

**Scientific Assistance Office of the NCA and NWPL,
WP on Morbidity and Mortality,
Task Force on Major and Chronic Diseases and
WP on Health Systems**



I n t e r i m R e p o r t

December 2005 – November 2006

Grant Agreement N° 2005103

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EXECUTIVE SUMMARY

I TECHNICAL INFORMATION

1. <u>AREA OF ACTIVITIES / WORKING PARTY:</u> Community Action in the field of Public Health (2003-2008)- Strand I: Health Information. Action 1.1: Developing and coordinating the health information and knowledge system.	
2. <u>TITLE OF PROJECT:</u> Scientific Assistance Office of the NCA, and NWPL, WP on Morbidity and Mortality, Task Force on Major and Chronic Diseases and WP on Health Systems.	
3. <u>START DATE OF THE PROJECT:</u> 01 December 2005	
4. <u>DURATION OF THE PROJECT:</u> 24 months	
5. <u>PROJECT LEADER / ORGANISATION :</u> Projectleader: W. Devillé (w.deville@nivel.nl) NIVEL- Netherlands Institute for Health Services Research PO Box 1568, 3500 BN Utrecht, The Netherlands www.nivel.eu	
6. <u>GRANT AGREEMENT NUMBER:</u> 2005103	
7. <u>SANCO REPRESENTATIVE:</u> Horst Kloppenburg (until 11/2006); Karl Freese (from 11/2006)	
8. <u>COUNTRIES INVOLVED</u>	
<input checked="" type="checkbox"/> B (Belgium)	<input type="checkbox"/> All MS, candidate countries, EFTA/EEA countries are involved at supported Networks
<input checked="" type="checkbox"/> CZ (the Czech Republic)	
<input checked="" type="checkbox"/> F (France)	
<input checked="" type="checkbox"/> LT (Lithuania)	
<input checked="" type="checkbox"/> NL (Netherlands)	
9. REPORT STATUS (INTERIM OR FINAL) / Date: Interim Report / January 2007	

II CONTENT RELATED INFORMATION

10. CONTEXT/INTRODUCTION:

Activities carried out under this project aim at supporting the Network of Competent Authorities (NCA), the Network of Working Party Leaders (NWPL), the Health Systems Working Party (HSWP), the Working Party on Morbidity and Mortality (WPMM), and the Task Force on Major and Chronic Diseases (TFMCD) in their work contributing to the operation of a Health Information and Knowledge System for the European Community. For this purpose NIVEL provides a Scientific Assistance Office (SAO). The NCA is the interface between scientific expertise and health policy. The NWPL represents the scientific expertise in specific fields of public health and is therefore essential for advice on the European Health Information and Knowledge Systems. The HSWP represents projects on the structure, organisation and functioning of health systems. The MMWP represents projects on morbidity and mortality, divided into a Task Force with all projects on major and chronic diseases (TFMCD) and a Task Force representing projects on rare diseases (TFRD).

Before SAO started, the largest WPs, namely WPMM/TFMCD and HSWP, only received administrative support from the Commission and lacked scientific assistance for and in between the meetings, lacked monitoring and coordinative support as well as means for internal communication in between the meetings. Without scientific assistance it will be difficult for these WPs/TF to make further progress in their field that surmounts the work of the individual projects. SAO fills these gaps for the HSWP, MMWP and TFMCD, and continued and expanded the work of its previous SNAW project in supporting the NWPL and NCA. Through its activities this project will contribute to strengthen the cooperation between scientific experts, public health experts, and health policy at European level.

11. AIM AND OBJECTIVES OF THE PROJECT:

The general objective is to create and operate a Scientific Assistance Office (SAO) for the NCA, NWPL, WPMM, including the TFMCD, and for the HSWP within the Health Information Strand of the European Public Health Action Programme (PHP).

SAO will assist scientifically and technically the above mentioned Networks, Working Parties and Task Force in their tasks to provide a forum for discussion and exchange of views and experiences on health information and knowledge in all seven fields (morbidity and mortality, accidents and injuries, mental health, lifestyle, health and environment, health systems, and European Community health indicators). More specifically it will support the fields of Morbidity and Mortality, Major and Chronic Diseases and Health Systems at sub-national, national and European Union level. The SAO will assist the DG Sanco and the Networks in their aim to develop and implement a sustainable European Health Information and Knowledge System. The SAO will assist the Working Parties and Task Force in contributing to the improvement of information and knowledge and in the contribution of health systems to public health. It will help these Working Parties and Task Force in assisting the Commission in the development and co-ordination of the Health Information System by executing its specific tasks as Scientific Assistance Office.

12. KEYWORDS:

Public Health, Health Systems, Morbidity, Mortality, Information Dissemination

13. PERFORMANCE PROCESS (ACTIVITIES / DESIGN / INSTRUMENTS) (limit 500 words):

A. Facilitating exchange of information: - by assisting the biannual meetings of the NCA, NWPL, WPMM, HSWP and TFMCD; - by monitoring the developments in the assisted WPs/TF and the impact of this PHP in the various countries; - by sharing the progress in the WPs and TF with the other Working Parties and reporting it to the NCA; - by organising the communication within and between the

supported Networks/WPs/TF and the SAO and the dissemination of progress and results through a Web accessible and interactive communication; - by reporting and disseminating the progress obtained in each WP and TF through a workshop or pre-conference, when needed. SAO will contribute to the content in collaboration with the Commission, NCA and MS.

- B. Synthesizing knowledge and information: by synthesizing the progress of the work in the various projects of each assisted Working Party and Task Force through reviews of their reports; - by studying specific problems or topics not currently covered by funded projects that need a review. Results will be presented to the NCA, NWPL, WPs and/or TF through background documents; - by assisting the WP Leaders and Deputies (e.g. keeping them abreast of particular issues arising out of projects, areas of overlap with other WPs, etc., preparation of WP summary reports).
- C. Providing public health intelligence: - by assisting the NCA, NWPL, WPMM, HSWP and TFMCD to further develop the ECHI indicator system; - by supporting the development of a work programme for each assisted Working Party and Task Force; - by the biannual meetings of NWPL/NCA contributing to the implementation of ECHI, providing feedback on the progress of the EU Knowledge and Health Information System at national level in the MS, and contributing to the development of the annual work plan of the Public Health Programme; - by assisting the WPMM/TFMCD in the contribution to the development of modules for Health Information and Health Examination surveys in the EU and the Member States; - by assisting the WPs/TF to produce lists of newly defined or amended EU health indicators in their respective fields of interest; - by supporting current and new projects in the WPs/TF by providing information on up to date developments in their field of interest through a newsletter, email updates, and the SAO websites.

14. OUTCOMES OF THE PROJECT / KEY HEALTH MESSAGES / ADDED VALUE FOR REACHING GOAL OF EU PUBLIC HEALTH PROGRAMME (limit 250 words);

- organisation of the biannual meetings of the NCA, NWPL, HSWP, MMWP and TFMCD. The organisation includes the preparation of meetings (agenda setting, invitations, content related documents, minutes and proceedings) in cooperation with the Commission Services;
- preparation of progress reports of the WPs and TFs, and the implementation of the Health Information activities in the MS, for the NCA/NWPL meetings;
- development of 3 password-protected web-infrastructures to facilitate internal communication for the NCA/NWPL, MMWP/TFMCD and HSWP
- development of work programmes for the HSWP and MMWP/TFMCD
- collation of inputs for the annual work plan of the PHP
- project database of the Health Information Strand (2000-2005)
- performing background document where needed
- monitoring and reporting the indicator related output of the WPs/TF to ECHIM
- ad hoc work group on Data Protection and Confidentiality
- supporting meetings of the EHSS experts/Steering Committee
- supporting editorial Board of the Report on the State of Major and Chronic Diseases in Europe in 2006

15. CONCLUSIONS:

SAO has been supporting the Networks continuously for three years now (started as predecessor project SNAW). As such, the Secretariat has established a solid position by

now. More and more it has gotten to grips with the policy developments within the European health field, and the needs of both the EC and the CAs and WPLs. This is reflected in the improving agendas for the NCA/NWPL meetings. Moreover, the fact that the Secretariat has been present for quite some time now, is a safeguard for the continuity of several important processes, such as the health policy reporting at MS level and the progress reporting of the Working Parties and Task Forces. With regard to the tasks the Secretariat performs for the NCA, it is also clear that without the (extensive) support of a Secretariat, it would be very hard to adequately respond to emerging needs, such as the data protection issue or the internal evaluation of the Strand.

The large working Parties and Task Forces are very different structures than the Networks the Secretariat had experience with. However, also for these structures by now it is hard to imagine them functioning without the Secretariat. During the past year, the Secretariat has been the safeguard for the continuity of processes, despite of changes of staff at SANCO or within the WPs and TF. The Secretariat has come to grips with the activities and aims of all the projects within the supported structures, and as such has become an indispensable source of information for the EC and ECHIM. Additionally, SAO has developed/will develop and manage several important communication tools, such as the Newsletters for the supported Working Parties, the internal and the public websites.

16. PLAN OF DISSEMINATION OF RESULTS:

- every important output that SAO has produced is presented either orally at the appropriate meeting, through e-mail to the WP/TF members/Networks and the Commission, or through the SANCO website or one of the SAO websites.
- three password protected websites for the NCA/NWPL, HSWP and the WPMM/TFMCD.
- progress reports of the HSWP and WPMM/TFMCD are presented at every meeting of the NCA/NWPL.
- SAO has started the development of WPMM and HSWP newsletters that will be disseminated among all members and experts attending the meeting, and published on the SANCO and SAO websites
- all presentations held at the meetings are published on the SAO and SANCO websites, and briefly described in the minutes of the meetings, to make them publicly available.
- SAO is preparing a workshop for the WPMM/TFMCD and HSWP which will contribute to disseminating the progress of the WPs and TF.
- The overall progress and results of the assistance given by SAO till November 2006, have resulted in this interim report as means of dissemination to the Commission and will be published on the SANCO website, accessible to the general public.

17. NEEDS FOR FUTURE POLICY DEVELOPMENT:

A discontinuation of SAO's activities after December 1st 2007 would harm the effectiveness and efficiency of the Health Information Strand structured as it is. One way or another, the role of the secretariat has to be continued, either by calling for a new Scientific Assistance Office project, or by transferring its task to another actor, such as the PHEA. The SAO research team urge the EC to give this issue considerable and timely thought.

1 Introduction

The Public Health Action Programme 2003-2008 of the European Commission consists of three Strands. Strand I concerns Health Information, which is the subject area for this project.

The Health Monitoring Programme, and especially the project 'European Community Health Indicators' under the previous Public Health Action Programme 1998-2002 of the European Commission have resulted in a long list of European Health Indicators. This list includes recommendations about definitions, operationalisations and preferred data sources. Actually, these European Health Indicators are being transformed and implemented into a European Health Information and Knowledge System. The first step towards an operational and manageable system is to prioritise indicators leading to a shortlist. Prioritisation is based on relevance for public health (large disease burden) and for public health policy (susceptibility to policy measures) and must provide added value compared to existing information on health (e.g. OECD, WHO, Eurostat). The composition of a short-list of health indicators has already been prepared within the framework of the European Community Health Indicator project (ECHI-II). After agreement on this shortlist of health indicators, the activities and projects of Strand I of the Public Health Action Programme 2003-2008 can focus on this shortlist thus contributing to the implementation of a European Health Information and Knowledge System.

To assist the Commission in the development and co-ordination of the Health Information System, two networks have been established: the *Network of Working Party Leaders (NWPL)* and the *Network of Competent Authorities (NCA)*. The Networks act according to the terms of Decision No 1786/2002/EC of the European Parliament and of the Council of 23 September 2002, adopting a program of Community action in the field of public health (2003-2008).

The NWPL represents the scientific expertise in specific fields of public health and is therefore essential for advice on the European Health Information and Knowledge System. After agreement on the shortlist of health indicators, the different working parties will gradually change their focus towards implementation of information systems providing the necessary data. The ECHI-II project played a key role by providing the conceptual framework for the health indicators. This task is taken over by the ECHIM project within the new cross-cutting Working Party on Health Indicators. The NWPL brings the (deputy) leaders of all Working Parties together, who coordinate research projects within the priority area Health Information of the Public Health Programme of the European Community. The NWPL advises the Commission on the content and scientific issues related to the development and implementation of European Community Health Indicators (ECHI).

