU.

GUIDELINES

Guidelines under development for competent authorities in support to their risk assessment and response to chemical and radiological incidents on ships while the ship is at port.

TRAINING

- Pool of trainers: **83 trainers from 20 countries**
- e-learning platform: **325 registered users** http://elearning.shipsan.eu
- Training courses (European and national) focused on IHR (2005) and EU SHIPSAN manual:
  - **96 seafarers and 101 port health officers** trained via **face to face** courses
  - **100 port health officers** received **on the job training**

INSPECTIONS

In 2013: **50 inspections** conducted on **48 passenger ships** in **22 ports** from **13 EUMS** based on EU standards by trained inspectors.
In 2014 (ongoing): **52 inspections** scheduled.

	2011	2013
Inspection Reports	42	48
Corrective Action Statements	20	31 (out of 48 requiring Corrective Action)
Number of Deficiencies	393	517
• Non compliances with requirements of the EU legislation	41	84
• Non compliances with recommended standards of the Manual	282	360
• Notations	70	73

WEB SYSTEMS

- **19 public health events** on ships were followed up by competent authorities using the web-based Communication Network https://www.shipsan.eu/comnet/
- **4192 certificates** were issued using the Information System for recording/issuing IHR Ship Sanitation Certificates http://ssc.shipsan.eu
- **Contact details of authorised ports** of 19 EU countries for issuing Ship Sanitation Certificates under IHR (2005) available via the European directory http://www.shipsan.eu/Inspections/AuthorisedportstoissueSSC.aspx

OCCUPATIONAL HEALTH

Web-based risk assessment tool for occupational health risks per cargo ship type by using the European Agency for Safety and Health at Work (EU-OSHA) Online Interactive Risk Assessment (OiRA) tool http://www.oiraproject.eu/

CONCLUSION

EU SHIPSAN ACT helps countries to preparedness planning and to develop IHR core capacities. It strengthens the EU's capacity to monitor and respond to health threats by facilitating rapid ship-to-port and port-to-port information exchange using web-based tools. It protects health of (a) ship travelling passengers in the EU, by strengthening compliance of ships with legislation, standards and guidelines and implementing an integrated strategy for epidemiological investigation; (b) crew working on ships, by providing training on ILO Maritime Labour Convention health related issues. Its actions contribute to protect the EU population against health threats and improve citizens' health security.

Acknowledgments: To the EU Commission for co-financing the Joint Action and to all participants from the EU and International institutions, the EU MS and the shipping industry.

Joint Action financed: EU Public Health Programme 2008-2013
Years of the Joint Action: 2013-2016 (39 months)
Total cost: 2.571.346€ **Subsidy from the Commission:** 1.799.942€
Leader Organisation: University of Thessaly (UTH), Greece
Contact Person: Prof. Christos Hadjichristodoulou xhatzi@med.uth.gr
Website: www.shipsan.eu

Partners: 30 partners from 23 EUMS, European and international Institutions, shipping Industry. Associated partners: Ministry of Health, Italy/Klaipeda Public Health Center, Lithuania/Directorate of Health, Centre for Health Security and Communication Diseases, Iceland/National Institute of Public Health, Slovenia/Instituto De Salud Carlos III, Spain/National School of Public Health/Special Research Account, Greece/Public Health England, Centre for Radiation Chemical and Environmental Hazards, United Kingdom/Department for Health and Consumer Protection, University Medical Center Hamburg-Eppendorf, Germany/Regional Health Inspection, Bulgaria/Association of Port Health Authorities, United Kingdom /Health Service Executive, Ireland /Robert Koch-Institute, Germany/Regional Health Inspection, Bulgaria. **Collaborating partners:** Ministry of Health, Austria/ Federal Public Service of Health, Belgium/ Ministry of Health, Cyprus/ Health Board, Estonia/ Ministry of Labour, Employment and Health, France/ Minister for Health, the Elderly and Community Care, Malta/ Norwegian Directorate of Health, Norway/ Ministry of Health, social services and equality, Spain/ Ministry of Health, Romania/ Ministry of Transport, Construction and Regional Development of the Slovak Republic/ Ministry of Health and Social Welfare, Croatia/ Municipal Health Services Rotterdam, Netherlands/ National Institute for Health and the Environment, Netherlands/ Ministry of Health, Portugal/ Medical University of Gdansk, Poland

