



**EuSANH-ISA**

**Improving Science Advice for Health in Europe, EuSANH**

**Report Kick-off meeting – executive summary**

**Work Package 4, deliverable 4.2**

**WP Leader: SHC, Superior Health Council Belgium  
June 2009**



**Background information on EuSANH and the project EuSANH-ISA****EuSANH**

EuSANH is a network of science advisory bodies in Europe, which are active in the field of health. Currently (April 2009) national science advisory bodies from twelve European countries are participating in EuSANH. Advisory bodies from more European countries are expected to join in the near future.

*Mission, goal and method*

The objective of EuSANH is to promote independent scientific advice on health issues to national and European health authorities and to support evidence-based health policy. Reports published to fulfil this objective may also be of interest to health professionals and the general public.

To achieve this goal EuSANH will focus on European exchange of information (national reports), mutual consultation of national experts, coordination of work programs and the joint work on the preparation of European science advisory reports on health.

**EuSANH project: Improving Science Advice for Health in Europe, EuSANH**

EuSANH received European funding in the 7th framework programme of DG Research for a 3-year project (1 February 2009-1 February 2012) entitled: Improving Science Advice for Health in Europe, EuSANH, abbreviated EUSANH-ISA.

*The general objective of this project is to improve the quality, effectiveness and efficiency of science advice for health across Europe*

Science advice is any recommendation for policy action based on scientific knowledge, considering also expert judgment, ethical and societal values, and experience from relevant stakeholders. Many EU Member States have national science advisory bodies. However, many health issues have transnational dimensions. Moreover, the rapid increase of scientific knowledge and health issues to be addressed, exceed what can be dealt with by national bodies separately. Accordingly, international collaboration between national bodies will lead to more effective and efficient science advice, in support of decision-making at national and EU level.

*The general objective has been translated into the following specific objectives and work packages*

- Describe the functions and structure of existing national science advisory bodies for health in the participating European countries and carry out a thematic analysis of reports from each country  
*Work package 2, WP Leader NIPH-NIH; task leader SNSPMS*
- Establish a common 'best practice' methodology for science advice  
*Work package 3, WP Leader ISCIII*
- Develop a plan for communication and cooperation in the expanding network of science advisory bodies, taking advantage of the Sinapse electronic communication system.  
*Work package 4, WP Leader SHC*
- Illustrate the common methodology and the functioning of the network by developing a pilot case study for a European science advisory report *Work package 5, WP Leader SBU*
- Disseminate the results of the project during and at the end of the project  
*Work package 6, WP Leader GR, task leader SNSPMS*

*Advantages of the project go beyond 3 year period*

A common methodology with improved transnational cooperation promotes open governance, as more evidence-based policy making in Europe will be more transparent to the public. The recently established European Science Advisory Network for Health coordinates activities among science advisory bodies within the EU, and is eminently suited to provide the infrastructure for these tasks. The consortium consists of six contractual partners supported by an External Advisory Committee. As improvement of science advice is a long-term goal, this coordinating action project will also aim at strengthening the network beyond the time frame of the project.

*Management structure*

The project management and coordination is the key to the success of the Coordination Action project. The Coordinator has overall responsibility for project management, the coordination actions and the dissemination of information. He is also responsible for all communication with the Commission.

The consortium consists of the following six beneficiaries all scientific advisory bodies and members of EUSANH

- Health Council of the Netherlands (GR), Coordinator
- Institute of Health Carlos III, Spain (ISCIII)
- The Superior Health Council, Belgium (SHC)
- Swedish Council on Technology Assessment in Health Care, Sweden (SBU)
- National Institute of Public Health - National Institute of Hygiene, Poland (NIPH-NIH)
- National School of Public Health and Health Services Management, Romania (SNSPMS)

The Steering Committee consists of one senior representative from each of the beneficiaries in the consortium, and is chaired by the Coordinator. It is responsible for all technical, strategic and management decisions in relation to the EuSANH-ISA Coordinating Action project and for reviewing the work programme and approving any changes. It is also responsible for reviewing the project progress and the technical quality and timely delivery of all project results.

Furthermore, an External Advisory Committee is invited to comment on the work programme and progress, and advise the Steering Committee. This committee will enable EuSANH-ISA to optimise its added value in science advice for health at the European level.