The NCA is the interface between scientific expertise and health policy. The NCA advises the Commission about policy and technical matters related to the priority area Health Information of the Public Health Action Programme of the European Community. The activities of this network will lead to a European Health Information and Knowledge System, which is not only scientifically sound but also relevant for health policy. The network seeks agreement on the shortlist of health indicators - to be approved by the Programme Committee and to be included in the European Health Information and Knowledge System -, on the time planning of inclusion in this system, and on the availability of information from and for Member States. The network therefore needs input from the Network of Working Party Leaders but also needs to build on expertise on health policy and the role of information necessary to develop health policy. Members of the NCA are representatives of all Member states (MS), candidate countries and EEA/EFTA countries. International organisations (e.g. WHO, OECD) or other EU Programmes or EU DGs (e.g. Eurostat, BIOMED, EMMCCD, DG Social Protection) are invited by DG SANCO to attend the NCA meetings.

The above mentioned structures of the Information and Knowledge System and its different levels have to be closely inter-linked, so that the policies will be implemented efficiently and synergies will

be taken account of. The work plan of the Public Health Action Programme of the European Commission for 2003 referred already to the need for a supporting Secretariat. This Secretariat had to provide the infrastructural arrangements and create the conditions for an optimally functioning Network of Competent Authorities. It also provides the necessary infrastructure and creates optimal conditions to use the network for the European Health Information and Knowledge System. It should support the Commission Services in order to coordinate the cooperation of the Programme Committee together with the Network of Competent Authorities and the Network of Working Party Leaders, in order to organise and monitor their actions and annual meetings and to link these actions to the work of the project coordinators.

Seven Working Parties are created to ensure coherence and to co-ordinate projects under the Public Health Programme 2003-2008 and former projects from the previous public health programmes. Their fields are Morbidity and Mortality, Accidents and Injuries, Mental Health (up to spring 2006), Lifestyle, Health and Environment, Health Systems and Health Indicators.

The specific fields of the Working Parties and Task Force supported by this Scientific Assistance Office (SAO), run by NIVEL, are: non-communicable diseases, rare diseases, causes of death, health surveys and health systems. Members of the Working Parties are project leaders of the projects in these fields, who have chosen among them a Working Party Leader and a Deputy Leader. In order to ensure a wide geographical representation as well as other necessary expertise, DG SANCO can invite to the Working Party meetings relevant competent national experts in morbidity and mortality as nominated by the Network of Competent Authorities among national institutions, as well as other experts from other international organisations (e.g. WHO, OECD) or other EU Programmes or EU DG's (e.g. Eurostat, BIOMED, EMCDDA). The Working Parties and Task Forces are meeting twice a year, and the Working Party Leaders also attend the NWPL meetings biannually. The Working Party on Morbidity and Mortality (WPMM) is an umbrella WP where the large amount of projects are gathering in originally two Task Forces and nowadays in three: the Task Force on Major and Chronic Diseases (TFMCD), the task Force on Rare Diseases and recently the Task Force on Health Expectancy. The Task force on Rare Diseases has its own Secretariat. SAO supports the WPMM and the TFMCD. The last coordinates more about 26 running and selected . SAO supports also the Working Party on Health Systems (WPHS), covering 23 running and selected projects.

Up to August 2005 the Networks were assisted by a Scientific Secretariat also run by NIVEL (Netherlands Institute for Health Services Research), in close cooperation with the Commission by preparing the content of their meetings, writing scientific reviews and documents, presenting progress reports about public health policies in the MS and about the work of the WPs/TF's. The WPs and TF have very limited scientific, administrative and financial assistance, only to organise their meetings, but not to monitor the working of the projects in their field, to review and report on the outcomes of these projects, to monitor overlap between content and outcomes of the various WPs or projects within WPs, or to develop and comment on new tools to assist the Commission in the development and co-ordination of the EU Health Information System. Participation and leadership of the Working Parties and Task Force is on voluntary base. The only administrative assistance comes from the Commission Services, limited by their own resources, and assistance on the content side comes from the Commission officer assigned to their fields of interest. This Scientific Assistance Office is meant to assist in a professional scientific way the WPs, TF and their WP leaders in their coordinative, monitoring and development work in their specific fields of interest. It will contribute, therefore, to a qualitative superior development of the EU Health Information System.

The Scientific Assistance Office has an Advisory board of four Associated Partner (AP), as one of the five Partners that the project originally had withdrew at the beginning of the project.

Firstly, in Chapter two this interim technical report describes the objectives and tasks of the project overall. In chapter three per Working Package the specific objectives, the planned and achieved products or deliverables of the Scientific Assistance Office for the NCA and NWPL, the Working Party on Morbidity and Mortality, Task Force on Major and Chronic Diseases and Working Party on

Health Systems are described. Each chapter ends with a reflection on the work achieved. Chapter 4 presents the planned activities for the second year and finally some thoughts are presented about the need for continuation of this support to the structure of the Health Information Strand in one way or another.

The project started in December 2005 and the report covers the period up to the end of November 2006. The duration of the whole project is two years up to 30 November 2007.

2 Work plan

2.1 General objectives

The general objective is to create and operate a Scientific Assistance Office (SAO) for the Network of Competent Authorities (NCA), the Network of Working Party Leaders (NWPL), the Working Party on Mortality and Morbidity (WPMM), including the Task Force on Major and Chronic Diseases (TFMCD), and for the Working Party on Health Systems (HSWP) within the Health Information Strand of the European Public Health Action Programme (PHP).

The SAO assists scientifically and technically the above mentioned Networks, Working Parties and Task Force in their tasks to provide a forum for discussion and exchange of views and experiences on health information and knowledge in all seven fields (morbidity and mortality, accidents and injuries, mental health, lifestyle, health and environment, health systems, and European Community health indicators). More specifically it supports the fields of Morbidity and Mortality, Major and Chronic Diseases and Health Systems at sub-national, national and European Union level. The SAO assists the DG Sanco and the Networks in their aim to develop and implement a sustainable European Health Information and Knowledge System. The most prominent step at this moment is the implementation and operationalisation of the first-phase-set of already available EU health indicators from the shortlist of European Community Health Indicators (ECHI) II, in cooperation with other European and international institutions. In addition, the SAO assists DG Sanco scientifically through the NCA and the NWPL by reviewing and summarising information relevant for public health issues on European level and with the cooperation and active involvement of the enlargement countries.

The SAO assists the Working Parties and Task Force to contribute to the improvement of information and knowledge and in the contribution of health systems to public health. It helps these Working Parties and Task Force assisting the Commission in the development and co-ordination of the Health Information System - completing the scientific and technical background work for the establishment of health indicators and other information needs in their field of competence. The Working Parties and Task Force are serving as expert groups to provide advice on information and knowledge for monitoring Community policies and other initiatives in their specific fields.

2.2 Specific objectives

- To assist with the Commission services the NCA in executing their mandate in advising the Commission on the implementation of the health indicators, the harmonisation of the collection of health information and in promoting the public health programme on Health Information in the Member States.
- To assist with the Commission services the NWPL in executing their mandate as coordinating network of the Working Parties, to formalise the list of indicators, to inform the NCA about the availability, validity, comparability and on the operationalisation of the indicators, to create synergies between the various Working Parties.
- To assist the WPMM/HSWP/TFMCD and Commission Services as components of the advisory structures within the Information Strand of the Public Health Programme 2003-2008. In particular, a/ to assemble the experience and knowledge within the WPs/TF (i.e. from national experts and outputs from projects); b/ to contribute to a better integration of the results of the Public Health Programme 2003-2008 into EU public health policy and practice; c/ to contribute to the preparation of the synthesis of the projects' outputs for the meetings of the NWPL and the NCA, in order to prepare decision making by the Member States; d/ to organise and assist the biannual meetings.
- To assist the WPMM and the HSWP in their specific tasks as stipulated in their specific mandates, such as: a/ contribute to the ECHI (short) list through advise on precisely-defined indicators, prioritisation and harmonisation of data-collection; b/ advise on the development of

health information, analysis and reporting systems; c/ contribute to the development of a comparable health measuring instrument for health surveys in the EU; d/contribute to the preparation of the annual work plan of the Public Health Programme.

- To keep the WPs/TF informed about the progress of the projects, their final outcomes and impact on national level, and to help setting priorities in their field of interest especially on subjects not covered by current or former projects, with the aim of producing integrated outcomes and reinforcing common strategic goals, as well as assisting the WPs/TF.
- To monitor the different fields of interest of both WPs and TF by examining possible overlap between the various WPs and related issues in other Commission policies and programmes, bringing it to the attention of the NWPL and NCA.
- To disseminate the results of the biannually meetings, the results of possible reviews and background documents, and the progress made in the different domains of both WPs and TF.

2.3 Tasks

- Facilitating exchange of information:
 - a. by assisting the biannual meetings of the NCA, NWPL, WPMM, HSWP and TFMCD in which all related projects and/or WP leaders and/or experts of the MS/candidate and EEA/EFTA countries are brought together; - by monitoring the developments in the assisted WPs/TF and the impact of this PHP in the various countries; - by sharing the progress in the WPs and TF with the other Working Parties and reporting it to the NCA; - by organising the communication within and between the supported Networks/WPs/TF and the SAO and the dissemination of progress and results through a Web accessible infrastructure for multi-national project management and interactive communication; - by reporting and disseminating the progress obtained in each WP and TF through a workshop or pre-conference, when needed. SAO contributes to the content in collaboration with the Commission, NCA and MS.
- Synthesizing knowledge and information:
 - b. by synthesizing the progress of the work in the various projects of each assisted Working Party and Task Force through reviews of their reports; - by studying specific problems or topics not currently covered by funded projects that need a review. Results are presented to the NCA, NWPL, WPs and/or TF through background documents; - by assisting the WP Leaders and Deputies (e.g. keeping them abreast of particular issues arising out of projects, areas of overlap with other WPs, etc., preparation of WP summary reports).
- Providing public health intelligence:
 - c. by assisting the NCA, NWPL, WPMM, HSWP and TFMCD to further develop the ECHI and to harmonise the specific data-collections; - by supporting the development of an annual work plan for each assisted Working Party and Task Force. It records aims that have to be realised for the development of the health information and knowledge system; - by the biannual meetings of NWPL/NCA contributing to the implementation of the first-phase-set of the ECHI, providing feedback on the progress of the EU Knowledge and Health Information System at national level in the MS, and contributing to the development of the annual work plan of the Public Health Programme; - by assisting the WPMM/TFMCD in the contribution to the development of modules for Health Information and Health Examination surveys in

the EU and the Member States; - by assisting the WPs/TF to produce lists of newly defined or amended EU health indicators in their respective fields of interest; - by supporting current and new projects in the WPs/TF by setting up a database of national data-providers contacted by current and former projects to enable coordination of approaches by various projects to these providers.

3 Project Activities December 2005 – November 2006

3.1 Coordination of the project (Work package 1)

Table 1: Members of the SAO Project Group

Project partners	Representative
NIVEL, Netherlands (main partner)	W. Devillé (project leader)
Haut Comité de santé Publique, France	G. Badeyan
Lithuanian Health Information Centre, Lithuania	A. Gaizauskiene
Scientific Institute of Public Health, Belgium	H. van Oyen
University Center for Healthcare quality, Masaryk University Medical Faculty, Czech Republic	A. Bourek

Objectives:

- To assist the NCA in executing their mandate, in advising the Commission about the implementation of the (short)list of health indicators, the harmonisation of the collection of the health information and in their task to promote the public health programme on Health Information in their respective MS.
- To assist the NWPL in executing their mandate as coordinating network of the various Working Parties, to formalise the list of indicators, to inform the NCA, to create synergies between the various WPs.
- To assist to WP leaders, their deputies and Commission Services with the management and the coordination of the WPMM, HSWP and TFMCD, and the execution of their specific tasks as stipulated in their specific mandates.

