



European  
Commission

EU support for key public health initiatives  
2008-2011

# JOINT ACTIONS

Health and  
Consumers

## ACKNOWLEDGEMENTS

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## Foreword



Good health is a value in itself, and something all Europeans aspire to. Europe can be proud of its health systems which are known to provide good healthcare encompassing health promotion and prevention of chronic diseases, as well as high quality care when necessary.

The economic crisis presents serious challenges to public health budgets in several EU countries. Under the current circumstances, it is necessary to optimise public health policies and ensure efficient healthcare spending for sustainable healthcare systems, so that every European citizen can continue to benefit from high quality health promotion and care. A number of Member States face similar obstacles in achieving this goal and would benefit from common solutions.

To help Member States share best practice and find solutions to these and other common public health challenges, the European Commission has established the concept of Joint Actions. Joint Actions, as their name suggests, are designed to encourage national authorities, academic and

non-profit organisations to join forces with the European Commission to address major public health issues where the added value of EU-level involvement is high.

Funding provided through these Joint Actions supports the goals of the Health Programme 2008-13 and directly contributes to the Europe 2020 Strategy, by promoting European and national-level investments in the health sector in Europe.

Since 2008, 20 Joint Actions have been funded under the Health Programme (for the period 2008-11). This has led to organisations joining together to develop the best solutions for common European public health problems, ready to be rolled out at national level. The European Commission's investment over this period has amounted to more than EUR 40 million, with a similar amount invested by participating organisations.

This brochure provides a comprehensive description of the Joint Action funding mechanism and a brief description of each these 20 Joint Actions, their results and impact on national health policies.

The success stories presented in this brochure convincingly illustrate the positive impact to the health of EU citizens attained by working together through Joint Actions. The European dimension clearly provides a boost to national, regional and local efforts in tackling specific health issues, and much more can be achieved if we continue to pool our knowledge and work together for the good health of all Europeans.

A handwritten signature in black ink that reads "Paola Testori Coggi".

**Paola Testori Coggi**  
**Director General for Health and Consumers**

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## Introduction

The Treaty on the Functioning of the European Union (Article 168) provides that the European Commission should contribute to the protection of human health. It should do this by complementing national policies that fight against the major health problems and are directed towards improving public health, preventing physical and mental illness and diseases, and reducing sources of danger to physical and mental health.

The EU strategy and a framework of actions to achieve these aims were set out in the European Commission's White Paper *Together for Health: A strategic approach for the EU 2008-2013*<sup>(1)</sup>. The strategy is being implemented and supported by the Second Health Programme<sup>(2)</sup>, which has three objectives, namely:

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

The Health Programme is one of the instruments implementing the European Health Strategy. Four different types of actions are financed under the Health Programme and administered by the Executive Agency for Health and Consumers (EAHC), one of which is known as Joint Actions (JAs). JAs are designed to stimulate governments, academic and other non-profit organisations to join forces at the EU level in order to tackle problems shared by many EU Member States. They should involve partner organisations from many different Member States, and jointly develop the most appropriate solutions that can be put into practice directly at national level.

This brochure explains how the JAs work, and how they are funded and monitored to ensure that they all contribute European added value. The second section gives a detailed overview of all 20 JAs funded on different key health challenges between 2008-11, with particular attention paid to their results, outputs and their impact on national health policies within the EU. Further JAs are continuing up to 2015 and beyond.

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<sup>(1)</sup> The Health Strategy: COM(2007) 630 final, [http://ec.europa.eu/health/ph\\_overview/Documents/strategy\\_wp\\_en.pdf](http://ec.europa.eu/health/ph_overview/Documents/strategy_wp_en.pdf)

<sup>(2)</sup> The second programme of Community action in the field of health (2008-13), established by the Commission Decision No. 1350/2007/EC, <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=OJ:L:2007:301:0003:01:EN:HTML>





# Joint Actions in the Health Programme

## What is a Joint Action?

A Joint Action (JA) is an initiative within the Second Public Health Programme conducted by national competent authorities (such as the Ministry of Health) and other public bodies or non-governmental organisations nominated by the EU Member States (MS) or other participating countries. JAs are jointly funded by the partners and the European Commission.

JAs are highly specific in that they address the greatest health policy needs from European Member States and the Commission. Partner organisations in each JA are committed to a fixed-duration project (usually 36 months, but in a few cases, 18 or 24 months). During that time they each complete a defined plan of actions. JAs have an average of 22 funding partners (known as associated partners), and also in most cases a number of others who contribute knowledge and expertise but not funding (collaborating partners).

The direct or indirect involvement of Member States' competent authorities ensures political commitment and the financial resources needed for the long-term sustainability and impact of the actions. Further, JAs should have high European added value with wide geographical implementation that justifies them in both technical and political terms.

Funding for the JAs – contributed by the Commission and by the Member States' partners – is in line with the high political commitment and high expectations that they yield new policy developments that might affect national policies. The Commission contribution can be up to 50%, or up to 70% in cases of exceptional utility.

The annual work plan of the Health Programme, elaborated by the Directorate-General for Health and Consumers, sets the priorities and actions to be undertaken for the four types of financial instruments under the Health Programme, including JAs. Every year the EAHC, which is responsible for the Health Programme implementation, publishes a call for proposals. Between 2008 and 2011, 20 JAs have been funded and the Health Programme will continue to run until 2016.

## How are the policy priorities identified?

The priorities for what should become a JA are decided by a comprehensive appraisal of public health needs in Europe, with input from Member

States and other interested parties, e.g. expert committees (Figure 1). Priorities for the coming year's JAs are defined through negotiation leading up to publication of the Health Programme's annual work plan.

The Commission conducts an evaluation of relevant EU legislation (Directives, Recommendations and Decisions) and also policy recommendations and Communications. Priority areas for JAs are sometimes defined by the Commission in order to propose and sustain a legislative process in a specific health field. In other cases, a legal framework already exists and more collaboration among the EU MS is needed to support the implementation. For example, JA MODE and ACCORD resulted from an EU Directive<sup>(1)</sup> while EPAAC<sup>(2)</sup> and EJA<sup>(3)</sup> resulted from Council Recommendations.

A second major source of JA priorities is the individual health problems that emerge in the global health environment. As they do not respect borders, they can affect several Member States so that common actions need to be developed. The priority area should emerge from a consensus among the MS, and must be in line with national health needs. QUANDHIP is an example as the national laboratory network addresses emergent pathogens, highly pathogenic viruses and bacteria.

Other JAs can arise in response to the work of EU expert committees that carry out horizon scanning to identify emergent health problems in Europe which could become priorities needing a European action. For example, the Equity Action JA from the Expert Group on Social Inequality, and EHLEIS and ECHIM JAs from the Working Party on health indicators.

Several specialised European networks contribute to the process by assessing specific health topics (e.g. EuroHealthNet, European Patients Forum, EuroSafe). The networks play an essential role in identifying policy and knowledge gaps and good practices, which can support the implementation of public health actions and contribute to the European added value by sharing of expertise between organisations from several Member States.

Lastly, Health Programme projects (another of its four types of funding mechanisms) can also identify priority issues. In particular, projects that result in examples of recognised good practices might be scaled up and further developed by the Commission and the Member States through the implementation

<sup>(1)</sup> Directive 2010/45/EU on standards of quality and safety of human organs intended for transplantation.

<sup>(2)</sup> Council Recommendation on Cancer Screening of 2 December 2003.

<sup>(3)</sup> Council Recommendation on an action in the field of rare diseases.



Table 1: Joint Actions funded 2008-11

YEAR	ACRONYM	JA TITLE
2008	RDTF	Scientific support to the Rare Disease Task Force activities
	ECHIM	European Community Health Indicators and Monitoring
2009	NANOGENOTOX	Safety evaluation of manufactured nanomaterials by characterisation of their potential genotoxic hazard
	EHES	European Health Examination Survey Pilot Joint Action
	EUnetHTA	European network for HTA Joint Action
2010	MODE	Mutual Organ Donation and transplantation Exchanges: Improving and developing cadaveric organ donation and transplantation programmes
	QUANDHIP	Quality Assurance Exercises and Networking on the Detection of Highly Infectious Pathogens
	ALCOVE	ALzheimer COoperative Valuation in Europe
	EPAAC	European Partnership for Action Against Cancer
	Equity Action	Joint Action on Health Inequalities
	EUROCAT	European Surveillance of Congenital Anomalies
	JAMIE	Joint Action on Monitoring Injuries in Europe
	Orphanet Europe	Development of the European portal of rare diseases and orphan drugs
	EHLEIS	European Health and Life Expectancy Information System
	EHGov	Joint Action eHealth Governance Initiative
2011	PaSQ	European Union Network for Patient Safety and Quality of Care
	ACCORD	Achieving Comprehensive Coordination in ORgan Donation throughout the European Union
	EJA	EUCERD Joint Action – Working for rare diseases
	EUnetHTA 2	European network for HTA Joint Action 2
	PARENT	Cross-Border Patient Registries Initiative

of a JA. Examples of such actions are the JAMIE, EHLEIS, Equity Action and QUANDHIP JAs.

This process has resulted in the establishment of the 20 JAs funded between 2008 and 2011. Their policy priorities lie in the public health aspects shown in Figure 2.

In that time, 40% of JAs concerned specific diseases, followed by health systems (25%) and health information and advice (20%). Two JAs addressed aspects of product legislation, while health determinants have only given rise to one JA.

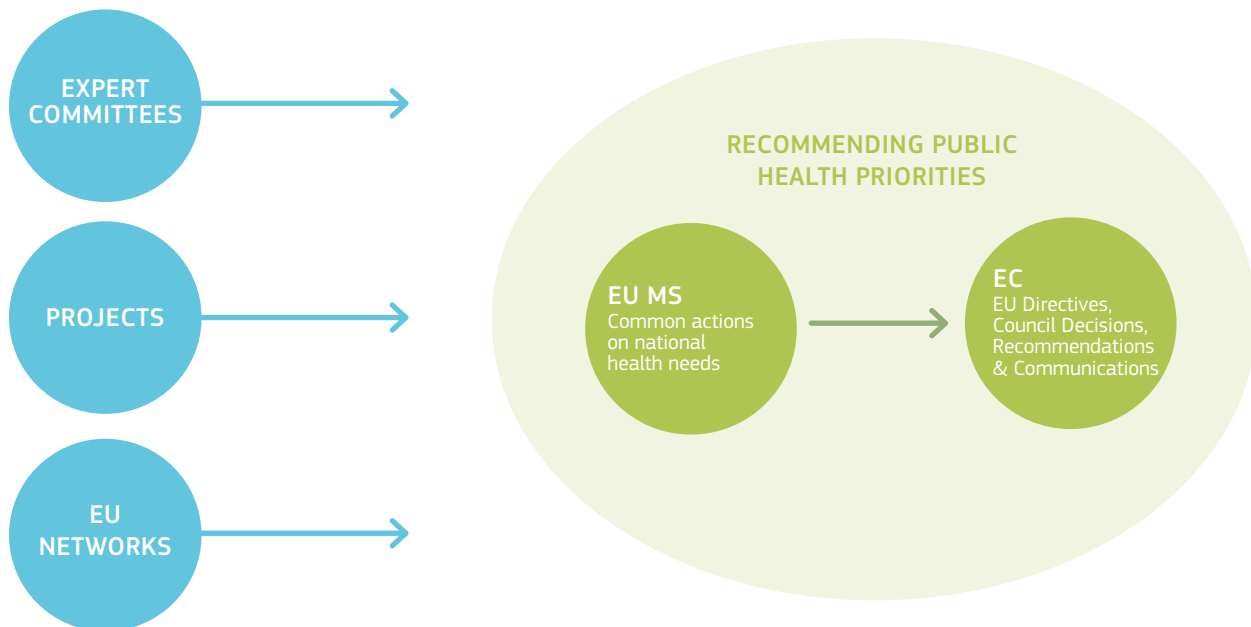
### What is European Added Value?

European added value is the value that results when an initiative undertaken at European level has a greater impact than the sum of what could be achieved by several national initiatives.

European added value can be achieved in many different ways: implementing EU legislation, achieving economies of scale, promoting best practice, benchmarking for decision making, considering cross-border threats, fostering movement of persons and/or networking.

- The implementation of the **EU Directives, Recommendations**, etc. has a very high added value in ensuring the legislation is implemented by the Member States' authorities concerned by the specific legislation. Correct implementation of the EU legislation ensures the Member States' return on investment and sustainability by reducing duplication of effort.
- **Economies of scale** aim to provide better service to citizens or to create European reference health services in an efficient manner, which can be assessed through cost/benefit analysis (Table 2).

Figure 1: Identifying policy priorities



- Identifying the **best practice** applied by participating Member States requires scientific rigour and political support. Health professionals and decision makers stand to benefit by employing the state-of-the-art, best practices and capacity building.
- **Benchmarking** for decision making through commonly accepted indicators with real impact is important in comparing health statistics at European level.
- **Communicable disease threats** do not respect national borders, and require a coordinated response to meet public expectations. The objective is to reduce the risks and to mitigate the consequences of health threats, by evaluating preparedness and performance during crises.
- The EU principle of **free movement** of persons across Europe requires implementation of strategies for cross-border care, preventing brain drain of health professionals and for managing migration issues. EU-level actions are needed to ensure continued good cross-border care.
- **Networking** is directed toward collaboration and exchange of knowledge, resulting in various forms of agreements, sharing of best practices and procedures.

### Who takes part in Joint Actions?

The Health Programme as a whole is open to EU Member states which contribute to the Health programme funding, and to third countries (including EFTA/EEA countries and acceding countries) which have signed a Memorandum of Understanding (MOU) with the Health Programme.

Participants in JAs can be either:

- **public bodies** representing the competent authorities; or
- **non-governmental organisations (NGOs)**, either designated by competent national authorities.

Additional partners from any Member State may participate if their special expertise is needed.

All participating organisations must be non-profit making and independent of industry, commercial and business and other conflicts of interest.

European networks (e.g. stakeholders' organisations) can express their interest in participating in a JA, and can be directly nominated by the European Commission.

International organisations can participate in the Joint Actions as collaborating partners.

The majority of participants in JAs are public bodies (81%), compared to less than a fifth that are non-governmental bodies (NGOs, 19%), and these include six EU networks (Figure 5).

Participants may take one of four different roles (Table 3):

- **Main partner** – the coordinator and contributes with national funding of the JA.
- **Associated partner** – an organisation managing and carrying out the JA action with the main partner, contributing funding and ensuring the objectives are met.
- **Subcontractor** – an organisation subcontracted for the purposes of providing special expertise to the JA.
- **Collaborating partner** – an organisation involved by contributing technical and scientific content of the JA without providing funding. It is not mandatory for JAs to have collaborating partners, but highly recommended.

Figure 2: Number of Joint Actions funded in various public health sectors, 2008-11

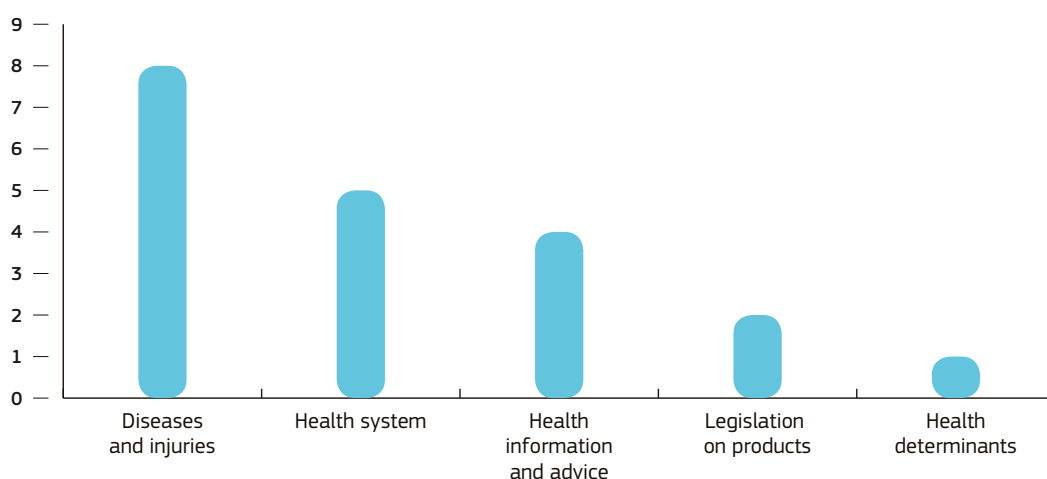


Table 2: Means of achieving EU added value, its objectives and success indicators

Path to EU added value	Objective	Indicator
Implementing EU legislation	Ensuring that legislation is implemented correctly	Institutions adopting the legislation
Achieving economies of scale	Providing better service to citizens in an efficient manner	Cost/benefit analysis
Promoting best practice	Benefiting citizens from state-of-the-art best practice and capacity building where necessary	Organisations and target populations reached by the best practice
Benchmarking for decision making	Facilitating evidence-based decision making	Availability of data at agreed quality level threshold
Tackling cross-border threats	Reducing risks and mitigating consequences of health threats	Qualitative assessment of preparedness/evaluation of performance during crises
Fostering movement of persons	Ensuring high quality public health across EU MS	Organisations and target population positively affected by cross-border care
Networking	Coordinated initiatives, exchange of best practices and procedures	EU MS agreements, sharing of procedures and best practices, common reporting, etc.

### Figure 3: Eligible participants in JAs

The following countries can participate in JAs:



In the 2008-11 JAs, the majority of European participants are from old MS (EU-15), while a very small percentage belonged to acceding and EFTA & EEA countries (Figure 4).

The main and associated partners are eligible for EC co-funding, considered the beneficiaries of the grant agreement, while the main body of actions is undertaken by the associated partners but limited for subcontractors and collaborating partners (Table 3). This means only the main and associated partners are in a contractual relationship with the Commission. The main partner signs the grant agreement and the associated partners sign mandate letters giving the power of representation to the main partner.

Out of the 20 JAs (18 in progress and two completed), only two are coordinated by a 'new' Member State – Slovenia (Figure 6). France has by far the highest involvement as the main partner, coordinating six JAs, followed by the United Kingdom, with three JAs. Only 10 out of 27 Member States have taken on the coordinating role in a JA in the period covered.

The main and associated partners are eligible for Commission co-funding, while subcontractors can receive funding through a contract with one of the JA beneficiaries. The main and associated partners are required to make a financial contribution to the JA, in line with the basic principles of Commission funding. Collaborating partners often contribute indirectly by covering their own costs, even though they do not have financial support from the Commission.

The number of associated partners and collaborating partners involved in the JAs increased steadily over the three years from 2008-10, but only five JAs were initiated in 2011, so the total partners involved from that year is smaller (Figure 7). However, the total partners involved per JA also rose rapidly from 2008-10 and then remained at a similar level for 2010-11, at just over 40 partners per JA (Figure 8).

This indicates steadily increasing interest from organisations participating in the JAs.

The increasing numbers of associated partners have been matched by an equivalent increase in the numbers of collaborating partners.

The 20 JAs have had a total of 445 associated partners, averaging 22 per JA and ranging from 5-38 (Figure 9). The number of associated partners depends entirely on the specific requirements of each JA and there is no general recommendation for the number involved. The choice and number of associated partners provides a balance between the required technical expertise, manageability of the project and sufficient geographical coverage.

The 20 JAs have involved 337 collaborating partners; most with 10-16 partners but ranging from zero to 39, depending on the specific requirements of the JA. In total, 474 organisations participated in the 20 JAs; many of them taking part in a number of different JAs. All the participating organisations are listed in the Annex, showing the JAs in which they were partners.

JAs within the policy areas of Health Systems and Diseases and Injuries tended to attract more partner organisations than JAs in the other three priority policy areas (Figure 10).

All of the JAs had partners from national or regional government and/or government agencies; in many cases from both (Figure 13). Almost all (90%) also had participating partners from universities or dedicated research centres, while hospitals were represented in 40% and European network organisations in almost a third of the JAs.

Figure 4: Joint Action partners, 2008-11

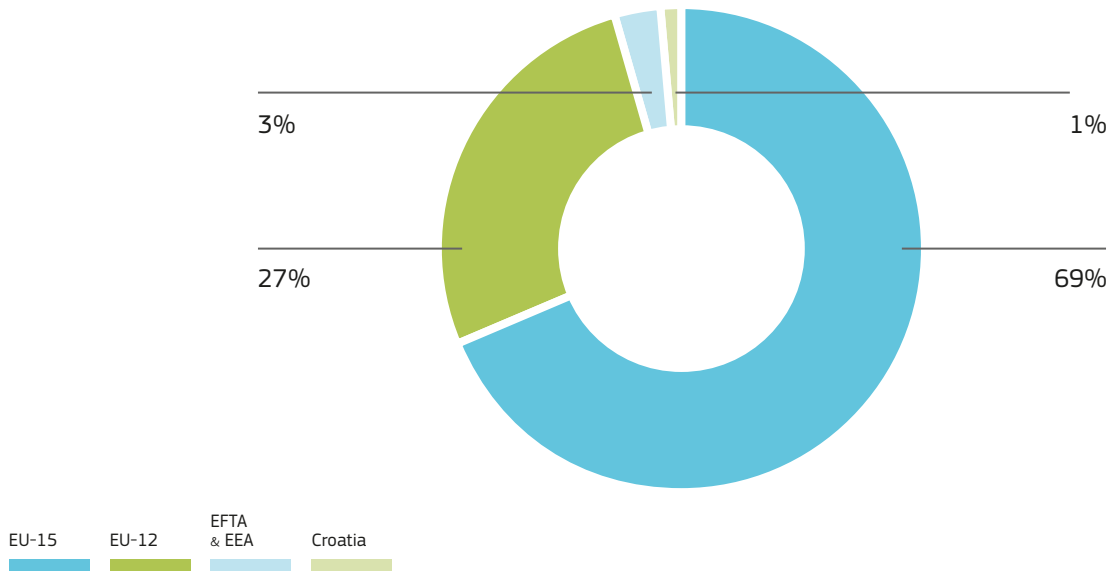
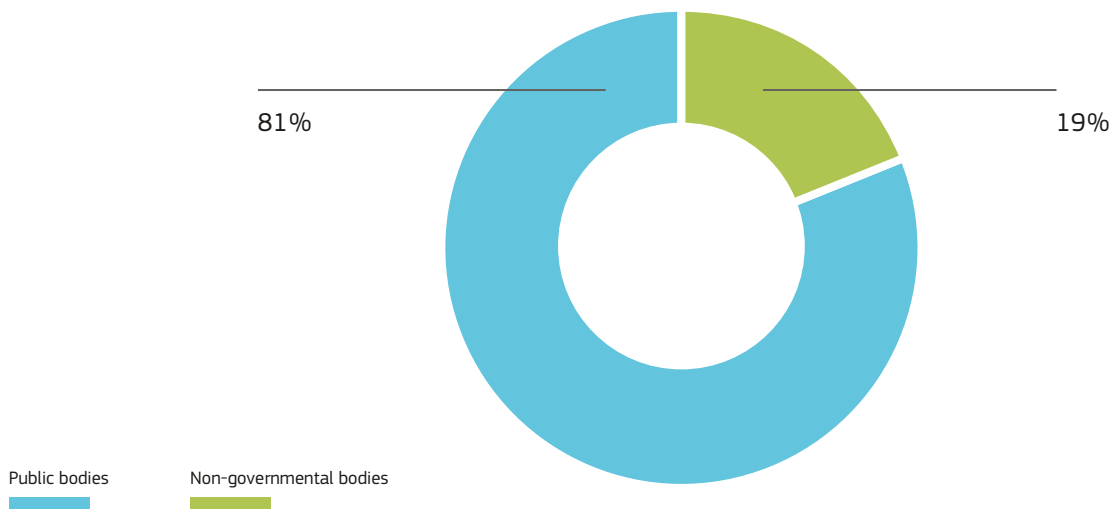


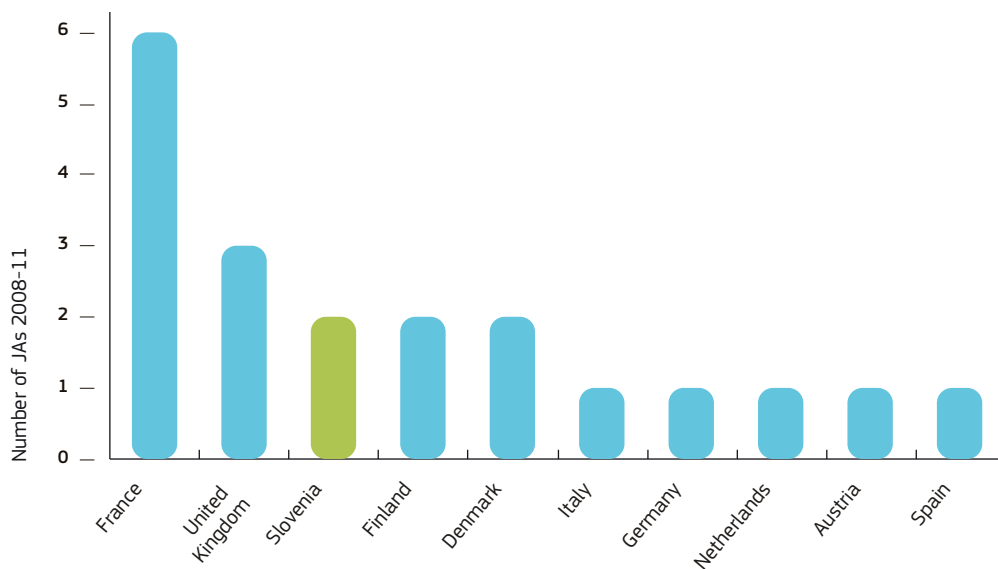
Figure 5: Legal types of participating organisations, 2008-11



**Table 3:** Roles and responsibilities of the participants

	Coordination	Core participation	Eligibility of costs	Financial contribution	Contractual relationship with EAHC
Main partner	X	X	X	X	X
Associated partner	–	X	X	X	X
Subcontractor	–	–	X	–	–
Collaborating partner	–	–	–	–	–

**Figure 6:** Countries acting as JA coordinators, 2008-11



### How are Joint Actions funded?

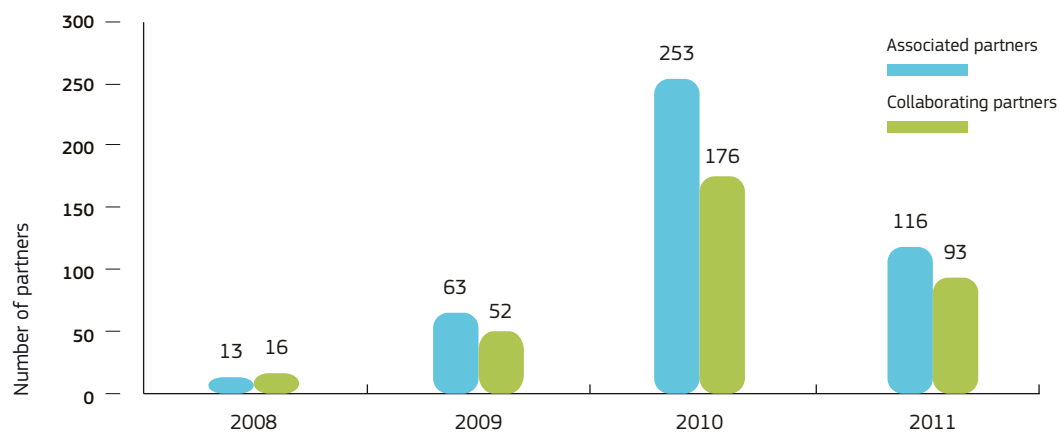
The funding of the JAs is based on the EU principles of co-funding – partly from the Commission and partly from the participating organisations from the Member States. The maximum rate of EU co-funding for the JAs is 50%, while in exceptional cases that percentage may be raised up to 70% for JAs considered of high European utility, i.e.:

- proposed by the Commission in the Health Programme annual work plan as having exceptional utility; and

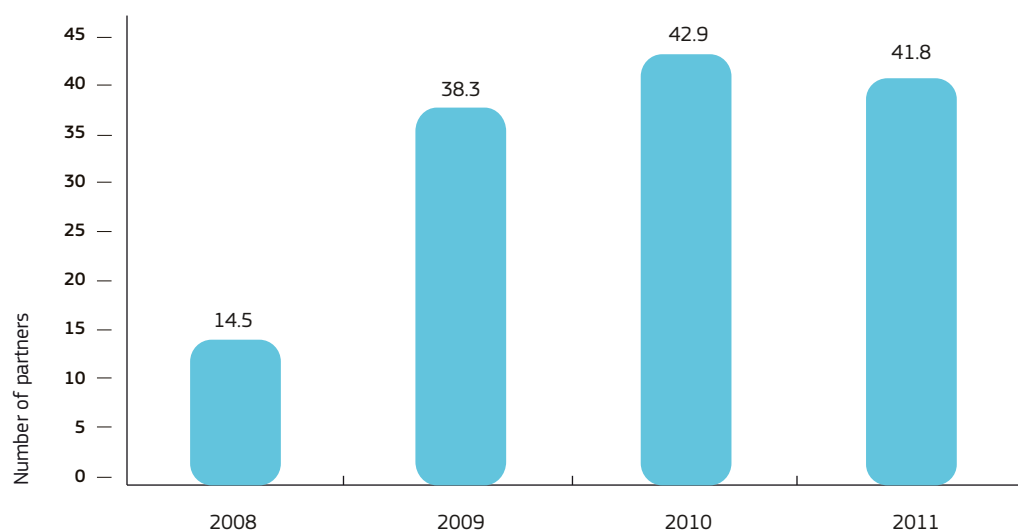
- complying with the criteria for exceptional utility criteria that are set out in Annex VII of the annual work plans.

The budgets of the JAs vary in size. The total budget of each JA between 2008-11 (the sum of EU co-funding and the Member State's contribution) varied from as little as EUR 0.6 million to EUR 9.5 million (Figure 14).

**Figure 7:** Total associated and collaborating partners in Joint Actions, 2008-11



**Figure 8:** Average number of associated and collaborating partners per Joint Action, 2008-11



Co-funding by the EU has varied from 27 – 68%. The level of funding has depended on a variety of factors, including policy area, size of action, planned activities and granting of exceptional utility status.

The Second Public Health Programme has given increasing importance to the JA initiatives, and this is supported by an increase through the four years in the overall level of EU co-funding (Table 4). The level of EU co-funding for the five JAs in 2011 (62.3%) represented a significant rise from the previous three years, which averaged 45-50%.

### How are Joint Actions administered and monitored?

Structure and governance are important for the success of JAs. The consortium and partnership agreement signed by JA partners set out the principles for collaboration and management.

The structure of the JA is based on a number of technical ('core') and administrative ('horizontal') work packages (WPs) (Figure 15). The horizontal WPs manage, assess and exchange information

Figure 9: Number of associated partners in individual Joint Actions, 2008-11

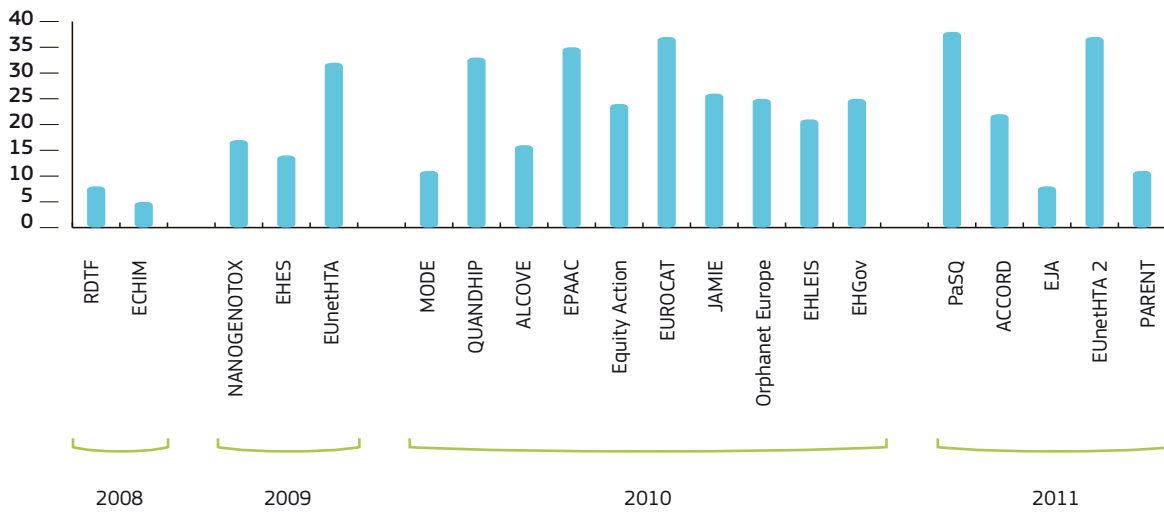
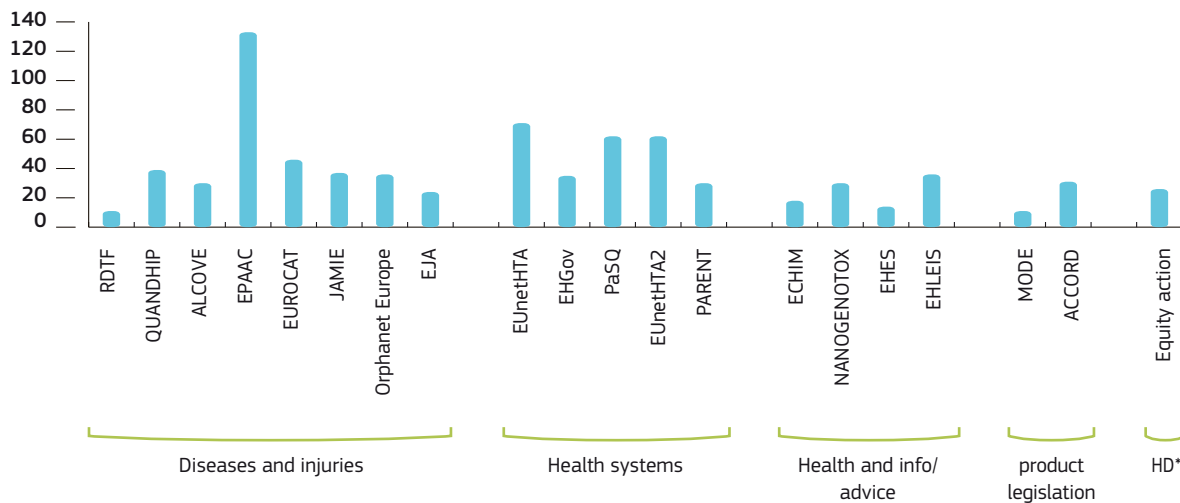


Figure 10: Total number of partners in the Joint Actions 2008-11, by priority policy area



\*HD = Health determinants

across the complete action. The number of technical WPs depends on the complexity and specific needs of each JA. However, all JAs contain three defined horizontal WPs, which continue throughout the duration of the project and contribute to the overall objectives by supporting and managing the technical WPs. The horizontal WPs are as follows:

- The **coordination WP**, which includes all the actions needed to manage the project and to make sure that it is implemented as planned. It also ensures efficient and effective exchange of information,

follow-up of the activities, budget management, guidance and interaction between all the partners.

- The **dissemination WP**, which covers all the actions undertaken to ensure that the results and deliverables of the project will be made available to the target groups defined.

- The **evaluation WP**, which includes the actions undertaken to verify that the project is being implemented as planned and that it achieves its objectives.



The main partner and associated partners develop a standard operating procedure (SOP) that defines the governance and decision-making arrangements. Each JA has a different governance structure, depending on its specifications and requirements. However, most of the JAs funded between 2008 and 2011 used the model shown in Figure 15.

Each technical WP has a **leader** who ensures collaboration within the working group, requests the contribution of collaborating partners and delivers work.

The **Steering Committee** involves the **coordinator**, representing the main partner, and the **WP leaders**. They serve as the project management team, by actively leading and contributing to implementation of the WPs. The Steering Committee oversees the work and progress of individual WPs, especially monitoring the milestones and deliverables through periodic conference calls and meetings. It also ensures that high standards of technical and administrative excellence are maintained, in order to facilitate successful delivery of the JA outputs. The Committee is also responsible for resolving any potential conflict. Officials of the Commission and EAHC are usually involved in the Steering Committee, but only as observers and have no voting rights.

The **main partner** has an executive role in supporting the technical implementation of the action. It controls contractual, financial and knowledge management of the JA, and coordinates the administration of the project. The main partner also implements decisions of the Steering Committee and promotes dedicated tools and templates for technical, administrative and financial management. Its other key function is to communicate and report regularly to the EAHC and the Directorate-General for Health and Consumers.

The **General or Plenary Assembly** meets on an annual or bi-annual basis to make strategic decisions, including the working and management plan for the JAs. It usually comprises a representative of the main partner and one representative of each associated partner. Usually decisions are taken by consensus, but the main and associated partners have equal voting rights. However, in some JAs, the Assembly also includes (non-voting) collaborating partners and Commission services.

The Assembly can also be viewed as the main policy-setting body, which involves wider participation and dissemination; particularly to Member States not in

the core group. Assembly meetings therefore often also involve representatives of relevant Directorates-General (e.g. DG Health and Consumers, EAHC, DG Research and Innovation) and other relevant EU-bodies (eg, EMA, CIE) that act as observers and have an advisory role.

The **Advisory Board** is a group of external specialists who advise on the coordination, evaluation and dissemination of the JA, and give recommendations on specific objectives and outputs of the project.

The JA structure also provides that a **temporary expert panel** can be established to assist in case actions are needed across WPs. Its role is to make sure information is flowing between different WPs, and that knowledge and results are fully integrated. In addition to the JA participants, temporary expert panels can invite experts from international organisations and third countries.