European Commission

Quality Action
Improving HIV Prevention in Europe

Quality Action
Joint Action on Improving HIV Prevention

Matthias Wentzlaff-Eggebert & Ursula von Rueden,
Federal Centre for Health Education, BZgA (Germany)

European Commission
DG Health & Consumers

SUMMARY

Rates of HIV diagnoses remain high among key populations and vary in different regions of the EU. **Quality Action** aims to increase the effectiveness of HIV prevention in Europe through the use of **practical Quality Assurance (QA) and Quality Improvement (QI) tools**. Quality Action is the EU co-funded Joint Action with 25 associated and 19 collaborating partners that started in March 2013 and will run for three years.

OBJECTIVES

The general objective of Quality Action is to improve the quality of the response to HIV and AIDS in Europe. Quality Action will: 1) integrate evidence-based quality assurance and quality improvement practices into HIV prevention across Europe; 2) build a network of trained HIV prevention stakeholders to apply practical QA/QI tools to projects targeting priority groups; 3) mainstream QA/QI into HIV prevention through development and dissemination of an agreed Charter for Quality in HIV prevention as well as policy guidance.

Quality Action contributes to the implementation of the Communication of the European Commission: 'Combating HIV/AIDS in the European Union and neighbouring countries (2009 -2013) and the Action Plan 2014-2016.

METHODOLOGY

Five tools for QS/QI were developed and adapted in an iterative, theory-based process. Standardized trainings for the tool application is provided. The capacity building includes practice-based learning as well as e-learning. The practical application of the tools will be evaluated and the results will be used to develop a 'Charter for Quality in HIV Prevention' with agreed quality principles and criteria to improve quality. A Policy Kit will promote the integration of QA/QI into HIV prevention strategies, policies and action plans at the European, regional and member state levels.

WP COORDINATION

WP Leader: Federal Centre for Health Education, BZgA (Germany)

BZgA is responsible for the overall management of Quality Action: coordination, financial management, problem solving and reporting to the CHAFEA. BZgA also convenes the Steering Group and the Advisory Group.

WP DISSEMINATION

WP Leader: EuroHealthNet

EuroHealthNet coordinates the dissemination activities of Quality Action. This includes the development of a visual identity, website (www.qualityaction.eu) and dissemination materials. It also entails the organisation of the Quality Action conference.

WP EVALUATION

WP Leader: Institute of Tropical Medicine ITM (Belgium)

ITM evaluates Quality Action.
It reports on the project's objectives using qualitative and quantitative methods for both process and outcome evaluation, and assess the future potential of QA/QI for HIV prevention across Europe.

This project has received funding from the European Union within the framework of the EU Public Health Programme 2008-2013
Years of the Project: 2013 – 2016
Total cost 3 530 012 euro out of which 1 499 571 euro EU contribution
Acknowledgements: To all persons who are participating in the project and applying the QA/QI tools. To the Advisory Board members and to the EC Commission for co-financing it.

RESULTS

Quality Action has developed and adapted **five practical QA/QI tools and support materials**.

Quality Action has **trained more than 100 HIV prevention experts** in one or more of the five Quality Action tools during European-level training workshops. National-level training reaches additional stakeholders.

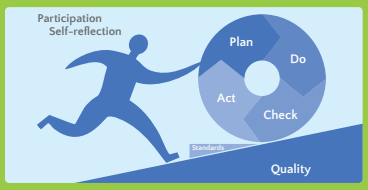
Quality Action provides collaboration and support to the people and organisations applying the QA/QI tools through its **online forum and support network** (www.qualityaction.eu)

Quality Action collects data and feedback from people and organisations applying the QA/QI tools. Their input will be used to produce a **package of core materials** (available in a range of languages) to support quality in HIV prevention.

Quality Action will develop a **Charter for Quality in HIV prevention** with quality principles and criteria for HIV prevention agreed by key stakeholders. A **Policy Kit** will support policy makers and strategic planners to support quality improvement in HIV prevention.

CONCLUSION

The Joint Action aims at improving the planning, implementation and evaluation of interventions, as well on maximising the impact on priority populations to improve health.