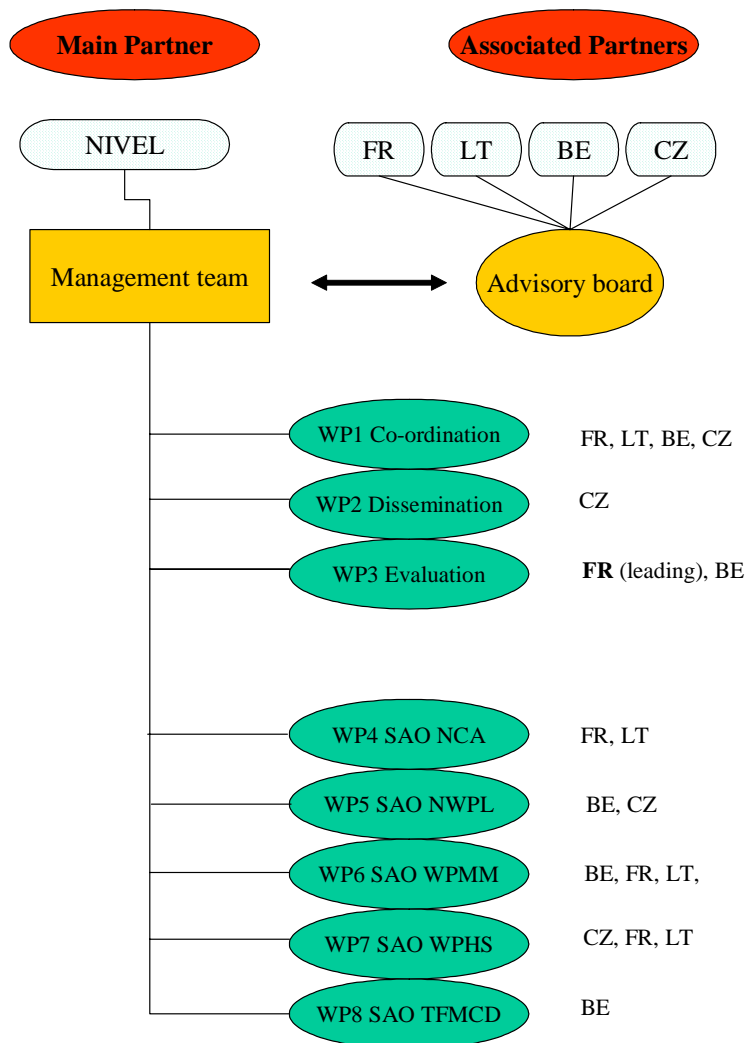
Description of undertaken coordinating activities

- SAO was set up with a senior project coordinator, a senior researcher for the NCA/NWPL and one researcher for the HSWP as well as for the WPMM and TFMCD. The team is assisted by secretarial, financial and ICT staff.
- The staff works as a team, to share actual workload between several staff members, and to be able to replace each other when necessary.
- The staff has at least 2-weekly team meetings in which recently undertaken and planned activities are discussed.
- The scientific team is assisted by the NIVEL scientific library for background documents.
- The scientific team is assisted by the NIVEL Knowledge Centre for developing and maintaining the websites for the HSWP, WPMM/TFMCD; the webboard for the NCA/NWPL; and its email facilities. Furthermore, the Knowledge Centre advised on the development on the WPMM Newsletter.
- SAO uses three different mailboxes to streamline its external communication: Nca.nwplsec@nivel.nl; Hswp.sao@nivel.nl; WPMM.sao@nivel.nl
- SAO regularly consults its Associated Partners on the content, subjects related to the NCA/NWPL, HSWP, WPMM, TFMCD, its planned activities, and the direction they should follow. The partners pre-view and comment on important documents prepared by SAO. More specifically: the Czech Partner is mostly involved on matters relating to the HSWP, NWPL and the electronic means of communication; the Belgian Partner is mostly involved on matters relating to the NCA, NWPL and WPMM/TFMCD and the evaluation of the project together with the French partner; the French and Lithuanian partners are mostly involved on matters relating to the NCA, but are also attending the meetings of the WPMM and WPHS.
- The complete SAO team had its first project meeting with its Associated Partners in October 2006 to discuss the progress made and plan and improve its work for the future.
- SAO has regular consultations (by phone, email, in person) with the WPMM, HSWP and TFMCD (deputy) leaders and with the Commission Services at SANCO C2.

- SAO uses an active approach in its communication with the projects within each WP/TF to monitor results and progress.
- SAO has prepared the agenda and the content, minutes and invited speakers of the biannual meetings of the NCA/NWPL/HSWP/WPMM/TFMCD in close collaboration with the (deputy) leaders and the Commission Services at SANCO C2.
- SAO has developed password protected websites for the NCA/NWPL/HSWP/WPMM /TFMCD, which it uses to keep the Networks and WP/TF members updated. SAO is also developing Newsletters for this purpose.

For further details, see sections 3.4 - 3.7.

Management structure:



3.2 Dissemination of the results (Work package 2)

Lead partner: NIVEL

Associated partner: University Center for Healthcare quality, Masaryk University Medical Faculty, Czech Republic

Objectives:

- To disseminate the results of the outcomes of the biannually meetings, the results of possible reviews and background documents, and the progress made in the different domains of both the HSWP, WPMM and TFMCD;
- To contribute to the preparation of the synthesis of the projects' outputs for the meetings of the NWPL and the NCA;
- To monitor the different fields of interest of both WPs and TF by examining possible overlap between the various WPs and related issues in other Commission policies and programmes, bringing it to the attention of the NWPL and NCA.

Description of undertaken dissemination activities

- In general, every important output that SAO has produced is presented either orally at the appropriate meeting, through e-mail to the WP/TF members/Networks and the Commission, or through the SANCO website or one of the SAO websites.
- SAO has developed and actively uses three password protected websites for the NCA/NWPL, HSWP and the WPMM/TFMCD.
- Progress reports of the HSWP and WPMM/TFMCD are presented at every meeting of the NCA/NWPL.
- SAO has started the development of WPMM and HSWP newsletters that will be disseminated among all members and experts attending the meeting, and published on the SANCO and SAO websites.
- All presentations held at the meetings are published on the SAO and SANCO websites, and briefly described in the minutes of the meetings, to make them publicly available.
- SAO is preparing a workshop for the WPMM/TFMCD and HSWP which will contribute to disseminating the progress of the WPs and TF.
- For the purpose of monitoring the different fields of interest of WPs and TF by examining possible overlap between the various WPs and related issues in other Commission policies and programmes and to assure a retrospective “ memory” of the HSWP and MMWP/TFMCD, a general framework (template) allowing for the collation of running, potential and -based on requests from NCA lacked – projects has been produced and is being used by the WPs/TF.
- For the process of monitoring of current projects a simplified version of the project progress templates was produced and is being used for the MMWP/TFMCD and HSWP.
- A common glossary of key terms used by the running projects of the HSWP is being produced to improve communication between various running projects.
- The overall progress and results of the assistance given by SAO till November 2006, have resulted in this interim report as means of dissemination to the Commission and will be published on the SANCO website, accessible to the general public.

For further details, see sections 3.4 - 3.7.

3.3 Evaluation of the project (Work package 3)

Lead partner: Haut Comité de Santé Publique, France

Associated partner: Scientific Institute of Public Health, Belgium

Objectives:

- To contribute to the synthesis of the projects' outputs in the WPs/TF for the meetings of the NWPL and the NCA.
- To organise and assist biannual meetings of the NCA/NWPL, HSWP, WPMM/TFMCD in Luxembourg.
- To contribute to the European Commission Health Indicators list through advise on precisely-defined indicators, prioritisation and harmonisation of data-collection.
- To contribute to the development of a comparable health measurement for health surveys in the EU.
- To contribute to the preparation of the annual work plan of the Public Health Programme.
- To help setting priorities especially for subjects not covered by current or former projects in the WPs/TF.

Interim evaluation report

This interim report provides an overview of the realised outputs and the produced deliverables, and provides a reflection on SAO's achievements. SAO's first project meeting (held in October 2006) with its associated partners formed the basis for this evaluation report on the projects progress. At the end of the project, a final evaluation report will be written.

3.4 Scientific Assistance Office of the Network of Competent authorities (Work package 4)

Lead partner: NIVEL

Associated partners: Haut Comité de santé Publique, France
Lithuanian Health Information Centre, Lithuania

Objectives:

- To assist the NCA in executing their mandate, in advising the Commission about the implementation of the (short)list of health indicators, the harmonisation of the collection of the health information in the various Member States and in its task to promote the public health programme on Health Information in their respective Member States.
- To contribute to the preparation of the synthesis of the projects' outputs for the meetings of the NCA, in order to prepare decision making by the MS.
- To examine possible overlap between the various WPs and related issues in other Commission policies and programmes, and bring it to the attention of the NCA.

3.4.1 Achievements

Deliverable 1: *Scientific Assistance Office*

Achievement: SAO has become operational as of December, 1st 2005. The SAO day-to-day execution of its tasks is performed by the NIVEL team. The team started out with a project leader and researcher supported by a secretary and technical staff, but was reinforced by two researchers in respectively March and November 2006. To introduce SAO, with its objectives, tasks and plans, SAO held introductory presentations at the first meetings of the HSWP and the WPMM following its starting date (see annexes 10a, 16a for the presentations). This was not necessary for the NCA and NWPL, as NIVEL already supported the networks during the preceding SNAW (Supporting the Networks of Competent Authorities and the Network of Working Party Leaders) project from February 2004 till August 2005. SAO uses a special e-mail address for NCA and NWPL related activities: NCA.NWPLSec@nivel.nl

Deliverable 2: *Web site or web board*

Achievement: SAO continued to use with the "web board", started by the predecessor project SNAW (see annex 3c). The web board is an information and discussion forum for the NCA and the NWPL with restricted access. It facilitates information exchange and discussion between members of the NCA and the NWPL, the Commission Officers of the Public Health C2 Unit and SAO. For information purposes, meetings and news-items are announced. All relevant documents (agenda's, minutes, presentations, background documents) for the NCA and NWPL meetings are published regularly here. Furthermore, it provides useful links, an overview of contact persons of other Working Parties and Task Forces active in the Health Information Strand, and all other information items that members find useful to distribute through the web board. In the evaluation report on the structure and organisation of the NCA and NWPL meetings that SAO prepared for the meeting of 5-6 July 2006, the web board users reported to perceive it as an useful tool to distribute information (see the presentation in annex 3b).

Deliverable 3: *NCA meetings*

Achievement: SAO has actively assisted the Commission in planning and organising the sixth and seventh meeting of the NCA that were held respectively on 7-8 February and 5-6 July 2006 in Luxembourg. It concerned parallel meetings with the NWPL in the morning of the first day, and joint sessions for the remaining afternoon and next day. Well in advance of the meetings SAO prepared a draft agenda, which through e-mail communication and one day visits to the Commission, (see annex 1 for list of meetings and visits) was finalised among the Commission and SAO. The draft agenda was circulated well in advance to the participant list of the NCA, which SAO continuously updated and maintained. Per agenda item it was discussed whether SAO or the Commission invites the planned speaker to participate in the meeting. All speakers received invitations and guidelines for their item for which they were asked to prepare a presentation. The Commission was responsible for the official

invitations to all participants. SAO functioned as the first contact point on all related NCA matters for the Competent Authorities, International Organisations and Experts that are members of the Network. An important part of the preparation of the meetings, was selecting and circulating well in advance background documents to the participants in order for them to be up to date on important public health developments, so that they are well prepared for the meetings. SAO circulated these documents either on request of the Commission or on its own initiative after approval of the Commission. During the meetings in Luxembourg, SAO was (mostly) represented by two staff members to write the draft minutes of the meeting and to assist the chair person in chairing the meeting, for example for the purpose of time management, answering questions, evaluating the order of agenda items, assisting speakers with their presentation, organising social events, etc. After the meetings, SAO was responsible for follow up of any agreements made during the meeting in which SAO could play a supporting role, and to finalise the draft minutes. SAO itself, presented its work related to either the support of the Network (e.g. its Plan of Activities, and the Evaluation report of the NCA and NWPL meetings) or on content subjects (e.g. on Confidentiality of Personal Data, and Country Progress Reports) during the NCA meetings (see annex 3a and 3b for SAO output related to the two meetings of the NCA).

Deliverable 6: *Minutes of the meetings*

Achievement: During the meetings of the Network, SAO has written first draft versions of the minutes. After the meeting, a second draft version was sent to the Commission which they either approved or asked for alterations before approval. After agreement, SAO published the minutes together with the participant list and the presentations on the web board, which the Commission also published on the DG SANCO website. The minutes of a previous meeting was officially approved by the NCA during the next meeting (see annex 3a and 3b for the minutes of the meetings).

SAO visited the Commission on August, 31st 2006 to evaluate the content and style of the minutes that SAO prepared for its Networks and WPs and TF (see annex 1 for an overview of meetings and visits). It was agreed that as of August 2006, SAO will produce summary reports instead of minutes. Aims of these summary reports are external communication (to show the EU citizen, the European Parliament and the Council what is going on within the Health Information Strand) and internal communication (to inform the Commissioner, other DG SANCO departments). It was agreed that it is therefore important that the reports are understandable for people who have no background knowledge on the Health Information Strand. The summary reports have to be focused and concise, reflecting outcomes of discussions and decisions taken.

Deliverable 7: *Progress reports*

Achievement: Twice a year, for every NCA meeting, SAO collated information on coordinating activities related to the Health Information Strand, that have been carried out by the Country Authorities at national level since the previous NCA meeting. The aim of this exercise was to update the Commission and other Member States, to share good and innovative practices and to enable SAO to summarise the direction of Health Information activities across the EU. SAO developed a template for this, which it asked all Competent Authorities to complete (see annex 7 for the form). CAs were asked to describe major activities and important publications related to Health Information, related to the EU Public Health Programme (once a year), and related to the key health themes of the upcoming EU Presidency, at national level (twice a year). Furthermore, the form gave CAs the possibility to report any issues they wished to raise during the upcoming NCA meeting. The complete progress reports have been published on the web board, so that all MS have access to the information provided. A summary of the progress reports was presented by SAO during the NCA meetings (see presentations in annex 3a and 3b).