### What are Joint Actions aiming to achieve?

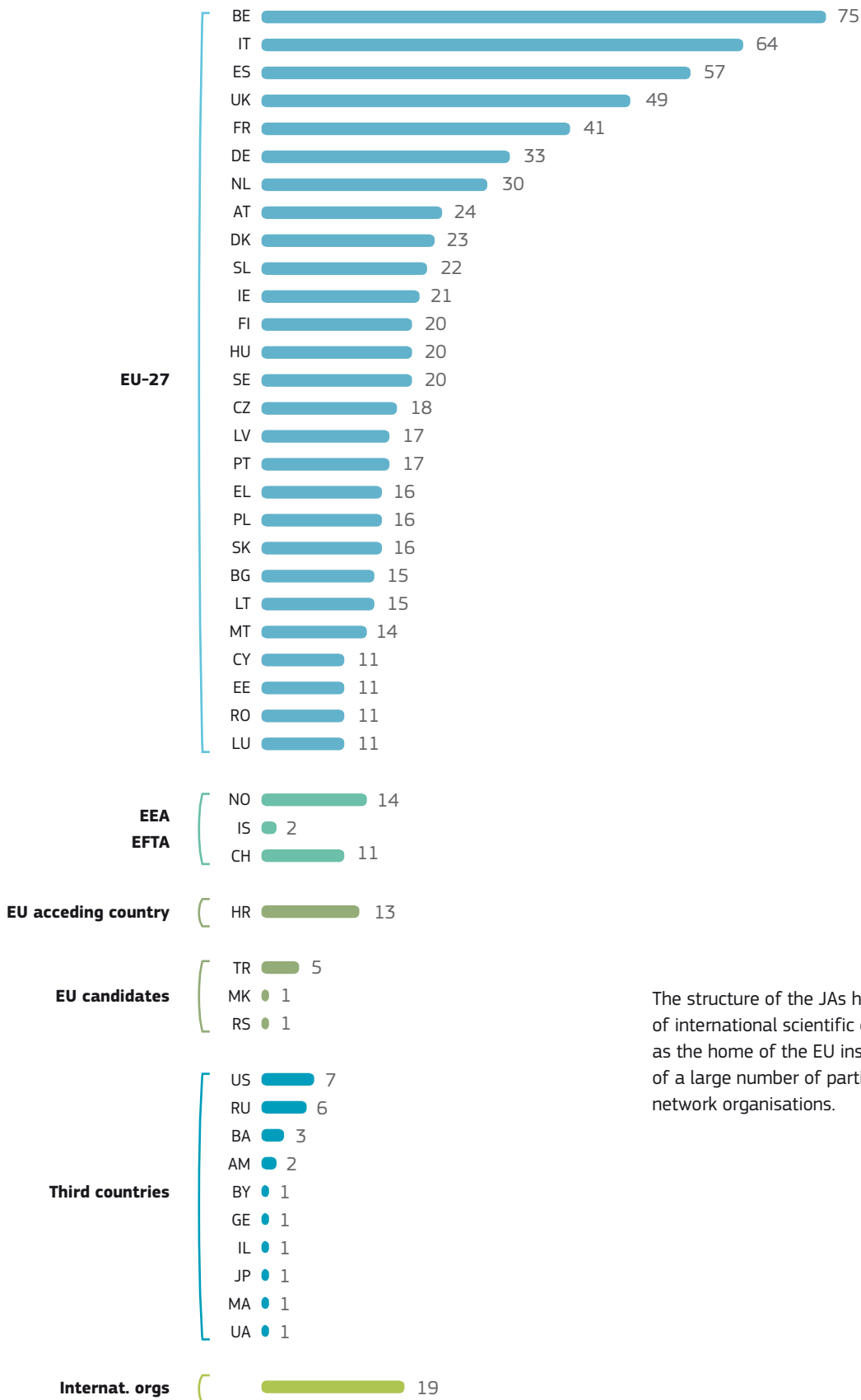
Joint Actions address six different policy areas (Table 5), but they have similar approaches – working through **networks** and **information exchange** as well as **preparation of statistical datasets, compilation of best practices** and **producing recommendations**.

The Joint Actions each have a simple and precise overall objective that clearly relates to its purpose and vision. In addition, they have up to six specific objectives that set out the details of actions the JA will carry out to achieve the overall objective. These relate to concrete activities and tend to be very positive, making use of active words such as *assess, revise, assemble, compare, investigate* or *develop*.

While each JA is designed to meet objectives in one primary policy area, many also impact on other areas.

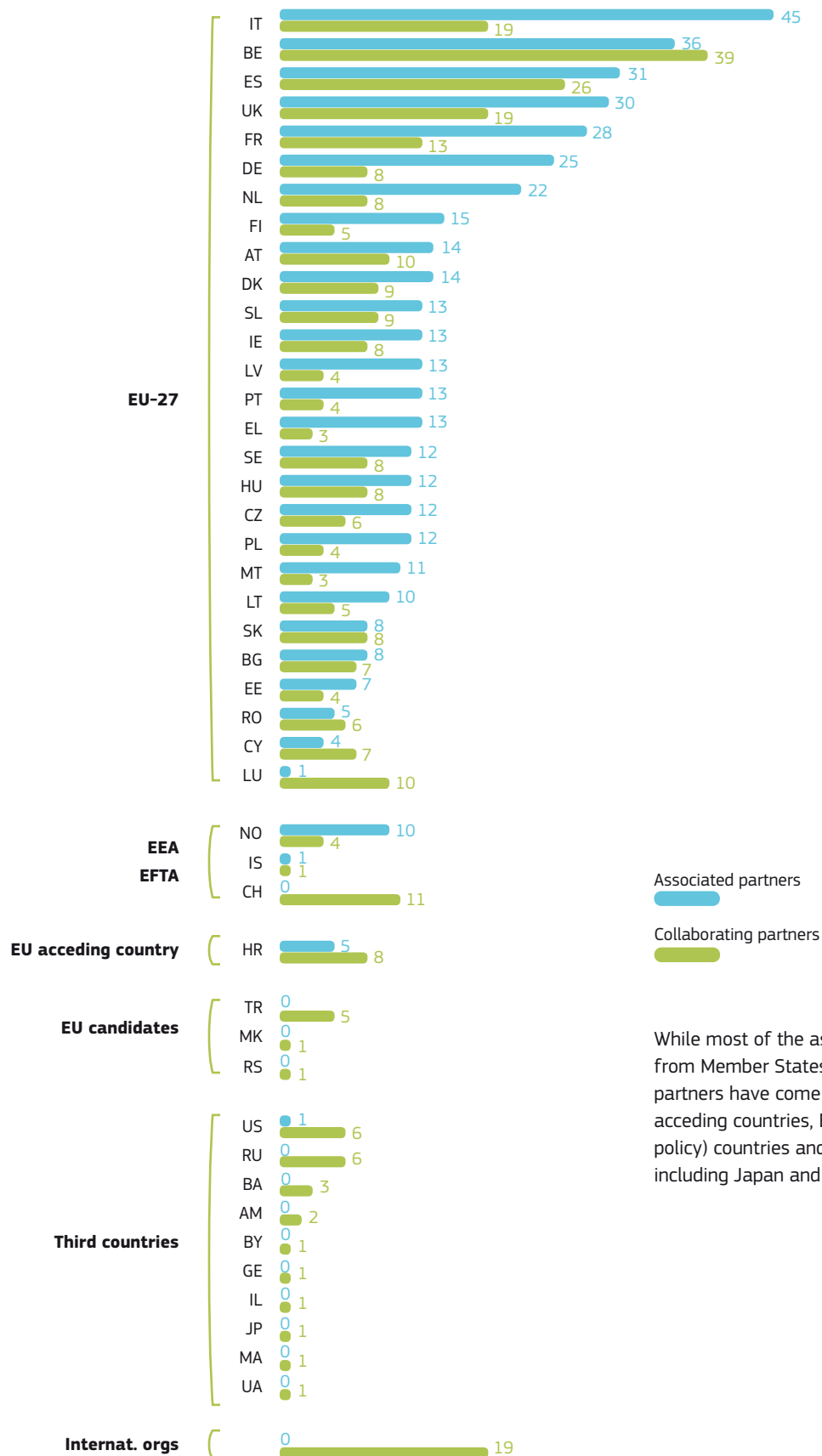
Organisations defining the objectives of JAs are advised to base them on the SMART principle (making them specific, measurable, appropriate, realistic and time-bound). Objectives that meet these ideals are essential in order to make the project's implementation effective, the monitoring clear and the evaluation process more productive.

Figure 11: Total number of partner organisations participating in Joint Actions 2008-11, by country



The structure of the JAs has enabled a wide level of international scientific collaboration. Belgium, as the home of the EU institutions, is the location of a large number of participating European network organisations.

Figure 12: Participation in Joint Actions 2008-11, associated and collaborating partners, by country



Associated partners

Collaborating partners

While most of the associated partners have been from Member States of the EU-15, collaborating partners have come from EU Member States, acceding countries, ENP (European neighbourhood policy) countries and also from third countries including Japan and the USA.

Figure 13: Types of organisations participating in Joint Actions 2008-11 as associated and collaborating partners

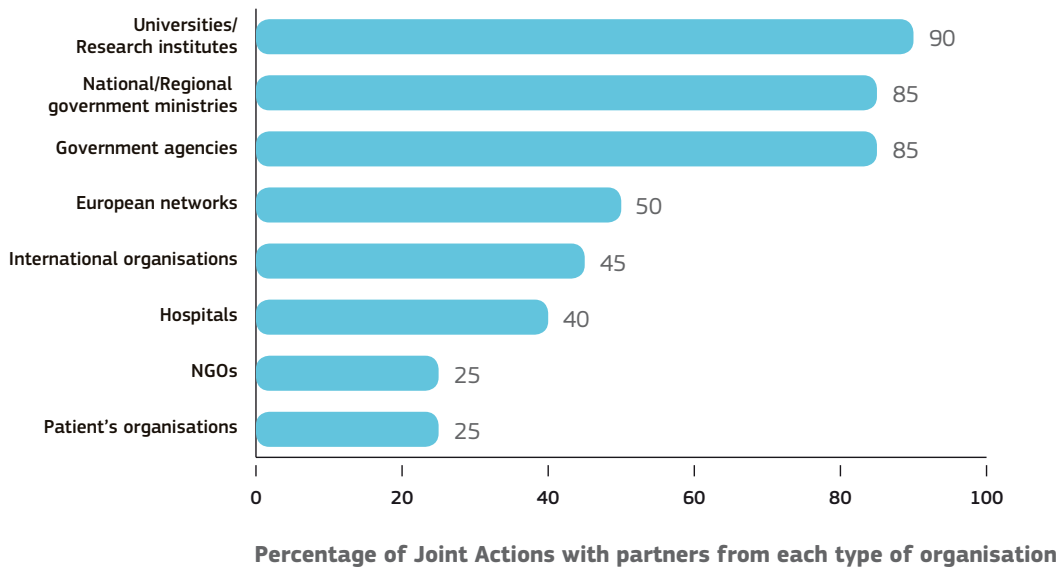


Figure 14: Funding of JAs: EU co-funding and Member State contribution, 2008-11

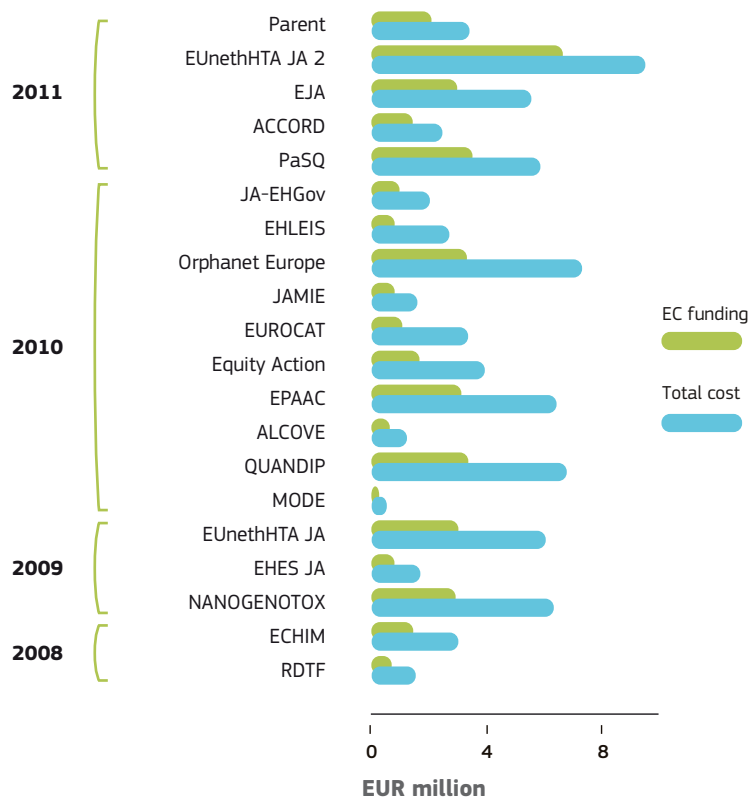
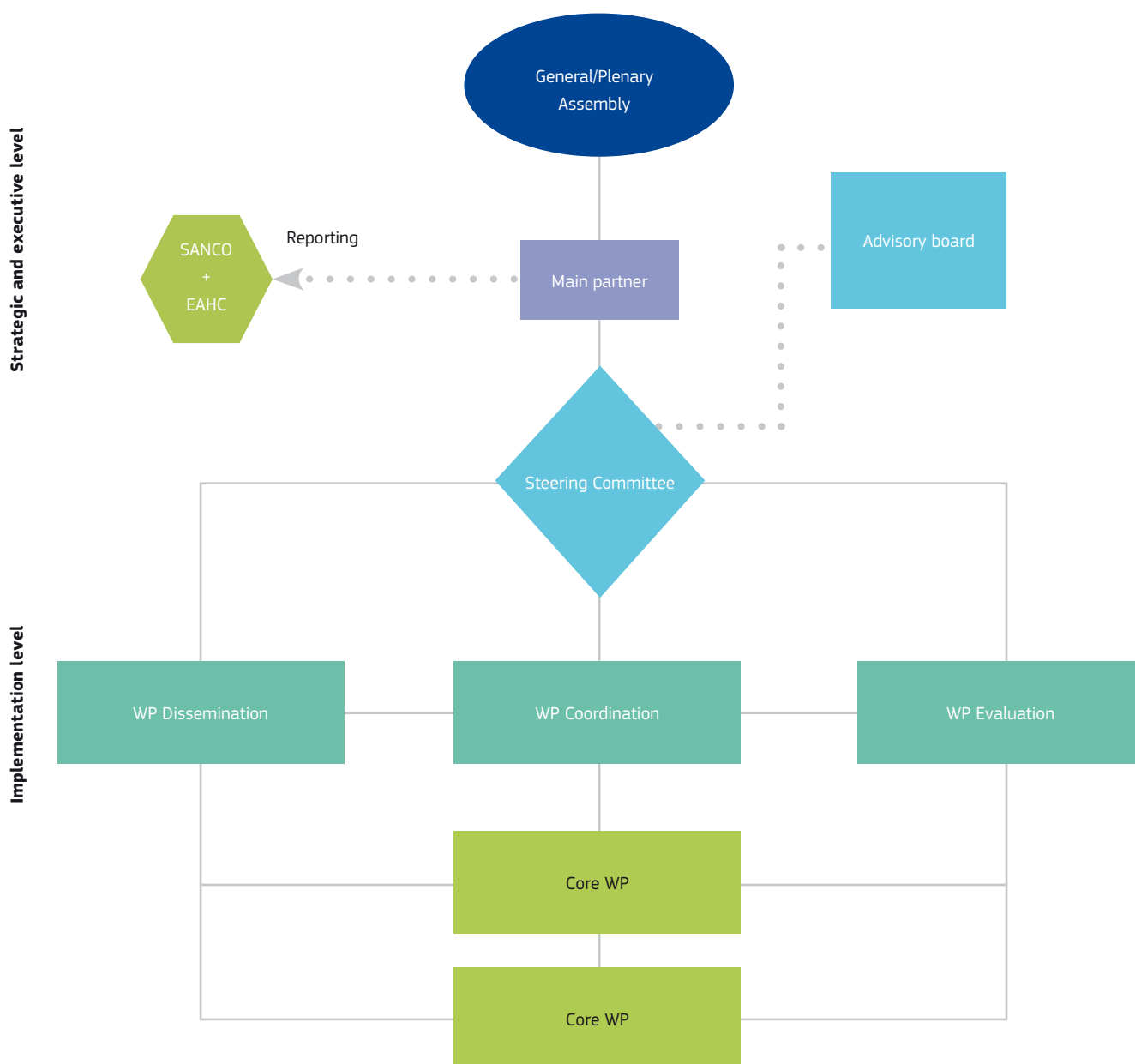


Table 4: Joint Action total funding and Commission co-funding by year, 2008-11 (in EUR)

Year	No. of JAs	Total EU co-funding	Total budget
2008	2	2 247 455	4 509 066
2009	3	6 711 770	13 880 125
2010	10	16 104 876	35 575 879
2011	5	16 546 334	26 578 727

Figure 15: Governance model typically used in the 2008-11 JAs



The activities within the project that will achieve these objectives need to be planned, with clear milestones to be met or outputs to be delivered at specific stages of the work. These deliverables or outputs cover four overlapping areas (Figure 16) areas, namely:

- knowledge sharing;
- capacity building;
- administrative aims; and
- evaluation and monitoring.

Deliverables related to knowledge sharing and capacity building can increase or share knowledge and best practice within as well as outside the project network. In addition, some deliverables have multiple purposes (e.g. online platforms and websites that might be used for either knowledge sharing or capacity building).

Project reports are the deliverables most often produced, accounting for almost 70% of all deliverables. The reports present the knowledge produced in the JA (e.g. state-of-the-art report, dissemination report, final conference report). They may be for public distribution, with the objective of sharing the knowledge gained or influencing policies, or internal, confidential reports that are intended only for the JA participants and Commission services (e.g. interim and final reports). Some are used for evaluation or monitoring (e.g. external evaluation reports, quality assessment reports) and others for capacity building (e.g. reports on workshops), depending on the specific aims of the JA.

Figure 16: Four types of JA deliverables

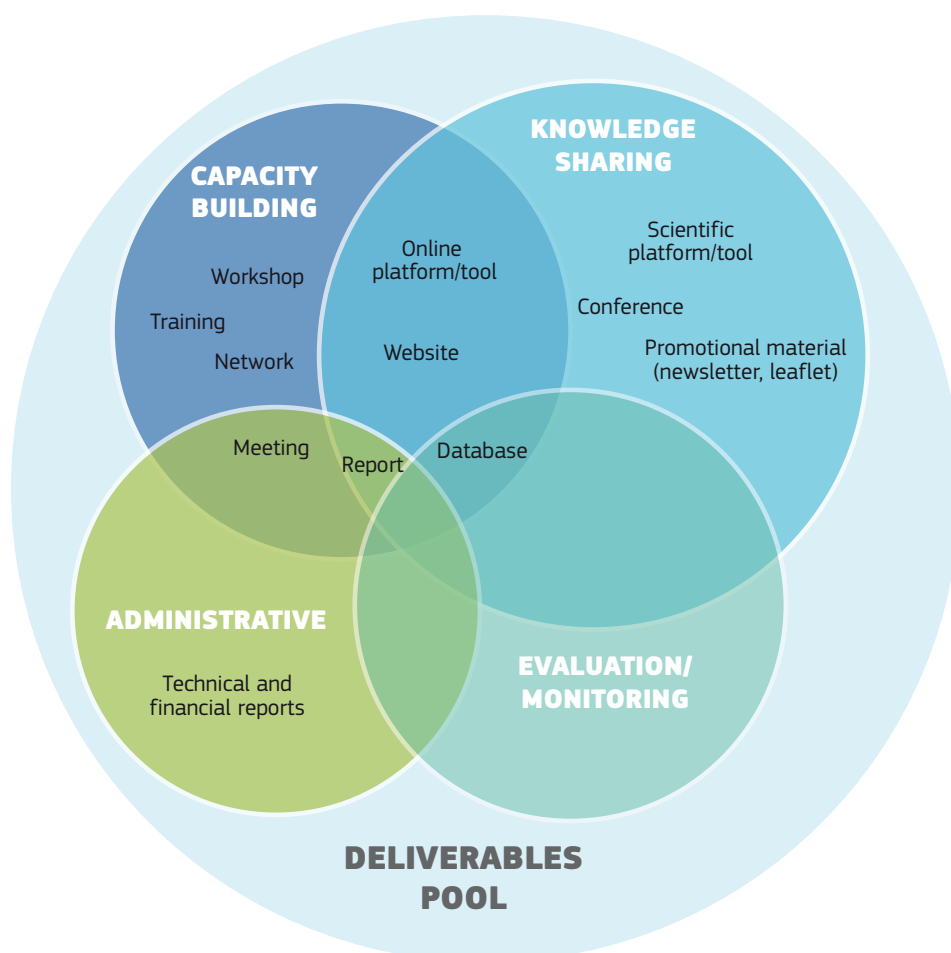


Table 5: Joint Action objectives within the five policy areas

	DISEASES AND INJURIES	HEALTH SYSTEMS	HEALTH INFORMATION AND ADVICE	LEGISLATION ON PRODUCTS	HEALTH DETERMINANTS
RTDF	x	●	●		
QUANDHIP	x	●	●		
ALCOVE	x	●	●		●
EPAAC	x	●	●		●
EUROCAT	x	●	●		
JAMIE	x	●			●
Orphanet Europe	x		●		
EJA	x	●			
EHGov		x		●	
PaSQ	●	x			
EUnetHTA		x			
EUnetHTA 2		x			
PARENT		x			
ECHIM		●	x		●
NANOGENOTOX			x		●
EHES	●	●	x		
EHLEIS		●	x		●
ACCORD		●		x	
MODE		●	●	x	
Equity Action		●			x

x main objective

● additional objective

## Objectives

- RTDF, EJA: prevent rare diseases and develop or implement policies.
- ALCOVE: improve data collection and exchange good practices in dementia care.
- EPAAC: develop national cancer plans and hospital-based surveillance.
- EUROCAT: raise awareness of prevention of congenital anomalies.
- JAMIE: develop surveillance of injuries and their causes.
- Orphanet Europe: compile information to aid diagnosis and treatment of people with rare diseases.
- QUANDHIP: provide an integrated laboratory network for detecting highly infectious pathogens.
- EHGov: include eHealth into national health policies and align eHealth investments to health needs.
- PaSQ: contribute to patient safety and high quality care.
- EUnetHTA: achieve effective and sustainable HTA: collaboration in Europe.
- EUnetHTA 2: strengthen cross-border collaboration over HTA and avoid duplication.
- PARENT: develop patient registries and harmonise and rationalise their governance.
- ECHIM: expand the EU Health Indicator System towards sustainable health monitoring.
- NANOGENOTOX: support national policies on the safety of nanomaterials and contribute to international standardisation in this field.
- EHES: prepare recommendations for standardised Health Examination Surveys and enable collection of comparable data.
- EHLEIS: develop the EU Health and Life Expectancy information system and healthy life years indicator.
- MODE, ACCORD: transfer best practices and strengthen the full potential of member states in organ donation and transplantation.
- Equity Action: reduce health inequalities.

## Making sure the results reach the right people

If they are to be effective, the results of the JAs and their implications need to be shared with the various different categories of people who are best placed to build them and implement them in the health policies of the Member States (Figure 17). To do that, each JA includes a dissemination strategy to make sure its findings reach the right stakeholders.

The dissemination strategy (Figure 18) sets out the methods used to present the results of the project, the targets to be reached and the channels that will be used to reach them.

Ideally, dissemination should be planned and put into practice on the basis of a stakeholder analysis. The stakeholders are individuals and organisations that have an interest in the JA results, and/or those who will be affected directly or indirectly by its outcomes; both at Member State level and EU level. Special effort should be made to reach users in Member States that are not participants in the JA.

The major stakeholder groups of the JAs funded in 2008-11 were mostly health professionals, followed by health policy makers, academia and patient groups. Other interested groups with a broader interest were healthcare organisations, the civil society, decision makers, NGOs, the media

and European expert networks from previously-funded related projects.

In preparing a stakeholder analysis for development of the dissemination plan, JA partners need to prioritise the identified target groups of stakeholders (Figure 18).

The choice of organisations within the primary target group is specific to each JA. Usually, the group consists of key users of the outputs and/or the entities most exposed to the JA results. The secondary target group is the funding providers, policy and decision makers on EU and national level. The third target group usually comprises other stakeholders that are specific to each JA, and includes the general public.

Once the target groups have been identified and prioritised, the dissemination strategy is completed. It should take account of what is to be disseminated; why (e.g. to raise awareness, inform, engage, promote etc.); how it is to be done and through which channels; when; and most importantly, who is the target audience (Figure 18).

The message and channels to be used should be adapted to the needs of the stakeholders in order to enable dissemination to be monitored. It is important to distinguish between dissemination channels, means of dissemination and means of verification (Table 6).

Figure 17: Dissemination target groups

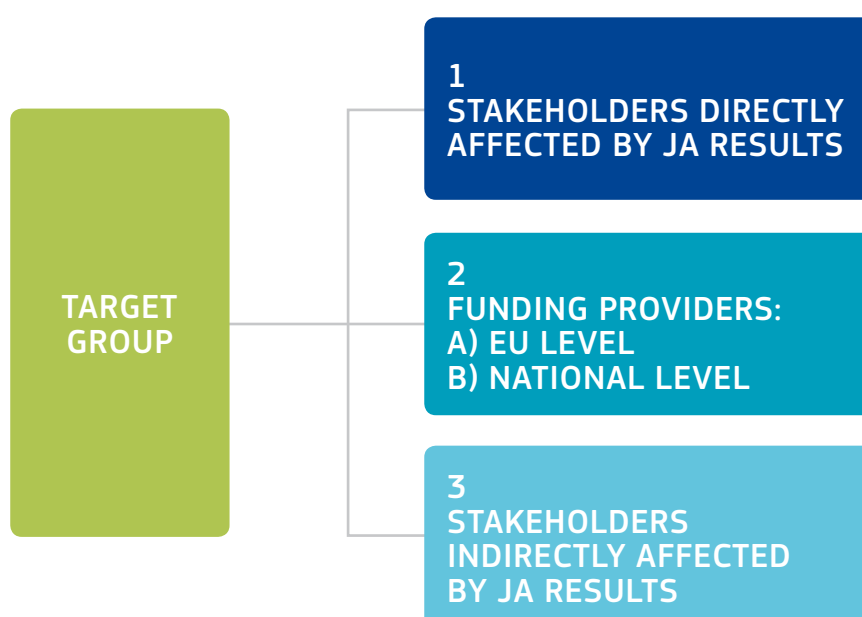




Figure 18: Design of the dissemination strategy



Table 6: Dissemination: means and verification

Channel	Means of dissemination	Means of verification
Electronic media E-mail	Various web publications (press release, progress report, newsletter, video material)	Website creation and frequency of activities
Print media Postal mail	Various printed material (paper in scientific journal, policy document, progress report, newsletter, leaflet, press release)	Uptake of printed material and registered downloads
Event (meeting, committee, network, workshop, training, conference)	Training material Presentations Newsletters Leaflets Posters	Outcome of the event Meeting minutes Conference proceedings

As with the project reports mentioned earlier, all types of dissemination can be internal, concerning communication within the JA, and external, concerning the dissemination to the scientific or public arena. The target group can be reached by electronic media, print media or through various events.

In the 20 JAs conducted between 2008-11, most (69%) dissemination was directed towards external

targets; i.e. a wider audience beyond the limits of the JA networks. This wide dissemination policy is very much in line with the aims of the Health Programme.

Publication in specialised scientific or medical journals was one of the most popular means of dissemination, while results were also disseminated through scientific meetings, committees, networks and conferences.

Most stakeholders outside the scientific community and the general public were reached by publications on the JA website and the Internet (e.g. newsletters, leaflets, public progress reports, etc.), and also by meetings, workshops and training sessions.

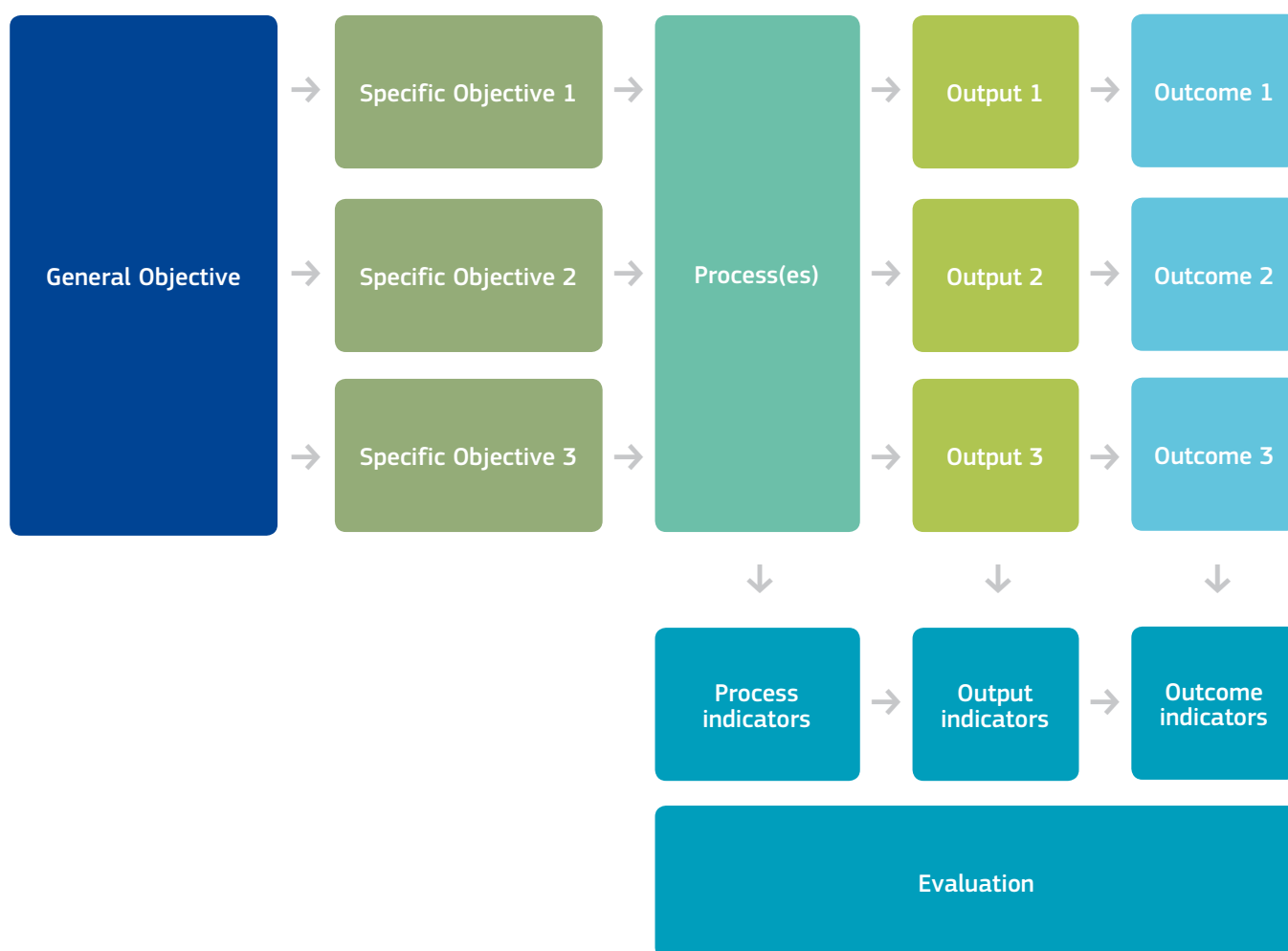
The JAs have been successful in disseminating their results to the target groups. For example, all developed their own websites, most of which were intended to inform a wide range of different stakeholder groups as well as the JA partners, and some made use of social media (Twitter). Many also produced technical or scientific papers for publication in academic journals or at conferences where they would reach healthcare professionals and policy makers. Newsletters and

information leaflets were also distributed widely to stakeholders by partners in many JAs. Where appropriate for the objectives of the JA, workshops and training sessions were organised to share best practices or raise skill levels in the staff of organisations from the Member States, about data collection methods (ECHIM, EHES, EUnetHTA) or rare diseases (RDTF) or technical aspects of healthcare (MODE, PaSQ).

### How are the Joint Actions evaluated?

The evaluation strategy is included from the start of each JA as part of the mandatory horizontal evaluation work package.

Figure 19: Implementation of evaluation strategy



**Table 7:** Frequently used indicators for the evaluation strategy – Examples from JAs 2008-11

PROCESS INDICATORS	OUTPUT INDICATORS	OUTCOME INDICATORS
Expert Meetings	Meeting reports	Identified prevention areas
Visits	Press releases	Increased awareness/willingness
Training courses	Recommendations	Results of self-evaluation
Design of programmes	Survey results	Greater knowledge
Organisation of conferences	Scientific papers	Proposed future objectives
Workshops	Responses to requests	Long-term political commitment

The evaluation strategy aims to allow the achievement of the aims and objectives to be measured, and the expected public health policy outcomes, to be demonstrated at national and European level. Evaluation is defined as a systematic appraisal of the success of a project, in terms of:

- results – have the objectives been met? and
- quality – do the results meet the needs of the stakeholders?

The evaluation process is designed to assess whether the project is being implemented as planned and reaches the specific objectives. Each specific objective can be measured using three different indicators (processes, output and outcome indicators – Figure 19, Table 7).

Process indicators are focused on measuring the activities (e.g. visits, workshops, conferences, etc.). Output indicators measure the results of the activities (e.g. published papers, press releases, reports, etc.). Outcome indicators measure the effects of the actions, e.g. producing changes in knowledge, awareness, improvement on practices, policy development. Outcome indicators require specific evaluation methods adapted to measure mid-term and long-lasting effects of the actual output (e.g. created knowledge, awareness, willingness to change practice, policies or programmes, etc.).

Partners in the JAs are expected to include specific targets for each of the indicators. This enables full verification of the intended implementation of the project and achievement of the objectives. This is especially important in relation to the outcome indicators.

The evaluation strategy usually defines important milestones – notably the evaluation plan and monitoring reports (regarding evaluation design, evaluations of meetings, conferences, trainings, committees or other relevant actions). However, some JAs condense the reporting into just one final evaluation report. The evaluation can also be supplemented by input from an expert advisory board, or an external evaluation report from independent experts.



Joint Actions  
funded under  
the Health  
Programme  
2008-11



2008



## Scientific support to the Rare Disease Task Force activities (RDTF)

**Keywords:** Rare diseases, public health policies, nomenclatures, health indicators

### Summary

*The objective of the RDTF Joint Action was to promote action on the prevention of rare diseases, and to support the development or implementation of a policy in the area of rare diseases and orphan drugs. The main action was through providing technical assistance to the Commission's Rare Disease Task Force (RDTF, now the EU Committee of Experts on Rare Diseases EUCERD). One key specific task of the JA was to improve the codification and classification of rare diseases in the context of revision of the WHO International Classification of Diseases (ICD).*

### How does the RDTF JA contribute added value to EU Health Policies?

The RDTF JA met the request from both the Commission and the Council of Ministers for technical and scientific support to be provided through the Health Programme to the RDTF/ EUCERD in its work on monitoring, evaluating and disseminating the results of Community and national measures in the field of rare diseases.

Revision of the ICD to include rare diseases will have an impact on Member States' health policies

as it will increase the visibility of rare diseases in information systems. This will in turn improve the traceability of rare disease patients, which will help Member States to provide more structured healthcare for these patients.

The work of the RDTF JA provided European added value because the coordinated activity it supported would not be possible at national level. Individual countries would not have been able to achieve progress against rare diseases without this concerted input from experts from across Europe and collaboration across the EU.

## Why are rare diseases an important problem for Europe?

Rare diseases are in most cases life-threatening, chronically debilitating conditions, and most are genetically determined. They each affect a relatively small number of people (a rare disease affects less than five in 10 000<sup>(1)</sup>), but their diagnosis and care is costly, and research into the individual diseases and their care presents problems when patients are widely dispersed. But today in the EU, 6-8% of the population, or up to 36 million people are affected by between 5-8 000 separate rare diseases. A combined approach to these diseases is better able to make progress in scientific and biomedical research, drug research and development, industry policy, information and training, social benefits, hospitalisation, and outpatient care.

## What did the JA set out to do?

The RDTF JA set out to help raise the visibility of rare diseases in the EU by providing technical and scientific support to the Rare Diseases Task Force. In particular, it worked toward inclusion of rare diseases in the WHO ICD.

## Methods

The RDTF JA provided scientific support for the Rare Diseases Task Force by identifying known indicators that are relevant to rare diseases, and collecting further data on a yearly basis. This information was distributed to interested organisations and stakeholders through ad-hoc reports and an electronic newsletter, including information on national and EU initiatives and incentives.

The JA developed further the results, experience and methodologies of several other information resources including the Orphanet database, RD information networks and EUROPLAN activities. It also liaised with EU agencies, services and major stakeholders, and developed methods for assessing the EU added-value of networks of centres of expertise for rare diseases.

The RDTF JA worked to improve the traceability of rare diseases in health information systems by proposing assignment of International Classification of Diseases codes (ICD10) to all rare diseases. Most

rare diseases are absent in ICD10 and those with a specific code are often misclassified. As a consequence, morbidity and mortality due to rare diseases is invisible in health information systems. The RDTF JA also proposed changes to improve the classification in view of future adoption of the ICD11 in 2015, using the technical platform developed by the WHO and with the assistance of an international expert group, and cross-referencing with other classification systems such as MedDRA and SNOMED-CT.

The JA was evaluated using a survey sent to all Members of the Rare Diseases Task Force/EUCERD and participants at the JA expert workshops. A satisfaction survey completed by readers of OrphaNews Europe newsletter in 2010 and also analyses of statistics of report downloads were taken into account in the final evaluation.