Project coordinator: Bundeszentrale für gesundheitliche Aufklärung, Germany

Partners: 1. EuroHealthNet, Belgium; 2. Prince Leopold Institute for Tropical Medicine – Foundation of Public Utility, Belgium; 3. Folkhälsomyndigheten, Sweden; 4. The Sexual Health Centre Ltd, Ireland; 5.Deutsche AIDS-Hilfe e.V., Germany; 6. Public Health England, UK; 7. Aids Hilfe Wien, Austria; 8. Sensoa vzw, Belgium; 9. Central National Institute of Public Health, Croatia; 10. HELP udruga za pomoc mladima, Croatia; 11. National Institute for Health Development, Estonia; 12. Hellenic Centre for Disease Control and Prevention, Greece; 13. Health Service Executive, Ireland; 14. Lega Italiana per la Lotta contro l' Aids, Italy; 15. National Institute for Infectious Diseases Lazzaro Spallanzani, Italy; 16. Centre for Communicable Diseases and AIDS, Lithuania; 17. Aidsberodung Croix-Rouge Luxembourgeoise, Luxemburg; 18. Aids Fonds -STOP AIDS NOW! – Soa Aids Nederland, Netherlands; 19. Spoleczny Komitet ds. AIDS, Poland; 20. National Institute for Infectious Diseases, Romania; 21. Slovak Medical University, Slovakia; 22. Drustvo SKUC, Slovenia; 23. Ministerio de Sanidad, Servicios Sociales e Igualdad, Spain; 24. Sida-studi, Spain.

Layout: Orangemetalic.be & Tinctuur.be

European Commission

Co-funded by the European Commission's EU Public Health Programme (DGSanco 2009 1108)
2010-2013

ODEQUS

Organ Donation European Quality System

Creating a pan-European methodology to evaluate the organ procurement performance at hospital level

Associated Partners
- Coordinator: UB – Spain
- MUV – Austria
- MHSW – Croatia
- ABO – France
- DSO – Germany
- FITOT – Italy
- Poltransplant – Poland
- IPST – Portugal
- FTP – Romania
- DTI – Spain
- SERMAS – Spain
- KI – Sweden
- NHSBT – UK

Collaborating Partners
- EOM – Greece
- HNBTS – Hungary
- MH – Malta
- ST – Slovenia
- MAHC – Turkey

InvitedPartners
- Donate life - Australia
- Universiy of Daman - KSA

Final Meeting, Sitges, May 30-31 2013

Conclusions

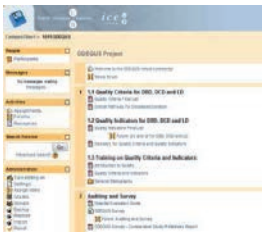
Permanent expert working group of representatives from 11 partner countries settled, most of them are also representatives on the European Competent Authorities in Organ Donation.

- 131 Quality Criteria identified
- 30 Quality Indicators developed
- Quality Indicators were tested successfully in 12 hospitals, proofing their feasibility and accuracy as evaluation tools: Vienna General Hospital, University Hospital Zagreb, Annecy Hospital, University Hospital Tübingen, Policlinico Hospital Umberto I Roma, Child Memorial Health Institute in Warsaw, Międzyleski Szpital Specjalistyczny in Warsaw, Hospital de Santo António do Porto, Hospital Doce de Octubre, Karolinska University Hospital, Queen Elizabeth Hospital in Birmingham, County Hospital in Timisoara.

The program has the European Commission through its 'Action Plan on Organ Donation and Transplantation (2009–2015)'.

Tools

Virtual Community



Quality Criteria

Quality Indicators

Dissemination activities

Expert involved: G. Guasch, G.Páez, M. Gómez, L. Teixeira, M. Manyalich.

www.odequs.eu

European Commission

PHASE project

Public Health Adaptation Strategies to Extreme weather events

Paola Michelozzi and Francesca de'Donato, PHASE Coordinator. Department and Epidemiology Lazio Regional Health Service, Rome, Italy.

BACKGROUND

Considering climate change scenarios extreme weather events are likely to become more frequent and more intense. Great attention has been devoted to the health effects of high temperatures while the impact of other extreme weather events (EWEs) have been less investigated.

OBJECTIVES

The project will provide a framework of tools for preparedness and response to EWE (heat waves, cold spells, flooding) and their environmental consequences (wildfires, air pollution) in order to reduce their impacts on public health. A specific contribution of the project will be to apply new methodologies to improve knowledge on the health effects of EWE.