Deliverable 8: *Annual work plan*

Achievement: SAO has stimulated NCA members to provide the Commission with input on the content of the Work Plan for 2007 which is currently still under development. SAO has collated the received inputs and distributed it to the Commission.

Deliverable 10: *Background/review documents: Evaluation report of the Meetings of the NCA and NWPL*

Achievement: SAO performed an evaluation on how participants of NCA and NWPL meetings perceive the organisation and content of the meetings, to optimize future meetings. For this purpose, a template was developed and sent to the participants of the meetings held on 7-8 February 2006 (see annex 4 for the templates). The complete evaluation reports were published on the web board and a summary of the results was presented during the NCA/NWPL meeting of 5-6 July 2006 (see annex 3b for the presentation). In collaboration with the Commission, future meetings were organised taking into account the resulting comments and suggestions for improvement.

Deliverable 10: *Background/review documents: NCA ad hoc Work Group on Data Protection and Confidentiality*

Achievement: SAO is actively taking part in, and coordinating an ad hoc NCA Work Group (WG) on Data Protection. In 2005, it had become apparent to the NCA that there were difficulties in the different MS with regard to the use of person identifiable register data for public health purposes as a result of data protection legislation. Since the aim of the Health Information and Knowledge Strand is to produce comparable information on health and health-related behaviour of the population, diseases and health systems on a European level, the NCA of this Strand is of the opinion that this situation is undesirable. Therefore a Work Group was initiated during the July 2005 meeting of the NCA. The aim of this WG was defined as the development of a statement on behalf of the NCA on preferred action of the EC in order to harmonize and enhance the current situation with regard to person identifiable health data in Europe. The WG consists of the Competent Authorities of Finland, Sweden, Malta, France, Spain, and Estonia, and SAO. To date, the WG has had 2 meetings in Utrecht at the premises of NIVEL and one in Luxembourg, all organised by SAO (see annex 5a-c for the agenda, minutes, participant lists and agreements made during the meetings).

Firstly the WG reviewed EU Directive 95/46/EC on data protection and came to a joint interpretation of the Articles dealing with the use of health data. This interpretation was presented to an expert in the field of health data protection of DG Freedom, Security and Justice, who commented the WG's interpretation during the NCA meeting of February 2006.

Furthermore, SAO, together with the other WG members, tried to get an overview of other EC activities in the field of health data protection. Within that framework, in 2006 representatives of EuroSoCAP project were invited to a joint meeting with the WG, as well as to the NCA meeting of July to present their conclusions in the context of the area of interest of the WG. Moreover, a representative of the Injury Database project was present at the WG meeting in June 2006 to present and discuss an overview of national legislature in the field of injury related health data.

Most importantly, the WG is performing an inventory of 1) the differences between the Members States' national data protection legislations, and 2) the bottlenecks experienced in practice within the Member States with regard to the processing of person identifiable health data for public health purposes. By the latter the use of routine health data (like survey data, data from health registrations) in epidemiological and statistical analyses for public health monitoring and health services research is meant. For making this inventory, the WG has developed two online questionnaires, which have been distributed to national experts in the field of health data protection (identified by the Competent Authorities) and national data protection officers, and project leaders within the Health Information Strand (period 2003-2005), respectively. The questionnaires are currently being completed by the respondents and processed by SAO (see annex 5d for the questionnaires).

SAO has presented the progress of the WG at both NCA meetings held in 2006 (see annex 3a and 3b for the presentations). It is expected that SAO together with the WG will finalise and present its final joint statement, which will be based on the outcomes of the questionnaires, at the NCA meeting of 30-31 January 2007.

The SAO project leader presented on behalf of the WG on invitation by the Dutch Ministry of Health, Welfare and Sports the presentation "EU Data Protection Directive and Health Statistics: problems to solve?" at the Invitational Expert Meeting "Health-ID Management in Europe" on 21 February 2006 in Schiphol-East, the Netherlands (see annex 5e).

Additional activity: *Organising a work visit for Estonian representative on Data Protection and Confidentiality in the context of exchange of best practices within the EU*

Achievement: In light of the WG on Data Protection and Confidentiality, SAO has organised and hosted a work visit on Data Protection and Confidentiality in the context of exchange of best practices within the EU for Estonian representative Ms. Kristiina Rebane. The visit took place from September 18th 2006- September 29th 2006 in the Netherlands.

Ms. Rebane's programme (see annex 5f) consisted of visits to different actors in the field of health data protection, such as, amongst others, the Ministry of Health, Statistics Netherlands, the legal representative of the Dutch Epidemiological Association and the Federation of Medical Scientific Associations, and the Cancer Register. In this way Ms. Rebane, as well as the NCA Work Group, obtained information on the Dutch health data protection system from various angles, allowing to see the different views existing in the field on certain important aspects of the system (such as informed consent, the definition of anonymous data and the necessity of a legal base for registers). With regard to the outcome of the visit it can be said that Ms. Rebane obtained the most important information on the Dutch health data protection system, provided to her by the main actors in the field. Besides oral information she was provided with English versions of the most important background documents. Finally, the experts she met during the visit might prove to be helpful contacts to her and her Estonian colleagues in the future, but also to the NCA Work Group.

Deliverable 14: *Database of national data-providers*

Achievement: It was no longer necessary for SAO to develop a database of national data-providers since all this information has been gathered and published in the course of 2006 by SANCO on their Public Health Portal.

Additional activity: *Project database of 2000-2005 of the Health Information Strand*

At the request of the NCA and the Commission, SAO has developed a database for every Member State with contact information of the leading and associated partners involved in projects within the Health Information Strand of the EU Public Health Action Programme (see annex 6). The database is continuously updated. Currently, the database has been completed for projects that were financed between 2000 and 2005. 116 projects have been reviewed of which the contact data of 1577 persons have been collected, and for 6 projects data still needs to be completed. In July 2006, SAO has sent the Commission the complete database with information on all Member States. The CAs received their own national database. SAO will keep updating and expanding the database and circulate updated versions regularly.

Deliverable 15: *Meetings with Commission Services*

Achievement: Whenever necessary, and when email contact or telephone conferences were not deemed sufficient, SAO met with the Commission Services in Luxembourg to discuss NCA related matters. Most often it concerned the preparation of the agenda of the meeting, but at other occasions also other organisational matters such as the style of the minutes, the communication between SAO and the Commission or new activities that the Commission would like SAO to undertake. Whenever possible, it was tried to combine visits to Luxembourg for different purposes. For example, during the official NCA meetings, SAO always tried to meet with the Commission to discuss its supporting activities (see annex 1 for the visits between the meetings).

Additional activities: *Supporting the Commission in distributing information and requesting input*

Achievement: On a daily basis SAO supports the Commission in distributing policy related information to the NCA members and asking input for different purposes. For example, SAO has helped the Commission in forming the editorial board of the Public Health Portal. Whenever input from NCA members is needed, for example when discussion documents or Communications are published, SAO actively brings this under the attention of the NCA through e-mail and its web board.

Additional activities: *Attending the meetings of the Working Party on Health Indicators.*

Achievement: For the sake of supporting the NCA/NWPL networks, SAO attended the meetings of the Working Party on Health Indicators (WPHI), to be able to coordinate activities between both

networks and the WPHI, as well as stimulating communication between the various structures of the HI Strand. At this occasion SAO presented the reports of the WP on Health Systems and the Task Force on Major and Chronic Diseases (see 3.6b.1 and 3.7.1)

3.4.2 Reflection on achievements

The support of a Scientific Secretariat for the NCA, as well as for the NWPL was only disrupted for three months after the SNAW project, which ended by the end of August 2005. By postponing the next NCA/NWPL meetings up to February 2006, SANCO was certain of the support by the SAO project in organizing these meetings once it had been selected for negotiations.

As the final report of SNAW stated, a Secretariat to support both Networks within the Health Information Strand in 2004 was a new concept for the Commission Services, as well as for NIVEL. It took some time to establish an efficient working relationship between the project team and the Commission services. Since 2005 the added value of a Secretariat for both networks has become more obvious. During the SNAW period NIVEL, being a research institute, had hoped that the project would provide more opportunity to support SANCO C2 in content related issues regarding the development of the European Health Information and Knowledge System. However, very few opportunities arose to this effect during the first part of the SNAW project.

Looking back at the actual achievements of the SAO project in relation to the NCA meetings, one can say that there have been considerable changes.

The project team and the Commission officers found that an efficient working relationship and less preparatory meetings with SANCO are needed to prepare the content of the meetings or to follow-up what was discussed or decided during the meetings. There were still some difficulties in finding a consensus in reporting the meetings of the Networks, but finally it was well understood what the Commission expected, and minutes were changed into summary records.

The agenda of the NCA meeting has developed a kind of standard number of items and a certain approach. At the suggestion of SAO, the Working Party and Task Force leaders are having a joint meeting with the NCA, where they report the activities of their respective WP/TF instead of a summary report by the Secretariat as was done at the former meetings. The presence of the WPL/TFL at the NCA meeting facilitates a closer contact between them and the CA: CA can directly address the leaders for additional clarification and information. The WPL/TFL in their turn can closely follow discussions on policy issues related to Health Information in a European Public Health context. By attending the NCA they receive first hand information from contributions by Eurostat related to the data collections needed to fill the prioritised ECHI indicators, developed by the projects in their respective groups. Issues directed at the CA only can be discussed during the morning session running parallel to the NWPL meeting.

Other common items on the agenda are Communications from the Commission, reports from Eurostat and country reports, summarized by the Secretariat. A new development appreciated by the CA are the plans and reports of the MS about the health activities under their coming or finished EU presidencies. Also the possibility to bring specific issues forward to be discussed during the NCA meeting fosters interaction between the Commission and the CA. Major issues brought forward that resulted in specific scientific work for SAO were the data protection issue and the internal evaluation of the Public Health Programme. While during the former project the SNAW Secretariat had hoped that the project would provide more opportunity to support SANCO C2 in content related issues, during the first year of the SAO project this was not a problem anymore. The coordination of the ad hoc workgroup on Data Protection and Confidentiality initiated quite some work for the Scientific Assistance Office: gathering information, organizing meetings, attending meetings of other related EU initiatives, organising a survey, developing recommendations that will be presented in 2007. Also for the internal evaluation a small workgroup was set up and coordinated by SAO. Here also a Health Information Strand wide survey was organised.

There is an additional value by organizing the support for the largest Working Parties and Task Forces in the Strand, as well as for both networks, and attending for all supported groups the meetings of the Working Party on Health Indicators. It provides deeper insights on what is going on in the programme of the Strand, where the bottle-necks are in communication and information as well as coordination between the various levels and groups of the structure of the Health Information Strand. This resulted, among other things, in the work of the Working Party on Health Indicators being more prominently on the agenda of both Networks.

There are still quite a few problems in running the CA as an advisory board for the Commission and as an in-between between the Commission and MOH in the MS. On the one hand the Commission is providing a lot of information to the CA, but they are given less opportunity to interact, to discuss and even to contribute actively to the annual Work plan. On the other hand CA are not always taking the opportunity to discuss issues; even the web board is not used as a discussion forum as it could be: it is still used as a one way instrument for information delivery. The Scientific Assistance Office tries as much as possible to influence the dynamics of the meetings by monitoring the content of the meetings, to facilitate communication by electronic means and by monitoring what's going on at the various levels of the structure supported by SAO and concerning Public Health in Europe. The instruments used to gather information from the CA are designed in such a way by addressing those issues that may invite the CA to provide interesting information for the aim of the whole Public Health Programme as much as possible.