This committee consists of scientific advisory bodies from European countries (all EuSANH members) and international (mostly European) organisations in the field of health: Czech Republic, National Institute of Public Health; Finland, National Public Health Institute; France, Haute Autorité de Santé; Germany, Institute for Quality and Efficiency in Health Care/German Institute of Medical Documentation and Information; Portugal (Ministry of Health, advisory body in establishment); Switzerland, Swiss Federal Office of Public Health (potential member); the European Centre for Disease Prevention and Control (ECDC); the Health Evidence Network (WHO Europe, HEN); the European Food Safety Authority (EFSA); the Federation of European Academies of Medicine (FEAM); the European Observatory on Health Systems and Policies; and the European Academies' Science Advisory Council (EASAC); the European Network for Health technology Assessment (EUnetHTA); the Institute of Medicine (IOM, USA) and the London School of Hygiene and Tropical Medicine (LSHTM).

## Executive Summary

The general objectives of this kick-off meeting are to establish effective work plans, get to know each other and commit to the project.

To reach the general objective of the project, improve quality, effectiveness and efficiency of science advice for health across Europe, four questions need to be answered: where are we, where do we want to go, how can we achieve this and finally: does it work? In a nutshell, EuSANH-ISA will describe the current practices of science advice in the 12 member countries, in relation to how advisory processes are organized, best practices with an ideal methodology will be developed and tested in a pilot case study, communication and co-operation structures will be put in place, results will be disseminated both internally and externally and the network will be expanded in order to represent all European countries.

One of the key issues to success of this project will be cooperation between the different beneficiaries, as all work-packages are interacting and different countries are involved in each work-package. One of the important means to improve interaction between participants will be SINAPSE, a standardized and well-supported e-communication tool provided by DG Research.

### **WP1: Project management**

For the duration of the project, the next three years, the GR of the Netherlands will be responsible for the general management of the project. They expect the beneficiaries to commit to the general management plan, to follow the procedures described in the project management handbook (including GA and CA), to timely submit financial and technical reporting and to actively participate during annual meetings and conference calls. All necessary information can be found in the handbook.

### **WP2: Task 2.1 Policy analysis & Task 2.2 Thematic analysis**

To avoid unnecessary work being done in WP 2, the criteria for selection should be the same in WP 2 as those used in WP 3 to define the methodological framework. The same instruments and the same criteria should be used to analyze the different countries to allow comparison afterwards. Chosen dimensions could be independency, resources, background experts, legal framework (mandate) etc.

Data on the resources (are they sufficient) and on the legal framework (mandates) of the Science Advisory Bodies (SAB) should be collected and a mapping of the different fields, normally covered by each SAB, is necessary before selecting the fields. Preference is being given to formal advisory bodies rather than informal ones. A lot of descriptions of existing bodies are available in documents of other projects.

Questioning advisory bodies at national level as well as at European level is important. The involved SAB currently do not aim to reach EU level but are specifically aimed at reaching national policy levels. However, this step could have an important added value in regard to the scope of the EuSANH-ISA project, namely to reach EU decision-making level. The SAB should strengthen their usefulness to their own government and aim at transnational collaboration, but also on the EU level, EuSANH will be able to deliver a useful contribution and might in the future be invited to collaborate on projects with a direct output on big EU projects.

The questionnaire will be based on the model in the project handbook (Annex 1 Description of work, part B, Figure 2: The relation of science with decision and policy makers, p 11), referring to particular aspects of the organizations. A thematic analysis of the topics per country will be useful: a question will be added to the questionnaire in regard to the topics covered by the advisory body. The TSAS report<sup>1</sup> with questionnaire would be a good

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<sup>1</sup> TSAS report - Typifying Scientific Advisory Structures and Scientific Advice Production Methodologies (TSAS), Steven Glynn, Paul Cunningham Kieron Flanagan (PREST University of Manchesters) Final Report, December 2003

example to start with. A test of the drawn up questionnaire could be sent to 10 respondents in different countries, in order to see if it is clear and how long it takes to fill out. A glossary should be established for the questionnaire. The form in which the questionnaire is sent should be carefully considered: EUnetHTA encountered problems with electronic documents. Known formats such as paper forms or documents attached to email seem to be preferable, when the format of the form is unknown, response rates drop drastically. Maybe a link to an online query on SINAPSE should be paralleled with a word document attached to the email. There is lack of studies assessing the framework that influences the uptake of an advice by policy. To assess uptake, it would be useful to investigate also what happened with the selected reports (task 2.3), to allow determining elements for success of uptake by politics interviewing politicians at national/regional level is proposed.