## What did the JA achieve?

The main result is the scientific support provided to the Rare Diseases Task Force/EUCERD and work on the revision of the ICD to make RD visible. The RDTF JA produced a wide range of outputs designed to raise awareness of rare diseases and contribute to shaping national and EU policies. Among these, the annual report on the State-of-the-art of Rare Disease Activities in Europe alone attracted 95 000 hits on the EUCERD website. Eleven expert workshops were organised for RDTF/EUCERD on rare diseases and the twice-monthly newsletter OrphaNews Europe now reaches over 13 000 subscribed readers.

The JA succeeded in gaining the potential assignation of a specific ICD code for all rare diseases in ICD11, and a proposal for a new classification of diseases within the current ICD revision in which rare diseases will be fairly represented, and its adoption by the WHO standing committees. It also completed cross-referencing of rare diseases in all coding systems: MedDRA (the WHO Medical Dictionary for Regulatory Activities), SNOMED-CT (Systematized Nomenclature of Medicine – Clinical Terms, from the International Health Terminology Standards Development Organisation) and MeSH (Medical Subject Headings, from the US National Library of Medicine). The RDTF JA also defined a range of reliable indicators in order to monitor the public health impact of rare diseases and the effect of policies in place.

<sup>(1)</sup> European Community Action programme on rare diseases 1999-2003.

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## How will the results be put into practice?

The revision of the ICD will have an impact on Member States' health policies, as it will increase the visibility of rare diseases in information systems; improving the traceability of rare disease patients, and helping to develop better-structured healthcare for these patients.

The various reports and recommendations produced by the EUCERD Scientific Secretariat with the support of the JA, particularly the report on the State of the Art of Rare Disease Activities in Europe, enable Member States to benchmark their own performance against that of other states, and encourage them to exchange information and experience in this area of health policy. The OrphaNews Europe newsletter and rare disease information from the JA on the OrphaNet website allow dissemination of key policy and scientific information and news to all stakeholders, including national health policy decision makers.

Revision of the ICD for adoption in 2015 will be achieved through the revision progress already under way. A Topic Advisory Group of experts for Rare Diseases has been established by the WHO.

Following the completion of the term of the RDTF JA in February 2012, its work was continued immediately by the EUCERD Joint Action: Working for rare diseases (EJA) from March 2011 onwards (see page 89).

## The benefits of working jointly at EU level

The RDTF Joint Action was the best possible initiative to supply the international scientific and technical resources to support the work of the RDTF/EUCERD. It enabled the experts of the Task Force/EUCERD to discharge their obligations under the Health Programme and the Council Recommendation of June 2009 on action in the field of rare diseases.



## RDTF: Key data

<http://www.eucerd.eu>

**MAIN PARTNER (M):**

Institut National de la Santé  
et de la Recherche Médicale, France

**PROJECT COST:**

Total: € 1 512 124

EC contribution: € 748 982

**PROJECT DURATION:**

01.01.2009 – 29.02.2012 (38 months)

Countries with associated and collaborating partners

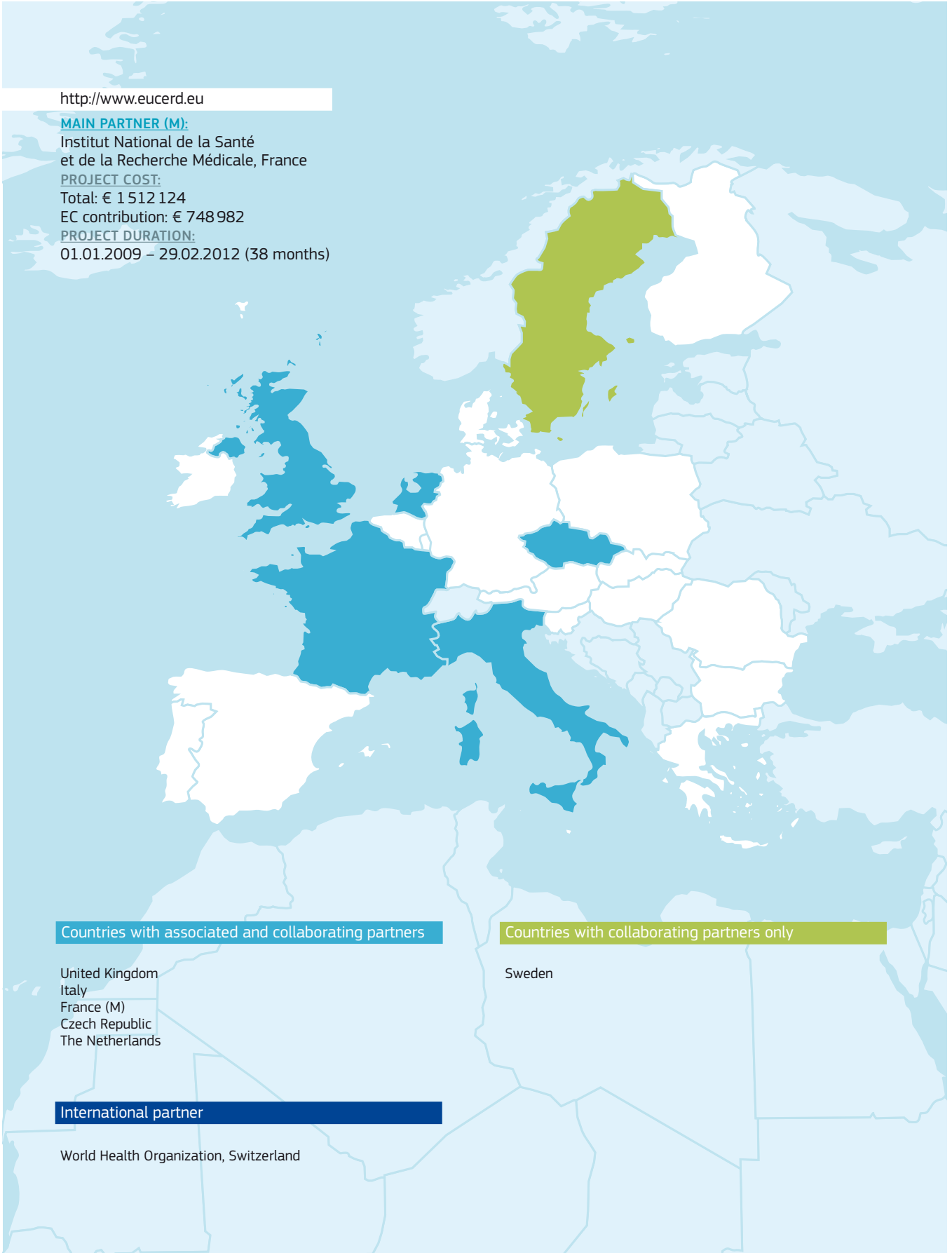
United Kingdom  
Italy  
France (M)  
Czech Republic  
The Netherlands

Countries with collaborating partners only

Sweden

International partner

World Health Organization, Switzerland



2008

## European Community Health Indicators and Monitoring (ECHIM)

**Keywords:** ECHI Indicators, health indicators, health information, health monitoring, health reporting

### Summary

*The Joint Action for ECHIM is expanding and implementing the ECHI list of comparable health indicators (European Community Health Indicators<sup>(1)</sup>) and developing a sustainable health monitoring system in the individual Member States and at EU level. Without it, the EU would have very uneven and non-comparable data on health in the Member States.*

*The existing ECHI shortlist of indicators had been developed since 1998 by previous projects. The ECHIM JA set out to develop the ECHI shortlist indicators further, and implement them in participating EU Member States, as well as several other European countries. This should lead to implementation of the list in all Member States by 2013, providing a foundation for a permanent Health Monitoring System in Europe. ECHIM partners added to, documented and disseminated comparable health data on 88 different indicators including demography, health status, health services and health promotion. The JA also maintained the existing network of experts on national health indicators and their collection.*

*The work was carried out in close collaboration with Member States, the European Commission, EuroStat, WHO, OECD and other international organisations, with the aim of supporting the EU Health Strategy.*

### How does the ECHIM JA contribute added value to EU Health Policies?

The ECHIM JA implemented the core tasks of the Health Programme and its Work Plan for 2008, by:

- assembling comparable data to enable assessment of the impact of disease, health risk factors and socioeconomic status;
- extending and implementing the ECHI system in each Member State and at EU level;
- supporting the data flow between Member States and a central EU facility for data

monitoring, by emphasising the importance of national comparability; and

- complementing other international databases (EuroStat, WHO, OECD) through its focus on the most relevant issues at national and EU level.

The ECHIM JA also contributed European added value by extending data collection to include new indicators of health promotion, disease prevention and public policy beyond the previous requirements, by promoting best practices in data collection, and by enabling benchmarking for international data comparisons.

<sup>(1)</sup> European Community Health Indicators (ECHI), [http://ec.europa.eu/health/indicators/echi/list/index\\_en.htm](http://ec.europa.eu/health/indicators/echi/list/index_en.htm)

## Why is health data collection important for Europe?

Data on the extent and growth trends of diseases, injuries and their relation with age and socioeconomic factors are vital for the effective planning and financing of public health initiatives for disease prevention, health promotion and healthcare provision. Comparable national data improves the ability of public health officials, governments, stakeholders and academics to monitor trends, assess needs, and benchmark activities and outcomes.

## What did the ECHIM JA set out to do?

The ECHIM JA set out to develop the ECHI shortlist indicators further, and implement them in participating EU Member States and other European countries. Its partners added to, documented and disseminated comparable health data on 88 different indicators including demography, health status, health services and health promotion. The JA also maintained a network of experts on national health indicators and their collection.

## Methods

A pilot data collection was carried out in participating countries to assess the availability of the ECHI Indicators that were not yet published in international databases. The ECHIM JA assembled data for these ECHI Indicators and monitored the methodology.

The ECHIM JA established a model plan for the implementation of ECHI Indicators. The data research and bilateral negotiations with the network of national experts, who had already been established in previous ECHI projects, led to development of country-specific implementation plans. The existing international network of health indicator experts supported the development of indicators and their implementation in all countries.

The work was carried out in close collaboration with Member States, the European Commission, EuroStat, WHO, OECD and other international organisations.

## What did the JA achieve?

The main result is the shortlist of 88 core indicators, each with a fully updated documentation list that defines its method of calculation and best available data source, taking into account the quality of methodology, availability of data, the burden for Member States if new or altered data collection is needed, and the political importance of the indicator. The ECHIM JA has also compiled information on the status of implementation in most European countries, and has analysed the health indicators not published in international databases. Its website gives complete data for all ECHI shortlist indicators, and a printed textbook based on the final report was published in July 2012. A method has been established to evaluate and update the ECHI shortlist, and country-specific guidelines have been prepared for Member States and the EU for implementing the ECHI shortlist.

Contacts to key research centres and decision makers in participating countries have been established through the network of country experts. The contacts have enabled ECHIM to be included in the national health indicator systems, and to be mentioned in national health reports.

The ECHIM JA has been evaluated by an external evaluator. Its results – new indicators and national data – have been disseminated to several hundred public health professionals and decision makers throughout Europe. Regular newsletters were published on the website ([www.echim.org](http://www.echim.org)) throughout the three-year project, and press releases, promotional leaflets, e-mails to country experts, presentations and workshops at international conferences were also used as appropriate. The ECHIM book was distributed to key people in national public health institutes, ministries and universities, and international organisations. National health attachés from the EU Member State representations were contacted directly by DG Health and Consumers to boost national implementation activities.

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## How will the results be put into practice?

The importance of having internationally comparable health data has been widely realised, and ECHI Indicators have been widely recognised as the core European set of health indicators. They are already being embedded in national health indicator systems in some participating countries, planned in almost all of the rest, and mentioned in national health reports.

## The benefits of working jointly at EU level

Many European countries still do not record key health indicators, despite increasing attention to the value of evidence-based medicine in health policy development. Even where health indicators are recorded, substantial differences between countries remain in the methodology used – which makes it impossible, or at best risky, to attempt to compare the data of different countries. Working together at EU level was the only way to establish systems robust enough to generate trustworthy data that is comparable between the Member States. The ECHIM JA was a highly effective mechanism to examine the status of existing data, identify the gaps, define the new indicators needed, and provide guidance to Member States to implement the ECHI shortlist into national policies.

## ECHIM: Key data

<http://www.echim.org>

**MAIN PARTNER (M):**

National Institute for Health and Welfare THL, Finland

**PROJECT COST:**

Total: € 2 996 942

EC contribution: € 1 498 473

**PROJECT DURATION:**

01.01.2009 – 31.06.2012 (42 months)

**Countries with associated and collaborating partners**

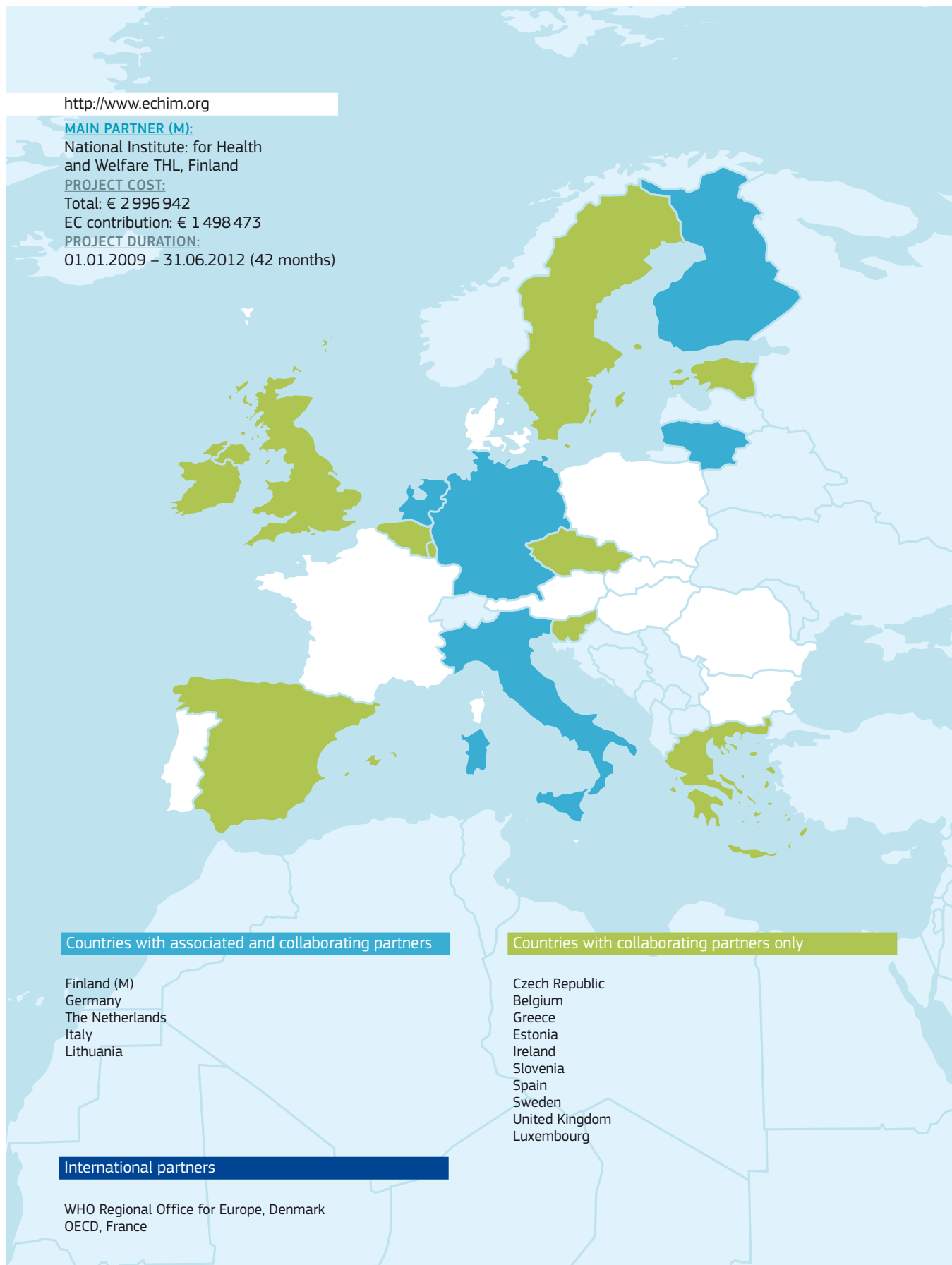
Finland (M)  
Germany  
The Netherlands  
Italy  
Lithuania

**Countries with collaborating partners only**

Czech Republic  
Belgium  
Greece  
Estonia  
Ireland  
Slovenia  
Spain  
Sweden  
United Kingdom  
Luxembourg

**International partners**

WHO Regional Office for Europe, Denmark  
OECD, France



2009



## Safety evaluation of manufactured nano-materials by characterisation of their potential genotoxic hazard (NANOGENOTOX)

**Keywords:** Genotoxicity, nanoparticles, silica, titanium, carbon nanotubes

### Summary

*Nanotechnology is a highly strategic industrial and economic sector, and materials composed of nanoparticles are finding applications in an increasing number of sectors, including consumer products such as cosmetics and foods. The lack of scientific knowledge on the safety of human exposure to manufactured nanomaterials makes regulation difficult. Public and government interest is growing on the safety of nanomaterials and their potentially toxic effects.*

*The objective of the NANOGENOTOX JA was to support and add value to Member States' policies in nanotoxicology and to contribute to increasing the safe use of nanomaterials in the EU. A priority aspect was to develop a reliable and cost-effective methodology for industry and EU regulatory bodies to assess the potential genotoxicity (DNA damage) from nanomaterials, and to generate data on the genotoxicity of a range of reference materials. The JA was also designed to facilitate overall safety evaluation and sharing of knowledge, towards implementing an EU-wide information management platform for nanosafety that would be in keeping with the general chemicals Regulation REACH (Registration, Evaluation, Authorisation and restriction of Chemicals<sup>(1)</sup>).*

### How does the NANOGENOTOX JA contribute added value to EU Health Policies?

The general objective of the JA was to support and add value to the Member States' policies for nanomaterial safety, and to contribute to increasing the safe use of nanomaterials in the European Union. It was set up to meet the objectives concerning the safety of manufactured nanomaterials that were set within the Programme of Community Action in the Field of Health.

These are to strengthen, expand and share the knowledge required for the assessment of the hazard, exposure and overall risk of nanomaterials, and to minimise their potentially harmful long-term effects. The Health Programme also called for actions to stimulate the application of existing data and the exchange of best practices in risk assessment and management, and to promote development throughout the EU of robust, specific and sensitive European Union to screen potentially genotoxic nanomaterials.

<sup>(1)</sup> REACH (Registration, Evaluation, Authorisation and restriction of Chemicals), [http://ec.europa.eu/enterprise/sectors/chemicals/documents/reach/index\\_en.htm](http://ec.europa.eu/enterprise/sectors/chemicals/documents/reach/index_en.htm)

## Why is the safety of nanomaterials an important problem for Europe?

Nanotechnology has many societal and environmental applications, with enormous potential benefits. The use of nanomaterials is increasing, and consumers may be exposed to them in consumer products at several phases of their life cycle, from synthesis, production and inclusion in products to the eventual release of the nanomaterials into the environment. Nanomaterials are now commonly used in cars, electronics, computers, personal care, cosmetics and household goods.

Regulating to protect human safety is very difficult because of the lack of evidence and the lack of scientific knowledge on the genotoxicity<sup>(2)</sup> of nanomaterials. Because of this, health and safety evaluation is attracting the attention of the public and of governments worldwide.

## What did the JA set out to do?

The NANOGENOTOX JA set out to provide high added value information to complement Member States' policies on the safety of nanomaterials, and in doing so, to contribute to improving the health and safety of citizens of the EU. The work would also extend the EU's world leadership in this field and its contribution to continuing related international work under the OECD, the International Organization for Standardization (ISO) and other bodies.

## Methods

After studying the existing data available, the JA partners characterised the physical and chemical properties of 14 reference nanomaterials, including silicon dioxides, titanium dioxides and carbon nanotubes. All are produced and readily available in European consumer products, and were provided by the Joint Research Centre (JRC), Ispra. This study enabled a detailed knowledge of their characteristics and behaviour, including morphology, water solubility, porosity and so on. The partners also developed a protocol to be used for toxicological testing, and determined the nature of any toxic effects and the distribution of nanomaterials in the organs of living

organisms after exposure. These tests were followed by genotoxicity studies both in living organisms and the results compared for validation with *in vitro* studies using cells corresponding to the route of exposure, i.e. whether the nanoparticles would be absorbed via the lung, intestine, skin or other organs. The data generated in this way on the 14 reference nanomaterials would then be usable as a reference point for comparison of other nanomaterials and their genotoxicity.

## What did the JA achieve?

The most important outcome was the set of SOPs for rapid characterisation of types of nanomaterials, together with the dispersion method for producing suitable media for exposure to nanomaterials, and the data sets of physico-chemical properties. The JA also generated *in vitro* genotoxicity data on the reference nanomaterials that can be used for risk assessment of medicinal products and medical devices, as well as consumer products. Its response to the needs expressed by regulators, industry and society therefore made a significant contribution to ensuring the future protection of human health.

The JA also developed tools for raising awareness of the safety of nanomaterials, including its website, logo and project identity. Four newsletters and a final report were produced, and partners presented the JA at national and international conferences and in scientific publications. Stakeholders – regulatory authorities, market surveillance bodies and policy makers – were consulted about their key concerns and informed of progress throughout the term of the JA.

## How will the results be put into practice?

The JA will provide information for policy makers and regulators upon which the nature of the risks posed by nanomaterials can be determined. That information is essential so that they can identify gaps in current legislation and the changes needed to ensure public safety. Industry stakeholders will be able to use the methodology before marketing their nanomaterials, either directly or in consumer products.

<sup>(2)</sup> Genotoxicity definition, Guidance for assessing systemic exposure in toxicology studies, European Medicine Agency (EMA), [http://www.ema.europa.eu/docs/en\\_GB/document\\_library/Scientific\\_guideline/2009/09/WC500002770.pdf](http://www.ema.europa.eu/docs/en_GB/document_library/Scientific_guideline/2009/09/WC500002770.pdf)

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The JA has contributed to the creation of a network of laboratories that will continue to work within the partner institutes. In the institutes participating in the JA, researchers and students have been trained in the experimental procedures developed, and will in the future contribute to their dissemination. The JA developed a database on widely produced and used nanomaterials, for which exposure occurs through different routes (oral, inhalation, skin application). The JA's genotoxicity method, which is an alternative to animal testing, will be transferred to other stakeholders outside the JA including ministries of the EU Member States. By reassuring the public about the risks potentially linked to the most widely used nanomaterials, the Member States and the EU should ensure the safe, sustainable and integrated development of nanotechnology; an industrial sector with huge potential.

### The benefits of working jointly at EU level

Participation from a large number of scientific teams from various Member States enabled a common methodology to be developed. This should allow results from genotoxicity testing to be shared and accepted by different Member States, which will avoid unnecessary duplication. The EU method could be taken up on an international level through OECD, ISO and other international institutions.

As a multi-partner initiative, the JA has accelerated the exchange of best practice for *in vitro* and *in vivo* genotoxicity studies, as well as in the physico-chemical characterisation of nanomaterials much more effectively than could have been done in a single Member State. The work is harmonised at EU level through staff training and cross evaluation, minimising potential variations and allowing better comparison and interpretation. The method can be used directly by EU regulatory bodies responsible for human health risk assessment (e.g. for REACH), and also by industries or for consumer or worker protection – leading to better public health protection in the EU.



## NANOGENOTOX: Key data

<http://www.nanogenotox.eu>

**MAIN PARTNER (M):**

Agence Française de Sécurité Sanitaire  
de l'Environnement et du Travail

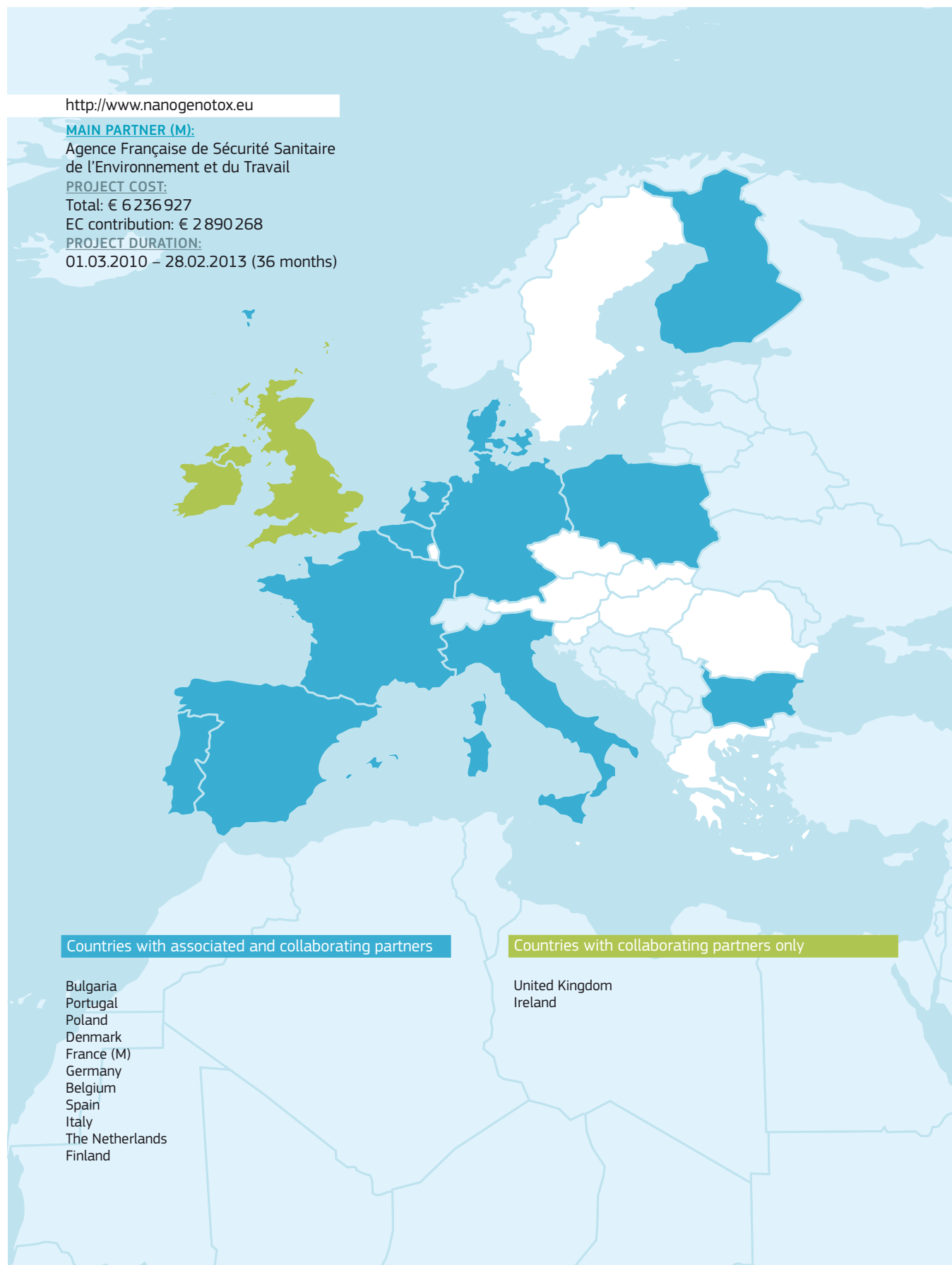
**PROJECT COST:**

Total: € 6 236 927

EC contribution: € 2 890 268

**PROJECT DURATION:**

01.03.2010 – 28.02.2013 (36 months)



2009



## European Health Examination Survey Pilot Joint Action (EHES)

**Keywords:** Health survey, standardisation, physical examination, questionnaire, chronic diseases

### Summary

*The European Health Examination Survey (EHES) is a collaborative initiative to collect high-quality data on the health of a nationally representative sample of people in individual countries of Europe, which are comparable among countries and over time. It includes a set of core measurements chosen to indicate chronic disease risk factors and disease prevalence, to which Member States can add extra measurements according to their national needs and resources.*

*The EHES JA was set up as part of the first phase of the EHES, in order to support the national activities needed to build the capacity for full-scale Health Examination Surveys (HES) in the first 14 countries. JA partners worked in collaboration with the European Health Examination Survey Reference Centre (EHES RC), including piloting the fieldwork, data collection, assessment and reporting.*

### How does the EHES JA contribute added value to EU Health Policies?

This pilot project was an important step towards a sustainable system of national health examination surveys covering all EU and EFTA/EEA countries. It was required in the Second Health Programme, and also mentioned as an option in the 2008 Regulation on community statistics on public health. It is also entirely in line with the WHO European region's action plan on prevention and control of non-communicable diseases, and the UN General Assembly's 2011 commitments to strengthening

country-level surveillance and monitoring for exposure to risk factors, outcomes, social and economic determinants of health.

The EHES JA tested and evaluated the applicability of the project on Feasibility of a European Health Examination Survey, gaining insight towards a sustainable system of standardised surveys in Europe. The results can be used to evaluate the need for health services and health promotion, to identify major target groups and adapt the activities to meet their specific needs and in the long term also to follow trends.

## Why is it important to measure the health of Europeans?

National Health Examination Surveys have become more frequent in Europe since the 1970s, linked with increasing recognition that many health determinants are affected by personal lifestyle choices. By measuring key indicators of health – such as blood pressure, blood glucose and cholesterol levels – in a representative sample of people, a good picture can be built of each nation's health and the risk factors it faces. Modern lifestyles favour physical inactivity and a diet rich in processed foods – factors implicated in rising obesity, cardiovascular disease and Type-2 diabetes. These conditions are widely recognised to present a major and still growing threat to the health of populations and to the economic future of national healthcare systems. The EHES JA set out to test how the European Health Examination Survey could be used or adapted for different cultures and healthcare systems, to evaluate the need for health services and health promotion, to identify major target groups and follow long-term trends. It can also be used to inform the public about health risk factors and lifestyle choices.

## What did the JA set out to do?

The EHES JA set out to test the procedures for full-scale national health examination surveys, by running a pilot study and identifying and resolving all the practical issues it presented. This pilot study, using a much smaller number of people in 12 countries, enabled best practices to be established that would enable all European countries to integrate full-scale EHES into their own health information systems. Availability of high quality, comparable data on health and its risk factors, which are obtainable only through health examination surveys, is essential for policy-making and for health protection.

## Methods

The EHES JA partners conducted a pilot study in each of 12 countries, using a random sample of 200 people. The participating countries were Greece, Malta, Poland, Czech Republic, Italy, Germany, Netherlands, Finland, United Kingdom (England), Norway, Slovakia and Portugal – originally 14 countries were involved, but two withdrew because of changed national priorities. The pilot study in each country involved gaining ethical approvals, sampling, logistics, training, fieldwork and quality control. The resulting data was transferred to the EHES Reference Centre. The JA partners provided

information for external quality assessment, reports of the pilot results and plans for local dissemination. Partners exchanged experiences and practical ideas throughout the project, making use of training seminars, JA coordinators' meetings and a workshop on national adaptations.

Some countries – Germany, Italy, Netherlands, and England – were also running their own full-scale health examination surveys at the same time as the EHES pilots. These countries built the JA activities into the full-scale surveys and evaluated any differences between the European and the local procedures.

The results and findings of the pilot studies identified and resolved numerous practical problems, enabling the partners to prepare a full-scale National Health Examination Survey.

## What did the JA achieve?

The EHES JA prepared the detailed plans and preparations needed for the national health examination surveys to be carried out in the next three years and produce high quality, comparable data on key health indicators. The countries involved in the pilot studies were ready to start the field work of the full-scale surveys in their countries after the pilots have been evaluated. This would be either a new survey as an HES component added to an established health interview survey, or an established national HES, adapted to European HES standards.

Those pilot countries with little earlier experience became confident, after the JA, to start full-size national surveys, provided that the funding was available. Nearly all of the countries with earlier national surveys were able to provide comparable data on the core measurements without compromising trends from their past surveys.

The main outcomes from the EHES JA were the national plans for health examination surveys and the reports of the national pilot surveys. An overview of the European Health Examination Survey Pilot Joint Action was accepted for publication in Archives of Public Health in Belgium. The EHES JA was presented in a total of 49 conferences and workshops, including the EHES conference in March 2012, attended by 60 HES experts and policy makers from 19 countries. Information about the JA was distributed on its website, through four EHES newsletters and other promotional material. The JA partners each prepared national dissemination plans for

future full-scale HES, covering distribution of information about national HES as a source of health data and indicators to national authorities, citizens, professional organisations, national NGOs, media and the public.

The JA was evaluated by a combination of assessment of all partners' participation in training seminars, coordinators' meetings, and evaluation of the regular partners' progress reports. The partners' evaluation of the outcomes was collected by questionnaire and during the EHES conference.

### How will the results be put into practice?

The results of the JA give strong encouragement to policy developers at the national and European level to set up the infrastructure to coordinate and standardise national surveys, and for the countries to make HES a part of their national health information systems.

The JA created a technically sustainable structure for full-scale EHES, which is supported by the interest and needs indicated by potential survey organisers in most EU and EEA countries. The main obstacle for national sustainability is the cost, but countries with existing surveys consider that the cost is low compared to the potential savings from successful prevention of the diseases, and have passed this experience to others. European-level coordination, support to countries in planning the national HES, sampling design, training, external quality assessment and reporting are essential for sustainable European health examination surveys.

Policy makers in the EU Member States have, in the EHES, a validated method that is realistic to implement and it can provide relevant health indicators. The full-scale health examination surveys that have been facilitated by the EHES JA will provide reliable health information with a wide range of applications for national policy makers, decision makers, national NGOs, researchers, healthcare professionals, the media reporting and the general public.

The EHES Pilot Project showed that standardised HES can now be conducted in the Member States which have varying experience and economic status. The core measurements of EHES can be standardised to provide objective information on important risk factors of the major chronic diseases, and this information cannot be obtained by other means.

In detail:

- Germany, Italy, the Netherlands and England carried out full-size national HES in parallel with the Joint Action.
- Slovakia started its full-scale HES in November 2011, and Finland started in January 2012.
- The Czech Republic, Greece, Malta, Poland and Portugal plan to start HES in 2013-14, although the funding for some of these is pending.
- Two countries which were not partners of the JA will carry out national surveys using the EHES procedures: Luxembourg in 2012 and France in 2013.

### The benefits of working jointly at EU level

The EHES JA showed that standardisation of full scale health examination surveys requires European-level coordination, a training programme and other means of quality assurance, which were developed by the JA partners and the EHES Reference Centre. The EHES Pilot Project, including the JA, showed that standardised surveys can now be conducted in Member States with varying experience of health surveys and varying economic status. The core measurements of EHES can be standardised to provide objective information on important risk factors of the major chronic diseases, and this information cannot be obtained by other means.

The results of the Joint Action give a strong message to policy development at the national and European level to set up the European level infrastructure for coordinating and standardising national surveys and for the countries to integrate health examination surveys as a part of their national health Information systems.

## EHES: Key data

<http://www.ehes.info>

**MAIN PARTNER (M):**

National Institute for Health and Welfare THL, Finland

**PROJECT COST:**

Total: € 1 683 682

EC contribution: € 841 837

**PROJECT DURATION:**

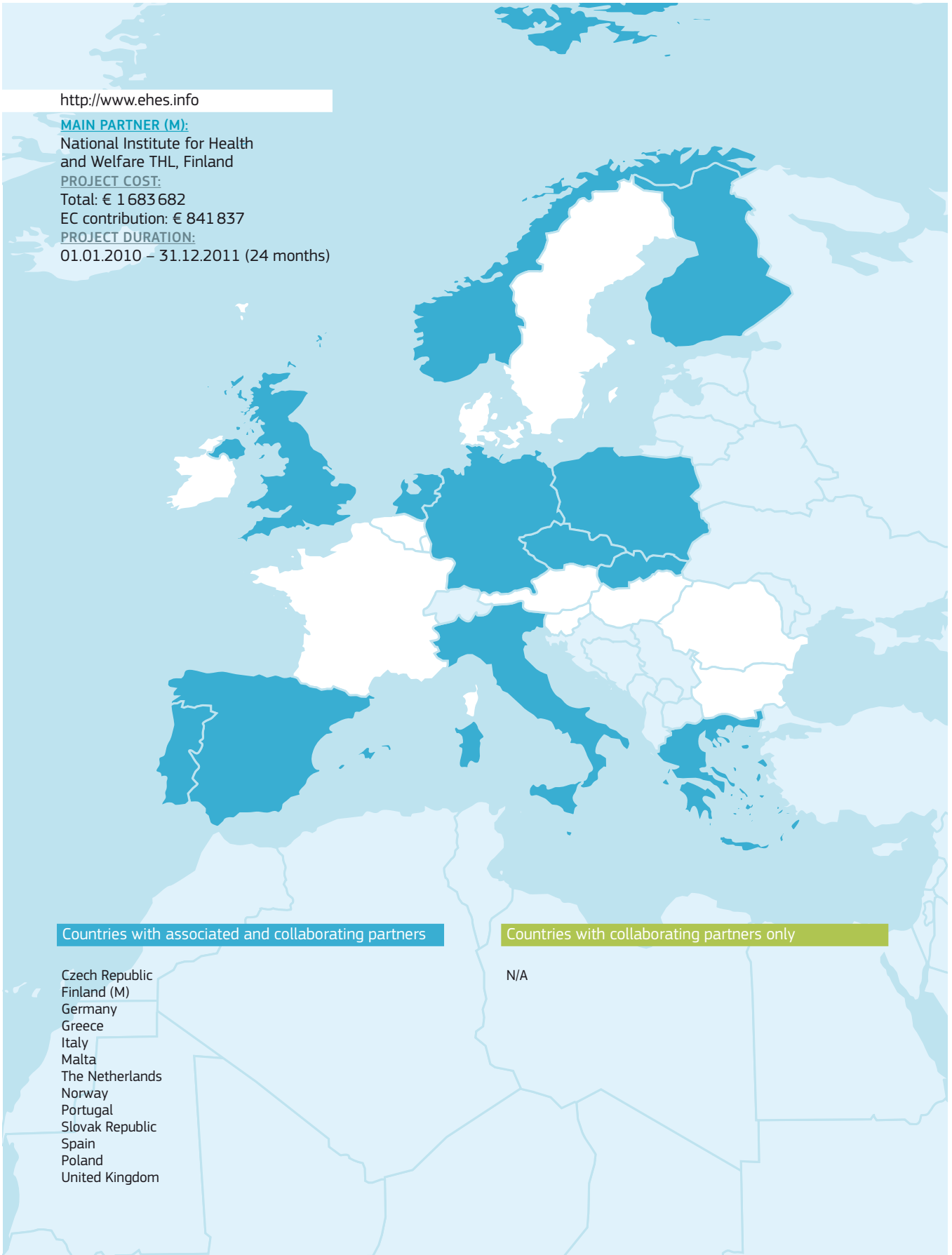
01.01.2010 – 31.12.2011 (24 months)

Countries with associated and collaborating partners

Czech Republic  
Finland (M)  
Germany  
Greece  
Italy  
Malta  
The Netherlands  
Norway  
Portugal  
Slovak Republic  
Spain  
Poland  
United Kingdom

Countries with collaborating partners only

N/A



2009



## European network for HTA Joint Action (EUnetHTA)

**Keywords:** Health technology assessment, health services research, healthcare efficiency, health systems, quality improvement

### Summary

*Health technology assessments are a means of analysing the medical, economic, social and ethical implications of the value, effectiveness, costs and impact of a medical treatment in healthcare. They are increasingly important and more widely used by healthcare administrators, as the demands and economic pressures on healthcare systems are both growing substantially.*

*The EUnetHTA Joint Action built a mechanism for collaboration between the organisations responsible for health technology assessment (HTA), with a view to adding value to their operation at European, national and regional level. The JA linked 34 HTA agencies and other institutions, from 24 EU Member States and two EEA/EFTA countries. The collaboration network it developed will assist organisations to improve the quality and efficiency of HTA and to deliver solutions to country-specific issues.*

### How does the EUnetHTA JA contribute added value to EU Health Policies?

The JA was a response to an explicit request in the 2009 work plan of the Second Health Programme for a sustainable Europe-wide network for health technology assessment. Developing and increasing the efficiency and transparency of HTA across Europe addresses issues of strategic importance identified in the Second Health Programme.