3.5 Scientific Assistance Office of the Network of Working Party Leaders (Work package 5)

Lead partner: NIVEL

Associated partners: Scientific Institute of Public Health, Belgium
(Department of Health and Children, Ireland)
University Center for Healthcare quality, Masaryk University Medical Faculty, Czech Republic

Objectives:

- To assist the NWPL in executing their mandate as coordinating network of the various WPs, to formalise the list of indicators, to inform the NCA about the availability, validity and comparability of the indicators on the (short) list, on the possibilities for operationalisation of the indicators and on strategies in case of incomparabilities, to create synergies between the various WPs.
- To communicate results of the respective WP/TF to the NWPL to prepare decision making by the Member States
- To contribute to the preparation of the annual work plan of the Public Health Programme
- To examine possible overlap between the various WPs bringing it to the attention of the NWPL

3.5.1 Achievements

Deliverable 1: *Scientific Assistance Office*

Achievement: see 3.4.1

Deliverable 2: *Web site or web board*

Achievement: see 3.4.1

Deliverable 3: *NWPL meetings*

Achievement: SAO has actively assisted the Commission in planning and organising the fourth and fifth meeting of the NWPL that were held respectively on 7-8 February and 5-6 July 2006 in Luxembourg. It concerned parallel meetings with the NCA in the morning of the first day, and joint sessions for the remaining afternoon and next day. Well in advance of the meetings SAO prepared a draft agenda, which through e-mail communication and one day visits to the Commission, (see annex 1 for list of meetings and visits) was finalised among the Commission and SAO. The draft agenda was circulated well in advance to the participant list of the NWPL, which SAO continuously updated and maintained. Per agenda item it was discussed whether SAO or the Commission invites the planned speaker to participate in the meeting. All speakers received invitations and guidelines for their item for which that were asked to prepare a presentation. The Commission was responsible for the official invitations to all participants. SAO functioned as the first contact point on all related NWPL matters for the Working Party (deputy) leaders. An important part of the preparation of the meetings, was selecting and circulating well in advance background documents to the participants in order for them to be up to date on important public health developments, so that they are well prepared for the meetings. SAO circulated these documents either on request of the Commission or on its own initiative after approval of the Commission. During the meetings in Luxembourg, SAO was (mostly) represented by two staff members to write the draft minutes of the meeting and to assist the chair person in chairing the meeting, for example for the purpose of time management, answering questions, evaluating the order of agenda items, assisting speakers with their presentation, organising social events, etc. After the meetings, SAO was responsible for follow up of any agreements made during the meeting in which SAO could play a supporting role, and to finalise the draft minutes. SAO itself, presented its work related to either the support of the Network (e.g. its Plan of Activities, and the Evaluation report of the NCA and NWPL meetings) or on content subjects (e.g. on Confidentiality of Personal Data, and Country Progress Reports) during the joint NCA/NWPL meetings (see annex 3a and 3b for SAO output related to the two meetings of the NCA/NWPL).

Deliverable 6: *Minutes of the meetings*

Achievement: During the meetings of the Network, SAO has written first draft versions of the minutes. After the meeting, a second draft version was sent to the Commission which they either approved or asked for alterations before approval. After agreement, SAO published the minutes together with the participant list and the presentations on the web board, which the Commission also published on the DG SANCO website. The minutes of a previous meeting was officially approved by the NWPL during the next meeting (see annex 3a and 3b for the minutes of the meetings).

SAO visited the Commission on August, 31st 2006 to evaluate the content and style of the minutes that SAO prepared for its Networks and WPs and TF (see annex 1 for an overview of meetings and visits). As for the NCA, it was agreed that as of August 2006, SAO will produce summary reports instead of minutes. Aims of these summary reports are external communication (to show the EU citizen, the European Parliament and the Council what is going on within the Health Information Strand) and internal communication (to inform the Commissioner, other DG SANCO departments). It was agreed that it is therefore important that the reports are understandable for people who have no background knowledge on the Health Information Strand.

Deliverable 7: *Progress reports*

Achievement: Twice a year, for every joint NWPL/NCA meeting, SAO gathered summaries of activities carried out by the Working Parties and Task Forces under the Health Information Strand since the previous NWPL/NCA meeting. It serves to inform the Competent Authorities, the leaders of the other Working Parties and Task Forces, as well as the Commission on the progress within the Strand. SAO developed a template for this, which it asked all WP/TF leaders and deputies to complete (see annex 8 for the form). The form included questions on main undertaken activities, the degree in which objectives were achieved and what the objectives are on the short term, whether the WP/TF has a Work Plan, and if there are any perceived problems. Furthermore, the form gave WPLs the possibility to report any issues they wished to raise either during the separate upcoming NWPL meeting, or during the next joint meeting with the NCA. The complete progress reports have been published on the web board, so that all MS have access to the information provided. In addition to filling in the form, Working Party and Task Force leaders were asked for every joint NCA/NWPL meeting to present their own progress reports. SAO provided them with guidelines for their presentations, and completed and presented itself at some meetings the progress of the HSWP and the WPMM and TFMCD (see annex 3a and 3b for the SAO presentations).

Deliverable 8: *Annual work plan*

Achievement: SAO has stimulated NWPL members to consult their Working Party or Task Force Project leaders in order to provide the Commission with input on the content of the Work Plan for 2007 which is currently still under development. SAO has collated the received inputs and distributed it to the Commission.

Deliverable 10: *Background/review documents: Evaluation report of the Meetings of the NCA and NWPL*

Achievement: SAO performed an evaluation on how participants of NCA and NWPL meetings perceive the organisation and content of the meetings, to optimize future meetings. For this purpose, a template was developed and sent to the participants of the meetings held on 7-8 February 2006 (see annex 4 for the templates). The complete evaluation reports were published on the web board and a summary of the results was presented during the NCA/NWPL meeting of 5-6 July 2006 (see annex 3b for the presentation). In collaboration with the Commission, future meetings were organised taking into account the resulting comments and suggestions for improvement.

Deliverable 10: *Background/review documents: NCA ad hoc Work Group on Data Protection and Confidentiality*

Achievement: The work of the NCA ad hoc work group on data protection and confidentiality which SAO coordinated, was at both meetings presented during the joint NCA/NWPL sessions, so that the NWPL could benefit from the information as well.

Deliverable 15: *Meetings with Commission Services*

Achievement: Whenever necessary, and when email contact or telephone conferences were not deemed sufficient, SAO met with the Commission Services in Luxembourg to discuss NWPL related matters. Most often it concerned the preparation of the agenda of the meeting, but at other occasions also other organisational matters such as the style of the minutes, the communication between SAO and the Commission or new activities that the Commission would like SAO to undertake. Whenever possible, it was tried to combine visits to Luxembourg for different purposes. Most often, NCA and NWPL matters are discussed during the same visit (see annex 1 for the visits between the meetings).

Additional activities: *Supporting the Commission in distributing information and requesting input*

Achievement: On a daily basis SAO supports the Commission in distributing public health related information to the NWPL members and asking input for different purposes.

Additional activities: *Keeping contact with the secretariats of the WPs/TFs under the HI Strand*

Achievement: SAO has been in close contact with the secretariats of the other WPs/TFs under the Health Information Strand. This facilitated the flow of information from and to SAO, the Commission and also between WPs/TFs. It also contributed to a learning environment on coordination strategies for WPs and TFs.

3.5.2 Reflection on achievements:

The Network of Working Party leaders has a clear function and mandate in bringing the various WPL together and being a platform addressing common issues related to the work of the various Working Parties and the whole Health Information Strand. At least that is how the Network evolved during the period covered by this report. It developed from a full day meeting where the WPL/TFL mainly reported to each other on the progress and developments of the work of their respective groups, into a meeting with two tracks. The first morning session became an interactive meeting whereby common issues are indeed discussed, as well as the progress of the work related to the European Community Health Indicators. The SAO suggested during the last meetings an active input from the WP on Health Indicators, giving the WP the opportunity to address general issues related to the development and implementation of the ECHI short list in the presence of all WPL/TFL. The agenda of this session is developed with active contribution of the WPL/TFL themselves. In stead of reporting the developments of the various WPs/TFs among them, nowadays the WPL/TFL are invited to attend the NCA meeting after lunch on the first day. So they are reporting the work of their WPs/TFs directly to the NCA, thus giving the opportunity for a closer contact and direct communication. Both sides are benefiting from this new approach. The CA receive a more detailed overview of the scientific work going on in the WPs/TFs and their respective projects, and the WPLs/TFLs get close information related to the developments in the European Health Survey System provided by the contributions coming from Eurostat, and related to EC policy issues within the EU Public Health programme.

The agenda of the NWPL and the interaction with the NCA developed in the right direction according to the opinion of SAO. However, the contribution of the NWPL to the Work plan of the HI Strand seems to remain minimal. But one can expect that their contribution is more directed through the respective Working Parties and Task Forces.

3.6a Scientific Assistance Office of the Working Party on Morbidity and Mortality (Work package 6)

Lead partner: NIVEL

Associated partners: Haut Comité de Santé Publique, France
Lithuanian Health Information Centre, Lithuania
Scientific Institute of Public Health, Belgium

Objectives:

- To assist the WPMM and the Commission Services with the management and the coordination of the WP
- To assemble the experience and knowledge within the WPMM
- To organise and assist biannual meetings of the WPMM in Luxembourg
- To assist the WPMM to execute their specific tasks as stipulated in their specific mandate
- To keep the WPMM informed on the progress of the projects, their final outcomes and also the impact on national level, and to help setting priorities in their field of interest especially for subjects not covered by current or former projects
- To monitor the different fields of interest by examining possible overlap between the various WPs

3.6a.1 Achievements

Deliverable 2: *Web site or web board*

A SharePoint site was developed by SAO for the WPMM. With SharePoint user friendly, interactive web environments can be made and managed. It is a web site with restricted access, for which users have to register. The website under construction was presented during the WPMM meeting in June 2006 (see annex 10b), and the site became operational in September 2006. All WPMM members were sent an e-mail with an invitation to register and instructions on how to do so. A reminder was sent out in November. The website contains, besides a home page with news items and announcements, several sub-pages: one containing Working Party related documents; one where users of the site can place information on themselves; one containing information on all the projects within the Task Force on Major and Chronic Diseases (note that the Task Force on Rare Diseases has its own website with this kind of information); a page with information on SAO, a page with links to important EC sites, project sites et cetera; a forum page; and a page for information on the future report on Major and Chronic Diseases in the EU in 2006 (the latter is still under construction). See annex 10c for a print of the homepage of the WPMM site.

Deliverable 5: *WP meetings*

Achievement: SAO supported the planning and organisation of two meetings of the WPMM; the third meeting of the WPMM in December 2005, and the fourth meeting of the WPMM in June 2006. During the June meeting it was decided that the WPMM was to meet only once a year from that point onwards, as more and more activities are being carried out within the Task Forces of the Working Party, rather than within the Working Party itself. Therefore no meeting was planned for December 2006.

The agendas for the meetings were drafted by SAO and decided upon in consultation with SANCO and the WPMM leaders. While SANCO took care of inviting the participants and arranging for the meeting facilities, SAO distributed the agenda and background materials. Usually speakers from the EC were invited by SANCO, and external speakers by SAO. See annex 10a-b for the agendas of the WPMM meetings.

Deliverable 7: *Progress reports*

Achievement: For the NCA/NWPL meetings, all Working Parties and Task Forces are requested to write a report on their progress during the past half year. For the projects of the Working Parties and the Task Force SAO is supporting, SAO developed a template for biannual information collection (see annex 8). SAO send out the template to the projects under the TFMCD, and, based on the information

gathered, Powerpoint presentations on the progress of the WP were prepared by SAO for both NCA/NWPL meetings that took place in the period covered by this report (see annexes 3a and 3b for the presentations). During the NCA/NWPL meeting of February, SAO gave this presentation; during the NCA/NWPL meeting of July the WPMM leaders did this.

Deliverable 8: *Annual work plans*

Achievement: SAO has distributed the request of the European Commission for suggestions for the Work Plan 2007 among the WP members. The provided input was collated and distributed to the Commission. Moreover, SAO has suggested to discuss the ongoing developments with regard to the realization of the Work Plans 2006 and 2007 on the agenda of the WP (and TFMCD) meetings that took place in the period covered by this report, as to keep the members informed and to give them another platform for communicating with the Commission on this topic.

Deliverable 9: *Project reviews*

Achievement: See 3.6b.1

Deliverable 10: *Background/review documents*

Achievement: No background or review documents were requested by the WPMM during the period that is reported on here. But see also Major and Chronic Disease Report under 3.6b.1

Deliverable 11: *Workshop/pre-conference*

Achievement: No workshop/pre-conference was prepared in 2006. See 3.6b.1 and chapter 5: 'Planned activities December 2006 - November 2007' for the planned EUPHA workshop(s) for the TFMCD.

Deliverable 12: *List of indicators*

Achievement: In the autumn of 2006, SAO has been making an inventory of the indicator related output of the projects within the TFMCD to provide to ECHIM. Project reports published after May 2005 were assessed, as the ECHI shortlist was finalized in May 2005 and all relevant project output available then had been taken into account in the shortlist. Moreover, SAO coordinated the actions related to a request from the WP on Health Indicators for suggestions for the update of the ECHI shortlist. First a draft e-mail, containing instructions for the project leaders on how to formulate suggestions was made based on the request of the WP on Health Indicators and discussed with the WPMM and TFMCD leaders. Subsequently, the project leaders were approached by e-mail and requested to send possible suggestions for updating the shortlist to SAO. The results of both these exercises were presented by SAO during the TFMCD meeting of December 2006. Therefore we will report on this in more detail in the final report, which will cover the period December 2006-November 2007.