### **WP3: Methodological framework**

The members of the advisory committee pointed out some overlaps with results of other projects and current gaps of knowledge in science advice. There are several international activities already going on in relation to science advice, mostly having a more specific scope. An important existing network is EUnetHTA, the European network for Health Technology Assessment (HTA). Compared to HTA, the scope of science advice is more general as, rather than specific health technologies and interventions, broad public health issues with multifactorial and multisectoral dimensions are usually addressed, also including comprehensive analyses of ethical and societal implications. This may also encompass the analysis of complex etiological problems and population health determinants of high societal and policy relevance. Thus existing ideal models for HTA reports do not apply to science advice, but could form a starting point. Furthermore, what was lacking in these projects was a model for the process of advisory making and the best practice on how to establish an advisory body and resources. Even though an ideal model exists for an HTA, from previous projects, this model doesn't seem to be applied or even known to the advisory bodies. Until now, nobody studied the best practice of the approach of advising at EU level. INAHTA established a list of 20 criteria in regard to the quality of an HTA report, which might prove to be useful here too.

The whole of the questionnaires, from all the different WP's, should be carefully coordinated and use of resources could be optimized between WP's 2 & 3. Coherence between the two WP's is of utmost importance and specific communication between these WP's via meetings or extra conference calls is needed to improve overall outcome. There is a problem with the time-schedule: WP3 has to start when WP2 is still ongoing: the schedule of implementation and the points of connection will be examined to see if timing can be improved. The WP2 and WP3 leaders agree to convene at a later moment to discuss the coordination between their WP's.

### **WP4: Network development**

The future management structure should provide EuSANH with a strong connection between members and members should be able to see proof of the impact of the network on their activities.

The positioning of EuSANH to other EU networks: what will be its importance and how will it distinguish itself from others. We should emphasize that we are permanent, statutory, independent science advisory bodies. Also in this context, the choice of the topic for the test case could be important: finding a topic that hasn't been explored by others could provide EuSANH with a niche.

As to the subtask to expand the network, this will be based on a list of possible contacts drawn up a few years ago by the Netherlands. Setting criteria for selection, such as statutory basis of the organisation as well as independence and an integrated approach, will be important. Focus for expansion should lie on formal science advisory networks, but an open mind should be kept open for informal ones. The inventory could lead to identifying countries where science advisory bodies are not well defined and where EuSANH could lay

foundations for development of such structures. As governments are not always aware in what fields they need science advice, it would be useful to establish a list of domains covered by science advice in each country. Help could also be asked from the EC itself, this would enable us also to include them in the discussion on the necessity of science based advice in health policy.

Furthermore, the representativeness of the network should be augmented, and expansion of the network is needed to cover all European countries (33 incl. EEA and CC). However, this would mean the involvement of 33 partners, which is a lot. Furthermore, the possibility exists that within one country, more than one organization could join, which will further increase the number of participants. We will have to consider how to manage this. A top down structure is proposed, with a national contact point for each country, who manages distribution within the country.

Similar networks within the EU will have to be identified and contacted to avoid overlap. The priority is internal communication: the kick-off report will be available soon and a newsletter will appear in May.

All involved are asked to make a direct link on their webpage to the EuSANH webpage.

### **WP5: Case Study**

The choice of the best topic for the pilot case study, which should be of European and national relevance, is of the utmost importance. Several issues should be taken into consideration: there must be a policy and societal need, the technical quality must be a *conditio sine qua non*, the approach should be comprehensive, interdisciplinary and multicultural, transparency towards stakeholders is needed, evidence gaps should be identified, the necessary input must be mobilized in a timely way, overlap and complementarities with other EU advisory structures should be avoided and both national and EU perspectives should be considered.

It will also be important to choose a topic for the test case that interested parties are concerned about. Therefore, it might be useful to include an extra step before deciding and explore the interest of the policy arena.