The EUnetHTA JA has met this need by creating a direct system for effective collaboration between HTA organisations across Europe, leading to a higher level of efficiency. Its actions contribute to implementation of the recommendations of the Pharmaceutical Forum<sup>(1)</sup> on relative effectiveness assessment for pharmaceuticals, and the JA has also responded to relevant developments in the EU and elsewhere that are relevant to HTA collaboration in Europe.

### Why are health technology assessments important for Europe?

At this time when populations are ageing worldwide and economic pressures force healthcare providers to evaluate all the elements and treatments they provide, health technology assessments are increasingly important for the successful and sustainable working of healthcare systems. HTA is a tool to

improve quality and efficiency of public health and healthcare interventions and policies. Developing and increasing the efficiency of HTA across Europe addresses issues of strategic importance identified in the Second Health Programme. Enabling HTA agencies to collaborate effectively will help to reduce unnecessary duplication of HTA activities, and promote both good practices and efficient use of resources.

<sup>(1)</sup> The Pharmaceutical Forum is the three-year high-level ministerial platform operating between 2005-08 linking Member States, EU institutions, industry, healthcare professionals, patients and insurance funds, for discussion of information to patients on diseases and treatment options; pricing and reimbursement policy and relative effectiveness.

## What did the JA set out to do?

The JA set out to build on the methods and tools developed by the EUnetHTA project of 2006-08, in order to develop a multi-stranded and comprehensive model for sustained collaboration between HTA organisations in Europe.

## Methods

Three interrelated streams of activities were used – a detailed business model for sustainable HTA collaboration in Europe; the methodologies needed to enhance the efficiency and transparency of HTA processes; and application of those tools, both in trans-national collaboration in Europe and at national, regional and local levels. Constant interaction between the streams enabled the JA to be responsive to the evolving needs of HTA organisations and those contributing to the assessments, allowing the JA partners to identify in which areas and to what extent the EU-wide collaboration worked best.

The JA made innovative use of the products developed by the earlier EUnetHTA Project, such as using the HTA Core Model and Adaptation Toolkit to produce HTA core information, and its resources give easy access to databases with a variety of information about ongoing and completed HTAs, HTA organisations, experts and training. It also shared a broad range of health technology information, including new, established and superseded technologies.

## What did the JA achieve?

The JA built widespread awareness of the EUnetHTA objectives, activities and results across the European and international HTA community, and also within European umbrella organisations for stakeholder groups. It developed a background review and an HTA Core Model for rapid relative effectiveness assessment of pharmaceuticals, together with reports on national HTA strategies and training needs, which was followed by a training workshop on EUnetHTA tools.

The JA also collaborated with the European Medicines Agency (EMA) on the improvement of European public assessment reports (EPARs), which are the full scientific assessment report published by EMA for every medicine granted a central marketing authorisation. The EUnetHTA JA has signed a Memorandum of Understanding with INAHTA, the International Network of Agencies for Health Technology Assessment, that links 52 Member agencies working with HTA, in 29 countries.

The work of the EUnetHTA JA was disseminated through its conference in Gdansk (PL), December 2011, an informative video and interaction with users through the LinkedIn group HTA in Europe, which has attracted over 900 Members. It was evaluated by regular surveys of the views of partner organisations and external stakeholders.

## How will the results be put into practice?

The work of the EUnetHTA JA will be continued by EUnetHTA JA 2, running for three years from October 2012 (see page 92). This second JA will test the tools and methodologies developed in the first EUnetHTA JA through a substantial number of pilots, generating evidence on the costs, quality and feasibility of European cooperation as applied to concrete assessment projects.

## The benefits of working jointly at EU level

Europe-wide collaboration on HTA had long been anticipated and was of high interest to HTA organisations in many Member States. The JA enabled topic selection based on common interests and sharing of work within the collaborative HTA projects. The very large number of associated and collaborating partners offered a large pool of expertise. With the wide support of these organisations, the JA generated increased international visibility for the importance of HTA, and also opened independent areas for communication between the agencies, institutions, and individuals working with HTA. All participants gained an increased understanding of national HTA practices and the varied role of HTA in national healthcare decision processes, together with a heightened awareness of the involvement of different stakeholder groups.

## EUnetHTA: Key data

<http://www.eunetha.eu>

**MAIN PARTNER (M):**

National Board of Health, Denmark

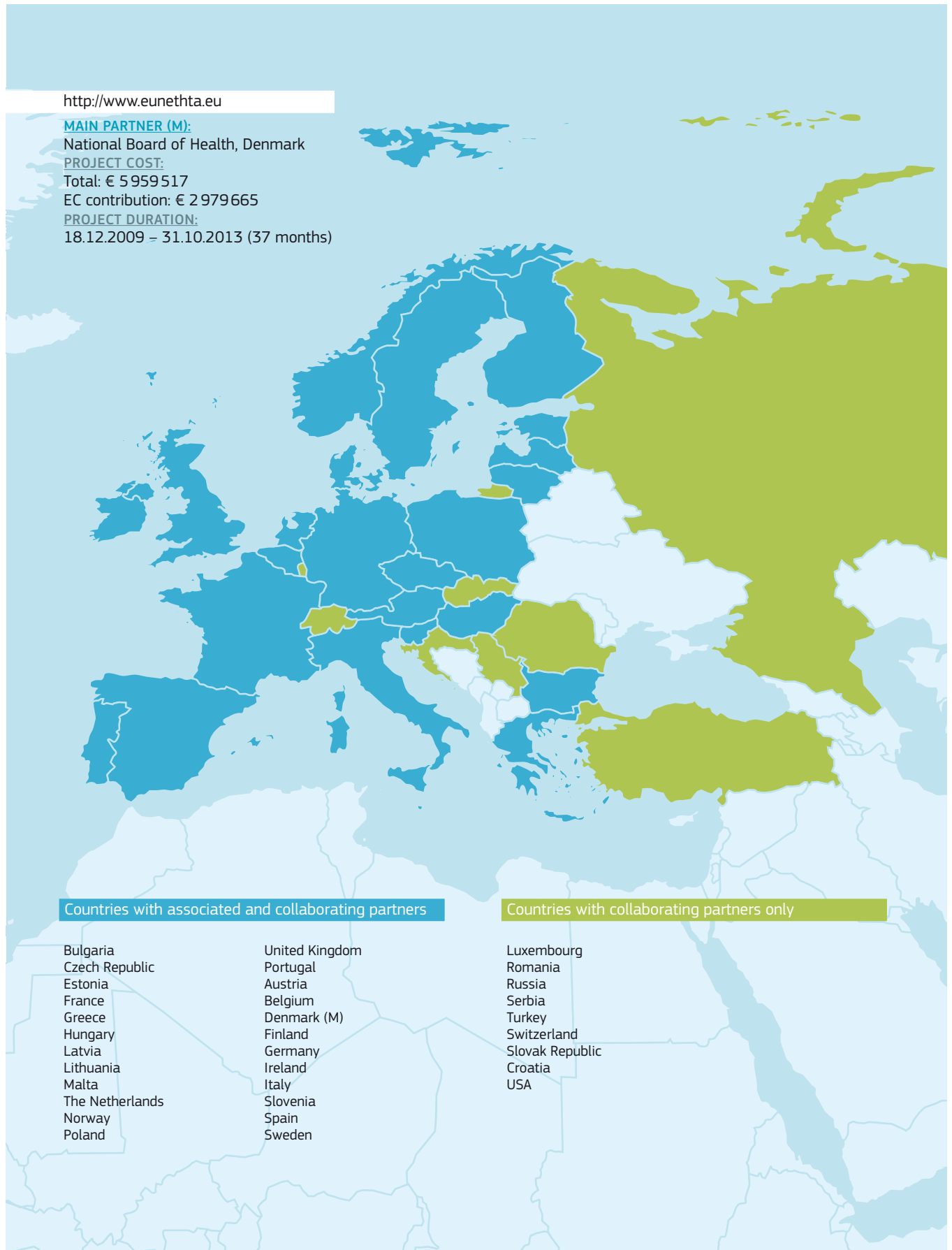
**PROJECT COST:**

Total: € 5 959 517

EC contribution: € 2 979 665

**PROJECT DURATION:**

18.12.2009 – 31.10.2013 (37 months)





2010



## Mutual Organ Donation and transplantation Exchanges: Improving and developing cadaveric organ donation and transplantation programmes (MODE)

**Keywords:** Transplant, organ donation, best practices transfer, quality improvement, transplant safety

### Summary

*The aim of the MODE JA was to improve the organisation of the systems in the EU and other European countries for organ donation and transplantation. Using a combination of exchange visits between participating partners and specialised training, the JA promoted the sharing of information and best practices among healthcare professionals, enabling them to benchmark their own procedures. The actions were applied to the key areas of increasing organ availability, enhancing the efficiency and accessibility of transplant systems, and improving quality and safety. Even those European countries with well-developed donation and transplantation systems showed differences in their organisation and procedures, and the outcome of the JA is wide distribution and uptake of best practices.*

### How does the MODE JA contribute added value to EU Health Policies?

The MODE JA responds to the Second Health Programme's 2010 work plan and its call for Member States to strengthen their cooperation and coordination activities in relation to organ donation and transplantation. This requirement also links with the Action plan on Organ Donation and Transplantation for 2009-15<sup>(1)</sup>. The action plan defined the three key areas – increasing organ availability, enhancing the efficiency and accessibility of transplantation systems, and improving quality and safety – that are addressed by the JA.

The sharing of best practices enabled by the JA will also contribute to implementation of the 2010 Directive<sup>(2)</sup> on standards of quality and safety of human organs intended for transplantation. The

directive requires each Member State to set up a competent authority if it does not already exist, and systems to provide for authorisation of organ procurement, continuous monitoring of transplantation and traceability of organs. In addition, transplant teams in all Member States will receive the correct and complete information, regardless of the origin of organs for transplantation. As the JA identified the areas in various countries where organ donation and transplantation showed room for improvement, this facilitated the steps needed to reach the standards required by the directive.

Because the JA partners were the national competent authorities for organ transplantation or alternative organisations delegated by the Member States, the outcome of the JA was assured proper support and implementation by national policy makers.

<sup>(1)</sup> Action plan on Organ Donation and Transplantation (2009-15): Strengthened Cooperation between Member States. COM(2008) 819 of December 8, 2008.

<sup>(2)</sup> Directive 2010/45/EU on standards of quality and safety of human organs intended for transplantation.

## Why is organ donation and transplantation an important issue for Europe?

For many patients, especially those with serious failure of organs such as the kidney, heart, liver, lung, pancreas, and bowel, organ transplantation is the only treatment that can save their lives. Transplantation is successful for about 80% of patients who undergo it. But today, 56 000 patients in the EU are waiting for a suitable organ donor, and it is estimated that every day 12 people die while waiting for transplantation. The current challenge in the EU is to increase the number of donors, but at the same time guaranteeing the quality and safety of the process from organ donation to transplantation.

The national systems for organ donation and transplantation in different Member States vary – and there is scope for sharing the best organisational approaches and procedures so that everyone in the EU who needs a transplant can benefit from the same high standards of care.

Transplantation is also important for healthcare economic reasons, in particular for kidney transplants. Here, dialysis is an alternative to transplantation, but it is expensive, in the region of EUR 50 000 per year. Dialysis keeps the patient alive, and may be needed for an unlimited length of time; in contrast to the one-time cost of transplantation.

## What did the JA set out to do?

The main objective was to exchange best practices in organ donation and transplantation, to investigate the feasibility of improvement in order to ensure effective implementation of the 2010 Directive. It was also designed to create an interactive network linking the relevant authorities of participating countries that could offer mutual support in policy development and decision making.

## Methods

The JA gave the opportunity for healthcare professionals within the national competent authorities concerned with organ transplantation to compare their system with those of other countries. Some of the JA partners were long-term Member States while others had only acceded in 2004. The national systems were varied, and had different organisation, legislation and plans for the future. The variation between their activities allowed a fruitful exchange of different experiences, even for countries with long-standing transplant programmes.

The project operated through exchange visits for partners' staff, followed by a set of specialised training sessions. Each participating country first presented its strengths and weaknesses through a questionnaire based on the Organ Action Plan. The questionnaire included sections to list topics on which partners could provide training to other countries, and topics on which they would like to receive specific training. Each country had the opportunity for five exchange visits on selected topics. These interest areas included donation from living or deceased donors, brain death diagnosis, traceability systems, quality assurance programmes including audit systems, lifesaving organ programmes and transplant urgencies, and also evaluation of transplant outcomes.

Following the visits, short reports and guidelines for improvement were developed, enabling follow-up training courses (two to three days or five days) to be developed and supplied, to meet the needs of healthcare personnel from organ coordinating and transplantation centres that had been highlighted during the visits. Full account was taken of previous of concurrent ongoing EU projects relating to organ transplantation (ALLIANCE-O<sup>(3)</sup>, DOPKI<sup>(4)</sup> and COORENOR<sup>(5)</sup>).

<sup>(3)</sup> European Group for Coordination of National Research Programmes on Organ Donation and Transplantation, ALLIANCE-O – <http://www.alliance-O.org>

<sup>(4)</sup> Improving the Knowledge and Practice of Organ Donation-DOPKI, [www.dopki.eu](http://www.dopki.eu)

<sup>(5)</sup> Coordinating an European Initiative among National organisation for Organ Transplantation, <http://coorenor.eu/>

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## What did the JA achieve?

The main achievement of the JA was a detailed understanding of the quality and effectiveness of the systems for organ donation and transplantation in participating countries, and the training of health-care personnel as needed to meet their individual countries' needs. The partners shared their findings with national and regional policy makers, healthcare professionals and transplantation system coordinators, through reports, brochures and presentations in national and international events.

## How will the results be put into practice?

The results of the JA are currently being put into practice by the staff responsible for donation and transplantation implementing the training they have received. This is sustainably improving the organisation and standards of service in participating countries, and contributing to Member States' ability to meet the requirements of the 2010 Directive.

## The benefits of working jointly at EU level

Collaboration at EU level and sharing of best practices has brought direct practical benefits to national systems by raising the quality of their donation and transplantation systems. Some Member States have already been able to implement changes in organisation and training that will increase organ donation rates and improve overall performance.

All participating countries, even those with well-developed services, have benefited from benchmarking their systems against those of other countries, and from investigating the possibilities of wider use of foreign donations. Together with the EU-wide implementation of the 2010 Directive on the quality and safety of donated organs, this should therefore contribute to an increased availability of organs for transplantation.

## MODE: Key data

<http://www.mode-ja.org/>

**MAIN PARTNER (M):**

Centro Nazionale Trapianti, Italy

**PROJECT COST:**

Total: € 550478

EC contribution: € 311591

**PROJECT DURATION:**

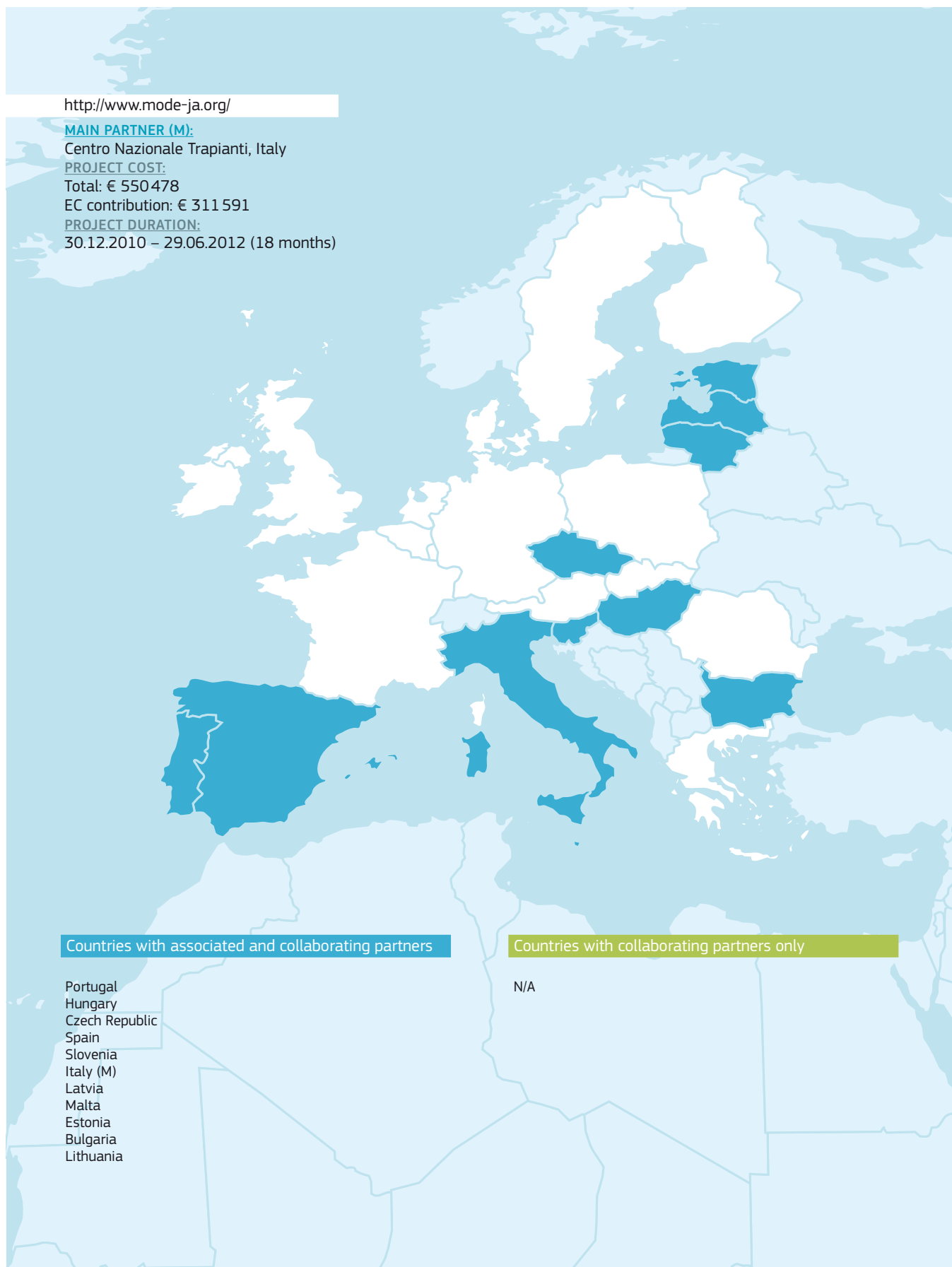
30.12.2010 – 29.06.2012 (18 months)

Countries with associated and collaborating partners

Portugal  
Hungary  
Czech Republic  
Spain  
Slovenia  
Italy (M)  
Latvia  
Malta  
Estonia  
Bulgaria  
Lithuania

Countries with collaborating partners only

N/A



2010



## Quality Assurance Exercises and Networking on the Detection of Highly Infectious Pathogens (QUANDHIP)

**Keywords:** Bioterrorism, biosafety and biosecurity, external quality assurance, highly infectious pathogens, reference laboratories

### Summary

*The aim of the QUANDHIP JA is to ensure and protect the security of the European population's health by improving the diagnostic capabilities of appointed European laboratories to detect highly infectious bacteria and viruses, whether occurring naturally or arising from deliberate or accidental release. The JA was designed to consolidate the outcome of two separate earlier EU-funded projects on bacteria and on viruses<sup>(1)</sup>. The established networks are linking 39 research and diagnostic laboratories in 23 European countries, to develop an integrated European laboratory structure for these highly pathogenic agents. In close cooperation, the activities of the QUANDHIP partners will reduce risk and mitigate the consequences of any such outbreaks or cross-border events by managing and coordinating laboratory diagnostic capacities.*

*The JA enables exchange of the most effective diagnostic strategies within the network and it generates a diverse resource of reference materials. It also developed a sustainable structure to enable the partners to perform external quality assurance exercises, bacterial antibiotic susceptibility testing, training, and a biosafety and biosecurity review of current practices.*

### How does the QUANDHIP JA contribute added value to EU Health Policies?

One of the primary aims of the Second Health Programme is to improve citizens' health security, and to protect citizens against health threats. The Health Programme continues to call more specifically for strategies and mechanisms for preventing, exchanging information on and responding to health threats caused by communicable diseases, and health threats from biological sources, including deliberate release. Action should also be taken to ensure high-quality diagnostic cooperation between Member States' laboratories; to support the work of existing laboratories carrying out work with relevance to the Community; and to set up a network of Community reference laboratories.

The QUANDHIP JA project focuses exactly on this area, by improving Member States' resources to protect the public and respond to such threats from highly infectious bacteria and viruses. It contributes to a closely-linked European network of specialised laboratories that can respond rapidly to an outbreak of infectious diseases, in support of clinical and public health measures. The network is unique with regard to biosafety and biosecurity measures for protection against both bacterial and viral agents. The network will also enhance the support of other agencies (veterinary, forensic) dealing with suspected or confirmed bioterrorism incidents. Its diagnostic tools will contribute to the capacity of global health security systems, and address the requirements of the WHO International Health Regulations.

<sup>(1)</sup> EQADeBa, coordinated by the Robert Koch-Institut (RKI), Germany (EAHC n° 2007 204) and the ENP4-Lab project, coordinated by L.Spallanzani National Institute for Infectious Diseases (INMI), Italy (EAHC n° 2006 208).

## Why are pathogenic bacteria and viruses – and the potential for bioterrorism – an important issue for Europe?

Outbreaks of highly pathogenic infectious bacteria or viruses do not respect national borders. In highly populated regions such as Europe, with widespread air travel enabling long-distance and rapid movement, their natural spread can be rapid and severe. In addition, the threat of a possible use of these agents for acts of bioterrorism raises the need for preparedness and for mechanisms to be in place to ensure the health security of Europe's citizens.

### What did the JA set out to do?

The QUANDHIP JA aims at improving Member States' resources for early response to protect the public from natural or deliberate outbreaks of infection from bacteria or viruses, and to inform and support public health control measures, clinical patient management, epidemiological and forensic investigations. The JA would achieve this by supporting a closely integrated network of specialised laboratories that can respond rapidly to threat of an outbreak of infectious disease. The laboratories would be able to ensure a universal exchange of the best diagnostic strategies to support a joint European response to outbreaks of highly pathogenic infectious agents, including the generation of a diverse repository of reference biological materials. The project would also provide a supportive European infrastructure and strategy for external quality assurance exercises (EQAE), training, and quality management for biosafety/biosecurity.

### Methods

The JA focuses on the diagnosis and detection of high-threat bacteria of a potential bioterrorism risk, including those that cause anthrax, tularemia, plague, glanders, melioidosis, brucellosis, and Q-fever; and also on the highest-risk viruses such as Filoviruses, Arenaviruses, Bunyaviruses such as CCHFV, Orthopoxviruses, and Paramyxoviruses such as Nipah and Hendra viruses.

The existing repositories of reference material for pathogenic bacteria and viruses of the highest biosafety levels (BSL) 3 and 4 were extended and distributed to JA partners for evaluation of new and established diagnostic tools and external quality assurance exercises. Beyond evaluation of correct

diagnostics, the exercises gave the opportunity to evaluate and compare the accuracy and suitability of rapid assays, to standardise quantification of agents and to evaluate methods for the antibiotic susceptibility of bacteria, data interpretation and transportation of samples. Training needs were identified and courses delivered by experienced partners, taking into account their experience of previous projects (such as EURONHID and ETIDE) and previous outbreak management.

### What did the JA achieve?

The QUANDHIP JA was launched with its first common meeting of partners in September 2011. Since then the work plans have been agreed and the first quality assurance exercises have been carried out by the bacterial and viral networks. The task to develop management procedures for laboratory response to cross-border outbreak events has been outlined. An overview of laboratory capacities and capabilities for the diagnostics of high-consequence pathogenic agents is in progress. A training programme was prepared and implemented.

Information on the JA will be distributed by scientific publications and on the project website. Key European and international organisations are fully informed, including the European Centre for Disease Prevention and Control, the Global Health Security Action Group Laboratory Network, WHO, EUROPOL and relevant Directorates-General of the European Commission.

### How will the results be put into practice?

The JA will result in a network of centres of competence, all capable of offering state-of-the-art diagnostic facilities, access to comprehensive reference resources and highly trained personnel, able to both guide and advise national public health policies, and respond to emergencies.

### The benefits of working jointly at EU level

The initiative to develop an EU-wide capability for rapid response to natural or deliberate threats from high-risk biological agents could only be achieved by linking the centres of highly specialised expertise across borders. In the case of national or international infectious disease outbreaks of relevant agents, the network will support the management of such health threats by laboratory diagnostic capacities.

## QUANDHIP: Key data

<http://www.quandhip.eu>

**MAIN PARTNER (M):**

Robert Koch-Institut RKI, Germany

**PROJECT COST:**

Total: € 6 631 963

EC contribution: € 3 315 981

**PROJECT DURATION:**

01.08.2011 – 31.07.2014 (36 months)

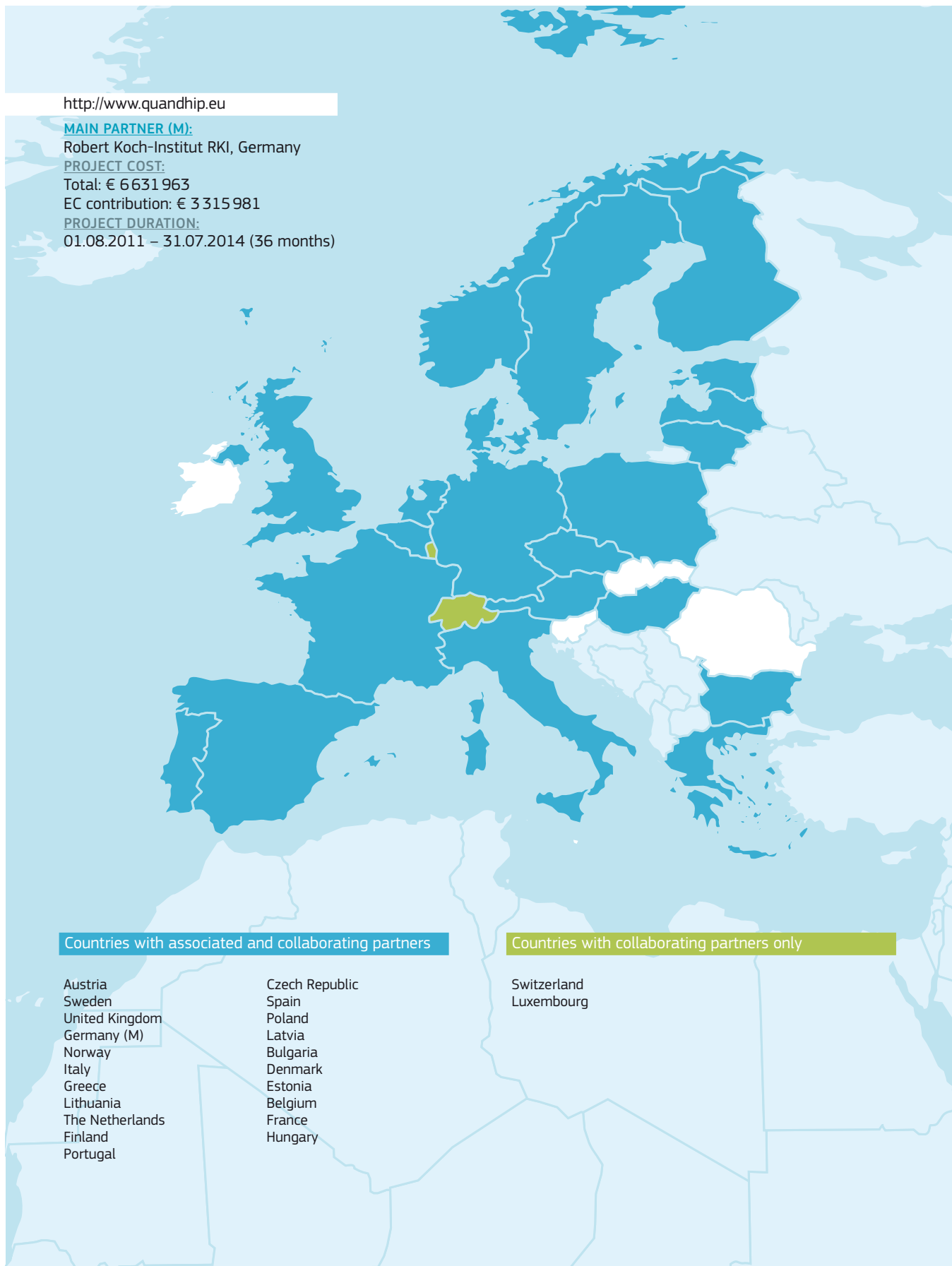
Countries with associated and collaborating partners

Austria  
Sweden  
United Kingdom  
Germany (M)  
Norway  
Italy  
Greece  
Lithuania  
The Netherlands  
Finland  
Portugal

Czech Republic  
Spain  
Poland  
Latvia  
Bulgaria  
Denmark  
Estonia  
Belgium  
France  
Hungary

Countries with collaborating partners only

Switzerland  
Luxembourg



2010



## ALzheimer COoperative Valuation in Europe (ALCOVE)

**Keywords:** Dementia, quality of care, BPSD, antipsychotics, health information system

### Summary

*The ALCOVE JA created a functional European network of healthcare institutions, for the exchange of knowledge and experience in order to improve the quality of care and services for Alzheimer's disease and other forms of dementia. The network covers 19 countries and 30 partners, and works in connection with European initiatives on dementia and in collaboration with Alzheimer Europe.*

*The JA has compiled current information about Alzheimer's disease and its care in Europe, which will serve as a basis for further development and the dissemination of up-to-date recommendations on health policy to decision makers, healthcare professionals, care givers, and the public. The JA has targeted good practice by aiming to reduce the risk to patients linked with the overuse of antipsychotic drugs in dementia, an objective designed to improve the quality of life for individuals living with dementia and their carers.*

### How does the ALCOVE JA contribute added value to EU Health Policies?

The ALCOVE JA was a response to the European Commission's White Paper, Together for Health: A Strategic Approach for the EU 2008-13, and specifically to its recommendation for fostering good health in an ageing Europe. Due to the nature of Alzheimer's disease and its impact on the ageing population, and therefore on national health systems, the diagnosis and treatment of

Alzheimer's are important factors to be considered for the sustainability of health systems, as well as addressing inequalities in health within and between Member States, and responses to health threats.

The involvement of the numerous organisations in the ALCOVE JA, with their different competences in the prevention and care of Alzheimer's and dementia, brings scientific excellence while laying the groundwork for future collaborations across Europe.



## Why is Alzheimer's disease an important problem for Europe?

Alzheimer's disease is one of the top priorities for European policy makers. An ageing population means soaring healthcare costs at a time of economic constraint, and the proportion of the population in the workforce, supporting social and medical costs, is decreasing. One recent estimate for the United Kingdom is that the number of people with dementia will increase by 40% over the next 15 years, with an annual cost of EUR 1.68 billion – more than stroke, heart disease and cancer combined<sup>(1)</sup>.

## What did the JA set out to do?

The ALCOVE JA set out to survey current treatment and care across Europe for Alzheimer's disease and other dementias, and to identify good practices and gaps in order to recommend improvements. Specific work packages focus on the possibility of improving practices in epidemiology, diagnosis, dementia care models and competence assessment.

## Methods

The JA compiled information on treatment and care practices for dementia in current use in the EU Member States. To do this, it used questionnaire-based surveys, literature reviews and exchanges with European experts and networks dedicated to dementia.

The aim was to identify good practices, gaps between real practices and evidence, and to propose recommendations and concrete options to support care improvement.

Specific work packages were devoted to the improvement of Alzheimer's and other dementia epidemiological data and timely diagnosis; improvement of existing practices and dementia care models for both professional and family carers (especially behavioural and psychological symptoms of dementia, BPSD); and investigating how advance declarations of will developed in various Member States and competence assessment in people living with dementia can support rights and autonomy.

The ALCOVE network has given particular priority to developing resources to inform and support carers, patients, health professionals and managers about

inappropriate over-prescribing of antipsychotics for BPSD. In the process, a system of tools and methods was developed, including informational support, indicators, and professional programmes and clinical guidelines. These have been published on the JA website.

## What did the JA achieve?

As a result of its investigations, the ALCOVE JA established a number of disturbing findings about dementia care in Europe. It found a discrepancy between the observed rate of prevalence in the various national health systems, and within countries, raising the need to improve the quality and coherence of data collection in order to develop national strategies. It also demonstrated under-diagnosis of Alzheimer's disease throughout Europe, indicating the need for more effective diagnosis. Better care for BPSD was found to be a common and high-priority issue and also a burden for daily carers and health professionals, leading to early institutionalisation and the overuse of antipsychotics. This last aspect has since been defined by the European Medicines Agency as a priority for 2013, as it affects patient safety and the quality of life for both patients and carers. Legal provisions for dementia and competence assessment varies significantly between Member States.

ALCOVE has produced detailed recommendations in the areas of improving epidemiological data and best practices for data collection; improving care for Alzheimer's disease with assessment of Member States' recommendations and diagnostic systems; improving practices in community and residential care settings with assessment of practices and training and a focus on BPSD; and recommendations on improving the rights and dignity of people with dementia. It also produced a set of indicators to assess national dementia strategies.

ALCOVE findings are to be published in full in 2013, however preliminary information has been released through newsletters to some 4 000 policy makers, healthcare providers, patients and carers. More than 15 presentations have been made in conferences and seminars, two scientific articles have been published and active dialogue established with other networks in the field, such as Alzheimer Europe and the Athens Alzheimer Association.

<sup>(1)</sup> Warner J. Behavioural and psychological symptoms of dementia (BPSD). St Charles Hospital and Imperial College, London.

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## How will the results be put into practice?

The ALCOVE JA will help Member States to improve their dementia policies by promoting the best options in care and support systems, and by providing practical recommendations including a toolbox for BPSD and antipsychotics safety. ALCOVE is also proposing ways to reduce BPSD, the institutionalisation and related antipsychotics risk, while promoting alternative treatments, and alerting and educating professional and family carers.

All of ALCOVE's recommendations could be implemented in new or current national strategies for dementia or in new business models. ALCOVE will provide details of the different options for each field, in order to help policy makers and care providers with benchmarking and implementation. ALCOVE has also expressed interest in becoming involved in the European Innovative Partnership Initiative, which is organised around the theme of Active and Healthy Ageing (EIP AHA), as an opportunity to disseminate and implement ALCOVE's propositions in an innovative way.

## The benefits of working jointly at EU level

ALCOVE offered each partner the opportunity to better understand the current practice in dementia diagnosis and care in other Member States, while identifying common problems and good practices. The partnership was a forum to share past research programmes and to position ALCOVE's objectives in such a way that the various EU networks benefit from each others' work rather than duplicate efforts.