Deliverable 13: *Electronic update memo/newsletter*

Achievement: In the autumn of 2006, SAO has been preparing the first edition of the WPMM Newsletter. This Newsletter addresses a broad audience: it aims to inform the interested EU citizen on the achievements of the WPMM, as well as the WPMM members on the major developments within Europe, within the WPMM and within the field of Morbidity and Mortality. The projects within the TFMCD were requested to provide short contributions for the Newsletter. These were edited by SAO. Furthermore, SAO collected information on major European developments in the field of Public Health, and on recent publications from the projects within the TFMCD. The first edition was published in December 2006 and therefore will be added to SAO's final report. For 2007 quarterly editions are planned (see chapter 5).

Deliverable 15: *Meetings with Commission Services*

Achievement: In April SAO went to Luxembourg to prepare the WPMM (and TFMCD) meeting of June 2006. In December 2006 no WPMM meeting took place; consequently a preparatory meeting was not necessary.

Additional Activity: *Supporting meetings of the EHSS experts/Steering Committee*

Achievement: On April 24th 2006, SAO attended an expert meeting organised by SANCO and EUROSTAT for the European Health Survey System, and on June 29th 2006 SAO attended the second meeting of the Steering Committee for the European Health Survey System. SAO was present at these meetings at the request of SANCO to make minutes (see annex 14).

Additional activities: *Supporting the Commission in distributing information and requesting input*

Achievement: On a daily basis SAO supports the Commission in distributing morbidity and mortality related information to the WPMM members and asking input for different purposes.

3.6a.2 Reflection on achievements:

In general it can be said that the role of the WPMM is not very clear. The WP in itself does not carry out any activities; it is the umbrella structure for all morbidity and mortality related projects within the Health Information Strand. It is difficult to find common issues within the very broad spectrum of topics the Task Forces cover. Moreover, there does not seem to be a lot of added value of reporting to the Commission at the WP level to that of reporting at TF level. The decision taken by SANCO to have only one WPMM meeting a year therefore seems a logical one. Nevertheless, we suggest to take a close look at the contents of the WPMM meetings. As the TFs and the WPMM have clustered meetings, the TFs might take the opportunity to use their own meeting for in depth methodological discussions. The WPMM meeting then could be used for informing the participants on EC and SANCO related developments, and for progress reporting at the TF level, though in our opinion the utility of the TFs keeping each other up to date during the meetings needs careful evaluation. The TF on Rare Diseases (TFRD) and the newly established TF on Health Expectancies (TFHE) have very informative websites, and we hope to have one online for the TFMCD in the first half of 2007. One can argue whether this, together with the WPMM and TFRD newsletters, does not provide enough means for the WP members to keep informed, if they wish to.

In practical terms for SAO it is difficult to separate WPMM and TFMCD activities. As the TF on Rare Diseases (TFRD) has an excellent secretariat itself, activities at the WP level in practice often mean an activity at the TFMCD level. This phenomenon is enhanced by the fact that all ECHI indicator related activities at the WPMM level in fact relate to the TFMCD (and to the TFHE), as rare diseases hardly play a role in the ECHI indicator system.

For the WPMM leaders it is/was also not clear what the role of the WP was, and hence what their own role is/was. In combination with the above-mentioned WPMM related difficulties, in general supporting this structure has not been a easy and clear cut task for SAO, which was enhanced by the fact that, probably due to a lack of staff, feedback from SANCO was often lacking. In this light the preparatory meetings in Luxembourg are deemed extremely valuable by SAO.

Unfortunately the leader of the WPMM was forced to resign during the autumn of 2006 due to personal circumstances. Currently the WP therefore only has a deputy leader.

3.6b Scientific Assistance Office of the Task Force on Major and Chronic Diseases (Work package 8)

Lead partner: NIVEL

Associated partners: Scientific Institute of Public Health, Belgium

Objectives:

- To assist the TFMCD and Commission Services with the management and the coordination of the TF
- To assemble the experience and knowledge within the TFMCD (i.e. from national experts and outputs from the project)
- To organise and assist biannual meetings of the TFMCD in Luxembourg.
- To assist the TFMCD to execute their specific tasks as stipulated in their specific mandates
- To keep the TFMCD informed on the projects' progress, their final outcomes and also the impact on national level, and to help setting priorities in their field of interest, especially for subjects not covered by current or former projects
- To monitor the different fields of interest by examining possible overlap between the various WPs.

3.6b.1 Achievements

Deliverable 2: *Web site or web board*

To bridge the time for the development of a WPMM website, the webboard of the NCA/NWPL was temporarily used for WPMM communication and information purposes from the start of the project (see 3.6a.1 and annex 3c).

Deliverable 5: *TF meetings*

Achievement: SAO supported the planning and organisation of two meetings of the TFMCD; the second meeting of the TFMCD in December 2005, and the third meeting of the TFMCD in June 2006. The agendas for the meetings were drafted by SAO and decided upon in consultation with SANCO and the TFMCD/WPMM leaders. While SANCO took care of inviting the participants and arranging for the meeting facilities, SAO distributed the agenda and background materials. Usually speakers from the EC were invited by SANCO, and external speakers by SAO. See annexes 12a-b for the agendas of the TFMCD meetings.

Deliverable 7: *Progress reports*

Achievement: For the NCA/NWPL meetings, all Working Parties and Task Forces are requested to write a report on their progress during the past half year. For the projects of the Working Parties and the Task Force SAO is supporting, SAO developed a template for biannual information collection (see annex 17). SAO send out the template to the projects under the TFMCD, and, based on the information gathered, Powerpoint presentations on the progress of the TF were prepared by SAO for the TF leaders for both NCA/NWPL meetings that took place in the period covered by this report (see annexes 3a-b for the presentations).

Deliverable 8: *Annual work plans*

Achievement: SAO has distributed the request of the European Commission for suggestions for the Work Plan 2007 among the TF members. The provided input was collated and distributed to the Commission. Moreover, SAO has suggested to discuss the ongoing developments with regard to the realization of the Work Plans 2006 and 2007 on the agenda of the TFMCD meetings that took place in the period covered by this report, as to keep the members informed and to give them another platform for communicating with the Commission on this topic.

Deliverable 9: *Project reviews*

Achievement: Structured project reviews were not carried out as yet. This deliverable was discussed during the meeting of the associated partners of the SAO project in October 2006; see chapter 5: 'Planned activities December 2006 - November 2007' for the decisions that were made during that meeting.

Deliverable 10: *Background/review documents*

Achievement: At the request of SANCO, SAO prepared a thematically structured overview of the aims and activities of the projects of the Task Force under the former Health Monitoring Programme and the current Programme on Community Action in the field of Health and Consumer Protection 2003-2008. Aims of the document are to provide a complete and informative overview of what has been/is going on within TF, to serve as a tool for identifying areas or topics which are not adequately covered as yet, and to serve as a tool to recognize common issues and common interests between projects. As this document was officially presented to the TF during the TFMCD meeting of December 2006, a copy will be provided in SAO's final report.

Deliverable 11: *Workshop/pre-conference*

Achievement: No workshop/pre-conference was prepared in 2006. See chapter 5: 'Planned activities December 2006 - November 2007' for the planned EUPHA workshop(s) for the TFMCD. SAO staff visited the EUPHA conference in November 2006 to attend pre-conferences and workshop from among others the WP on Life Style and related topics, to form ideas on the organisation of a TFMCD workshop/pre-conference at EUPHA in 2007. Contact was made with the President of the newly established EUPHA Section on Chronic diseases to discuss this idea.

Deliverable 12: *List of indicators*

Achievement: In the autumn of 2006, SAO has been making an inventory of the indicator related output of the projects within the TFMCD to provide to ECHIM. Project reports published after May 2005 were assessed, as the ECHI shortlist was finalized in May 2005 and all relevant project output available then had been taken into account in the shortlist. Moreover, SAO coordinated the actions related to a request from the WP on Health Indicators for suggestions for the update of the ECHI shortlist. First a draft e-mail, containing instructions for the project leaders on how to formulate suggestions was made based on the request of the WP on Health Indicators and discussed with the WPMM and TFMCD leaders. Subsequently, the project leaders were approached by e-mail and requested to send possible suggestions for updating the shortlist to SAO. The results of both these exercise were presented by SAO during the TFMCD meeting and during the WP on Health Indicators meeting of December 2006. Therefore we will report on this in more detail in the final report, which will cover the period December 2006-November 2007.

Additional Activity: *Presenting overview of TFMCD indicator related activities at the WP on Indicators meeting*

Achievement: SAO was present at the WP on Indicators meeting in May 2006, representing the TFMCD. SAO prepared an gave a presentation, which consisted of an overview of TFMCD indicator related activities (see annex 18).

Deliverable 13: *Electronic update memo/newsletter*

Achievement: In the autumn of 2006, SAO has been preparing the first edition of the WPMM Newsletter. This Newsletter addresses a broad audience: it aims to inform the interested EU citizen on the achievements of the WPMM, as well as the WPMM members on the major developments within Europe, within the WPMM and within the field of Morbidity and Mortality. The projects within the TFMCD were requested to provide short contributions for the Newsletter. These were edited by SAO. Furthermore, SAO collected information on major European developments in the field of Public Health, and on recent publications from the projects within the TFMCD. The first edition was published in December 2006 and therefore will be added to SAO's final report. For 2007 quarterly editions are planned (see chapter 5).

Deliverable 15: *Meetings with Commission Services*

Achievement: In april SAO went to Luxembourg to prepare the TFMCD (and WPMM) meeting of June 2006. In October SAO went to Luxembourg to prepare the December meeting.

Additional Activity: *Supporting the Editorial Board for the Major and Chronic Diseases report 2006*

Achievement: On request of the Commission, the TFMCD is preparing a report on the state of play of Major and Chronic Diseases in the EU in 2006. An editorial board has been established for this report, consisting of SANCO officers, the TFMCD and WPMM leaders and SAO. The Editorial Board has met twice; once in April and once in June (after the WPMM/TFMCD meeting). SAO made the minutes of the first meeting, and a detailed report of the discussions that took place during the TFMCD meeting in June when the editorial board presented its plans to the TF. Based on the discussions of the first editorial board meeting, SAO prepared a draft universal template for the chapters of the report, and a list of projects within the TFMCD that could be addressed for contributions to the report. SAO prepared a presentation for the chair of the editorial board (the TFMCD leader), which he presented during the NCA/NWPL meeting of July 2006. See annex 13 for all contributions mentioned in this paragraph.

Additional activities: *Supporting the Commission in distributing information and requesting input*

Achievement: On a daily basis SAO supports the Commission in distributing major and chronic diseases related information to the TFMCD members and asking input for different purposes.

3.6b.2 Reflection on achievements

SAO's experiences with regard to its supporting function for the TFMCD generally are positive: during the past year SAO has gotten to grips with the broad range of activities that are being carried out within the TF, which is reflected in the increasingly improving agendas for the TFMCD meetings, and the overview of indicator related output and the thematically structured overview of past and current activities SAO has made. Moreover, the project leaders (including the TF leaders) and SAO have gotten to know each other during the past year, resulting in a pleasant and efficient working environment. More and more the project leaders (and third parties) find their way to the secretariat for information. The collaboration between the SAO and the secretariats of other WPs/TFs is growing as well. Also worth mentioning is the maturation of the relationship between SAO and ECHIM. During the past year SAO has become more and more aware of ECHIM's needs with regard to the indicator system, and ECHIM has become more and more aware of the role and knowledge of SAO and hence of its (possible) use for ECHIM. The establishment of a productive relationship between SAO and ECHIM is of major importance for the very core activity of the Health Information Strand.

Just as with the WPMM, a lack of feedback from SANCO has interfered with SAO's work for the TFMCD. Nevertheless, with the appointment of a new SANCO officer for the TFMCD in the autumn of 2006, more manpower is available, which has improved the situation.

Though in general SAO reflects positively on its achievements for the TFMCD, the supporting of the editorial board for the report on Major and Chronic Diseases 2006 has not been without problems. SAO has not succeeded (as yet) to acquire full coordination of the processes involved in the realization of the report.

All in all SAO is confident that, based on the foundations that have been laid during the past year, the goals set for next year, such as the organisation of a EUPHA workshop, the realization of four WPMM Newsletters, and the continuous and structured monitoring of indicator related project output for the information of ECHIM, SANCO and the TF itself, will be successfully achieved.