The objectives are:

- provide national and local governments, health and social services with tools to improve adaptation and help mitigate the impacts of EWE on health, taking into account local health care systems and infrastructure characteristics
- to increase population and institution awareness on the health risks associated to EWEs
- to identify vulnerable subgroups most at risk of the health impact of EWEs and target prevention measures to these subgroups.

WP1 COORDINATION

Project meetings was organized every year to discuss progress and present results to partners and stakeholders. The coordinating partner, ASLRME.DE, maintained contact with and provided support for administrative, financial and technical aspects.

METHODOLOGY

A common approach was defined for each EWE which comprised of:

- Literature review to identify research gaps and at risk subgroups
- Estimate health effects (risk) related to exposure to each EWE in case study areas taking into account temporal variations in exposure and vulnerability factors
- Survey public health plans (warning, systems, surveillance systems, prevention measures) for each EWE in EU countries
- Identify best practise public health actions targetted to high-risk subgroups

WP2 DISSEMINATION

The project results were disseminated through:

- Project website
- Leaflet
- Topical newsletter
- Presentation of interim and final reports
- Presentations at local and international events and conferences
- Topical workshop on flooding
- WP and project meetings
- Scientific papers

WP3 EVALUATION

The project was evaluated with process indicators and outcome indicators every 6-12 months. The majority of indicators had a value above 80 (100 was the maximum).

RESULTS

Extreme weather events have a significant impact on human health and are heterogenous among population subgroups and between European cities.

For example in WP4 Heat:

•A temporal variation in the effect of heat was observed in 9 EU cities, with a reduction in Mediterranean cities (adaptation) and an increase in Scandinavian cities (higher exposure).

•Susceptible subgroups to heat/cold include: children, pregnant women (risk of preterm delivery), subjects with chronic disease, living in at risk areas (floodplains, hydrogeological instability, wildfire prone areas, polluted cities).

•Susceptibility characteristics (age, chronic conditions, socio-economic characteristics) vary over time.

CONCLUSION

The results of this project will be used to provide measures to improve best practice of emergency and public health prevention actions.

The Project has set up a collaborative network of researchers and policy makers from different countries on the climate and health topic.

Project financed: EU Public Health Programme 2008-2013
Years of the Project: 2011-2014 (38 months)
Total cost: 1.397.889,21€
Subsidy from the Commission: 744.037,82€
Acknowledgments: all partners who have collaborated in the project. To CHAFEA for co-financing it.

Project coordinator: Department of Epidemiology, Lazio Regional Health Service, Rome , Italy
Partners: 1. Public Health England, UK. 2. National and Kapodistrian University of Athens, Greece. 3. Université Pierre et Marie Curie, France. 4. Umea Universitet, Sweden. 5.National Institute for Health and Welfare, Finland. 6. Fundacion para el Fomento de la Investigacion Sanitaria y Biomedica de la Comunitat Valenciana, Spain. 7. National Institute of Environmental Health, Hungary. 8. Institut de Veille Sanitaire, France. 9. Dipartimento delle Protezione Civile, Italy. 10. WHO Regional Office for Europe

Website : www.phasecliamtehealth.eu

European Commission

SHARE:

Single Hub and Access point for paediatric Rheumatology in Europe

Background

A specific problem for rare diseases is that their low prevalence hinders sound and representative research. As a consequence there is a lack of evidence based guidelines for disease (and pain) management of Pediatric Rheumatic Diseases (PRD). Therefore, PRD treatment differs substantially throughout Europe and even within a single country. There is thus a need for standardized diagnosis and management of PRD throughout Europe.

OBJECTIVES

In short the aim of this project is to define what is needed in order to optimize care to children with PRD throughout Europe.

More specifically we aim to:

- summarize the needs for uniform management of rare pediatric rheumatic diseases throughout Europe

- provide recommendations for management of these diseases in European countries on which optimal treatment is based

- update the existing PRINTO (Pediatric Rheumatology International Trial Organisation) website with interactive tools and updated patient information

- provide a proposal for state of the art postgraduate education and training for health care professionals dealing with these diseases

COORDINATION

Work-Package (WP) leaders of all 8 WP met twice year to review progress in all the work packages. SHARE organizes 7 international meetings deicated to the development and execution of the project. The coordinating partner, University Medical Center Utrecht, maintained contact with all partners and invited experts on each PRD. The PRINTO office gives support on the execution of data anlysisis in WP4 and execution of WP7.