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## ALCOVE: Key data

<http://www.alcove-project.eu/>

**MAIN PARTNER (M):**

National Authority for Health HAS,  
France

**PROJECT COST:**

Total: € 1 227 849  
EC contribution: € 613 100

**PROJECT DURATION:**

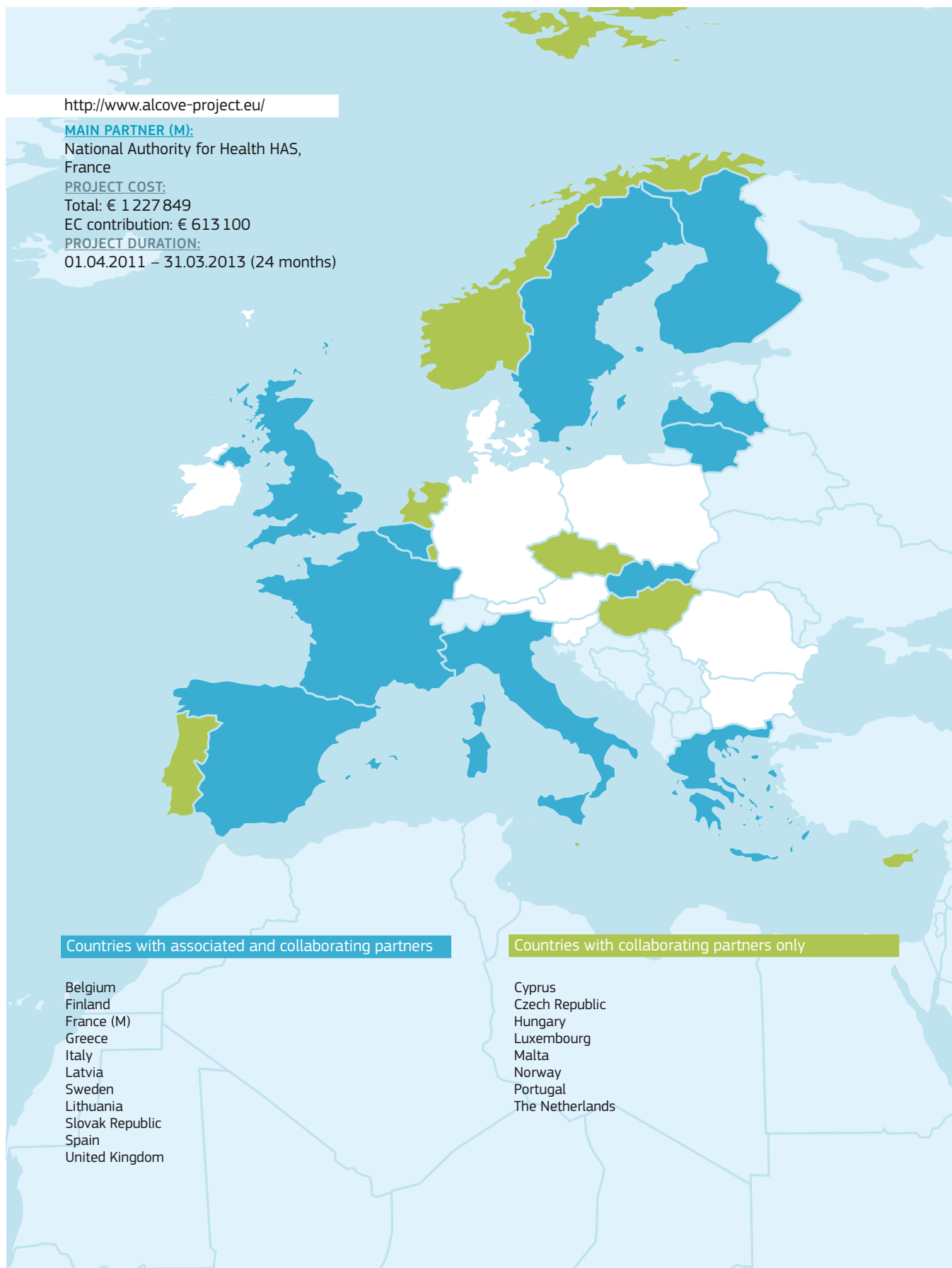
01.04.2011 – 31.03.2013 (24 months)

Countries with associated and collaborating partners

Belgium  
Finland  
France (M)  
Greece  
Italy  
Latvia  
Sweden  
Lithuania  
Slovak Republic  
Spain  
United Kingdom

Countries with collaborating partners only

Cyprus  
Czech Republic  
Hungary  
Luxembourg  
Malta  
Norway  
Portugal  
The Netherlands





# 2010

## European Partnership for Action Against Cancer (EPAAC)

**Keywords:** Cancer information system, cancer prevention, cancer screening and early diagnosis, cancer care quality standards

### Summary

*The EPAAC Joint Action is contributing to reducing the cancer burden in the EU by a wide range of actions in the areas of health promotion and prevention, screening and early diagnosis, cancer-related healthcare, coordination of cancer research, and cancer information and data. The overall objective is to support Member States in developing and implementing their National Cancer Plans (NCPs).*

### How does the EPAAC JA contribute added value to EU Health Policies?

EPAAC is a response to an explicit request by the European Commission and the Member States for bringing considerable added value in tackling major health challenges more effectively, through information sharing and exchange of expertise and best practice. The Second Health Programme calls for better knowledge and information on the prevention, diagnosis and control of major diseases; one of which is cancer.

The initiatives within the EPAAC JA are supporting improved health protection and safety of citizens in the field of cancer control. Its work has contributed to better knowledge of exactly these aspects of cancer, in relation to Europe's ageing population, while emphasising the importance of a healthy lifestyle. EPAAC has helped to identify the causes of cancer inequalities within the EU and to exchange the best practices to tackle them, also a priority of the Second Health Programme, in the context of recent and expected future enlargement of the EU.

### Why is cancer an important problem for Europe?

The Second Health Programme identified cancer as one of the eight diseases causing most morbidity and mortality in Europe. Each year, 3.2 million people in Europe are diagnosed with cancer, mostly breast, colorectal or lung cancer. It is also the second most common cause of death, causing 1.7 million deaths each year in Europe and over 1.2 million deaths in the EU<sup>(1)</sup>. Cancers are a major challenge to the EU's healthcare systems, costing the EU EUR 117 billion each year or EUR 234 per EU citizen, including primary care, hospital care and medications, as well as the cost of informal care and of productivity lost through time off work through illness and early retirement<sup>(2)</sup>.

### What did the JA set out to do?

The EPAAC JA set out to determine the state of development and implementation of NCPs in the EU in order to develop a formula for high-standard common contents. It used a variety of mechanisms to establish a European-level data resource on cancer and best practices for its treatment and care, that will be used to develop, review and harmonise clinical guidelines. Other initiatives will address cancer prevention and screening to enable early diagnosis.

<sup>(1)</sup> Sullivan R et al. The economic burden of malignant neoplasms in the European Union. Health Economics Research Centre, University of Oxford. <http://www.herc.ox.ac.uk/research/economicsofpopulationhealth/Malignant%20neoplasms>

<sup>(2)</sup> Luengo-Fernandez R et al. The economic burden of malignant neoplasms in the European Union. ESMO 2012 Congress of the European Society for Medical Oncology.

## Methods

The contents of existing NCPs were established by questionnaires to the Member States. Key aspects needed in an NCP were identified, and guidelines prepared for the content of a high-level standard NCP, to include those key areas. The JA partners also re-established the EU Week Against Cancer, to promote cancer prevention measures. Schools of Screening Management will be initiated, and exchange of information and collaboration will be promoted between Member States. Best practices in cancer care will be identified and assessed, and further information gathered through review of published experiences, mapping of existing regional networks and expert workshops. These survey, mapping and workshop exercises will be used to develop, review and harmonise clinical guidelines. In addition, questionnaires will be developed on cancer research, and a European map of cancer information will be developed.

## What did the JA achieve?

Within the first year of operation, the JA has achieved important results. The National Cancer Plan Collection has been published and the JA's report on NCPs prepared, together with a proposal for a European Cancer Information System. European Week Against Cancer was re-launched, with conferences, youth competitions and performances to attract public awareness. Cervical cancer screening programmes have been developed and also a literature review conducted on inequalities in the implementation of cancer screening programmes. In the area of research, a report has been compiled on the instruments used for research coordination and the future of cancer research at EU level, and also a list of priority areas for cancer research. The other main outcome has been a conference and report on European standards of care for children with cancer.

EPAAC results have been and will continue to be widely disseminated to healthcare and research professionals, the public and particular target groups (e.g. young people), and the media. Information has been publicised through JA open forums and professional conferences, the HEIDI WIKI platform (Health in Europe: Information and Data Interface<sup>(3)</sup>), press releases for journalists and social media channels.

## How will the results be put into practice?

The results of the JA, and particularly the NCPs, will be used in the sustainable development of public health

programmes and policies in the Member States, to ensure coordinated and centrally-managed, evidence-based strategies for prevention, early detection, diagnosis, treatment, rehabilitation, palliative care and research, and to evaluate outcomes. Engagement of policy makers at the European, national, and sub national levels will contribute to the improvement of the implementation of the Council Recommendation on Cancer Screening by alleviating key barriers to the provision of screening of appropriate quality, as recommended by the Council of the EU.

The outcomes of EPAAC will contribute to improved quality of healthcare and an improved quality of life for people with cancer, and to a higher awareness of the importance of cancer prevention, leading to a positive change in individuals' behaviour.

Early diagnosis of cancer will be facilitated and the medical knowledge of health professionals about screening and early diagnosis will be enhanced. The JA will also contribute to improved patient treatments, proper and efficient use of financial resources for cancer research, and currently dispersed data on cancer will be readily available in a united EU data map.

In research, a concerted approach is being developed to achieve coordination of one third of cancer research in selected subject areas, from all funding sources, by 2013. This initiative will have a long-term impact on the quantity, quality and applicability of cancer research outcomes in the future.

## The benefits of working jointly at EU level

Individual partner organisations in most of the Member States are gaining access to high quality cancer related information through the EPAAC partnership platform. By sharing information and comparable national cancer data and by working together, partners avoid duplicating their cancer-related activities, saving time, money and most importantly improving health of their citizens. Involvement of a diverse range of stakeholders and experts enables emerging ideas on optimal cancer management and high quality professional information to be shared. The information amassed during the course of the JA will represent a firm evidence base for preparation of national strategic health policy documents and will present a Europe-wide context for national decision making.

<sup>(3)</sup> EPAAC webgate: [https://webgate.ec.europa.eu/sanco/heidi/index.php/Cancer\\_partnership](https://webgate.ec.europa.eu/sanco/heidi/index.php/Cancer_partnership)

## EPAAC: Key data

<http://www.epaac.eu/>

**MAIN PARTNER (M):**

National Institute of Public Health  
NIPH, Slovenia

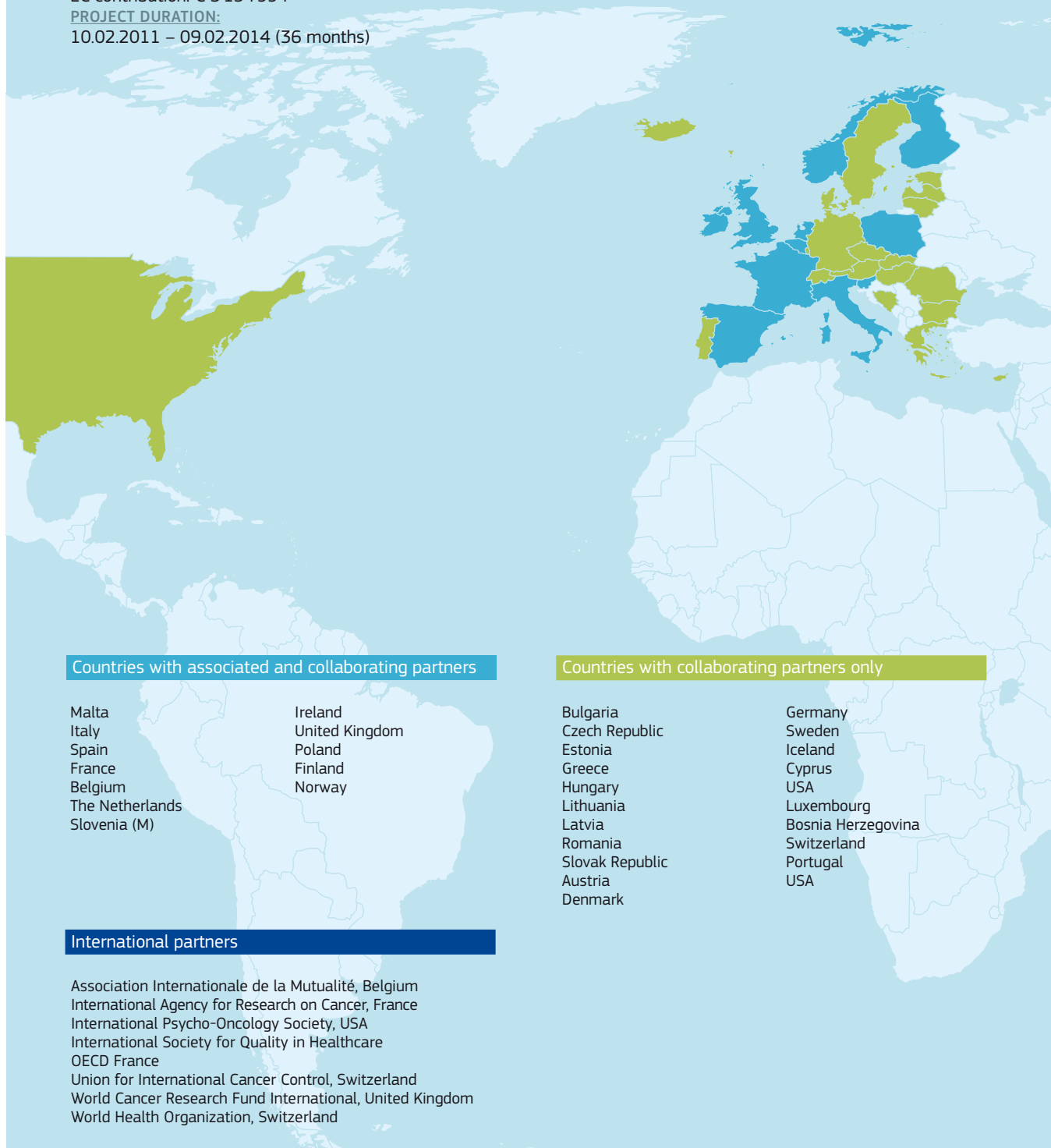
**PROJECT COST:**

Total: € 6 312 115

EC contribution: € 3 154 994

**PROJECT DURATION:**

10.02.2011 – 09.02.2014 (36 months)



2010



## Joint Action on Health Inequalities (Equity Action)

**Keywords:** Equity Action, health inequalities, social determinants of health, health equity audit, Structural Funds

### Summary

*Despite the best attempts of Member States, there are large differences in the level of people's health between and within the EU Member States. Health is significantly affected by socio-economics, geography and by a wide range of public policies which affect people's quality of life and living conditions. Tackling health inequalities therefore requires action across a number of policy areas. The aim of the Equity Action JA is to assist the EU and Member States to develop effective policies to address health inequalities through a process of information exchange and knowledge development. The JA initiatives involve a wide range of stakeholders, to tackle address these health inequalities at national, regional and local level. The JA uses four key approaches: to develop a detailed knowledge of health inequalities and what measures have been effective to address them, and to engage the support of Member States, regions and other stakeholders. The JA has also developed tools such as health inequality audit to improve policy development; and exchanged this information between all the concerned organisations.*

### How does the Equity Action JA contribute added value to EU Health Policies?

The Equity Action Joint Action is a key vehicle for implementing the European Commission's strategy on health inequalities set out in its 2009 communication, Solidarity in Health<sup>(1)</sup>

and it responds directly to the 2010 Work Plan's call for a Joint Action on health inequalities. The Equity Action JA also builds on key global policy initiatives, such as the WHO's Rio Declaration on the Social Determinants of Health (2011), and a number of other EU Presidency events and Council conclusions on health inequalities.

### Why are health inequalities an important problem for Europe?

Large differences in health are apparent between and even within the EU Member States. This is illustrated by the wide variation in life expectancy across the EU, which can vary by ten years for men and six for women between the lowest and highest socioeconomic groups<sup>(2)</sup>. These health inequalities are the result of varying environmental and economic conditions, social protection, health services and health-related behaviours. Many of these factors significantly increase the risk of many illnesses, although their effects could be prevented by effective public policies.

### What did the JA set out to do?

The Joint Action set out to contribute to reducing health inequalities by supporting policy development at all levels. It aimed to develop a detailed knowledge of health inequalities and what measures have been effective to address them. In addition would engage Member States, regions and other stakeholders in a process to address health inequalities, and develop tools such as health inequality audit to improve policy development.

The JA also set out to establish how best to audit health inequalities, and to promote inclusion of these inequalities as a priority area in cooperation on

<sup>(1)</sup> Solidarity in Health: Reducing Health Inequalities in the EU. <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2009:0567:FIN:EN:PDF>

<sup>(2)</sup> Health inequalities in the EU. [http://www.health-inequalities.eu/HEALTHTHEQUITY/EN/about\\_hi/health\\_inequalities/in\\_the\\_eu/](http://www.health-inequalities.eu/HEALTHTHEQUITY/EN/about_hi/health_inequalities/in_the_eu/)

health between the European regions and the EU. It would review possibilities to help the Member States to make better use of the EU's cohesion policy in actions to address the causes of health inequalities.

Finally, the Joint Action should develop ways to involve relevant stakeholders to promote the uptake and spread of good practice in this area.

## Methods

The work of the Joint Action is organised in four packages. The first (Tools) is concerned with developing health impact assessments, health equity audits and health inequality strategies to promote a cross-government approach. The Regions work package will identify and support regional approaches to health inequalities, including promoting greater use of the EU Structural Funds in this area. The Knowledge package involves engaging scientific experts to develop a European research agenda on the effectiveness of inter-sectorial action to support policy makers. Finally, key guidance will be developed for building alliances and networks with key stakeholders at national and EU level, in order to promote and embed the aims of the WHO agenda on the Social Determinants of Health<sup>(3)</sup>.

The JA will also generate a focus for health equity between governments. It will establish a regional network that will use case studies to define the focus, information, resources, drivers, opportunities and barriers to regional action on health inequality, and access to Structural Funds. Its recommendations will inform the future drafting of Structural Funds. A priority will be to influence the drafting of the 2014-20 Structural Funds guidelines, so that they can be used more effectively to address social determinants of health at regional level, and identify effective use of the funds for tackling health inequalities.

## What did the JA achieve?

The JA has documented health inequalities activities across the EU and brought these together in a European portal on health inequalities (<http://www.health-inequalities.eu/>).

At the time of writing, the JA is at the halfway-stage. So far the partners have mapped the Member States' approaches to health inequalities and reviewed possibilities for emphasising equity in their policies, with discussion tools on both aspects. Training on health impact assessments and HIA pilot studies have begun, linking partners from different Member States, and partners are now preparing a review of approaches to Structural Funds. A debate with a wide range of organisations concerned with health equity has examined how best to involve stakeholder organisations and collaborations to address health inequalities in early years and childhood.

The main outcome so far is increased mutual learning about socioeconomic and area-based inequalities in health, and increased commitment to improving the situation in Europe. More specifically, the project will lead to a greater consensus on which approaches really work, and also knowledge and awareness of tools and methods that help to promote a cross-government approach to health equity.

The outcomes will be communicated to policy makers and other stakeholders through the JA website, Twitter and external newsletters. All WPs are producing a range of reports, briefings, presentations and tools. However, the partners believe that the most important pro-active mechanisms are promoting active discussion and engagement using tools developed by the JA, e.g. the discussion tool on Health in All Policies. Partners also attach importance to capturing the experience of using these tools, and sharing outcomes across Member States. In addition, it is highly important to strengthen relationships with Member State and regional representations, and with key European-level NGOs.

<sup>(3)</sup> [http://www.who.int/social\\_determinants/en/](http://www.who.int/social_determinants/en/)



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The JA is at too early a stage for full evaluation, but it has already established that health inequalities across Europe exist and need to be addressed – a position that would not have been demonstrated in the absence of the JA.

### How will the results be put into practice?

The initiatives within the Equity Action JA will be put into practice through their contribution to health inequalities policies at all levels. This requires a focus on reaching people in a position to tackle health inequalities from either a socio-economic or geographic viewpoint. This will inform and encourage promotion of health equity across all government departments, through organisation, management and use of tools.

Dissemination will include publications of experience and tools, the European internet portal on health inequalities, a series of national and European dialogues with stakeholders, meetings with regional representatives and a major conference to take place in January 2014 in Brussels.

The programme is also establishing links and collaborations with the WHO Regional Office for Europe, the European Commission's Expert Group for Health Inequalities and the Social Determinants of Health, the Institute for Health Equity, the European Public Health Alliance on the development of Health Equity Audit, and NGOs such as Eurochild, the European Youth Forum and Save the Children.

Partners are developing an engagement plan to establish working relationships with Member State representations at EU level, that will be used to ensure a sustainable connection with the Member States at policy level.

### The benefits of working jointly at EU level

The JA enables good practice sharing between Member States while they participate in its WPs. It has strengthened and developed ideas and concepts of health impact assessment and to gaining the support of stakeholders that allow a more consistent approach across the EU. It also provides a longer term and visible commitment to action, which has enabled partners to work more readily across sectors, and maintain action in challenging economic circumstances.

At an EU level, the JA has been able to contribute to the work of the expert working group on inequalities and the social determinants of health, and further developing European and global knowledge on what is effective to address health inequalities through EU, national and regional policy.

## Equity Action: Key data

[http://www.health-inequalities.eu/HEALTHEQUITY/EN/projects/equity\\_action/](http://www.health-inequalities.eu/HEALTHEQUITY/EN/projects/equity_action/)

**MAIN PARTNER (M):**

National Heart Forum, Health Action Partnership International, United Kingdom

**PROJECT COST:**

Total: € 3 923 939

EC contribution: € 1 666 295

**PROJECT DURATION:**

15.02.2011 – 14.02.2014 (36 months)

**Countries with associated and collaborating partners**

Belgium  
Czech Republic  
Italy  
Finland  
France  
Germany  
Greece  
Ireland

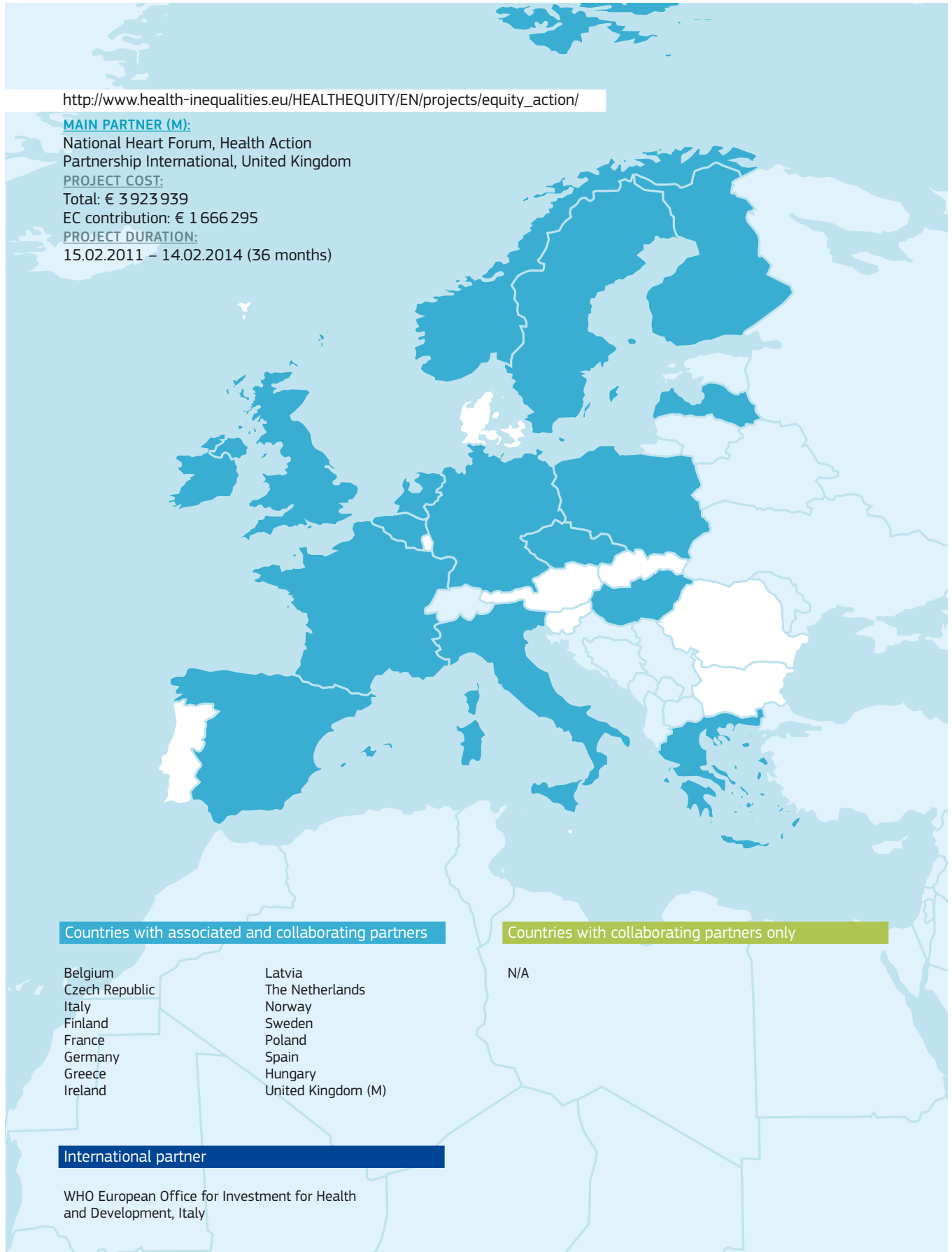
Latvia  
The Netherlands  
Norway  
Sweden  
Poland  
Spain  
Hungary  
United Kingdom (M)

**Countries with collaborating partners only**

N/A

**International partner**

WHO European Office for Investment for Health and Development, Italy



2010

## European Surveillance of Congenital Anomalies (EUROCAT)

**Keywords:** Congenital anomalies, epidemiological surveillance and registers, rare diseases, pharmacovigilance, prevention and risk factors

### Summary

*The impact of congenital anomalies (CA) on public health is being evaluated under the EUROCAT JA, through analysis of the epidemiological data collected since 1979 by the European Surveillance of Congenital Anomalies (EUROCAT)<sup>(1)</sup>. This network compiles records of all major congenital and chromosomal anomalies from almost all of the population-based congenital anomaly registries in Europe (38 registries in 21 countries).*

*The EUROCAT JA is pooling this information with a view to reducing the public health burden of congenital anomalies, which include neural tube defects, congenital heart defects and Down syndrome. The coding and classification is being improved and the data analysed to detect and investigate trends in the prevalence of these conditions, and to assess the possible impact on the foetus of chronic diseases in the mother, or environmental exposure to infections or medications. The JA will use an extremely wide range of high-impact publications and events to raise awareness of the importance of extra care pre-conception and in early pregnancy, and policies targeting population exposure to reduce the incidence of congenital anomalies.*

### How does the EUROCAT JA contribute added value to EU Health Policies?

Congenital anomalies were identified in 2008-09 as a priority for concerted action across Europe by policy statements from the European Commission and the Council of Ministers<sup>(2)</sup>. Both recognised the need for registries and databases that were coordinated at a European level, for pooling of expertise at European level, for improving the

coding and classification of rare diseases, for comparable epidemiological data at EU level, and for identifying the possibilities for primary preventive measures, e.g. the national plans for rare diseases. The EUROCAT JA is actively pursuing all these areas.

The results of the EUROCAT JA 2011-13 are expected to have an important impact on Member States' future policy on rare diseases.

<sup>(1)</sup> [www.eurocat-network.eu](http://www.eurocat-network.eu)

<sup>(2)</sup> Council Recommendation of 8 June 2009 on an action in the field of rare diseases, and the Communication from the Commission on Rare Diseases: Europe's challenges of November 2008.

## Why are congenital anomalies an important problem for Europe?

Congenital anomalies or birth defects have been identified as one of the major groups of rare diseases in need of concerted action across Europe. EUROCAT has recorded that together they affected 253 people in every 10 000 births in 2003-07, and they cause major medical, social and educational problems to children<sup>(3)</sup>. Diagnosis of CA is a major cause of pregnancy termination, but the level of termination varies considerably between European countries.

## What did the JA set out to do?

The EUROCAT JA set out to support and enable reduction of the public health burden of CA, using epidemiological surveillance through the EUROCAT network of population-based congenital anomaly registers. The EUROCAT JA is one of a number of JAs in the area of rare diseases, and will establish a sustainable, high quality and easily accessible information system on CA for almost one third of the European birth population. The EUROCAT JA provides globally accessible and updated epidemiological information (within six weeks of receiving it) on the EUROCAT website.

## Methods

EUROCAT currently surveys more than 1.7 million births per year in Europe, covered by 39 registries in 21 countries. Cases of all major structural congenital and chromosomal anomalies among live births, stillbirths and terminations of pregnancy for fetal anomaly are registered using multiple sources of information. Using common software, each member registry transmits a standard dataset to a central database at EUROCAT Central Registry, where further quality validation is performed. The programme will

evaluate the public health impact of CA through analysis of the EUROCAT data. It will pool expertise from the partner organisations in order to detect and investigate the geographic clusters and trends in prevalence, and build capacity for rapid response through a new task force for evaluation of clusters that will address situations needing immediate action. The JA will assess the potential impact on pregnancies of new or changing environmental exposures, e.g. infections including swine flu, or maternal conditions including diabetes and epilepsy.

The JA will also contribute to national health policies. A strategic framework for building prevention of CA into national plans for rare diseases is being established. The JA will be making studies of whether the provision of folic acid to women around the time of conception is helping to reduce the level of neural tube defects. Another will evaluate what impact the widespread delay in childbearing, and also changes in prenatal screening techniques and policy, are having on Down syndrome in Europe. Two European Symposia on the Prevention of Congenital Anomalies will be organised, to bring together public health professionals, clinicians, scientists, patient organisations and governmental agencies and share the latest scientific and clinical results on monitoring and prevention.

In terms of information management to enable Europe-wide surveillance, the JA partners will evaluate the potential for linking EUROCAT databases with electronic information systems on exposure, such as the European environmental pollution information systems and drug prescription databases. The EUROCAT JA will develop the coding and classification of CA by contributing training and expertise to the revision of the International Classification of Disease. It will add new registries to the EUROCAT network, and provide guidelines and software to new participating countries and regions.

<sup>(3)</sup> Dolk H et al. The prevalence of congenital abnormalities in Europe. *Adv Exp Med Biol.* 2010; 686:349-64.

## What did the JA achieve?

The JA will continue until the end of 2013, so its results are not yet complete. The partners have already completed substantial updating and monitoring of data, including updating prevalence tables to 2009 for 33 registries, including three regions not previously included, now uploaded to the EUROCAT website. Statistical monitoring for trends and clusters over time has been conducted to include 2009. This has shown increasing trends in some congenital anomalies, such as Down syndrome, while others, including neural tube defects and severe congenital heart disorders are decreasing. No new clusters of immediate concern have been identified.

The JA has completed and published a number of scientific publications including a survey of policies in European countries for vaccination against pandemic flu. Information about the JA has been published through the EUROCAT website, conferences and also a leaflet and e-newsletters distributed globally. The EUROCAT registry is also a WHO Collaborating Centre for the surveillance of CA. The EUROCAT JA links with the projects and networks of other European projects (EURORDIS<sup>(4)</sup>, EUCERD/EUROPLAN<sup>(5)</sup>) and the EUROCAT national committees. An evaluation plan for the JA is currently under development.

## How will the results be put into practice?

Epidemiological surveillance is longer than the term of any JA, and EUROCAT has become a sustainable reference centre in Europe for questions on prevalence, coding and classification of congenital anomalies. Its results become a major part of the evidence base in this area. The setting up of a pharmacovigilance system to monitor medication use in pregnancy have yielded results in relation to anti-epileptic drug exposure that are important evidence contributing to the guidelines for optimal treatment of epilepsy.

The EUROCAT JA partners are working towards inclusion of primary prevention of congenital anomalies as part of the national rare diseases plans. The JA comparisons of national prenatal screening policies will contribute to informing EU and Member States' policy. The nature of the European population of pregnant women and the factors affecting their unborn children changes over time. Higher maternal age, more chronic diseases and obesity, new infections, pollutants, medications and changing immigration all have a bearing on the possibility of anomalies. Surveillance policy and prevention must follow these changes.

The outcomes of the JA also offer a degree of reassurance that no major time clusters of concern have been detected in the general population. The areas in need of improvement have been identified, and these will inform national public health policies. Epidemiological data are needed to set the agenda in terms of the public health importance of CA and their prevention, and to provide evidence on prevalence, risk factors and the importance of prevention.

## The benefits of working jointly at EU level

Working jointly has enabled the JA partners to achieve a sustainable, high quality and easily accessible information system on CA for almost one third of the European new-born population<sup>(6)</sup>. Pooling of data is essential, as most types are rare diseases, so large populations must be studied to obtain sufficient statistical evidence. In addition, working jointly enables comparison of data, sharing of expertise, a joint approach to European public health questions and on policy. The Joint Action is enabling EUROCAT to establish a structure that involves national committees and to avoid the duplication of effort at national and EU level.

<sup>(4)</sup> EURORDIS is the European Organisation for Rare Diseases, Rare Diseases Europe, <http://www.eurordis.org/>

<sup>(5)</sup> EUCERD is the European Union Committee on Rare Diseases; EUROPLAN is the European Project for Rare Diseases National Plans Development.

<sup>(6)</sup> Boyd P et al. Paper 1: The EUROCAT network: organization and processes. Birth Defects Research (Part A) 2011; 91: 2-15.

## EUROCAT: Key data

<http://www.eurocat-network.eu>

**MAIN PARTNER (M):**

University of Ulster, United Kingdom

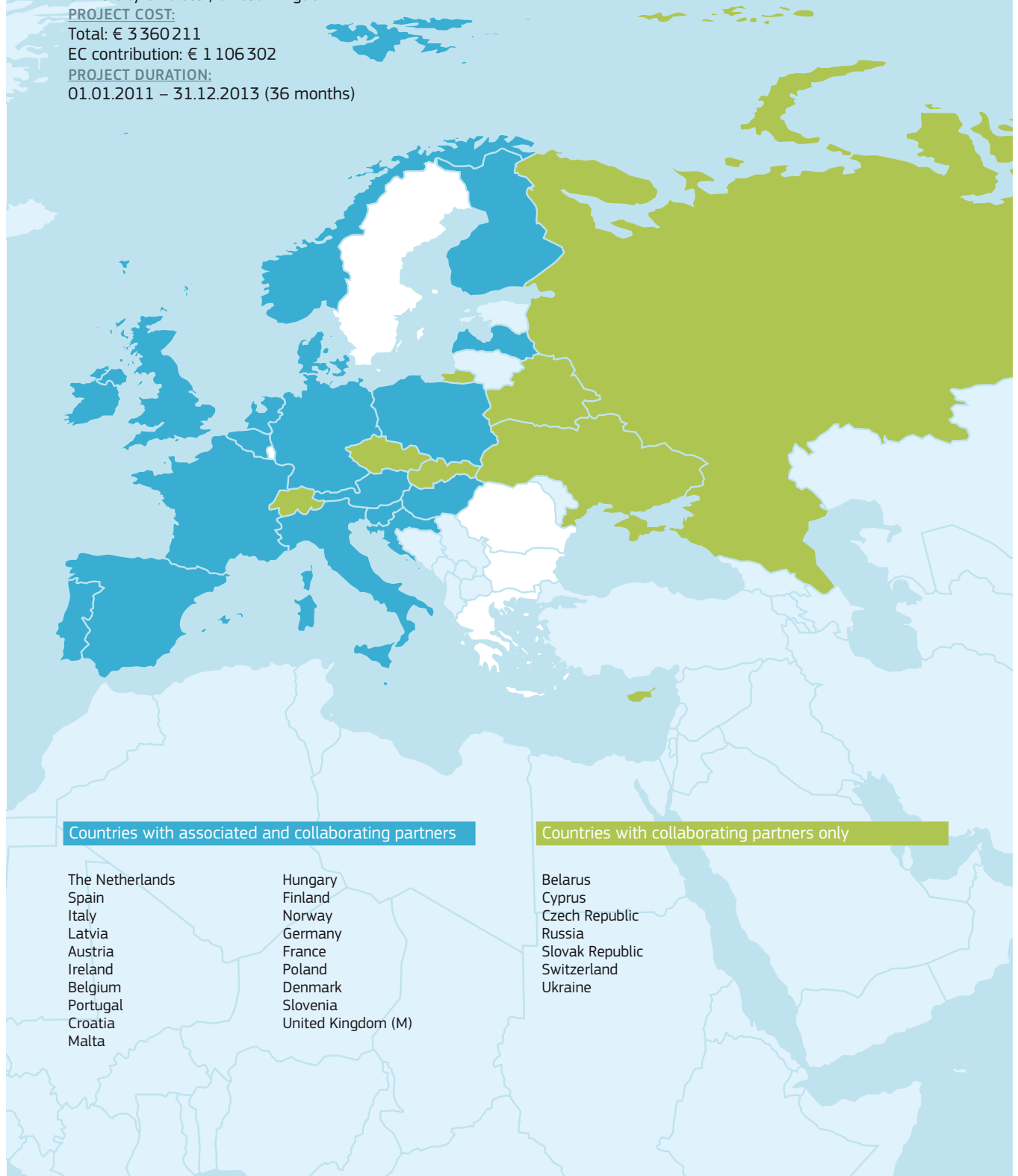
**PROJECT COST:**

Total: € 3 360 211

EC contribution: € 1 106 302

**PROJECT DURATION:**

01.01.2011 – 31.12.2013 (36 months)



2010

JAMIE project

## Joint Action on Monitoring Injuries in Europe (JAMIE)

**Keywords:** Injuries, accidents, health data, data collection, hospitals

### Summary

JAMIE is developing and refining a common hospital-based surveillance system on injuries that will be in operation by the end of 2013 in 22 countries. As well as injuries, it will also cover key information on their external causes. The aim is to improve the ability of the European Commission and EU Member States to monitor injury risks, with a view to allowing benchmarking and comparison between the Member States. Up to now, the European Injury Database (IDB) has been generated, tested and harmonised and is fully implemented in 13 EU Member States. This experience will be used by the nine Member States joining the IDB within the framework of the Joint Action. An additional four countries will have an IDB plan in place by 2014.

JAMIE will refine the data collection methods to make it easier in less resourced countries and to ensure that the data meets EuroStat<sup>(1)</sup> requirements. It will also offer standardised training for national data administrators, twinning programmes, on-site consultations and country-specific coaching for countries which are yet to start or restart a system, continuous supervision, and joint monitoring actions levels of implementation in each Member State. These modifications and improvements will allow the IDB to become eligible for inclusion in the European Statistical System<sup>(2)</sup>.