Screening would be a good topic for several reasons: it is a popular topic, it meets the criteria of a niche market (vaccination ~ECDC) and it is a very important topic in itself. It is a fast developing area with growing production of scientific evidence. Screening could be regarded in general (are the WHO criteria still valid?) or be focused on specific topics (e.g. genetic screening). *Kevin McCarthy*, head of the sector public research, DG Research, has some important remarks in regard to the choice of the topic. As to the topic screening: this topic appeared on a shortlist of topics 18 months ago (policy brief on screening, WHO Observatory, but was put into cold storage due to lack of interest. However, DG research pointed out 'screening for rare diseases in neonates' could be a relevant topic.

Vaccination was a topic in the 2nd call; ECDC was interested in a comprehensive approach of vaccination policies over Europe. Unfortunately, there was also poor response; this topic did not seem to be on people's agendas.

Another interesting topic emerged: the relation between the movement towards open governance and science advice. It would be important to define what makes science advice scientific and how non-scientific partners can be involved in scientific advice. This would be an interesting concept to explore.

After the case study, there should also be a report on what we learned from doing this case study.

One should keep in mind, that even topics proposed for the test case which are not chosen, can be integrated in specific projects on national level, in annual programs of the advisory bodies or in small cooperation projects between a few members.

A close cooperation between WP 3 and WP 5 will be necessary. The choice of the topic will be decided during the next steering committee.

The border between informing and advising in the context of policy is a very sensitive area. EuSANH should respect policy makers and offer a scientific point of view but could also take one step further and promote what science advisors think is the best solution.

**WP6: Dissemination**

The EuSANH visibility must be combined on European and national level: sometimes a common approach should be used, sometimes countries can also disseminate on a national level. It is important to define messengers in each of the participating countries. The coordinator must be informed of each dissemination action. For communication within each country a standard set of documents will be available: a standard EuSANH presentation, an information package (WP4) for ministries of health and information for the media.

**Importance of EuSANH-ISA for European Health Policy**

EuSANH should keep in mind that to have an impact, especially at European level, all member states should be represented: one of the important tasks of the EC is to treat all member states equally. Furthermore, EuSANH should consider the EU legal framework (implication of EU lawyers) and EU policy framework in order to decide on priorities for topics, taking into account outcomes of overlapping EU activities (e.g. FP6). Knowledge of and reference to European Community Health Indicators (ECHI) by EuSANH, will improve usability of its science advisory reports in health policy.

If EuSANH wants to have an impact on the research agenda, timely communication on the subjects EuSANH is working on is of the utmost importance. Also, all kinds of instruments for funding are available, such as support actions for organizing conferences on topics of interest.

**Learning from the experience of the IOM**

The European Union and the US are quite different on historical and political levels. Therefore, different tensions play a role in the US compared to the EU. The IOM was established in 1970 under the charter of the National Academy of Sciences (1863). The charter is a public one, but with a private structure of the organization. The Institute of Medicine provides independent, objective, evidence-based advice to policymakers, health professionals, the private sector, and the public. There are no other contenders, like universities or other organizations, in the IOM's field of expertise. Three important dualities define the specific nature of the IOM: a public charter combined with a private structure, an honorific membership with purposefulness and independence combined with connectedness. In the end, what we, the IOM and EuSANH, do, matters because they aim to better and alter people's lives. Therefore they should try to deliver reports of technical excellence, because if these are adopted by policy, they should deliver the best possible answers. This should never go at the cost of enhancing their chance of adoption.

The EuSANH-ISA project has a very inclusive and comprehensive approach. Synchronization of the work will be one of the great challenges. After the dissemination, an important step of evaluating the use and impact of EuSANH will have to be performed in order to measure the success of the project. As for the IOM, balancing independence and connectedness will prove to be an interesting challenge for EuSANH. Although outreach and collaboration will be important, one should also guard that the independence necessary to develop the advice is not contaminated. The dual approach where advices are aimed at national as well as European levels is a challenging one.

It would be ideal if EuSANH produces its distinctive signature of its efforts. This can be done by use of internet communication tools, a distinctive character of the product, etc. In this way EuSANH will prove to be an example for the rest of the world.

The essence is bringing science to bear on policy.

All presentations of the Kick-Off meeting can be found at <http://europa.eu/sinapse/directaccess/EUSANH/Public-Library/>, annual meetings, 2009.