METHODOLOGY

Five WP are the core of the project:

WP4 aims to define the need for optimal care for PRD by providing nation wide recommendations based on a detailed evaluation of current standards of care, access to care, and protocols. This is organized through a web-based survey intended for both pediatric rheumatologist and patients throughout Europe.

WP5 aims to develop best practices for diagnosis and treatment of paediatric patients suffering from PRDs. This is accomplished through a systematic literature review for each PRD (as described in the EULAR method for achieving recommendations Guidelines on treatment of patients) plus the organisation of 2 consensus meetings with international experts on each PRD.

WP6 aims to update a central platform for data collection and analysis and for sharing of information both for health care professionals and patients. PRINTO and PReS, the largest European networks on PRD (see http://www.PRES.org.uk/ and http://www.PRINTO.it), will be partner in this.

WP7 will identify best practices for obtaining ethical consent from parents, children and adolescents, and for data and sample collection. To achieve this goal an analysis of ethical and legal issues surrounding data collection and procedures for informed consent will be performed. This includes a literature review on ethical issues and the development of a test-research proposal to be submitted to ethical comittees throughout Europe to identify differences in ethical approval and develop standards of best practices in ethical procedures.

WP 8 addresses training and education is addressed), aiming to ensure the implementation of the best practices identified in WP5 in the European training programmes. Again, a survey is used to identify existing national and international training programmes. From this, a proposal will be drawn up for inclusion of the results in the existing training programme of PReS and its members.

RESULTS

WP 4 is currently finalizing the survey to map the current situation of care for pchildren with PRD in all EU members.

WP5 has finalized systematic literature reviews for diagnosis and treatment of PRD. Together with the input of WP4, these data will be used for the development of best practices of care for children with PRD, including country specific recommendations to bridge the gap between the current and optimal situation.

WP6 is currently translating the updated patient information on PRD in 11 languages for the PRINTO website (www.printo.it).

WP8 is analyzing the comments of different ethical committees on a test proposal for clinical research in PRD in 14 Pediatri Rheumatology Centers in 8 European countries.

DISSEMINATION

The outputs of the project will be disseminated in a number of ways:

- Project website www.ucan-u.org/share

- Updated website www.PRINTO,it

- Presentation at rheumatology congresses in Europe and the US

- Organization of a patient organisation meeting (September 2014, Belgrade)

-Publications in Scientific Journals

- Organization of a Final dissemination Meeting for all stakeholders (Sept 2015)

CONCLUSION

The SHARE initiative will bridge the current differences between European countries in the care for children with PRD. This will be accomplished by inventarisation of the current situation, developing best practices for diagnosis and treatment of PRD, and developing recommendations in issues related to research and training of professionals. Finally, patient participation in the future care for PRD will be highly encouraged and facilitated.

Project financed: EU Public Health Program 2008-2013
Years of the Project: 2012-2015 (36 months)
Total cost: € 1.455.731
Subsidy from the Commission: € 860.244
Acknowledgments: to all experts who have participated in the project. To the EU Commission for co-financing it.

Project coordinator: Wilhelmina Childrens Hospital, University Medical Center Utrecht, n.wulffraat@umcutrecht.nl and b.vastert@umcutrecht.nl

The SHARE consortium consists of the following partners:
Jordi Anton (Barcelona, Spain), Tadej Avcin (Ljubliana, Slovenia), Brigitte Bader-Meunier (Paris, France), Michael Beresford (Liverpool, UK), Paul Brogan (London, UK), Liza McCann (Liverpool, UK), Tamas Constantin (Budapest, Hungary), Jasmin Kummerle Deschner((Tuebingen, Germany), Pavla Dolezalova (Prague, Czech Republic), Ivan Foeldvari (Hamburg, Germany), Helen Foster (Manchester, UK), Joost Frenkel (Utrecht, the Netherlands), Marco Gattorno (Genua, Italy), Claudia Grave (JIA Patient Organization, Germany), Veronique Hentgen (Paris, France),

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European Commission

More information:

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

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

Consumers, Health and Food Executive Agency – Project database
http://ec.europa.eu/chafea/projects/database.html

Scientific Committees website
http://ec.europa.eu/health/scientific_committees/index_en.htm

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