### How does JAMIE contribute added value to EU Health Policies?

JAMIE supports the aims of the second Health Programme 2008-13 of complementing, supporting and adding value to the policies of the Member States with a view of protecting and promoting health and safety. In addition, the Council's 2007

Recommendation on the prevention of injuries called on Member States to develop national injury surveillance and reporting systems. The Council also invited the Commission to establish a Community-wide injury surveillance system to make the information contained in the database easily accessible to all stakeholders.

<sup>(1)</sup> [http://epp.eurostat.ec.europa.eu/portal/page/portal/statistics/search\\_database](http://epp.eurostat.ec.europa.eu/portal/page/portal/statistics/search_database)

<sup>(2)</sup> [http://ec.europa.eu/health/reports/european/statistics/index\\_en.htm](http://ec.europa.eu/health/reports/european/statistics/index_en.htm)

## Why are accidents and injuries an important issue for Europe?

The data currently available in national health statistics fail to give enough understanding of the causes and circumstances of injuries, and tend to focus on fatal injuries while giving little attention to lesser injuries that nonetheless cause pain, distress and economic cost, both for treatment and for time off work. For each fatal injury, hundreds more casualties due to accidents or violence are treated in hospitals. In most Member States, information on the background to these injuries is not compiled, and Member States are ill-informed on how to address the rising problem of injuries.

A number of projects in the EU have begun to address this problem, and at present, 13 Member States have a common monitoring system in hospitals that collects the missing information along with existing health and accident statistics. This is the European Injury Database (IDB), covering all age groups and injuries, and it is a unique source of information about the external causes and circumstances, needed for targeted prevention. It has been proven as very cost-effective due to a sampling procedure in hospitals, and can be used to produce national extrapolations of data on the basis of available hospital discharge statistics.

## What did the JA set out to do?

The JAMIE JA set out to address the lack of accurate and comparable statistics on the occurrence and causes of injuries in Europe. It is developing and refining a common hospital-based surveillance and reporting system that will support Member States' approaches to promoting safety and preventing injuries.

## Methods

All JAMIE JA partners first provided a baseline report on the current infrastructure for injury surveillance in their country, followed by a plan for implementing the JAMIE methodology in the second phase of the project. They also all received instructions for delivering 2009 and 2010 data to be uploaded online. Countries were encouraged to collect such data retrospectively if they did not already have a data collection system in operation.

A manual was prepared and training developed for national administrators, project leaders in reference hospitals and key persons responsible for national injury reporting through standardised training events, twinning programmes and standardised reporting. The objective has been to enhance the competence in injury surveillance of IDB national data administrators in establishing and maintaining a hospital-based injury monitoring system in their countries in line with the JAMIE principles. This means that they implement a minimum set of data collection in a representative sample of hospitals, and a full injury surveillance data set in at least one reference hospital.

The minimum data set has been made available to all partners for their preparations for national injury data collection. The achievable level of quality will be defined in accordance with EuroStat criteria in consultation with an international scientific advisory group and EuroStat experts for injuries and public health statistics. The Member States' data (including quality audits) will be centrally checked and released for annual online publication by the European Commission. Most Member States will be able to report IDB data on a regular basis, allowing benchmarking between countries and also EU-level monitoring.

Information about the JA has been distributed mainly through newsletters and the website; also by presentations at conferences. Progress has been monitored throughout, and the project will be evaluated by a specific survey among the main stakeholders in the project: government experts, relevant EU services and the WHO.

## What did the JA achieve?

After the completion of the JA, at least 26 countries will have designated national injury data administrators, who are well trained in the Community approach to injury surveillance and able to implement and sustain a national injury monitoring system.

The methods, geographical coverage, data quality and organisation of the entire IDB system have been considerably improved, and therefore ready for starting the next phase. This is the complex political, technical, and legal consultation process to transfer the IDB to the European Statistical System as part of the set of public health statistics.



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## How will the results be put into practice?

The IDB will be increasingly used for injury prevention initiatives at national level. All injury data from emergency departments in the EU will provide detailed statistical injury information that will help to assess priority setting for injury prevention according to public health criteria. EuroStat is being invited to consider the inclusion of injury data exchange in its programme for health data exchange from 2015 onwards.

The IDB makes it possible to compare Member States' level of safety for different risk groups (e.g. children, elderly people) in different settings (e.g. home, workplace, recreation, transport), which will motivate the Member States to monitor and improve their performance, and to work towards significant improvements in injury rates.

## The benefits of working jointly at EU level

Through the JAMIE JA, the Commission and the Member States have been provided with the proper support structure and tools to make a difference in injury prevention and safety promotion, and to initiate focused actions for safety promotion in response to the 2007 Council Recommendation on injury prevention.

JAMIE has helped to enhance the level of cooperation and exchange of experiences between the partners from 26 Member States. It has resulted in a strong consensus as to the methodology for injury data collection in emergency departments in the Member States. Nine new countries have started collecting injury data in emergency departments, and 13 other countries, already collecting data, have engaged in consolidating and streamlining their operations in line with the agreed methodology.

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## JAMIE: Key data

<http://www.eurosafe.eu.com/csi/eurosafe2006.nsf/wwwVwContent/l3projects-333.htm>

### MAIN PARTNER (M):

European Association for Injury Prevention and Safety Promotion, The Netherlands

### PROJECT COST:

Total: € 1 618 646

EC contribution: € 799 823

### PROJECT DURATION:

01.04.2011 – 31.03.2014 (36 months)

### Countries with associated and collaborating partners

Austria  
Cyprus  
Czech Republic  
Denmark  
Estonia  
Germany  
Greece  
Hungary  
Ireland  
Iceland  
Lithuania  
Latvia

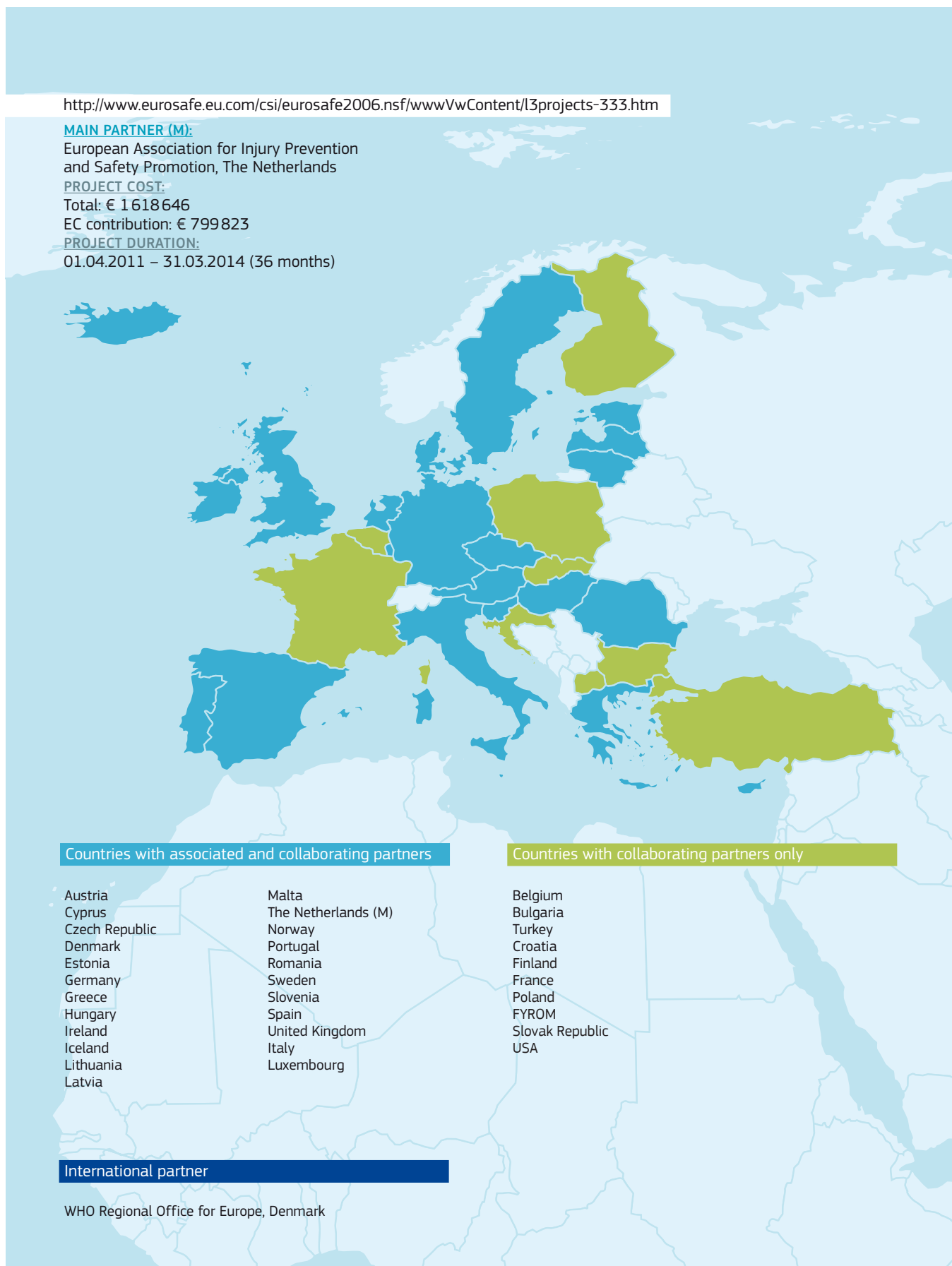
Malta  
The Netherlands (M)  
Norway  
Portugal  
Romania  
Sweden  
Slovenia  
Spain  
United Kingdom  
Italy  
Luxembourg

### Countries with collaborating partners only

Belgium  
Bulgaria  
Turkey  
Croatia  
Finland  
France  
Poland  
FYROM  
Slovak Republic  
USA

### International partner

WHO Regional Office for Europe, Denmark



2010

orphanet

## Development of the European portal of rare diseases and orphan drugs (Orphanet Europe)

**Keywords:** Rare diseases, database, orphan drugs, health access, quality of care

### Summary

*The objective of the Orphanet Europe JA is to support and develop further the publicly available, comprehensive set of information on rare diseases (RD) and their treatments (orphan drugs) known as Orphanet, in order to contribute to more effective diagnosis, care and treatment of patients with rare diseases. Orphanet includes an inventory of rare diseases, an encyclopaedia in as many languages as possible, and a directory of expert resources in the participating countries, all accessible online<sup>(1)</sup>.*

*The JA is also establishing a process for rapid updating of the encyclopaedia and directory of resources, with swift collection and validation of data before publication. Member States will have the opportunity to develop their national website as the entry point to the international database and to supply the information in the national languages. All the collected information will serve as a source to map healthcare services in Europe. By the inclusion of the Member States in the JA and with their support, the JA will also establish the governance that Orphanet deserves to ensure its mission at international level.*

### How does the Orphanet JA contribute added value to EU Health Policies?

Rare diseases are a priority for action in the Second Health Programme (2008-13). The Commission's 2008 Communication on rare diseases<sup>(2)</sup> was followed in 2009 by recommendations from the Council<sup>(3)</sup>; both emphasising the importance of providing accurate information on RD and the expert services available to everyone in Europe.

They both mention the Orphanet database as the basis of current information about rare diseases in the EU, and as a strategic part of any national strategy in this area. Orphanet is currently the number one international website dedicated to rare diseases in general, and the only one that establishes a link between the diseases, the information about them and the appropriate services for the patients, healthcare professionals and policy makers. The Orphanet Europe JA is therefore a vital source of support for Orphanet.

<sup>(1)</sup> From [www.orpha.net](http://www.orpha.net)

<sup>(2)</sup> Rare diseases: Europe's challenges. Commission communication COM(2008) 679 of 11 November 2008.

<sup>(3)</sup> Council recommendation of 8 June 2009 on an action in the field of rare diseases, 2009/C 151/02.

## Why are rare diseases and orphan drugs an important issue for Europe?

Rare diseases are defined as those affecting less than five in 10 000 people<sup>(4)</sup>. It is estimated that between 5-8 000 distinct RD exist today, affecting between 6 and 8 % of the population in the course of their lives. Although each RD affects a small number of people, the total number of people affected by rare diseases in the EU is between 27 and 36 million. 'Orphan' drugs are those developed to treat rare diseases<sup>(5)</sup>, and the Council's Recommendation called for Member States to make special provisions for these, to help to accelerate the price negotiation at national level, and therefore reduce the delays in supplying them to patients with RD.

## What did the JA set out to do?

The Orphanet Europe JA set out to harness the knowledge of key relevant organisations nominated by the Member States in support of the Orphanet Europe database on rare diseases and orphan drugs. It would contribute to the collection of information and its publication in the form of an inventory for policy makers and healthcare professionals, and an encyclopaedia of rare diseases and a directory of expert services. All of this information is freely distributed through the Orphanet website.

## Methods

The JA uses a number of methods to collect, validate, update and disseminate information about RD and orphan drugs. The inventory of rare diseases is compiled through a systematic search of relevant literature, and information articles are prepared and reviewed by invited experts. Data for the directory of resources is collected at national level using an established methodology, and it is validated by experts in all Member States before uploading into the database. Each expert re-validates or modifies annually the data in his/her speciality. All JA partners have access to a user-friendly tool in order to manage their national website and

another to extract data from Orphanet in order to disseminate it at country level.

Specific tools are being developed to improve workflow management. To enable the publication of data in new formats, the architecture of the servers has been modified and a new tool developed. Several committees have been created to oversee and evaluate the project.

## What did the JA achieve?

The overall outcome is to serve as the reference source of information on rare diseases for all European citizens – currently Orphanet offers information on well over three thousand RD, in English, French, German, Italian, Portuguese and Spanish.

The inventory of RD will be completed and made available as Orphanet Report Series for easy use by policy makers and healthcare managers. The encyclopaedia of rare diseases will be expanded, updated and translated into 5 languages or more if funds allow. The directory of expert resources will be truly comprehensive, and both this and the encyclopaedia are expected to be of interest to both healthcare professionals and patients.

Data collection on expert resources in the participating countries has continued, and includes information on thousands of expert clinics, medical laboratories, registries and patient organisations. Quality control of the data is carried out monthly and validation processes are agreed on with the national health authorities of the Member States.

The information provided on orphan drugs will be comprehensive, from pre-clinical research information up to information on availability at country level, and the whole Orphanet dataset will be directly accessible. The governance of Orphanet is being improved, to reflect the new involvement of health authorities of the Member States.

<sup>(4)</sup> Orphanet. Prevalence of rare diseases: Bibliographic data. Orphanet Report Series, Rare diseases collection. May 2012, No 1.

<sup>(5)</sup> Regulation (EC) No 141/2000 of 16 December 1999 on orphan medicinal products.

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## How will the results be put into practice?

Several Member States are developing guidelines in the field of RD and national plans, and many of the national Orphanet partners are implicated in the national working groups to develop these national initiatives. The Orphanet portal is an important tool for policy makers as it provides an overview of the resources currently available in 36 countries, and information on the public health relevance of RD.

The European Union Committee of Experts on Rare Diseases has recently proposed that the Orphanet list of expert centres should be considered in the process of official designation in the context of the EU Directive on Cross-border Healthcare, which is to be implemented at national level by 2013.

Orphanet is a strategic element of any national strategy in the field of RD, and as a unique source of validated information, the inventory, encyclopaedia and list of resources is extensively used by patients and families, healthcare professionals, healthcare managers, researchers, policy makers and industry. The data on orphan drugs is of wide interest as it is not available anywhere else in the format proposed by Orphanet (compiled data).

## The benefits of working jointly at EU level

Each partner benefits from the investment already made in the available infrastructure. The summaries, definitions, and inventory of rare diseases are made available to the partners for translation (when funding is available). Each partner is responsible for collection of information on national expert resources, which supports the international database. Working together enables relevant information about available resources on rare RD in 36 different countries to be made available in six different languages.

## Orphanet Europe: Key data

<http://www.orpha.net>

**MAIN PARTNER (M):**

Institut National de la Santé et de la Recherche Médicale INSERM, France

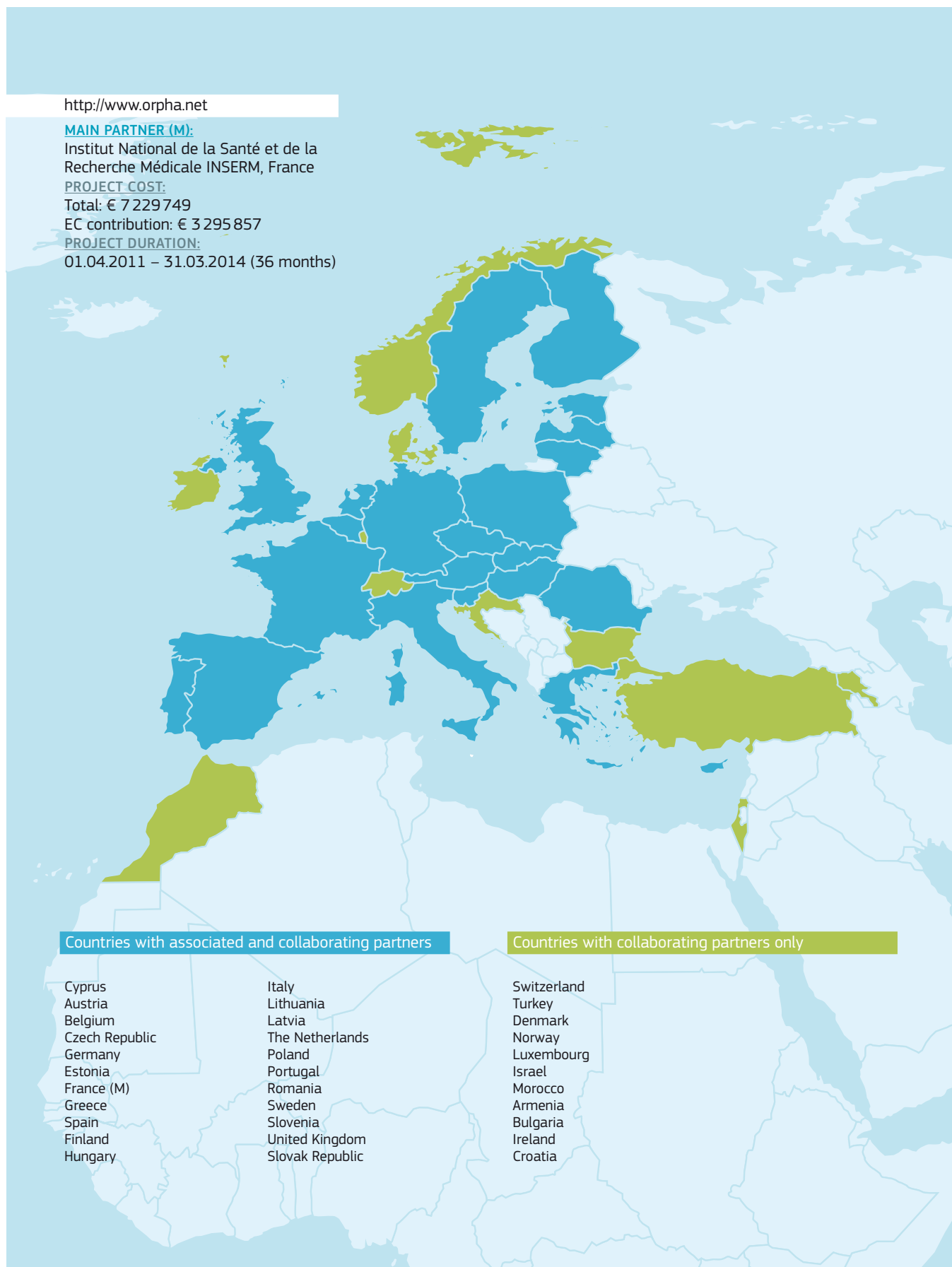
**PROJECT COST:**

Total: € 7 229 749

EC contribution: € 3 295 857

**PROJECT DURATION:**

01.04.2011 – 31.03.2014 (36 months)



2010

## European Health and Life Expectancy Information System (EHLEIS)

**Keywords:** Healthy life years, life expectancy, disability, self-perceived health, chronic diseases

### Summary

*Life expectancy in the EU is steadily increasing, but there are large differences between the Member States and between men and women. Even larger differences occur between the Member States in terms of life years in good health or without chronic conditions or disability. Healthy Life Years (HLY) is the one key health indicator in Europe that is strictly comparable, and it has been implemented by the European Health and Life Expectancy Information System (EHLEIS) in order to improve and harmonise its calculation.*

*The EHLEIS JA will support EHLEIS by consolidating the existing information system through yearly HLY calculations and dissemination, and monitoring the trends. It will develop methods to analyse the socioeconomic factors related to differences in healthy life years, and develop arrangements to promote the longer-term implementation of HLY in Member States' health policies. This work will lead to proposals for a common international measure of population health that is comparable with the USA and Japan.*

### How does the EHLEIS JA contribute added value to EU Health Policies?

The EU strategies for economic sustainability and growth<sup>(1)</sup> all make reference to healthy life years as a key indicator<sup>(2)</sup>. A higher level of HLY indicates a healthier workforce, less retirement due to ill health, and potentially less use of health and social care use. It is therefore a measure of reducing economic and social risks: of vital importance in these times of economic difficulty for governments against the background of ageing populations.

The EHLEIS JA will contribute directly to two of the three objectives of the Second Health Programme: to promote health, including the reduction of health inequalities – specifically increasing healthy life years and promoting healthy ageing; and to generate and disseminate health information and knowledge. It also contributes to the objectives of the European Year for Active Ageing 2012<sup>(3)</sup>, and the European Innovation Partnership on Active and Healthy Ageing<sup>(4)</sup>.

### Why is life expectancy data an important issue for Europe?

Life expectancy at birth has steadily increased during the last decade in the EU Member States by more than three years for men and two years for women, leading to the population ageing at an accelerating rate. However, the Member States show large differences, widening for men from 13 years in 1997 to 14 years in 2007. For women the difference between life

expectancy between Member States has reduced from nine years to eight between 1997 and 2007. There is also a six-year difference between the life expectancy at birth for men and women (2007 data).

These differences between Member States reach 20 years when years of life in good health, without chronic morbidity or without disability are taken into account. There is therefore a major issue to be addressed if all the Member States are to improve

<sup>(1)</sup> Lisbon Strategy for Growth, 2000. [http://ec.europa.eu/archives/growthandjobs\\_2009/index\\_en.htm](http://ec.europa.eu/archives/growthandjobs_2009/index_en.htm)

<sup>(2)</sup> <http://epp.eurostat.ec.europa.eu/portal/page/portal/sdi/indicators>

<sup>(3)</sup> <http://europa.eu/ey2012/>

<sup>(4)</sup> [http://ec.europa.eu/research/innovation-union/index\\_en.cfm?section=active-healthy-ageing](http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing)

towards the better life expectancy achieved by some, and all improvements in health life expectancy will contribute to a healthier population and a better economic performance for the EU.

### What did the JA set out to do?

The EHLEIS JA set out to consolidate the existing EHLEIS information system and to analyse trends and differences in life expectancy across the EU. The information would also be used to analyse the relationship between life expectancy and socio-economic conditions. It would promote the use of healthy life years as a key indicator in Member States' health policies, and also set out to develop an alternative measure of population health that would be usable internationally for comparison with the USA and Japan.

### Methods

The JA uses a wide range of methods: computational, web and standard demographic techniques are the basis for consolidating the information system. The substantive analysis of trends and gaps uses statistical techniques and multi-level analyses. The work towards maximising the usability and pan-European comparability of HLY requires the JA partners to resolve differences in the definition of the indicator used to measure disability known as Global Activity Limitation Indicator (GALI), and also to examine the differences in HLY in terms of the origin and age group. The usefulness and comparability of HLY also depends on whether it can be computed reliably by sub-national groups and socioeconomic subgroups.

### What did the JA achieve?

The main outcome of the JA will be a consolidated EHLEIS information system allowing online calculation of health indicators (prevalence, life and health expectancies including HLY). Its incoming data will be drawn from European<sup>(5)</sup> and/or national surveys. It has produced two series of country reports on health expectancy, to be published in the national languages, and also publishing proceedings of the EHLEIS annual meetings, to encourage Member States to use health expectancies, including HLY, in their social policies. New statistical tools have been developed for attribution, decomposition, and health impact assessment, and technical reports and scientific analyses explore geographical variations in HLY within Europe, trends over time, social differentials in HLY

between Member States, and calibration with European Health Interview Survey (EHIS) data of the GALI used for disability. Finally, the partners are developing a blueprint for an internationally harmonised summary measure of population health.

Information on the new HLY values and latest trends in Europe is released regularly in press releases and through the JA website. This information is addressed to the Member States, health and non-health policy-makers at national and Commission level, health professionals and researchers as well as the media and general public.

### How will the results be put into practice?

Increasing involvement of Member States in health monitoring is one of the main priorities of the JA. The JA partners from the Member States are involved in production and discussion of their annual country report on health expectancies, translation into national languages for the majority of countries, and uploading on national websites. During the second year of the JA, countries start using the information system with their own national data to compute health expectancies by sub-national geographic areas. Belgium is the pilot country for this initiative. More countries are regularly using health expectancies, and especially HLY, to monitor trends and gaps in health within their population. Belgium, Denmark, France the Netherlands and the United Kingdom can be named as examples.

Another priority is to promote the wider use of HLY in national policy making – even in non-health areas such as fiscal policy. Readily accessible scientific material will be provided to the health professional and research communities through: databases, technical reports and scientific publications, adding to the papers already published by EHLEIS. Special attention will be paid to provide easier access to HLY information for the media, general public and NGOs.

### The benefits of working jointly at EU level

The JA has clearly improved the dissemination, comprehension and use of summary measures of population health, including the HLY. Already, 10 Member States have started coordinating their research programmes on health expectancies, and share their work; almost all other Member States are participating in the production and translation of their country reports.

<sup>(5)</sup> EU Statistics on Income and Living Conditions (SILC), Survey of Health, Ageing and Retirement (SHARE), and the European Health Interview Survey (EHIS).



## EHLEIS: Key data

<http://eurohex.eu>

**MAIN PARTNER (M):**

Institut National de la Santé et de la Recherche Médicale INSERM, France

**PROJECT COST:**

Total: € 2 717 138

EC contribution: € 643 259

**PROJECT DURATION:**

21.04.2011 – 20.04.2014 (36 months)

**Countries with associated and collaborating partners**

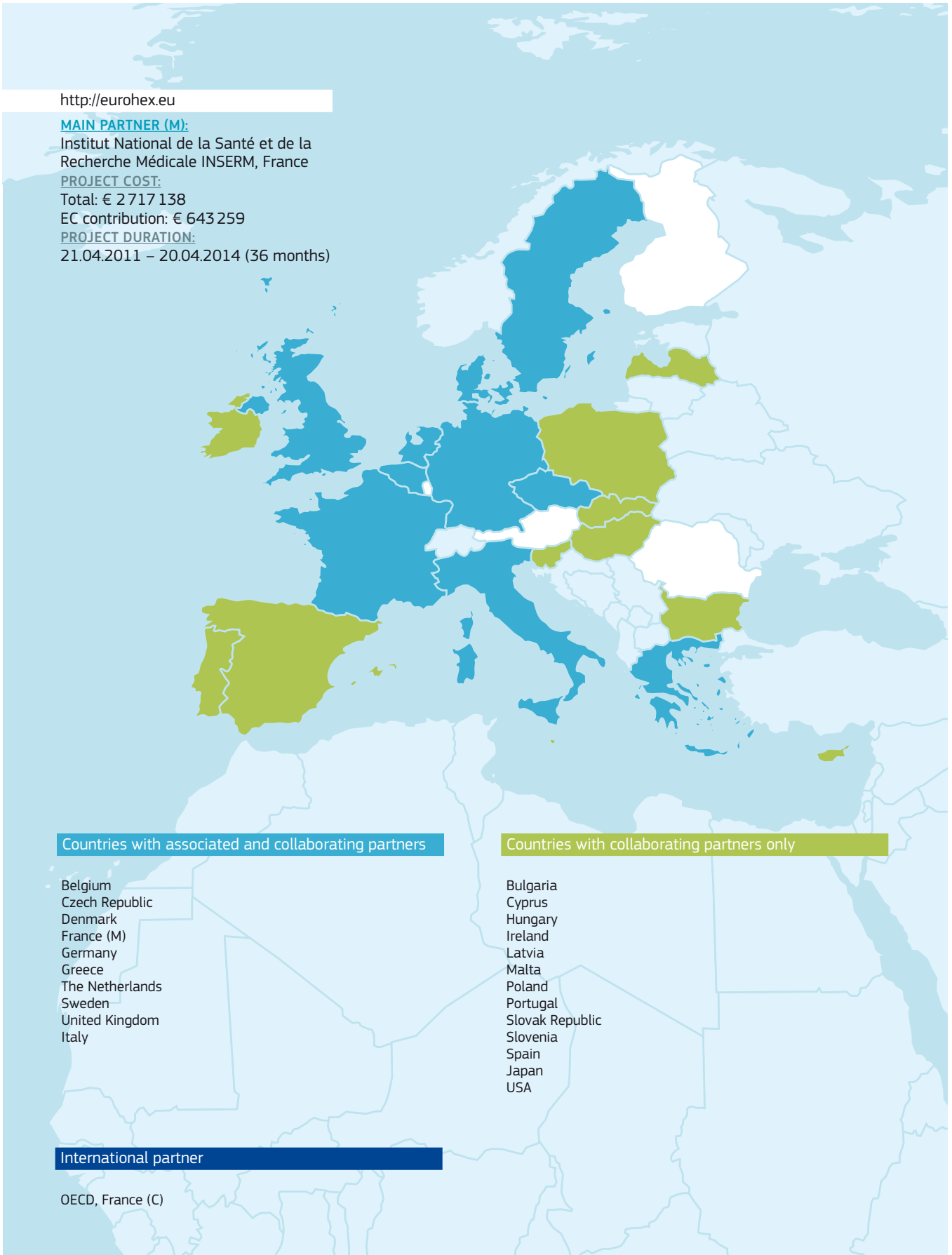
Belgium  
Czech Republic  
Denmark  
France (M)  
Germany  
Greece  
The Netherlands  
Sweden  
United Kingdom  
Italy

**Countries with collaborating partners only**

Bulgaria  
Cyprus  
Hungary  
Ireland  
Latvia  
Malta  
Poland  
Portugal  
Slovak Republic  
Slovenia  
Spain  
Japan  
USA

**International partner**

OECD, France (C)



2010



## Joint Action eHealth Governance Initiative (EHGov)

**Keywords:** eHealth, patients' rights, healthcare systems, quality of care, electronic health records

### Summary

Many Member States are today in the process of starting or expanding large-scale eHealth investment and implementation programmes. The European eHealth Governance Initiative (eHGI) aims to help in this process and benefit the healthcare systems of Member States through promoting the opportunities offered by eHealth systems and services and ensuring harmonised and prioritised introduction. The eHGI project is aiming at improving the coordination of Commission and national policies relating to eHealth, and one component of it is the EHGov Joint Action. It is establishing the structure for a coordinated action involving the Member States that will enable eHealth capabilities to be fully incorporated into healthcare policies, enhancing quality, continuity, safety and efficiency of healthcare services. In particular, the initiative will increase access to healthcare services, support home care and wellbeing of the general population, and generate confidence and acceptance of eHealth among healthcare professionals, patients and the public.

### How does the EHGov JA contribute added value to EU Health Policies?

The EHGov JA is an extension of the general cooperation on eHealth that has been running within the EU for some years. A number of Member States have been granted financial support from European Structural or Regional Funds in order to reform their national healthcare systems, and substantial funding for developing eHealth has been allocated through Community Research Funds. Member States are in the process of moving towards concrete actions to launch cross-border services. These changes present the opportunity to use common European or international standards within healthcare systems that ensure the same high quality of care

to be offered in all Member States. If the opportunity is not taken, there is a clear risk that national investments in eHealth will be less efficient.

The EHGov JA supports the requirements on eHealth of the Directive on patients' rights in cross-border healthcare<sup>(1)</sup>, and in particular the work of the eHealth network set up by that Directive that links the national authorities in this area designated by the Member States. Its results will contribute expert guidance to the network's discussions on the political and strategic aspects of eHealth implementation in the EU. It also contributes to the objectives of the European Innovation Partnership on Active and Healthy Ageing<sup>(2)</sup>.

<sup>(1)</sup> Directive 2011/24/EU on the application of patients' rights in cross-border healthcare. OJL 88 of 4.4.2011.

<sup>(2)</sup> [http://ec.europa.eu/research/innovation-union/index\\_en.cfm?section=active-healthy-ageing](http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing)

## Why is eHealth an important issue for Europe?

eHealth, the use of electronic informatics and communication in support of healthcare, is a powerful approach for solving today's healthcare issues such as the ageing population, demographic crises, chronic diseases and new opportunities based on information and communication technology (ICT), genomics, proteomics or nanotechnology. Some Member States are already making use of eHealth applications in telemedicine, disease management, and personalised medicine, while others are at an earlier stage. At this time there is therefore a strong need that national plans are based on common European or global standards in order to ensure that they are interoperable and support the continuity of healthcare across borders and the free movement of EU citizens.

## What did the JA set out to do?

The JA proposal is not a classic technical IT project, but it set out to create a politically driven mechanism to coordinate current and future activities on eHealth in the Member States and across the EU. In order to address the needs set out by the Council of Ministers, it would define a European governance model for eHealth, built on cooperation between the appropriate authorities of the Member States.

## Methods

The JA partners are using the project website, meetings and conferences to build a European governance framework for eHealth, including establishment of high-level policies and auditable processes, leading to policy development and strategy alignment. This involves close collaboration with existing eHealth-related projects<sup>(3)</sup> to ensure a more coordinated European approach and an efficient use of resources. The interaction will enable and facilitate the development, integration and Europe-wide deployment of knowledge-driven and interoperable eHealth services and infrastructures, taking EU and national laws into account and aiming to remove barriers to electronic collection, analysis and transfer of health information. As well as the governance framework, the JA is preparing plans for interoperability of eHealth systems, which will be one of the main components for decision-making in the eHealth network. It will also develop a security and data protection framework to address the needs for enhanced security.

A variety of methods is in use to raise awareness about the EHGov project, including press releases, newsletters, flyers, brochures and journal articles; also fact sheets, brochures, conference presentations and conference posters aimed to inform healthcare professionals and healthcare organisations.

## What did the JA achieve?

The former High Level eHealth Governance Group has been transformed into the eHealth Network according to the requirements of the Directive on the application of patients' rights in cross-border healthcare. The eHealth Network is still acting as a voluntary network, but is not providing a legal basis for decision making that has effects at both EU and Member State level. The Network is co-chaired by the Director General of the European Commission's Directorate-General for Health and Consumers and the Project Coordinator of the eHealth Governance Initiative. Among other JA activities to generate closer and sustainable cooperation between Member States in the field of eHealth, country reports and their translation and uploading on national health and statistical websites is underway. Information about the JA is disseminated to project partners through the website, and more widely through folders, posters and conference presentations.

## How will the results be put into practice?

The effect of the JA depends on the long-term involvement of the Member States, other European countries and eHealth stakeholder groups, working in a permanent coordination and cooperation process with the Commission and with other related projects on the EU level. This should have a long-term effect on national investments in the field of eHealth, leading to a sustainable benefit for patients and also for the sustainability of European healthcare systems.

## The benefits of working jointly at EU level

Collaboration at EU level has been essential for the success of the EHGov JA, since its whole purpose is to generate a structure for common governance of eHealth initiatives. National decisions to continue working towards a joint strategy on eHealth on a European level have led to intense cooperation among all of the partners and stakeholders. The enrolment of national health bodies as project partners and the start of new activities on a national level have also contributed to the progress of the JA.

<sup>(3)</sup> e.g. Smart Open Services for European Patients (epSOS), Digital Agenda <http://ec.europa.eu/digital-agenda/>, Secure Identity Across Borders Linked (STORK), European Health Professional Card (HPRO).