3.7 Scientific Assistance Office of the Working Party on Health Systems (Work package 7)

Lead partner: NIVEL

Associated partners: Haut Comité de Santé Publique, France
Lithuanian Health Information Centre, Lithuania
(Department of Health and Children, Ireland)
University Center for Healthcare quality, Masaryk University Medical
Faculty, Czech Republic

Objectives:

- To assist the HSWP and the Commission Services with the management and the coordination of the WP
- To assemble the experience and knowledge within the HSWP
- To organise and assist biannual meetings of the HSWP in Luxembourg
- To assist the HSWP to execute their specific tasks as stipulated in their specific mandate
- To keep the HSWP informed on the progress of the projects, their final outcomes and also the impact on national level, and to help setting priorities in their field of interest especially for subjects not covered by current or former projects
- To monitor the different fields of interest by examining possible overlap between the various WPs

3.7.1 Achievements

Deliverable 2: *Web site or web board*

To bridge the time for the development of a HSWP website, the webboard of the NCA/NWPL was temporarily used for HSWP communication and information purposes from the start of the project (see annex 3c).

In the course of 2006, a SharePoint site was developed by SAO for the HSWP. With SharePoint user friendly, interactive web environments can be made and managed. It is a web site with restricted access, for which users have to register. The website under construction was presented during the HSWP meeting in June 2006 (see annex 16c), and the site become operational in September 2006. All HSWP members were sent a an e-mail with an invitation to register and instructions on how to do so. A reminder was sent out in November. The website contains, besides a home page with news items and announcements, several sub-pages: one containing Working Party related documents; one where users of the site can place information on themselves; one containing information on all the projects within the Working Party; a page with information on SAO, a page with links to important EC sites, project sites et cetera; and a forum page. See annex 16e for a print of the homepage of the HSWP site.

Deliverable 5: *WP meetings*

Achievement: SAO supported the planning and organisation of four meetings of the HSWP; the fifth meeting of the HSWP, and its back-to-back meeting with the DG INFSO Work Group on eHealth in December 2005, and the sixth meeting of the HSWP, and its back-to-back meeting with the DG INFSO Work Group on eHealth in June 2006.

The agendas for the meetings were drafted by SAO (except for the June meeting with DG INFSO) and decided upon in consultation with SANCO and the HSWP deputy leader. While SANCO took care of inviting the participants and arranging for the meeting facilities, SAO distributed the agenda and background materials. Usually speakers from the EC were invited by SANCO, and external speakers by SAO. See annex 16 for the agendas, minutes and SAO presentations of the HSWP meetings.

Deliverable 7: *Progress reports*

Achievement: For the NCA/NWPL meetings, all Working Parties and Task Forces are requested to write a report on their progress during the past half year. For the projects of the Working Parties and the Task Force SAO is supporting, SAO developed a template for biannual information collection (see annex 8). SAO send out the template to the projects under the HSWP, and, based on the information gathered, Powerpoint presentations on the progress of the WP were prepared by SAO for both NCA/NWPL meetings that took place in the period covered by this report (see annexes 3a-b for the

presentations). The Deputy Working Party leader presented the presentations during both NCA/NWPL meetings.

Deliverable 8: *Annual work plans*

Achievement: SAO has distributed the request of the European Commission for suggestions for the Work Plan 2007 among the WP members. The provided input was collated the received inputs and distributed it to the Commission. Moreover, SAO has suggested to discuss the ongoing developments with regard to the realization of the Work Plans 2006 and 2007 on the agenda of the WP meetings that took place in the period covered by this report, as to keep the members informed and to give them another platform for communicating with the Commission on this topic.

Deliverable 9: *Project reviews*

Achievement: Structured project reviews were not carried out as yet. This deliverable was discussed during the meeting of the associated partners of the SAO project in October 2006; see chapter 5: 'Planned activities December 2006 - November 2007' for the decisions that were made during that meeting.

Deliverable 10: *Background/review documents*

Achievement: No background or review documents were requested by the HSWP during the period that is reported on here.

Deliverable 11: *Workshop/pre-conference*

Achievement: SAO staff visited the EUPHA conference in November 2006 to attend pre-conferences and workshop from among others the WP on Life Style and related topics, to form ideas on the organisation of a HSWP workshop/pre-conference at EUPHA in 2007. At the annual meeting of the Health Services Section of EUPHA, SAO together with SANCO, presented the possibility of a HSWP session at the next EUPHA, which was welcomed by the section. See further, chapter 5: 'Planned activities December 2006 - November 2007' for the planned EUPHA workshop(s) for the HSWP.

Deliverable 12: *List of indicators*

Achievement: In the autumn of 2006, SAO has been making an inventory of the indicator related output of the projects within the HSWP to provide to ECHIM. Project reports published during the Public Health Programme were assessed. Moreover, SAO coordinated the actions related to a request from the WP on Health Indicators for suggestions for the update of the ECHI shortlist. First a draft e-mail, containing instructions for the project leaders on how to formulate suggestions was made based on the request of the WP on Health Indicators. Subsequently, the project leaders were approached by e-mail and requested to send possible suggestions for updating the shortlist to SAO. The results of both these exercise were presented by SAO during the HSWP meeting and during the WP on Health Indicators meeting of December 2006. Therefore of December 2006, we will report on this in more detail in the final report, which will cover the period December 2006-November 2007.

Additional Activity: *Presenting overview of HSWP indicator related activities at the WP on Indicators meeting*

Achievement: SAO was present at the WP on Indicators meeting in May 2006, representing the HSWP. SAO prepared and gave a presentation, which consisted of an overview of HSWP indicator related activities (see annex 18).

Deliverable 13: *Electronic update memo/newsletter*

Achievement: Starting 2007, SAO will prepare the first edition of the HSWP Newsletter. See further, chapter 5: 'Planned activities December 2006 - November 2007'.

Deliverable 15: *Meetings with Commission Services*

Achievement: SAO prepared every HSWP meeting in advance together with SANCO (except for the December 2005 meeting, because the SAO contract was not signed well in advance of the meeting). For this purpose, SAO visited in May 2006 SANCO offices in Luxembourg, and convened meetings

during the EUPHA conference in November and during the European Health Forum in Gastein to pre-discuss the next HSWP meetings and related SAO activities.

Additional activities: *Supporting the Commission in distributing information and requesting input*

Achievement: On a daily basis SAO supports the Commission in distributing health system related information to the HSWP members and asking input for different purposes.

Additional activities: *Drafting a HSWP Glossary*

SAO has started with developing a glossary that covers the work field of the HSWP. It will consist of definitions of a selection of important terms used by the projects in the field of Health Systems. The glossary aims to achieve common understanding and consistency in use of these terms for the projects, the Commission and related work in the European Community.

Deliverable 10: *Background/review documents: Work Programme of the HSWP*

Achievement: SAO prepared a Work Programme for the HSWP, that will continuously be updated. The introduction of the Work Programme provides a definition of the goal of the HSWP, and provides contact information for support and coordination purposes of the WP. The Work Programme overview itself is divided into 2 high level areas of 'Health Systems Performance' and 'Health System Organisation & Structure'. It provides for each area a thematically structured overview of the aims and activities of the projects of the HSWP under the former Health Monitoring Programme and the current Programme on Community Action in the field of Health and Consumer Protection 2003-2008. Aims of the document are to provide a complete and informative overview of what has been/is going on within WP, to serve as a tool for identifying areas or topics which are not adequately covered as yet, and to serve as a tool to recognize common issues and common interests between projects. The Work Programme also includes the identification of overlapping projects with other Working Parties in the Health Information Strand of the Public Health Programme. The document was for the first time discussed during the HSWP meeting of 21 June 2006.

3.7.2 Reflection on achievements

Overall, SAO is satisfied in how it has been coordinating the activities of the Health Systems Working Party. SAO has tried to be as transparent as possible towards the Commission and the WP members on how it sees its role and activities in supporting the WP, by presenting and communicating its passed and planned activities continuously during and between the meetings. This has resulted in increased cooperation by project leaders when SAO needs their feedback or input, and increased awareness of the function of SAO, reflected in contacts with the projects and the Commission.

Soon after the start of the project, SAO was confronted with a change of staff by the Commission officer responsible for the HSWP, as well as a maternity leave (later on followed by a resignation) of the WP leader. At the time, these sudden developments created some uncertainty in the direct communication between SAO, the Commission and the WP. However, it turned out quite well. A new SANCO officer became in office in February 2006, with whom SAO communicates on a daily basis and from whom SAO receives sufficient feedback. The deputy working party leader replaced immediately the working party leader, and was very willing in cooperating actively with SAO.

SAO has tried to improve the transparency of the working area and output of the WP by creating a Work Programme. This turned out to be helpful not only for SAO itself because it simplifies the comprehensive work field of the WP, but also for the Commission in identifying gaps in health system areas that potentially need to be addressed in the annual work plans, and for the Working Party on Indicators. The relation with ECHIM has improved during the course of the project, by inviting ECHIM to every meeting, by synthesizing the indicator output of the HSWP projects and presenting the results during the HSWP meetings, as well as during the meetings of the WP on Indicators.

The joint meetings with the eHealth Work Group of DG INFSO were useful for the WP, because it allows them to act as Health System advisors for the more technically oriented eHealth projects and to identify overlaps in projects between the groups. SAO organised (agenda setting, inviting speakers, writing minutes, etc) the HSWP meetings, but limited its activity for the joint meetings to taking minutes.

By recurrently inviting the High Level Group on Health Services and Medical Care to provide the WP updates on their work, the WP felt more in touch with the policy development of the Commission. The recurrent agenda points for the Commission to inform the WP on general developments taking place within the HI Strand also greatly contributed to this. Between meetings, SAO keeps informing the WP members on SANCO policy, and more general European health system developments, though SAO depends greatly on the information it receives from the Commission.

In addition to the day-to-day coordination activities, SAO tries to take up some more in-depth activities. Among these are the development on a public website now that the internal one has been completed; publishing regularly a HSWP newsletters to inform the WP, Commission and the general public on important WP and health system developments; developing a glossary for the WP on its key working terms; continuing synthesizing the indicator output of the HSWP and communicating it to the WP on Indicators; and organising a HSWP workshop at an international conference. Though SAO's activities depend greatly on the needs of the WP and the Commission, it will keep identifying new activities to improve the coordination, effectiveness and efficiency of the HSWP.

4 Planned activities December 2006 - November 2007

4.1 NCA/NWPL

Meetings:

In the period December 2006-November 2007 SAO will support the organization of 2 NCA/NWPL meetings. SAO will make the summary reports for these meetings.

Preparatory meetings with SANCO:

At least one meeting will be planned with SANCO for the preparation of each NCA/NWPL meeting. If necessary additional meetings can be planned.

Web board:

SAO will continue to keep the NCA/NWPL web board up to date, especially prior to NCA/NWPL meetings.

Public website:

During the first half of 2007, SAO will develop a public website for the NCA/NWPL. Main component of this site will be an organization chart of the Health Information Strand, which SAO is currently developing at the request of SANCO (see below).

Electronic organization chart:

At the request of SANCO, SAO is preparing an electronic organization chart of the Health Information Strand. Currently, a paper version of the chart has been worked out, in which all the links to the appropriate pages of the SANCO website have been collected. This outline will be presented to the EC and to the NCA at the forthcoming meeting of the NCA in January 2007. Comments and suggestions will be processed, after which SAO will, during the first half of 2007, transpose the paper chart into a web based chart.

Information package Health Information Strand:

During both NCA, NWPL and WP and TF meetings, it became apparent that for newcomers to the Strand it is very difficult to get an overview of its structure, and to find out what specifically is expected of the newcomer in terms of contributing to the goals and aims of the Strand. Therefore the Commission asked SAO to prepare an information package, which can be provided to newcomers to the Strand. SAO will develop this information package alongside the development of the organization chart (see above).

Work Group on Data Protection of the NCA:

SAO will organize a WG meeting in December 2006, in which the results of the questionnaires (see achievements SAO for the NCA) will be discussed, and the statement on desired actions will be formulated. SAO will do the reporting. The WG will present the statement to the EC and the NCA during the NCA meeting of January 2007. SAO will support the WG in preparing this presentation. Furthermore, SAO will prepare a scientific publication on the outcomes of the questionnaires on behalf of the WG.

Internal evaluation of the Health Information Strand:

During the NCA meeting of July 2006 it was decided, in the light of the forthcoming New Programme on Community Action in the field of Health 2007-2013, to carry out an internal evaluation of the Health Information Strand. SAO was assigned to coordinate this evaluation. In consultation with the Evaluation Committee that was formed by SAO in the autumn of 2006, a questionnaire will be developed, which SAO will distribute among all the actors in the field. SAO will report on the (preliminary) outcomes of the questionnaire at the NCA meeting of January 2007.

Project database:

At the request of the NCA and the Commission, SAO has developed a database for every Member State with contact information of the leading and associated partners involved in projects within the Health Information Strand of the EU Public Health Action Programme (see annex 6). SAO will continue updating the database.