## EHGov: Key data

<http://www.ehgi.eu>

**MAIN PARTNER (M):**

Federal Ministry of Health, Austria

**PROJECT COST:**

Total: € 2 003 791

EC contribution: € 1 001 894

**PROJECT DURATION:**

01.02.2011 – 31.01.2014 (36 months)

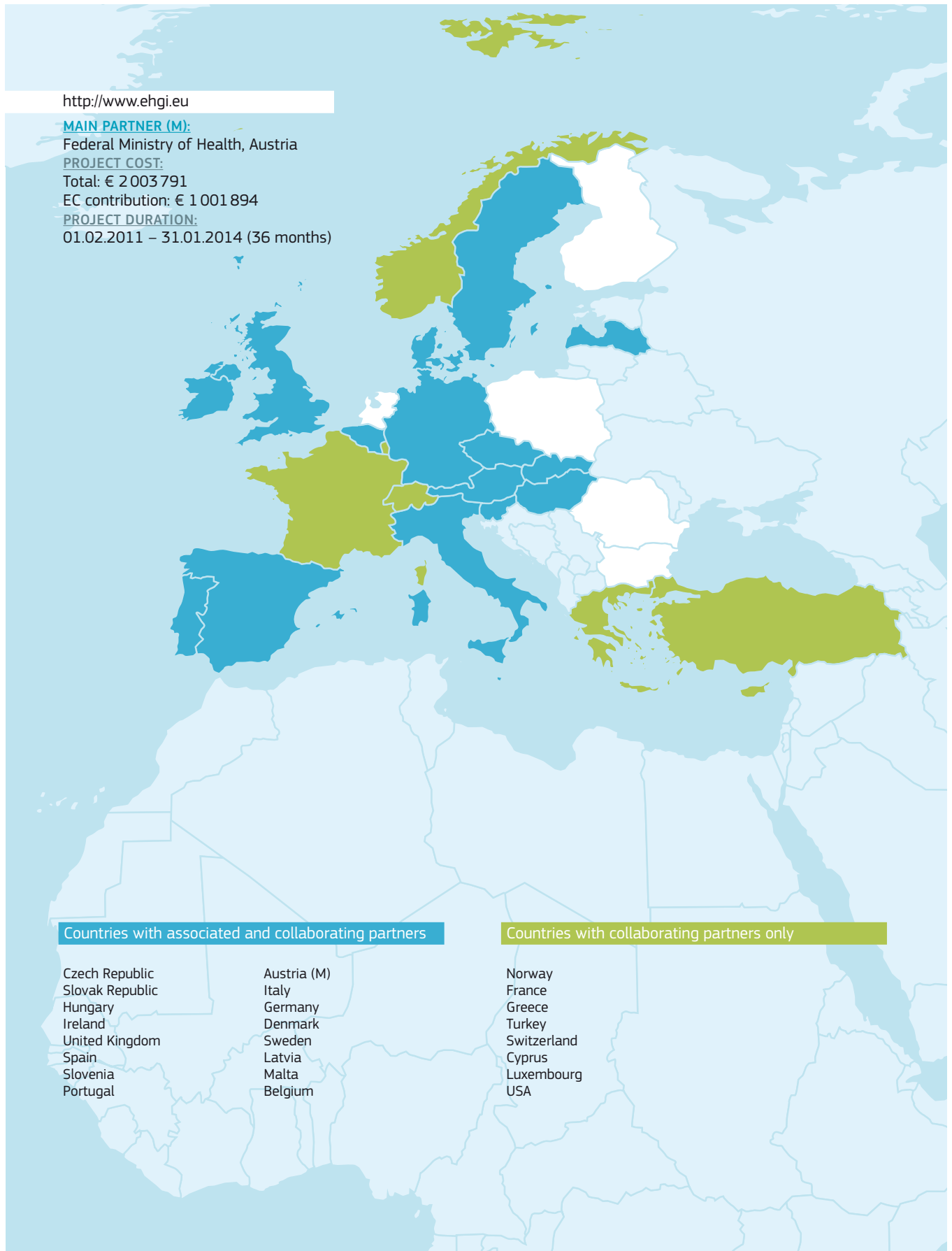
Countries with associated and collaborating partners

Czech Republic  
Slovak Republic  
Hungary  
Ireland  
United Kingdom  
Spain  
Slovenia  
Portugal

Austria (M)  
Italy  
Germany  
Denmark  
Sweden  
Latvia  
Malta  
Belgium

Countries with collaborating partners only

Norway  
France  
Greece  
Turkey  
Switzerland  
Cyprus  
Luxembourg  
USA



2011



## European Union Network for Patient Safety and Quality of Care (PaSQ)

**Keywords:** Quality of healthcare, cost-effectiveness, patient safety, patient involvement, quality management systems

### Summary

*As a key dimension of the quality of healthcare, patient safety is increasingly of interest at the EU level. Safe healthcare can improve an individual's health outcome and can also contribute, in the longer term, to a cost-effective use of healthcare resources. It is therefore doubly beneficial for governments, healthcare providers and patients. The PaSQ JA aims to strengthen cooperation between the Member States, international organisations and EU stakeholders on issues relating to the quality of healthcare, focusing on patient safety and patient involvement. It will achieve this through the PaSQ Network for Patient Safety and Quality of Care, whose object is to share, evaluate and recommend principles and examples of good quality healthcare (particularly patient safety), and how to ensure EU collaboration in this area after the completion of the JA. It will achieve this through organising patient safety and quality of care platforms in all Member States, centred on PaSQ national contacts.*

### How does the PaSQ JA contribute added value to EU Health Policies?

The PaSQ JA, designed to contribute to the provision of safe and high quality healthcare for everyone in the EU, is a response to a number of EU policy statements and recommendations. The 2009 Council Recommendation on patient safety<sup>(1)</sup> calls for the sharing of knowledge, experience and good practices on patient safety strategies, and also on the effectiveness of initiatives in this area and how far they can be put into practice in other settings. In addition

to this overall objective, the Working Party on Public Health at Senior Level called for enhanced collaboration between Member States and the Commission on Healthcare Quality<sup>(2)</sup>, and the same working party requested the Commission to help Member States to exchange good practices in the area of patient involvement. The PaSQ JA will provide a platform for collaboration and networking between Member States, international organisations and stakeholders so that they can identify and exchange good practices at a range of levels.

<sup>(1)</sup> Council Recommendation of 9 June 2009 on patient safety, including the prevention and control of healthcare associated infections. 2009/C 151/01.

<sup>(2)</sup> Council Working Party on Public Health at Senior-level Second meeting, 29 May 2009: Healthcare quality.

## Why is patient safety and quality of care an important issue for Europe?

All Member States are responsible for providing healthcare for their citizens, but services are not currently at the same level across Europe. Ensuring that the services and treatments they provide are of high quality, and that they provide for patient safety and involvement in treatment decisions, is important not only for patients but also for healthcare administrators and providers. It is in the interests of everyone to keep people healthy and active, so that they can contribute to the economy of Member States and to containing healthcare costs. Providing healthcare services that take full account of patients' preferences and views allows them to take a more informed role and to participate more fully in their care.

## What did the JA set out to do?

The PaSQ JA set out to establish a platform for collaboration and networking between Member States, international organisations and stakeholders so that they can identify, exchange and implement good practices and strategies in ensuring patient safety and a high quality of care.

## Methods

Following the initial steps to stimulate active participation from the Member States, and national coordination of stakeholders, JA partners are exchanging information on patient safety and care quality in the different Member States through site visits and interviews with stakeholder organisations. The information is being consolidated into reports on good clinical practices in patient safety and on quality management systems in the Member States.

A selection of good practices will be made, with a preference for those that are relevant for most Member States. This voluntary exchange of experiences could lead to a peer-review system for quality management systems in healthcare.

The work should also contribute to the establishment of national patient safety and quality networks or platforms, involving all relevant national stakeholders.

The main outcome will be the consolidation of the permanent network for patient safety in Europe that has been established under the 2007 EUNetPaS project<sup>(3)</sup>. The commitment expressed in that project by the 27 Member States to build a permanent collaborative network on patient safety will be enlarged by the PaSQ JA to address quality issues, and strengthened by assuring long-term Member State and Commission engagement in the PaSQ network.

Dissemination of the work of the PaSQ JA is mainly through conferences and by integration of PaSQ materials in national campaigns.

## Further progress

Details of the achievements of the JA, how its results will be put into practice and why it was beneficial to work at EU level are not yet available.

<sup>(3)</sup> European Network for Patient Safety. <http://ns208606.ovh.net/~extranet/>

## PaSQ: Key data

<http://www.pasq.eu/>

**MAIN PARTNER (M):**

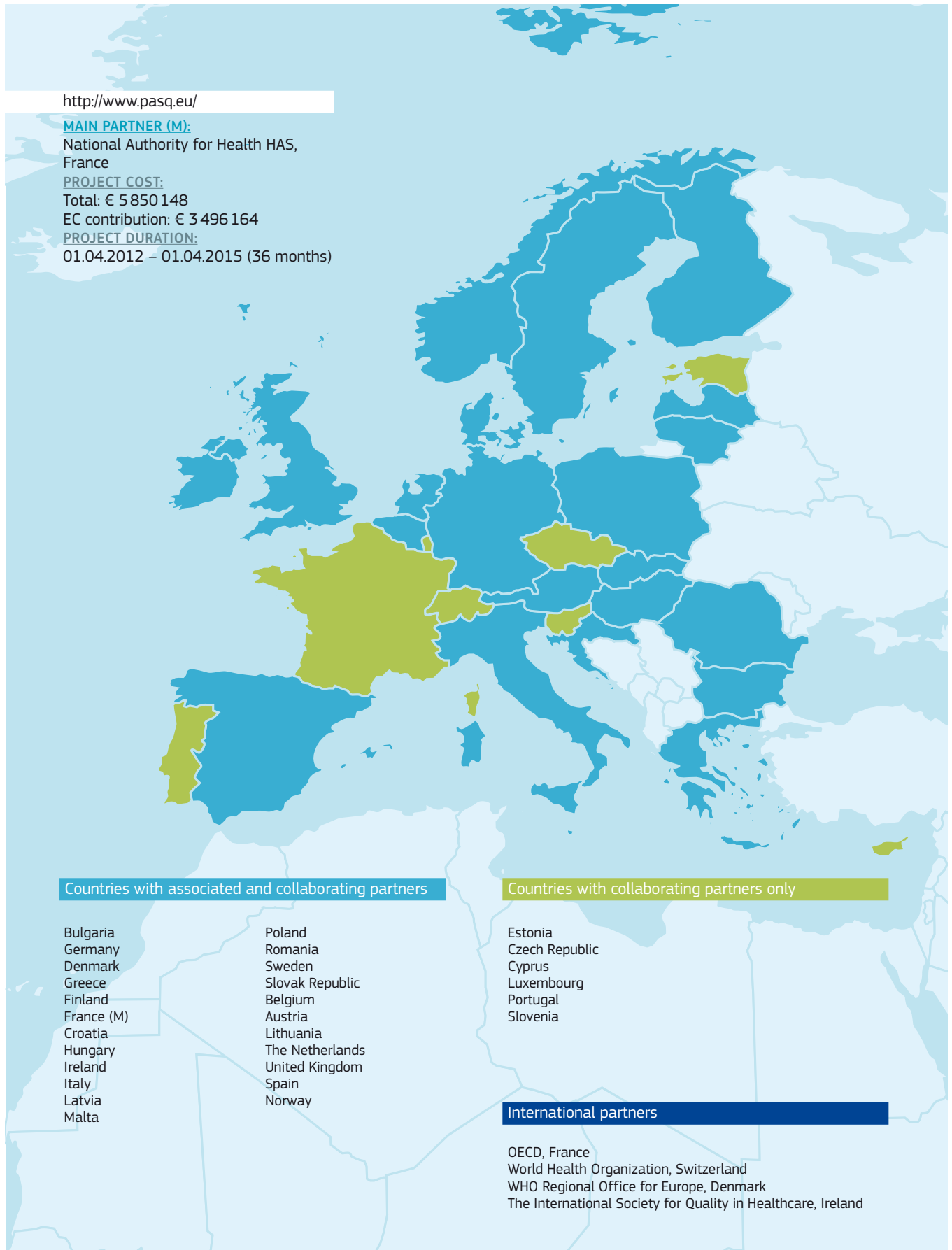
National Authority for Health HAS,  
France

**PROJECT COST:**

Total: € 5 850 148  
EC contribution: € 3 496 164

**PROJECT DURATION:**

01.04.2012 – 01.04.2015 (36 months)



2011



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

**Keywords:** Donation and procurement, transplantation, intensive care, living donors, registries

### Summary

*The ACCORD Joint Action aims to support Member States to achieve the full potential of organ donation and transplantation on both national and international levels. To do this, the Member States will be supported to develop registers of potential live organ donors and to set the basis for international data sharing in this area. The JA will also increase the potential use of organs from deceased donors, by fostering cooperation between intensive care professionals and donor transplant coordinators, while at the same time respecting the varying end-of-life practices in Europe. Specifically designed collaborative initiatives (twinning) will also enable the exchange between Member States of best practices in the field of organ donation and transplantation.*

### How does the ACCORD JA contribute added value to EU Health Policies?

The ACCORD JA will contribute to the Health Programme and its work plan for 2011. Specifically, it will support the implementation of the 2010 Directive on standards of quality and safety of human organs intended for transplantation<sup>(1)</sup>, and the accompanying action plan on organ donation and transplantation (2009-15)<sup>(2)</sup> on strengthened cooperation between Member

States. The Directive sets common standards of quality and safety of human organs intended for transplantation, while the action plan includes 10 priority actions targeted to increasing the availability of organs, to make the make transplantation systems more efficient and accessible and to improve the quality and safety of the organs. The ACCORD JA is in place at a strategic time, while the national provisions to transpose and subsequently implement the Directive are being worded, and ACCORD is well placed to support their alignment.

### Why is coordinated organ donation an important issue for Europe?

Thousands of patients in the EU benefit from organ transplantation, but the availability of organs does not meet the need for transplantation. In 2007 the number of patients waiting for a suitable donor in the EU was estimated at more than 56 000, but only about 25 000 transplant procedures were performed<sup>(2)</sup>. As a result, patients' conditions deteriorate or they die while waiting for transplantation.

While the shortage of organs is a universal problem, the transplantation needs of patients are unequally met by the Member States, mainly due to variability in live and deceased donation rates. This heterogeneity and the need to establish a common framework for quality and safety of human organs intended for transplantation led to the Directive and action plan. Action is urgently needed to stimulate greater availability of organs for transplantation in the Member States, and to share best practices to ensure their quality and safety, and that of live donors.

<sup>(1)</sup> Directive 2010/53/EU of 7 July 2010 on standards of quality and safety of human organs intended for transplantation. OJL 204 of 6.6.2010.

<sup>(2)</sup> Action plan on organ donation and transplantation (2009-15): Strengthened Cooperation between Member States. COM(2008) 819 of 8.12.2008.



## What did the JA set out to do?

The ACCORD JA set out to take action in three areas: live donor registries, cooperation between intensive care units (ICUs) and donor transplant coordinators (DTCs), and twinning. First, ACCORD will support Member States in the development of registries on the characteristics and follow-up of live organ donors and set down the basis for international data sharing in this area. Setting up a registry of this nature, a requirement laid down in the Directive, is an essential part of an appropriate framework of donor care for the purposes of traceability and for building evidence on the consequences of live donation of an organ.

Secondly, ACCORD intends to strengthen cooperation between ICUs and DTCs, through a dedicated study exploring end-of-life care patterns and models of intervention that facilitate donation while respecting the different patterns of care. This intervention seeks to increase organ availability from deceased donors in participating countries.

Finally, ACCORD will promote international exchange of best practices and experience through collaborative initiatives in which countries with more experience in areas of interest of the Directive and the action plan will be twinned with, and support, others at an earlier stage of developing their systems.

## Methods

Setting the recommendations for a live donor registry and for international data sharing will first require a comprehensive description of live donor registries currently in function in Europe. A specific survey will be developed to gather precise information on the design (variables used and definitions applied) and requirements of these registries. Expert discussion will then set the basis for recommendations to address the main questions to be answered through these tools. The core of the recommendations produced (the minimum data set and requirements) will also be the starting point for international data sharing on live organ donors and complications derived from donation in the short, medium and long term. Data sharing will be piloted with data provided by two to four partners with consolidated live donor registries.

Strengthening the relationship between ICUs and DTCs requires a precise description of the different pathways of care applied in Europe to patients with a devastating brain injury and potential for effective deceased organ donation. A specific study will be designed and implemented during the project lifetime to capture such differences and identify the factors critical for success. The knowledge gained through this study, with input from an ad-hoc Clinical Reference Group involving relevant stakeholders in the field, will provide the basis for development of methodology for rapid and repeatable improvement. This will include a practical toolkit of recommendations for professionals dealing with end-of-life care and/or donor transplant coordination, intended to be validated by its implementation during ACCORD.

Twinning initiatives will be developed during the JA lifetime in areas related to the national priority actions. Each twinning will be based on an ad-hoc protocol with achievable and quantifiable objectives, a dedicated methodology and description of expected outcomes. Implementation of the twinings during the project will enable preparation of a guide for further twinings in the area of donation and transplantation, after completion of the JA.

## Further progress

A plan for dissemination and sustainability is under development. Details of the achievements of the JA, how its results will be put into practice and why it was beneficial to work at EU level are not yet available.

## ACCORD: Key data

<http://www.accord-ja.eu/accord>

**MAIN PARTNER (M):**

Organización Nacional de Trasplantes,  
Ministerio de Sanidad, Servicios  
Sociales e Igualdad, Spain

**PROJECT COST:**

Total: € 2 435 123

EC contribution: € 1 440 000

**PROJECT DURATION:**

22.05.2012 – 21.11.2015 (42 months)

Countries with associated and collaborating partners

Italy  
United Kingdom  
Germany  
Poland  
Greece  
Bulgaria  
Hungary  
Portugal  
Croatia  
Czech Republic  
Estonia

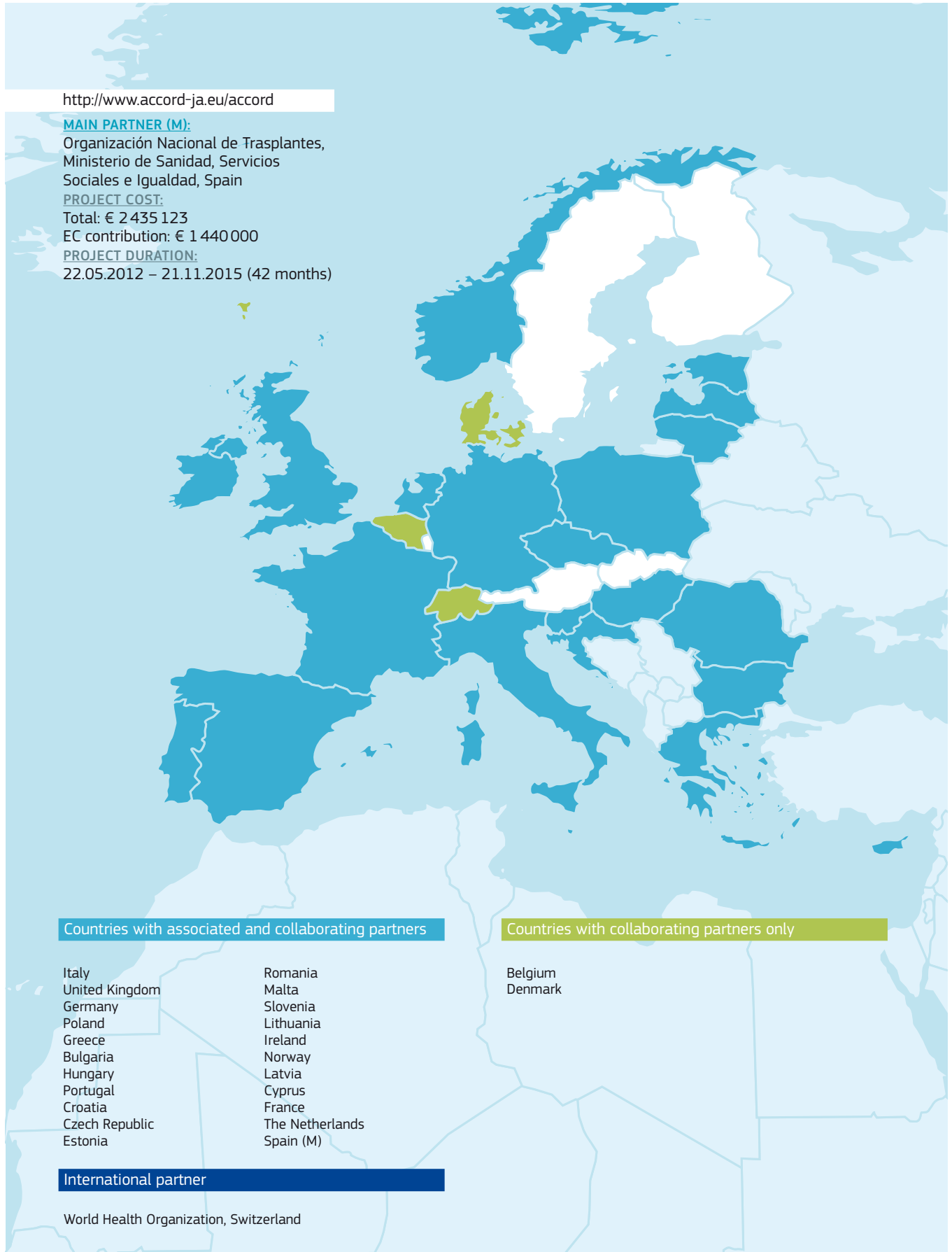
Romania  
Malta  
Slovenia  
Lithuania  
Ireland  
Norway  
Latvia  
Cyprus  
France  
The Netherlands  
Spain (M)

Countries with collaborating partners only

Belgium  
Denmark

International partner

World Health Organization, Switzerland



2011



## EUCERD Joint Action – Working for rare diseases (EJA)

**Keywords:** Rare diseases, national plans for rare diseases, non-health policies, quality of care, healthcare access

### Summary

*Although each rare disease affects a small number of people, together the several thousand diseases classified as rare affect up to 36 million people in the EU. No Member State, even those with the largest populations, can tackle the challenges of rare diseases alone because of the need for research and information sharing on an international scale and for expert opinions to be sought from a broad range of areas.*

*The EUCERD Joint Action (EJA) continues the work of the RDTF JA described earlier, and it supports the work of the European Union Committee of Experts on Rare Diseases (EUCERD). This includes further development of national plans for rare diseases and mapping how effectively rare diseases are integrated into mainstream social services or specialist social services. A critical aspect is to encourage the inclusion of initiatives supporting rare diseases into a wide range of non-health policies in the Member States.*

### How does EJA contribute added value to EU Health Policies?

Rare diseases are a priority for action in the Second Health Programme (2008-13). The Commission's 2008 Communication on rare diseases<sup>(1)</sup> was followed in 2009 by a Recommendation from the Council<sup>(2)</sup>; both emphasising the importance of providing accurate information on rare diseases and expert services to everyone in Europe. The European Union Committee of Experts on Rare Diseases (EUCERD) is mandated to support the initiatives to meet these recommendations, and its technical support is provided by the EJA.

EU policies have already led the world in the area of rare diseases, through a number of previous initiatives that have developed expertise and collaborative tools. The EJA will consolidate and develop these further, as a basis for sustainable future policies. It will promote the sharing of best practices in rare diseases, which should contribute to achieving economies of scale by reducing the number of emergencies and inappropriate treatments. The EJA will enable Member States to benchmark their policies and identify areas for integration of their findings into national plans. The EJA is operating alongside implementation of the Directive on cross-border healthcare<sup>(3)</sup>, so one key role will be identification of areas where the Directive could facilitate and improve the diagnosis and treatment of rare diseases.

### Why are rare diseases an important problem for Europe?

Most rare diseases are genetically determined, chronically debilitating conditions. They each affect a relatively small number of people (a rare disease affects less than five in 10 000<sup>(4)</sup>), but 6-8% of the EU population, or up to 36 million people are affected

by between 5-8 000 separate rare diseases. Diagnosis and care is costly, experts are few and widely separated, and research into the individual diseases and their care is hampered by the sheer difficulty of assembling patients in statistically significant numbers. A combined approach to these diseases is necessary in order to make real progress across the EU, especially in scientific and biomedical

<sup>(1)</sup> Rare diseases: Europe's challenges. Commission communication COM(2008) 679 of 11 November 2008.

<sup>(2)</sup> Council Recommendation of 8 June 2009 on an action in the field of rare diseases, 2009/C 151/02.

<sup>(3)</sup> Directive 2011/24/EU of 9 March 2011 on the application of patients' rights in cross-border healthcare. OJL 88 of 4.4.2011.

<sup>(4)</sup> European Community Action programme on rare diseases 1999-2003.

research, drug research and development, and also in healthcare policy, information and training.

### What did the JA set out to do?

The EJA set out to support the actions of the EUCERD in the field of rare diseases, and in particular through raising awareness of rare diseases, contributing to the distribution of knowledge ranging from research outcomes to patient information, and helping to improve patients' access to quality services and care throughout the course of their illness. It aims to develop a model for sustainable action on rare diseases, cutting across specific themes, which will be applicable to the whole European region.

### Methods

The EJA builds on the work of previous projects in the area of rare diseases, including EUROPLAN, the Orphanet Joint Action, the outputs of the Rare Disease Task Force and the several rare disease networks that have received EU funding in the past years. It focuses on supporting the developing national plans and strategies for rare diseases, and maps the national provision of specialised social services and Member States' progress in making rare diseases a part of mainstream social policies. It has encouraged networking at the EU and national levels between partners and stakeholders, with the aim of identifying best practices and improving the quality of care for rare diseases, while also integrating rare disease initiatives into wider policies in the Member States. Another major task has been to work towards standardisation of rare disease nomenclature at the international level.

The EJA also draws on the results, experience and methodologies of other key structures and resources, such as the Orphanet database of rare disease and expert services in all Member States and its information platform. Partnership with EURORDIS enables the EJA to take full account of the patient perspective. The EJA also engages with rare disease information networks, and embarks upon other specific collaborations, e.g. on genetic testing, quality control of laboratories, biobanks etc.

The work of the EJA is supported by a variety of methodologies, including literature reviews, questionnaires or Delphi procedures, dissemination of information and web-based exchange platforms, consensus workshops, and generation and validation of specific recommendations.

### What did the JA achieve?

The expected outcome of the EJA is an integrated strategy for the implementation of rare disease policies, achieved by exchanging experience between Member States' health authorities that were already implementing national plans and by clear communication of recommendations from EUCERD to national policy makers, patient organisations and professional associations.

The EJA is accelerating the elaboration and implementation of national action plans, eventually developing a report on capacity-building for the plans as a continuation of EUROPLAN. It will have established the definition, classification and codification of rare diseases, and it has also raised general awareness of rare diseases through its website, reports and OrphaNews Europe newsletter. Other reports have presented the EUCERD guiding principles and recommendations for social care in rare disease, the state-of-the-art in healthcare systems and a database on good practices in rare diseases, and proposals for sustainability of rare disease network tools and resources.

### How will the results be put into practice?

The main outcome of the EJA is the implementation of national plans or strategies for rare diseases that have been and are being elaborated by policy makers in the Member States and other European countries. Also important is the adoption by the Member States of an appropriate classification, standardised nomenclature and coding of rare diseases.

The EJA's official directory, applying to all Member States, describes specialised social services and the integration of rare diseases into mainstream social policies and services. The EJA has studied and mapped the organisation of healthcare systems and good practices in rare diseases, covering the entire process of care from prevention, to diagnosis, treatment and rehabilitation.

A further legacy of the EJA is the model it has prepared for sustainable action in the area of rare diseases, developed from the concept of integrating rare disease initiatives across policy areas and across the EU. This is a framework for recognition of rare diseases and sharing of knowledge and expertise, and it promotes actions in this area at both national and EU level.

## EJA: Key data

<http://www.eucerd.eu>

**MAIN PARTNER (M):**

University of Newcastle upon Tyne,  
United Kingdom

**PROJECT COST:**

Total: € 5 503 969

EC contribution: € 2 994 023

**PROJECT DURATION:**

01.03.2012 – 31.08.2015 (42 months)



2011

## European network for HTA Joint Action 2 (EUnetHTA 2)

**Keywords:** HTA, efficacy, safety, health technology assessment, health services research

### Summary

*This second Joint Action on Health Technology Assessment (EUnetHTA 2) continues the work of EUnetHTA (see page 44) and will strengthen the practical application of tools and approaches to cross-border collaboration on HTA. It aims to bring collaboration to a higher level, resulting in better understanding for the Commission and Member States of the ways to establish a sustainable structure for HTA in the EU. In order to do that, EUnetHTA 2 will develop a general strategy, principles and a proposal to implement a sustainable European HTA collaboration. These actions will respond to the requirements of the Directive for cross-border healthcare.*

### How does EUnetHTA 2 contribute added value to EU Health Policies?

The Directive on cross-border healthcare (Article 15)<sup>(1)</sup> called on the Member States and the Commission to develop a sustainable network of national institutions responsible for HTA, which will be supported and facilitated by the Commission. EUnetHTA 2 is of particular strategic relevance for bringing these requirements

into operation within the next few years. It will test the capacity of national HTA institutions to cooperate in specific assessments within a network structure, and how they use common structures for HTA information in producing national reports. Pilot work will deliver information on the added value and costs of collaboration, and provide experience on the management and functioning of the network.

<sup>(1)</sup> Directive 2011/24/EU of 9 March 2011 on the application of patients' rights in cross-border healthcare. OJL 88 of 4.4.2011.

## Why is health technology assessment an important problem for Europe?

HTA is a tool to improve quality and efficiency of public health and healthcare interventions and policies. Since the start of the first JA in this area (EUnetHTA), the need for HTAs has become more urgent and the Directive on cross-border healthcare has spelt out the need for collaboration between the responsible national institutions to ensure that HTAs are efficient, promote good practices and avoid duplication across Europe.

## What did the JA set out to do?

EUnetHTA 2 sets out to test collaborative models and tools for a sustainable, integrated network of the national organisations responsible in the Member States for conducting health technology assessments. The network will enable the national bodies to achieve more efficient and comparable HTAs, avoiding duplication and building on the experience gained in earlier related projects.

## Methods

EUnetHTA 2 builds upon the activities of the first JA and also on earlier projects (the EUnetHTA Project 2006-08 and the EUnetHTA Collaboration 2009). In the current EUnetHTA 2 'production stream' of activities, project partners will collaboratively produce core information for priority technologies, including rapid assessments, based on the methods and recommendations generated in the EUnetHTA Project and EUnetHTA JA1. This core information will be then used to produce local HTA reports, accounting for specific national issues.

In a second stream (structure and methodology), the information and knowledge management tools developed during EUnetHTA JA1 will be refined and additional methodologies, guidelines and models developed, taking into account the experiences from the pilots in the production of core information. In this development of tools and guidelines, manufacturers will be specifically involved in the development of a data template for submission to authorities for HTA. Partners and stakeholders will be given training in the use of EUnetHTA tools.

## What will the JA achieve?

The main outcome will be a permanent, consolidated network for HTA in Europe, resulting from recognition of its added value. Exchange of information among agencies will be increased and unnecessary duplication of work reduced. The availability of core HTAs will allow agencies to concentrate resources formerly used for the methodologically sound assessment of context-dependent aspects, towards increasing the ability of HTAs to meet the needs of local users of the products and services concerned.

## Further progress

As the EUnetHTA 2 only began in October 2012, details of its achievements, how its results will be put into practice and why it was beneficial to work at EU level are not yet available.

## EUnetHTA JA2: Key data

<http://www.eunethta.eu>

**MAIN PARTNER (M):**

Danish Health and Medicines Authority,  
DHMA

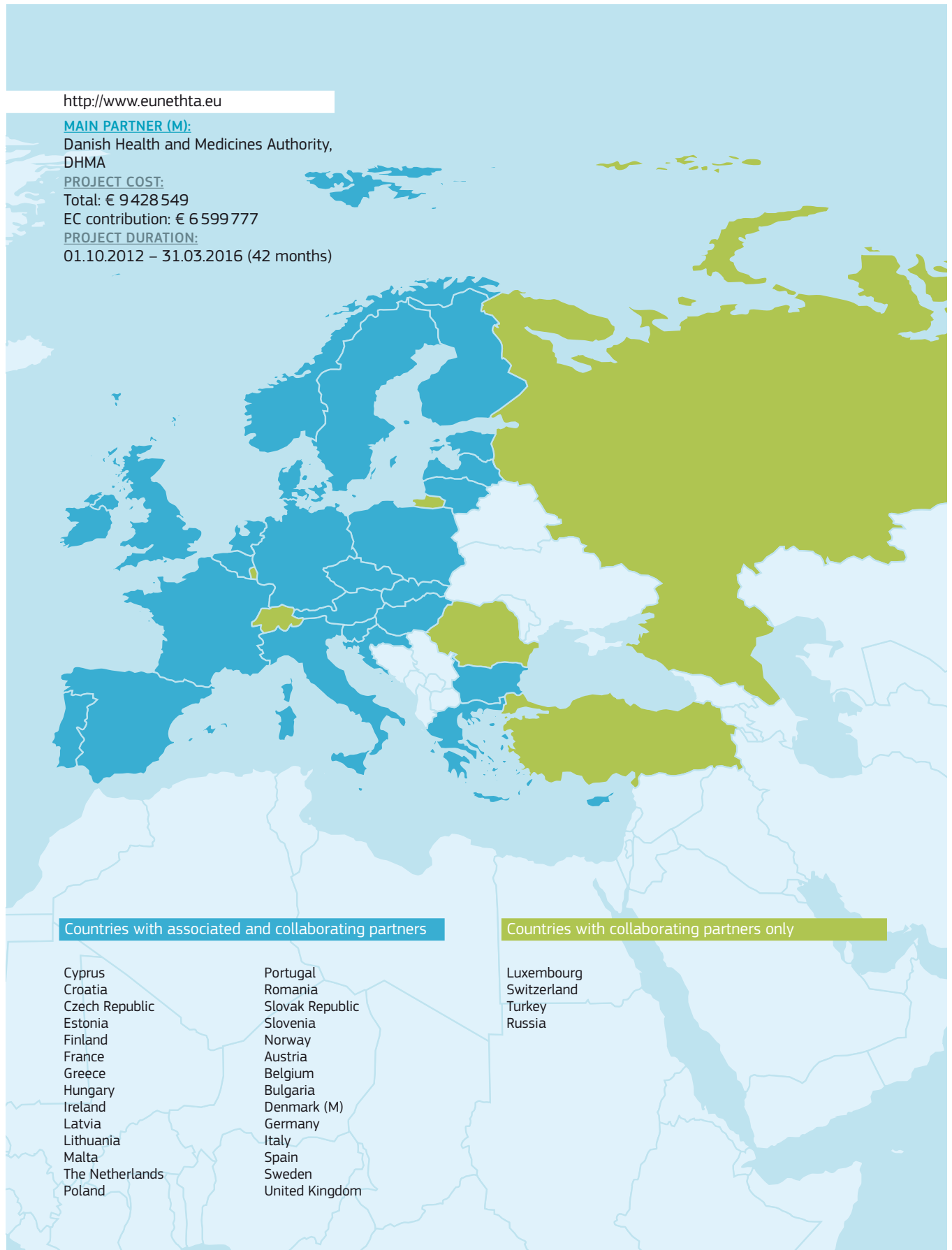
**PROJECT COST:**

Total: € 9 428 549

EC contribution: € 6 599 777

**PROJECT DURATION:**

01.10.2012 – 31.03.2016 (42 months)





2011



## Cross-Border Patient Registries Initiative (PARENT)

**Keywords:** Registries, patient registries, quality healthcare, health technology assessment effectiveness

### Summary

*The PARENT JA aims to support Member States in developing comparable and coherent patient registries in key fields where this need has been identified, e.g. chronic diseases, rare diseases, and medical technology. It will rationalise and harmonise the development and governance of patient registries, which will enable analyses to contribute to public health and research needs. In doing so, the JA will support Member States on the process of gathering data from primary sources. The information on patient treatment and outcomes needs to be objective, reliable, timely, transparent, comparable and transferable, and they will also need to present data on the short- and long-term effectiveness of health technologies. Having collected this high-quality data, the mechanisms need to be in place to enable its effective exchange between the national authorities or bodies. All these actions will contribute to rationalisation, avoid the duplication of assessments, and increase availability and quality of data that was previously retained in local patient registries.*

### How does the PARENT JA contribute added value to EU Health Policies?

The PARENT JA responds to an explicit request within the Second Health Programme for the Commission and Member States to add value in tackling major health challenges by sharing information and exchanging expertise and best practice. The JA will add value to the information already held in national patient registries and enhance their usefulness. This will be achieved by surveying the status of registries, their development and governance across Europe, and providing recommendations, guidelines and tools

to help the Member States maintain and make use of them. The work will also outline the role of registries as supporting structures of the cross-border healthcare Directive<sup>(1)</sup>, and propose next steps towards implementing the Directive.

The outcome of the JA will have additional benefits for more efficient and higher quality HTA, because of the harmonisation of secondary registry data and its availability for cross-border exchange. A further benefit will be benefits for eHealth initiatives at both Member State and EU level, through the improved alignment of registries.

<sup>(1)</sup> Directive 2011/24/EU on the application of patients' rights in cross-border healthcare. OJL 88 of 4.4.2011.

## Why are cross-border registries an important issue for Europe?

The registries held in Member States are a vast resource of primary information about patient conditions, treatment and outcomes. This information could be of immense value in analysing public health trends and research needs. However, steps to ensure that data from the many different countries of Europe is accurate and comparable, so that meaningful interpretation is possible.

## What did the JA set out to do?

The PARENT JA set out first to establish the current presence and status of patient registries and how they are regulated; and then to propose how they can be improved and to provide tools to help the process. It would also propose the contribution of harmonised registries to support implementation of the cross-border healthcare Directive in future.

## Methods

The JA partners will use questionnaires to determine an overview of the current development of patient registries and best practices in the EU. The results will be analysed and evaluated, and recommendations and plans prepared for the future development of registries, together with guidelines and IT tools for use by Member States' authorities.

In addition, the JA partners will also establish a wider framework for the future use of its core actions. They intend to create a prototype Register of Registries, as an EU-level source of information, which together with methodology and governance guidelines will ensure sustainable cross-border collaboration in this field after the end of the JA. They will also establish a plan of policies and actions for registries as a support mechanism for the directive on cross-border healthcare, and a mechanism to make use of the synergies with other related EU projects and Joint Actions.

## What did the JA achieve?

The PARENT JA began operation in mid-2012, so detailed results are not yet available. However, the actions are expected to result in reduced costs for managing and using the data, and better scope for its use. One such use will be that it will lead to more efficient and higher quality health technology assessment, at both national and EU levels. This should be of particular benefit for rare diseases,

where the cost of HTA has in the past been a limit to providing new treatments. More broadly, more efficient use of patient registries will contribute to reducing inequalities in treatment or quality of care of patients, and better analysis of secondary registry data should help to patients make an informed choice when seeking healthcare in other Member States.

## How will the results be put into practice?

Setting up standardised patient registries opens the way for a variety of public health analyses that are likely to lead to development of policies in different fields. The benefits from these analyses can therefore be available to the whole EU population, irrespective of cultural or political factors.

The development of improved patient registries will be publicised through a wide range of routes in the Member States and Commission information. This will result in improved awareness of the initiative, and also of its relevance to analysis and consequent health policy improvement, and to the uptake of cross-border healthcare.

The role of registers in supporting the implementation of the cross-border healthcare Directive will be analysed from the healthcare system and services, and from the research and innovation perspective. Progress will be accompanied by plans for the establishment of the National Contact Points and their supporting infrastructure and sources of data. Analysis of information on national level planning will allow the identified needs and requirements for data provision through registers, which may differ between Member States, to be identified. Any areas will be identified where updated Member State policy is needed for cross-border use of registry data.

## The benefits of working jointly at EU level

Several key EU projects related to patient registries are running at the same time as PARENT (i.e. EUnet HTA, EPIRARE<sup>(2)</sup>, EUBIROD<sup>(3)</sup>) and their activities and deliverables are often interdependent. An Associated Projects Group is to be established to coordinate work and to ensure that parallel activities are not duplicated or divergent in terms of methodology, semantics, or policy. The Associated Projects Group will actively engage decision makers from associated projects to align their activities and exploit results, sharing resources with PARENT.

<sup>(2)</sup> European Platform for Rare Diseases Registries, [www.epirare.eu/](http://www.epirare.eu/)

<sup>(3)</sup> European Best Information through Regional Outcomes in Diabetes, [www.eubirod.eu/](http://www.eubirod.eu/)

## PARENT: Key data

<http://www.patientregistries.eu>

**MAIN PARTNER (M):**

National Institute of Public Health  
NIPH, Slovenia

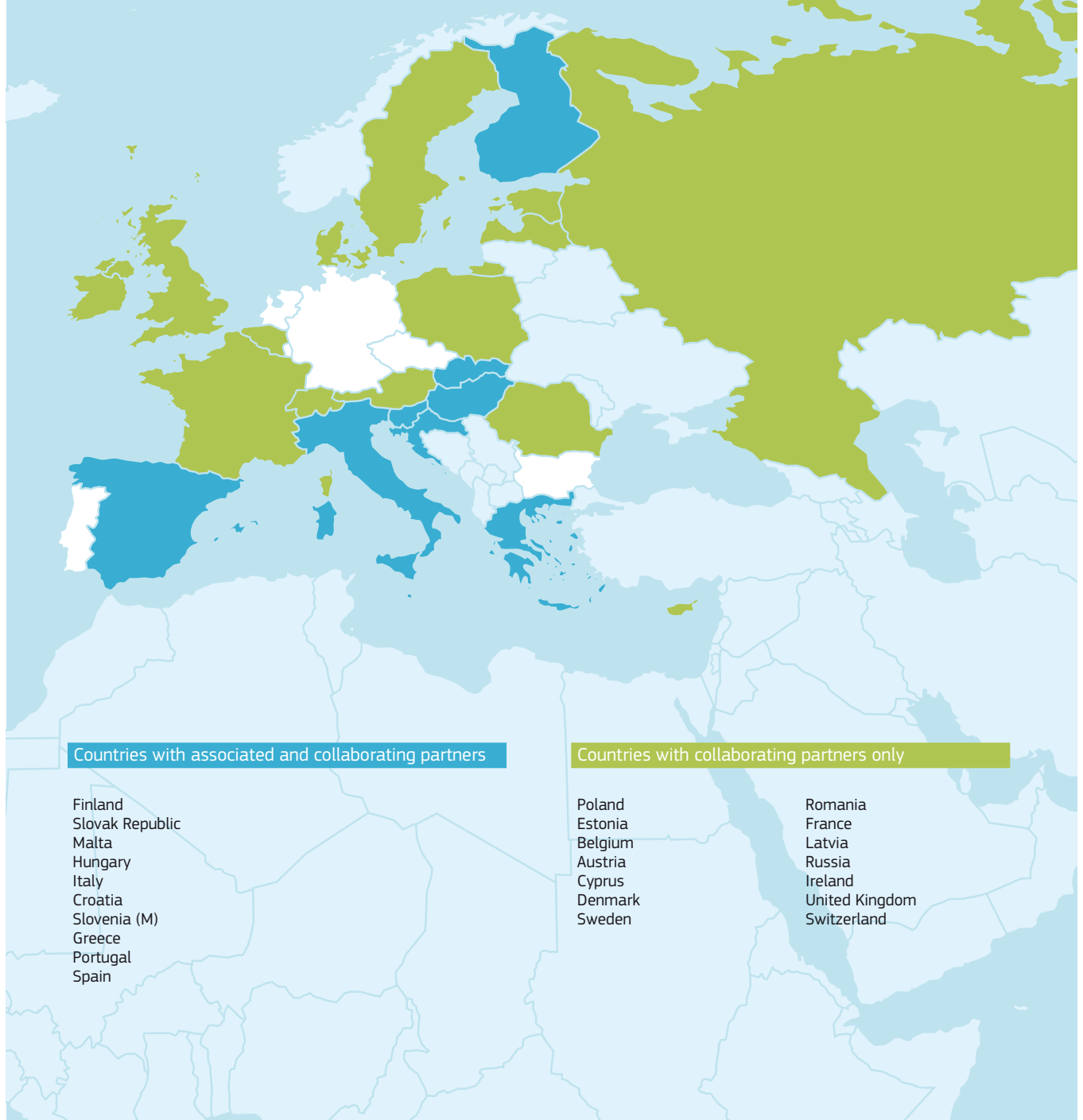
**PROJECT COST:**

Total: € 3 360 649

EC contribution: € 2 016 231

**PROJECT DURATION:**

02.05.2012 – 01.11.2015 (36 months)





## Annex 1

### Associated partner lists

#### RDTF

##### Main partner

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##### Associated partners

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- Rouen University Hospital, France
- Istituto Superiore di Sanità ISS, Italy
- Regione Veneto, Italy
- Leids Universitair Medisch Centrum, The Netherlands
- Netherlands Institute for Health Services Research, The Netherlands
- University of Manchester, United Kingdom

#### ECHIM

##### Main partner

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##### Associated partners

- Robert Koch Institute RKI, Germany
- Istituto Superiore di Sanità ISS, Italy
- Institute of Hygiene HI, Vilnius, Lithuania
- National Institute for Public Health and the Environment RIVM, The Netherlands

#### NANOGENOTOX

##### Main partner

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 Email: Salma.Elreedy@Afsse

##### Associated partners

- Scientific Institute for Public Health IPH, Brussels, Belgium
- Veterinary and Agrochemical Research Centre VAR, Belgium
- Institute of Molecular Biology IMB-BAS, Bulgaria
- Institute of Mineralogy and Crystallography IMC-BAS, Bulgaria
- National Research Centre for the Working Environment NRCWE, Denmark
- Finnish Institute of Occupational Health, Finland
- French Atomic Energy and Alternative Energies Commission CEA, France
- Institut National de Recherche et de Sécurité pour la Prevention des Accidents du travail et des Maladies professionnelles, INRS, France
- Institut Pasteur of Lille IPL, France
- Agence Française de Sécurité Sanitaire des Aliments, France
- Federal Institute for Risk Assessment BfR, Germany
- Istituto Superiore di Sanità ISS, Italy
- National Institute for Public Health and the Environment RIVM, The Netherlands
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- Instituto Nacional de Saúde Dr. Ricardo Jorge INSA, Portugal
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- Hellenic Centre for Disease Control and Prevention HCDCP, Greece
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- University of Tartu UTA, Estonia
- National Institute for Health and Welfare THL, Finland
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- Terviseamet (Health Board), Estonia
- National Institute for Health and Welfare THL, Finland
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- Direction Générale de l'Armement, France
- Friedrich Loeffler Institute, Institute for Animal Health, Germany
- Bundeswehr Institute of Microbiology, Germany
- Bernhard-Nocht-Institute for Tropical Medicine, Germany
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- National Veterinary Research Institute, Poland
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- National Institute of Public Health – National Institute of Hygiene, Poland
- Instituto de Salud Carlos III, Madrid, Spain
- Fundación Vasca de Innovación e Investigación Sanitarias, Spain
- Swedish Institute for Infectious Disease Control (Bacteriology), Sweden
- Swedish Institute for Infectious Disease Control (Virology), Sweden

- Health Protection Agency HPA-NIB (Bacteriology), United Kingdom
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- European Cancer Organisation ECCO, Belgium
- SIOF Europe, Belgium
- European Hospital and Healthcare Federation, Belgium
- European Society for Clinical Nutrition and Metabolism, Belgium
- European Oncology Nursing Society, Belgium
- Cancer Society of Finland
- Cancers and Populations, Institut National de la Santé et de la Recherche Médicale INSERM, France
- Institut National du Cancer, France
- Department of Health, Dublin, Ireland
- Irish Cancer Society, Ireland
- European Health Management Association Ltd, Ireland
- Istituto Superiore di Sanità ISS, Italy
- Ministry of Health, Italy
- Lega Italiana per la Lotta contro i Tumori, Italy
- Regione Toscana, Italy
- IRCCS Foundation National Cancer Institute, Italy
- Alleanza Contro Il Cancro, Italy
- IRCCS Azienda Ospedaliera Universitaria San Martino – Istituto Nazionale per la Ricerca sul Cancro, Italy
- AO City of Health and Science of Turin
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- Foundation Nederlands Normalisatie Instituut, The Netherlands
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- Federal Centre for Health Education, Germany
- National Centre for Social Research, Greece
- National Institute for Health Development, Hungary
- Institute of Public Health, Ireland
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- Centre for Disease Prevention and Control, Latvia
- National Institute for Public Health and the Environment RIVM, The Netherlands
- Norwegian Directorate of Health, Norway
- National Institute of Public Health – National Institute of Hygiene, Poland
- Ministry of Health and Social Policy, Spain
- Fundación Vasca de Innovación e Investigación Sanitarias, Sweden
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- Region Syddanmark, Denmark
- National Institute for Welfare and Health, Finland
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- Université de Strasbourg, France
- Otto-von-Guericke University Magdeburg, Germany
- University Medical Centre of the Johannes Gutenberg University Mainz, Germany
- National Centre for Healthcare Audit and Inspection, Hungary
- Health Service Executive, Ireland
- Istituto Superiore di Sanità ISS, Italy
- Istituto di Fisiologica Clinica del consiglio Nazionale delle Ricerche, Italy
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- Azienda Ospedaliero Universitaria di Ferrara, Italy
- Centre for Disease Prevention and Control of Latvia
- Children's University Hospital (Bernu Kliniska universitates slimnica), Latvia
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- Fundación Vasca de Innovación e Investigación Sanitarias, Spain
- Agencia de Salud Publica de Barcelona, Spain
- Asociacion Espanola para el Registro y Estudio de las Malformaciones Congenitas, Spain
- Fundacio Centre de Recerca en Epidemiologia Ambiental, Spain
- Centre Superior de Investigacion en Salud Publica, Spain
- Southampton University Hospitals Trust, United Kingdom
- The Chancellor, Masters & Scholars of the University of Oxford, United Kingdom
- Public Health Wales, United Kingdom
- Queen Mary University of London, United Kingdom
- University of Leicester, United Kingdom
- University of Newcastle upon Tyne, United Kingdom
- Directorate of Health, Iceland
- National Suicide Research Foundation, Ireland
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- Archbishop Makarios III Hospital, Cyprus
- University of Tartu, Estonia
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- Universitatea de Medicina si Farmacie GR. T. Popa UMF, Romania
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- University Hospital of Aarhus, Denmark
- University of Copenhagen KU, Denmark
- Institut National d'Études Démographiques –INED, France
- University of Montpellier, France

- Centre Régional de Lutte Contre le Cancer, CRLC, France
- Robert Koch Institute RKI, Germany
- Rostock Center for Demographic Change UROS, Germany
- Hellenic Statistical Authority HAS, Greece
- University la Sapienza DSSEAD, Italy
- National Institute for Public Health and the Environment RIVM, The Netherlands
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- Integrating the Healthcare Enterprise – Europe, Belgium
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- European Health Management Association Ltd, Ireland
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- European Patients Forum EPF, Belgium
- European Union of Private Hospitals UEHP, Belgium
- European Health Management Association EHMA, Ireland

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- Agency for Quality and Accreditation in Health Care and Social Welfare AQAH, Croatia
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- Hellenic Transplant Organisation HTO, Greece
- Hungarian National Blood Transfusion Service, Hungarian Transplantation Society HNBTS
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  - Emilia Romagna, Agenzia Sanitaria e Sociale Regionale, Regione Emilia Romagna, Italy
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  - National Authority of Medicines and Health Products INFARMED, Portugal
  - National School of Public Health, Management and Professional Development NSPHMPD, Romania
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  - Institute for Economic Research IER, Slovenia
  - Instituto de Salud Carlos III, ISCIII, Madrid, Spain
  - Swedish Council on Health Technology Assessment SBU, Stockholm, Sweden
  - National Institute for Health and Clinical Excellence NICE, United Kingdom
  - NIHR Evaluation, Trials and Studies Coordinating Centre NETSCC, University of Southampton, United Kingdom
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  - Ministry of Health MdS, Italy
  - Direcção General de Saúde Pública DGS, Portugal
  - Ministry for Health, the Elderly and Community Care MHEC, Malta
  - National Health Information Centre NCZI, Slovak Republic
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## Annex 2

### Table of partner organisations in the Joint Actions, 2008-2011

Country/ Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO- GENETOX	EHES	EUnetHTA	
<b>EU-27</b>							
<b>Austria</b>	Agency for Health and Food Safety						
	Association of Austrian Social Security Institutions, Vienna					A	
	Austrian Patient Safety Platform						
	Die Oö. Gesundheits- und Spitals-AG						
	Donau Universität Krems						
	European Society of Radiology						
	Federal Ministry of Health						
	Forschungsverein zur Registrierung steirischer Geburtsfehlbildungen						
	Gesundheit Österreich GmbH, Vienna					A	
	Institute for Quality in Healthcare						
	Kuratorium für Verkehrssicherheit						
	Ludwig Boltzmann Institute, Vienna					A	
	Medical University of Vienna						
	University for Health Sciences, Medical Informatics and Technology					C	
<b>Belgium</b>	Association of European Cancer Leagues						
	Belgian Cancer Centre						
	Belgian Health Care Knowledge Centre, Brussels					A	
	Council of European Dentists						
	Directorate-General for Healthcare Facilities						
	EC DG Enterprise and Industry						
	EC Committee of the Regions, NAT Commission						
	ENRICH Network of European Regions						
	EU Joint Research Centre			C			
	EuroMelanoma						
	European Academy of Cancer Sciences						
	European Cancer Organisation						
	EUROCARE						
	European Cervical Cancer Association						



Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	

	European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry						
	European Diagnostic Manufacturers' Association						
	European Federation of Nurses Associations						
	European Federation of Pharmaceutical Industries and Associations						
	European Health Telematics Association						
	European Hospital and Healthcare Federation						
	European Institute of Women's Health						
	European Liver Patients' Association						
	European Network EuroHealthNet						
	European Network for Smoking Prevention						
	European Observatory on Health Systems and Policies						
	European Oncology Nursing Society						
	European Patients Forum						
	European Public Health Alliance						
	European Regional and Local Health Authorities						
	European Society for Clinical Nutrition and Metabolism						
	European Society of Intensive Care Medicine						
	European Society of Oncology Pharmacists						
	European Society for Therapeutic and Radiation Oncology						
	European Union of General Practitioners						
	European Union of Private Hospitals						
	Federal Public Service for Health, Food chain safety and Environment			C			
	Flemish Agency for Care and Health						
	Fondation Roi Baudouin						
	Health First Europe						
	Institut de Recherche Scientifique en Pathologie et en Génétique						
	Integrating the Healthcare Enterprise – Europe						
	Ministry of Health						
	National Institute of Health and Disability Insurance					C	
	Organisation of European Cancer Institutes						
	Pharmaceutical Group of the European Union						

2010									2011				
QUANDHIP	ALCOVE	EPAAC	Equity Action	EUROCAT	JAMIE	Orphanet Europe	EHLEIS	EHGov	PaSQ	ACCORD	EJA	EUNetHTAZ	PARENT
		C						C					
		C											
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		C											
		A						A	A				

Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
	Provincial Institute of Hygiene						
	Scientific Institute for Public Health, Brussels		C	A			
	SIOP Europe						
	Smokefree partnership						
	Standing Committee of European Doctors						
	Veterinary and Agrochemical Research Centre			A			
<b>Bulgaria</b>	Bulgarian Association for Promotion of Education and Science						
	Bulgarian Executive Agency for Transplantation						A
	Institute of Mineralogy and Crystallography			A			
	Institute of Molecular Biology			A			
	Medical University of Sofia						
	Ministry of Health						
	National Centre of Infectious and Parasitic Disease						
	National Centre for Public Health and Analyses						
	National Centre of Public Health Protection, Sofia					A	
<b>Cyprus</b>	Archbishop Makarios III Hospital						
	Ministry of Health						
<b>Czech Republic</b>	Charles University, Prague	A					
	Coordination Centre for Departmental Medical Information Systems						
	Czech Alzheimer's Society						
	Institute of Health Information and Statistics, Prague		C				
	Ministry of Health, Prague					A	
	National Institute for Nuclear, Chemical and Biological Protection						
	National Institute of Public Health				A		
	The University Hospital Brno						
	Thomayer University Hospital, Prague						
	Transplantation Coordinating Centre						A
<b>Denmark</b>	Centre for Applied Health Services Research and Health Technology Assessment, University of Southern Denmark, now: HTA and Health Services Research, Public Health and Quality Improvement, Central Denmark Region					A	
	Connected Digital Health on behalf of the Ministry of the Interior and Health						



2010									2011				
QUANDHIP	ALCOVE	EPAAC	Equity Action	EUROCAT	JAMIE	Orphanet Europe	EHLEIS	EHGov	PaSQ	ACCORD	EJA	EUNetHTAZ	PARENT
				A									
						A	A						C
		A											
		C											
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A													
						C					C		
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		C			C								
A													
		C							A				
							C					A	
	C	C		C	A	A	C	C	C	A		A	C
						A							
								A					
	C												
							A						
									C		C	A	
A													
		C	A										
					A								
				C									
										A			
								A					

Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
	Danish Health and Medicines Authority, formerly National Board of Health					M	
	Danish Institute for Health Services Research					C	
	Danish Institute for Local and Regional Government Research						
	Danish Ministry of the Interior and Health						
	Danish Society for Patient Safety						
	Dept of Health Services Research and HTA, Centre for Public Health Central Denmark Region					C	
	Economic Council of the Labour Movement						
	Institute for Rational Pharmacotherapy					C	
	ScandiTRANSPLANT						
	National Research Centre for the Working Environment			A			
	National Veterinary Institute, Technical University of Denmark						
	Region Syddanmark						
	University Hospital of Aarhus						
	University of Copenhagen						
	University of Southern Denmark						
<b>Estonia</b>	Ministry of Social Affairs, Tallinn		C				
	Tartu University Hospital						A
	Terviseamet (Health Board)						
	University of Tartu					A	
<b>Finland</b>	Cancer Society of Finland						
	Finnish Institute of Occupational Health			A			
	Finnish Medicines Agency					C	
	Ministry of Social Affairs and Health			C			
	National Institute for Welfare and Health		M		M	A	
	University of Turku						
	Väestöliitto ry – The Family Federation of Finland						
<b>France</b>	Agence de la Biomédecine						
	Agence Française de Sécurité Sanitaire des Aliments			A			
	Agence Française de Sécurité Sanitaire de l'Environnement et du Travail			M			
	Agence Française de Sécurité Sanitaire des Produits de Santé			C			
	Assistance Publique-Hôpitaux de Paris						
	Centre Régional de lutte contre le Cancer						

2010									2011				
QUANDHIP	ALCOVE	EPAAC	Equity Action	EUROCAT	JAMIE	Orphanet Europe	EHLEIS	EHGov	PaSQ	ACCORD	EJA	EUNetHTA2	PARENT
							A					M	C
												C	
		C							A				
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A													
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						C							
							A						
					A		2A						
		C			A								C
A									C	A			
						A						A	
		A										A	
A	A	C	A	A	C				A		A	A	A
		C											
						A							
										A			
	A												
							A						

Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
	Coordinating Centre for Cancer Screening						
	Direction Générale de l'Armement						
	Direction Générale de la Santé						
	European Directorate for the Quality of Medicines and Health Care, Council of Europe						
	European Organisation for Rare Diseases						
	French Atomic Energy and Alternative Energies Commission			A			
	French Institute for Public Health Surveillance						
	Garnier International						
	Haute Autorité de Santé					A	
	Institut National du Cancer						
	Institut National de l'Environnement industriel et des Risques			C			
	Institut National d'Études Démographiques						
	Institut National de Recherche et de Sécurité pour la Prévention des Accidents du Travail et des Maladies professionnelles			A			
	Institut National de la Santé et de la Recherche Médicale	M					
	Institut Pasteur of Lille			A			
	Institut de Veille Sanitaire						
	Laboratoire National de Métrologie et d'Essais			C			
	Ministère du Travail de l'Emploi et de la Santé			C			
	Research Centre of the Army Health Services						
	Rouen University Hospital	A					
University of Montpellier							
University of Strasbourg							
<b>Germany</b>	Agency for Quality in Medicine						
	Bernhard-Nocht-Institute for Tropical Medicine						
	Brandenburg University of Technology, Cottbus						
	Bundeswehr Institute of Microbiology						
	Department of Health						
	Deutsches Institut für Medizinische Dokumentation und Information					A	
	Deutsche Stiftung Organtransplantation						
	European LeukemiaNet Foundation						
	Federal Centre for Health Education						
Federal Institute for Risk Assessment			A				



Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
	Federal Ministry for the Environment, Nature Conservation and Nuclear Safety			C			
	Federal Ministry of Health						
	Friedrich Loeffler Institute, Institute for Animal Health						
	Gemeinsamer Bundesausschuss						
	Institute for Public Health and Nursing Research, Bremen					C	
	Interdisciplinary Centre for HTA and Public Health, University of Erlangen-Nuremberg, National BMBF Cluster of Excellence						
	Johann Wolfgang Goethe Universität, Frankfurt am Main						
	Johannes Gutenberg University, Mainz						
	Medizinische Hochschule, Hannover						
	National Association of Statutory Health Insurance Physicians						
	Otto-von-Guericke University, Magdeburg						
	Pfizer						
	Philipps University, Marburg						
	Robert Koch Institute		A		A		
	Rostock Center for Demographic Change						
	Stiftung für Qualität und Wirtschaftlichkeit im Gesundheitswesen					A	
University of Bonn							
<b>Greece</b>	Aristotelean University						
	Athens Association of Alzheimer's Disease and Related Disorders						
	Hellenic Centre for Disease Control and Prevention				A		
	Hellenic Health Foundation				A		
	Hellenic Statistical Authority						
	Hellenic Transplant Organisation						
	Institute of Child Health						
	National Centre for Social Research						
	National and Kapodistrian University of Athens						
	National School of Public Health, Athens					A	
University of Patras		C					



Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
<b>Hungary</b>	Central Statistical Office						
	Hungarian National Blood Transfusion Service, Hungarian Transplantation Society						A
	Ministry of Health						
	National Centre for Healthcare Audit and Inspection						
	National Centre for Epidemiology (Bacteriology)						
	National Centre for Epidemiology (Virology)						
	National Institute for Health Development						
	National Institute of Oncology						
	National Institute for Quality- and Organizational Development in Healthcare and Medicines					A	
	National Institute for Strategic Health Research						
	Public Association for Healthy People						
	Semmelweis University						
	University of Szeged						
<b>Ireland</b>	Department of Health, Dublin		C				
	European Health Management Association						
	Health Information and Quality Authority					A	
	Health Service Executive						
	Institute of Public Health						
	Irish Cancer Society						
	Ministry of Health						
	National Cancer Screening Service						
	National Centre for Medical Genetics						
	National Centre for Pharmacoeconomics, St. James's Hospital, Dublin					C	
	National Suicide Research Foundation						
	Stakeholders' Forum						
	United European Gastroenterology Federation						
University College Dublin			C				
<b>Italy</b>	Agenzia Regionale per i Servizi Sanitari (Piedmont Health Care Agency)					C	
	Agenzia Sanitaria e Sociale Regionale, Regione Emilia Romagna					C	
	Alleanza Contro Il Cancro						
	AO City of Health and Science of Turin						
	Azienda Ospedaliero Rilievo Nazionale 'Gaetano Rummo' Benevento						





Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
	Aziende Ospedaliera Universitaria Integrata, Verona						
	Azienda Ospedaliera Universitaria San Martino – Istituto Nazionale per la Ricerca sul Cancro						
	Centre for Economic and International Studies, University of Roma Tor Vergata						
	Centro Nazionale Trapianti						M
	Europa Donna						
	Europa Uomo						
	European Association for Palliative Care						
	European School of Oncology						
	Fondazione IRCCS, Istituto dei Tumori						
	Surveillance of Rare Cancer in Europe RARECARE Project						
	Hospital Bambino Gesù, Rome						
	Istituto di Fisiologica Clinica del consiglio Nazionale delle Ricerche						
	Istituto Oncologico Veneto						
	Istituto Superiore di Sanità	A	A	A	A		
	Istituto Zooprofilattico Sperimentale della Lombardia e dell'Emilia Romagna						
	Istituto Zooprofilattico Sperimentale della Puglia e della Basilicata						
	Italian Federation of Cancer Volunteer Associations						
	Italian Medicines Agency, Rome					A	
	L. Spallanzani National Institute for Infectious Diseases						
	Laziosanità – Agenzia di Sanità Regione Lazio					C	
	Lega Italiana per la Lotta contro i Tumori						
	Ministero del Lavoro e delle Politiche Sociali			C			
	Ministry of Health						
	National Agency for Regional Healthcare Services					A	
	National Statistics Institute						
	Novartis						
	Observatorio Nazionale sulla Salute della Donna						
	Regione Lombardia					C	
	Regione Toscana						
	Regione Veneto	A				A	
	Università degli Studi di Brescia, Italy						



Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
<b>Latvia</b>	University Hospital of Ferrara						
	University la Sapienza, Rome						
	University Hospital A Gemelli, Rome					C	
	Centre for Disease Prevention and Control of Latvia						
	Centre of Health Economics (now National Health Services NHS) Riga					A	
	Children's University Hospital (Bernu Kliniska universitates slimnica)						
	Infectology Centre of Latvia						
	Pauls Stradins' Clinical University Hospital, Riga						A
	Psychiatry and Addiction Centre						
Riga East University Hospital							
University of Latvia							
<b>Lithuania</b>	Institute of Hygiene, Vilnius		A				
	Lithuanian University of Health Sciences						
	Ministry of Defence						
	Ministry of Health						
	National Bureau on Transplantation						A
	National Public Health Surveillance Laboratory						
	State Health Care Accreditation Agency, Vilnius					A	
	Vilnius University Medical Faculty						
Vilnius University Hospital Santariskiu Klinikos Centre for Medical Genetics							
<b>Luxembourg</b>	Cellule d'Expertise Médicale					C	
	Direction de la Santé						
	EuroStat, Luxembourg		C				
	Laboratoire National de Santé						
	Ministère de la Famille et de l'Intégration						
<b>Malta</b>	Ministry for Health, the Elderly and Community Care				A	A	A
<b>The Netherlands</b>	Central Statistics Bureau CBS						
	Consumer Safety Institute						
	Dutch Society of Clinical Genetic Foundations	C					
	Dutch Transplantation Foundation						
	European Association for Injury Prevention and Safety Promotion						
	European Cancer Patient Coalition ECPC						
	European Partnership for Supervisory Organisations in Health Services and Social Care						
	Eurotransplant						

2010									2011				
QUANDHIP	ALCOVE	EPAAC	Equity Action	EUROCAT	JAMIE	Orphanet Europe	EHLEIS	EHGov	PaSQ	ACCORD	EJA	EUNetHTAZ	PARENT
				A			A						
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			A	A	A	A							C
		C						A				A	
				A							C		
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	A									A			
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	C												
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	C	C			A	C		C	C			C	
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	C	A		A	A		C	A	A	A	C	A	A
					A		A						
					M						A		
		C											
									C				
										C			

Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
	Foundation Nederlands Normalisatie Instituut						
	Health Care Insurance Board					A	
	Integraal Kankercentrum Noord-Oost						
	Leids Universitair Medisch Centrum	A					
	Ministry of Health, Welfare and Sport						
	Ministry of Infrastructure and the Environment			C			
	National Institute for Public Health and the Environment		A	A	A		
	Netherlands Erasmus Medical Center						
	Netherlands Institute for Health Services Research	A					
	Radboud University Nijmegen Medical Centre (withdrawing 2013)						
	University of Groningen						
	University Hospital Groningen						
	University of Neijmegen						
	<b>Poland</b>	Agency for Health Technology Assessment in Poland, Warsaw					A
Cardinal Stefan Wyszyński Institute of Cardiology					A		
Health Promotion Foundation							
Institut Pomnik, Centrum Zdrowia Dziecka							
Medical University of Warsaw							
Ministry of Health							
National Centre for Quality Assessment in Healthcare							
National Institute of Public Health – National Institute of Hygiene							
National Veterinary Research Institute							
Nofer Institute of Occupational Medicine				A			
Polish Transplant Coordinating Centre Poltransplant							
Poznan University of Medical Sciences							
<b>Portugal</b>		Administração Central do Sistema de Saúde, IP					
	Directorate General Sante						
	Instituto de Biologia Molecular e Celular (IBMC)						
	Instituto Nacional de Saúde Dr. Ricardo Jorge			A	A		

2010									2011				
QUANDHIP	ALCOVE	EPAAC	Equity Action	EUROCAT	JAMIE	Orphanet Europe	EHLEIS	EHGov	PaSQ	ACCORD	EJA	EUNetHTA2	PARENT
		A										A	
		A											
						A							
	C	C											
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		C											
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A				A	A		C				A		

Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
	Ministry of Health						
	National Authority of Medicines and Health Products					A	
	National Coordination for Mental Health, High Commission for Health						
	Portuguese Blood and Transplantation Institute						A
<b>Romania</b>	Babes-Bolyai University Cluj-Napoca						
	I Chiricuta Oncology Institute						
	Ministry of Health						
	Ministry of Public Health						
	National Health Insurance House						
	National School of Public Health, Management and Professional Development					C	
	National Transplant Agency						
	Norwegian-Romanian Partnership for Progress in Rare Diseases						
	Universitatea de Medicina si Farmacie GR. T. Popa						
	<b>Slovak Republic</b>	Children's University Hospital in Bratislava					
Healthcare Surveillance Authority HCSA							
Hospital Žilina							
Institute of Neuroimmunology, Slovak Academy of Sciences							
Ministry of Education							
Ministry of Health							
National Health Information Centre NCZI							
Regional Public Health Authority					A		
Slovak Agency for Health Technology Assessment, Bratislava							
Slovak Medical University Bratislava							
Statistical Office							
<b>Slovenia</b>	Agency for Medicinal Products and Medical Devices Slovenia					C	
	Institute for Economic Research					C	
	Institute of Medical Genetics, University Medical Centre						
	Institute of Oncology Ljubljana						
	Institute for Transplantation of organs and tissues						A



2010									2011				
QUANDHIP	ALCOVE	EPAAC	Equity Action	EUROCAT	JAMIE	Orphanet Europe	EHLEIS	EHGov	PaSQ	ACCORD	EJA	EUNetHTAZ	PARENT
		C											
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		A											
										A			

Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	

	Ministry of Health						
	National Institute of Public Health		C			A	
	PARENT Joint Action						
	University Clinical Centre, Maribor						
	University Medical Centre, Ljubljana						
Spain	Agencia de Salud Publica de Barcelona						
	Andalusian HTA Agency					C	
	Asociacion Espanola para el Registro y Estudio de las Malformaciones Congenitas						
	Avedis Donabedian Foundation						
	Basque Agency for HTA					C	
	Catalan Agency for Health Information, Assessment and Quality					C	
	Centre for Biomedical Network Research on Rare Diseases						
	Centro Superior de Investigacion en Salud Publica						
	Directorate General for Pharmacy and Health Care Products						
	European Donation Committee, European Transplant Coordinators Organization						
	Federació Catalana Entitats contra el càncer						
	Fundacio Centre de Recerca en Epidemiologia Ambiental						
	Fundacion Josep Carreras contra la Leucemia						
	Fundación Vasca de Innovación e Investigación Sanitarias						
	Galician HTA Agency					C	
	Hospital Clínic i Provincial, Asesoría de Trasplantes, Barcelona						
	HTA Unit, Agencia Lain Entralgo					C	
	Institut Catala d'Oncologia						
	Instituto de Salud Carlos III, Madrid					A	
	Ministry of Health and Social Policy; later the Ministry of Health, Social Services and Equality		C	C		A	
Organización Nacional de Trasplantes ONT, Ministry of Health, Social Services and Equality						A	
Spanish Cancer Screening Network							



Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
	Prestacions d'Assistència Medica				A		
	Servei d'Avaluació i Epidemiologia Clínica						
	Servicio Navarro de Salud – Osasunbidea						
	Sociedad Española de Calidad Asistencial						
	Universitat Autònoma de Barcelona			A			
	Universidad Miguel Hernandez de Elche						
<b>Sweden</b>	Dental and Pharmaceutical Benefits Agency TLV					C	
	Karolinska Institute						
	Karolinska University Hospital, Stockholm Cancer Screening Programme						
	Kolding Hospital and University of Southern Odense	C					
	Medical Products Agency						
	Ministry of Health and Social Affairs						
	National Board of Health and Welfare, Stockholm		C				
	National Institute of Public Health						
	Region Västra Götaland						
	Swedish Council on Health Technology Assessment, Stockholm					A	
	Swedish Institute for Infectious Disease Control (Bacteriology, Virology)						
<b>United Kingdom</b>	Care Quality Commission						
	Department of Health, London		C				
	EUCERD Joint Action – Working for rare diseases (EJA)						
	Europacolon						
	European Medicines Agency						
	European Nutrition for Health Alliance						
	Glaxo SmithKline						
	Health Foundation						
	Healthcare Improvement Scotland						
	Health Protection Agency (Bacteriology, Virology)			C			
	Lynn's Bowel Cancer Campaign						
	National Heart Forum, Health Action Partnership International						
	National Institute for Health and Clinical Excellence					A	
NCRI Informatics Initiative							



Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
	NHS Commissioning Board						
	NHS Institute for Innovation and Improvement						
	NHS Blood and Transplant						
	NHS Sefton						
	NIHR Evaluation, Trials and Studies Coordinating Centre, University of Southampton					A	
	North-West Region of England						
	Office for National Statistics						
	Public Health Wales						
	Queen Mary University of London						
	Scottish Executive						
	Southampton University Hospitals Trust						
	Swansea University						
	The Chancellors, Masters & Scholars of the University of Oxford						
	University of Brighton		C				
	University College London				A		
	University of Glasgow						
	University of Leicester						
	University of Manchester	A					
	University of Newcastle upon Tyne						
	University of Stirling						
	University of Ulster						
	Welsh Government						
<b>EEA</b>							
<b>Iceland</b> (also an EU candidate country)	Directorate of Health						
	Ministry of Welfare						
<b>Norway</b>	Det Norske Veritas AS						
	Ministry of Health and Care Services						
	Norwegian Directorate of Health						
	Norwegian Institute of Public Health				A		
	Norwegian Knowledge Centre for the Health Services, Oslo					A	
	Norwegian Safety Forum						
	Norwegian University of Science and Technology						



Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	
<b>EFTA</b>							
<b>Switzerland</b>	European Academy of Allergy & Clinical Immunology						
	European Broadcasting Union						
	European Society for Medical Oncology						
	Federal Office for Civil Protection (Bacteriology, Virology)						
	Inselspital, Berne University Hospital						
	Institute of Medical Genetics CMU						
	Service de Génétique, Lausanne						
	Swiss Network for HTA					C	
	Swiss Federal Office for Public Health						
<b>EU Acceding country</b>							
<b>Croatia</b>	Agency for Quality and Accreditation in Health Care and Social Welfare					C	
	Children's Hospital Zagreb/Medical School of the University of Zagreb						
	Croatian Institute of Public Health						
	Ministry of Health and Social Welfare						
	University of Zagreb						
<b>EU candidate countries</b>							
<b>FYROM</b>	Institute for Health Protection						
<b>Serbia</b>	Ministry of Health					C	
<b>Turkey</b>	Turkish Evidence-based Medicine Association					C	
	University of Akdeniz						
	University of Istanbul						
<b>Potential EU candidate country</b>							
<b>Bosnia Herzegovina</b>	Federal Ministry of Health						
	Ministry of Civil Affairs, Department of Health						
	Ministry of Health and Social Welfare, Serbian Republic						





Country / Region	Joint Action → Organisation	2008		2009			MODE
		RDTF	ECHIM	NANO-GENETOX	EHES	EUnetHTA	

<b>European Neighbourhood Countries</b>							
<b>Armenia</b>	Centre of Medical Genetics and Primary Health of Armenia						
	Yerevan State Medical University						
<b>Belarus</b>	Belarus Research and Clinical Centre for Mother and Child						
<b>Georgia</b>	Georgian Foundation for Genetic and Rare Diseases						
<b>Israel</b>	Tel Aviv University						
<b>Morocco</b>	Institut National d'Hygiène du Maroc						
<b>Ukraine</b>	OMNI-NET Centre						
<b>Third countries</b>							
<b>Japan</b>	Collaborative Research Group on Health Expectancy, funded by the Ministry of Health, Welfare and Labour						
<b>Russian Federation</b>	National Association of Organizations of Patients with Rare Diseases						
	National Centre for HTA						
	Research Centre for Clinical and Economic Expertise and Pharmacoeconomics					C	
	Research Institute of Pediatrics and Child Surgery, Moscow						
	Russian National Research Medical University						
<b>USA</b>	American Cancer Society						
	Centers for Disease Control and Prevention						
	Center for Medical Technology Policy					C	
	Continua Health Alliance						
	HL7 International Foundation						
	Vital Options International						
<b>International organisations</b>							
Association Internationale de la Mutualité							
International Agency for Research on Cancer, European Cancer Network							
International Psycho-Oncology Society							
International Society for Quality in Healthcare							
Organisation for Economic Cooperation and Development			C				
Union for International Cancer Control							
World Cancer Research Fund International							
World Health Organization		C	C				

2010									2011				
QUANDHIP	ALCOVE	EPAAC	Equity Action	EUROCAT	JAMIE	Orphanet Europe	EHLEIS	EHGov	PaSQ	ACCORD	EJA	EUNetHTAZ	PARENT
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