Country progress reports:

Based on the outcomes of the evaluation of the NCA meetings that SAO carried out in 2006, the templates for the country progress reports will be adapted prior to the next meeting of the NCA (January 2007). In preparations of the NCA meetings in January 2007 and in the summer of 2007, SAO will send out this template to the CAs and process their reports into presentations, which SAO will give during the NCA meetings.

Supporting the Commission in distributing information and requesting input

SAO will continue to support on a daily basis the Commission in distributing policy related information to the NCA members and asking input for different purposes.

4.2 WPMM/TFMCD

Meetings:

In the period December 2006-November 2007 SAO will support the organization of 1 WPMM meeting (June 2007) and 2 TFMCD meetings (December 2006 and June 2007). SAO will make the summary reports for these meetings.

During the TFMCD meeting in December 2006 it was decided that additional meetings for the projects related to cancer and the projects related to child health will be organized in 2007. As yet the role of SAO in these meetings is not clear.

Preparatory meetings with SANCO:

At least one meeting will be planned with SANCO for the preparation of the WPMM and TFMCD meetings in June 2007. If necessary additional meetings can be planned. SAO visited SANCO in October 2006 to prepare the meeting of the TFMCD in December 2006.

Internal website:

SAO will continue to keep the internal website for the WPMM up to date. Special attention will be paid to ensuring all (new) members register for the site, especially prior to WPMM/TFMCD meetings. Actions will be developed to enhance active use of the site by the members, as to stimulate its platform function for the WPMM.

Public website:

During the first half of 2007, SAO will develop a public website for the TFMCD. This site will contain TF and project related information of interest to the EU citizen. An access to the internal website will be placed on the public website, as to logically establish a link between both sites. The precise structure of the website (WPMM website with links to the sites of the 3 TFs, or just TFMCD site) will be have to be decided upon in consultation with SANCO and the WP and TF leaders.

WPMM Newsletter:

SAO will make 4 editions of the WPMM Newsletter in 2007 (spring, summer, autumn and winter edition). The projects will be asked for contributions (news, introduction of new projects) and SAO will collect information on major (European) developments in the field of Morbidity and Mortality.

Progress reports:

As during the past year, SAO will send out templates for progress reporting to the projects of the TFMCD prior to the NCA/NWPL meetings, and will prepare presentations on the TFMCD (and, if appropriate, WPMM) progress for the TF (WP) leaders to be given during these meetings.

Updating and improving overview document of past and current activities TFMCD:

SAO will present the overview document at the TFMCD meeting of December 2006. Suggestions and remarks made during that meeting will be processed. In consultation with the TFMCD members and SANCO, SAO will develop procedures for how to keep the document updated, and how to identify adaptations necessary to guarantee that the document can fulfil its aims. SAO will aim to develop these procedures during the first quarter of 2007. The document can then be updated before the TFMCD meeting of June 2007, and the updated version can be discussed during that meeting.

List of indicators:

SAO will continue to monitor the indicator related output of the TFMCD. Interim and final reports and, if necessary, additional publications of projects will be checked for relevant information on a continuous basis. During the first quarter of 2007, SAO will develop a suitable database to store this information in. ECHIM and SANCO will receive regular updates of this database. TF members will be able to reach the latest version of the database at the internal WPMM website.

SAO will prepare presentations on behalf of the TFMCD on the indicator related output for the meetings of the WP on Indicators in December 2006 and in the spring/summer of 2007. In consultation with the TF leaders, it will be decided whether SAO will represent the TFMCD at these meetings, or whether the TF leaders will attend the meetings themselves.

Organising workshop:

SAO will initiate, coordinate and support the organisation of a workshop for the European Public Health Association, which will have its annual conference in the autumn of 2007. Deadline for submission will probably be early May 2006. SAO will develop proposals for possible topics, which will be discussed with the TF leaders and SANCO. After a joint decision has been taken, SAO will start the organisation and coordination process, resulting in a fully worked out (and hopefully successful) submission.

Supporting the editorial board for the Major and Chronic Diseases Report 2006:

SAO will report the meetings of the editorial board. Moreover, SAO will continue to attempt to get to grips with the coordination of the realization process of the board. Task SAO probably will carry out within the framework of supporting the editorial board are: coordinating all correspondence with the writers of the chapters, monitoring progress and keeping a watch on the timetable, being the contact for EUROSTAT on behalf of the authors, addressing external experts for the review committee, collecting all contributions and coordinating the review process.

Project review:

SAO will propose, during the first quarter of 2007, to SAO's associated partners, a methodology for carrying out at least two structured reviews of final reports of projects within the TFMCD. Main aim of these reviews is to establish to what extent the presentation of results and conclusions attributes to the overall goal of the Health Information Strand.

During the October 2006 meeting of the associated partners of the SAO project, it was decided to make an inventory of the usage of the template for the executive summary of projects' final reports, which the SNAW project (predecessor of SAO) made in 2004. SAO will make this inventory during the half of 2007.

The results of this exercise, together with the outcomes of the structured reviews of final reports, will be summarized in a report, which will be discussed with the associated partners. After finalization, this report will be presented to SANCO.

Supporting the Commission in distributing information and requesting input

SAO will continue on a daily basis to support the Commission in distributing morbidity, mortality, and major and chronic diseases related information to the WPMM/TFMCD members and asking input for different purposes.

4.3 HSWP

Meetings

In the period December 2006-November 2007 SAO will support the organization of 3 HSWP meetings (December 2006, June 2007, and December 2007). SAO will make the summary reports for these meetings.

Preparatory meetings with SANCO:

At least one meeting will be planned with SANCO for the preparation of the HSWP meetings in 2007. If necessary additional meetings can be planned. SAO met SANCO in November 2006 in Montreux to prepare the meeting of the WP in December 2006.

Internal website:

SAO will continue to keep the internal website for the HSWP up to date. Special attention will be paid to ensuring all (new) members register for the site, especially prior to HSWP meetings. Actions will be developed to enhance active use of the site by the members, as to stimulate its platform function for the HSWP.

Public website:

During the first half of 2007, SAO will develop a public website for the HSWP. This site will contain WP and project related information of interest to the EU citizen. A password protected entry to the internal website will be placed on the public website, as to logically establish a link between both sites. The precise structure of the website will have to be decided upon in consultation with SANCO and the HSWP leaders.

HSWP Newsletter:

SAO will make at least 2 editions of a HSWP Newsletter in 2007. This Newsletter will address a broad audience: it aims to inform the interested EU citizen on the achievements of the HSWP, as well as the HSWP members on the major developments within Europe, within the HSWP and within the field of Health Systems. The projects within the HSWP will be asked for contributions (news, introduction of new projects) and SAO will collect information on major (European) developments in the field of Health Systems. Furthermore, SAO will collect information on major European developments in the field of Public Health, and on recent publications from the projects within the HSWP. All contributions will be edited by SAO.

Progress reports:

As during the past year, SAO will send out templates for progress reporting to the projects of the HSWP prior to the NCA/NWPL meetings, and will prepare presentations on the HSWP to be given during these meetings.

Updating and improving Work Programme document of past and current activities HSWP:

SAO will continuously update the Work Programme document. Updated versions will always be published on the internal website of the WP. In particular, before every HSWP meeting the updated programme will be brought under the attention of HSWP members, to initiate discussion during the meeting on it, if necessary.

List of indicators:

SAO will continue to monitor the indicator related output of the HSWP. Interim and final reports and, if necessary, additional publications of projects will be checked for relevant information on a continuous basis. ECHIM and SANCO will receive regular updates of this information. SAO will prepare presentations on behalf of the HSWP on the indicator related output for the meetings of the WP on Indicators in December 2006 and in the spring/summer of 2007. In consultation with the HSWP leaders, it will be decided whether SAO will represent the HSWP at these meetings, or whether the WP leaders will attend the meetings themselves.

Organising workshop:

SAO will initiate, coordinate and support the organisation of a workshop for the European Public Health Association, which will have its annual conference in the autumn of 2007. Deadline for submission will be early May 2006. SAO will develop proposals for possible topics, which will be discussed with the HSWP leaders and SANCO. After a joint decision has been taken, SAO will start the organisation and coordination process, resulting in a fully worked out (and hopefully successful) submission.

Project review:

SAO will propose, during the first quarter of 2007, to SAO's associated partners, a methodology for carrying out at least two structured reviews of final reports of projects within the HSWP. Main aim of these reviews is to establish to what extent the presentation of results and conclusions attributes to the overall goal of the Health Information Strand.

During the October 2006 meeting of the associated partners of the SAO project, it was decided to make an inventory of the usage of the template for the executive summary of projects' final reports, which the SNAW project (predecessor of SAO) made in 2004. SAO will make this inventory during the half of 2007.

The results of this exercise, together with the outcomes of the structured reviews of final reports, will be summarized in a report, which will be discussed with the associated partners. After finalization, this report will be presented to SANCO.

Developing a HSWP Glossary

SAO will complete the development of a glossary that covers the work field of the HSWP. It will be a joint activity with the WP leaders and project leaders, coordinated by SAO. The internal website will provide a good shared working environment for this purpose. The glossary will consist of definitions of a selection of important terms used by the projects in the field of Health Systems, which will complete the one's done by other bodies like WHO and OECD. The glossary aims to achieve common understanding and consistency in use of these terms for the projects, the Commission and related work in the European Community.

Supporting the Commission in distributing information and requesting input

SAO will continue on a daily basis to support the Commission in distributing health system related information to the HSWP members and asking input for different purposes.

5 Continuation of the Scientific Assistance Project

At this moment, it is not yet clear whether the EC will call for a continuation of the SAO project, as the Public Health Work Plan 2007 has not been published as yet. Given the establishment of the Public Health Executive Agency (PHEA) on 1 January 2005, however, a change in the position and function of the secretariats for the Working Parties and Task Forces at least is to be expected. The newly established PHEA, combined with the fact that the New Programme of Community Action in the field of Health 2007-2013 has not been approved as yet, provides for a climate of uncertainty in which it is hard for the EC to oversee all the changes for the Health Information Strand ahead, and hence to anticipate adequately.

Reflecting on SAO's activities, it is clear that SAO is supporting several important structures in the Strand; the NCA, the NWPL, and the two largest Working Parties in the Strand; the HSWP and the WPMM. Of the latter, SAO also supports its largest sub-structure; the TFMCD. SAO's precursor project, SNAW, supported only the Networks of CAs and of WPLs. It ran from February 2004 until March 2005. Within the existing budget limits it was possible to stretch the duration of the project to cover the July 2005 meeting of the NCA. The current project started its activities with supporting the December 2005 meeting, which implies that the Scientific Secretariat has been supporting the Networks continuously for three years now. As such, the Secretariat has established a solid position by now. More and more it has gotten to grips with the policy developments within the European health field, and the needs of both the EC and the CAs and WPLs. This is reflected in the improving agendas for the NCA/NWPL meetings, which SAO increasingly is drafting itself. Moreover, the fact that the Secretariat has been present for quite some time now, is a safeguard for the continuity of several important processes, such as the health policy reporting at MS level and the progress reporting of the Working Parties and Task Forces. With regard to the tasks the Secretariat performs for the NCA, it is also clear that without the (extensive) support of a Secretariat, it would be very hard to adequately respond to emerging needs, such as the data protection issue or the internal evaluation of the Strand.

With the start of the current Secretariat, the SAO project, the HSWP, the WPMM, and the TFMCD were to be supported as well. The WPMM furthermore comprises the TFRD, and the recently established TFHE. As the TFRD has a very active Secretariat itself, the main focus of the Secretariat during the past year has been the support of the HSWP and TFMCD. Working Parties and Task Forces are very different structures than the Networks the Secretariat had experience with. Moreover, the Working Party and Task Force SAO is supporting are very extensive structures, holding large numbers of projects covering a wide range of topics. Therefore it took some time for SAO's role to become clear and for relationships between SAO and the different actors in the field to develop. However, also for these structures by now it is hard to imagine them functioning without the secretariat. During the past year there have been many changes of staff at SANCO. Moreover, every year new projects start within the Working parties and Task Forces. This has made that, even within the relatively short period SAO has been supporting the HSWP and TFMCD, the Secretariat is the safeguard for the continuity of processes. The Secretariat has come to grips with the activities and aims of all the projects within the supported structures, and as such has become an indispensable source of information for the EC and ECHIM. Additionally, SAO has developed/will develop and manage several important communication tools, such as the Newsletters for the supported Working Parties, the internal and the public websites.

In conclusion it seems justified to state that a discontinuation of SAO's activities after December 1st 2007 would definitely harm the effectiveness and efficiency of the Health Information Strand structured as it is. One way or another, the role of the secretariat has to be continued, either by calling for a new Scientific Assistance Office project, or by transferring its task to another actor, such as the PHEA. The SAO research team urge the EC to give this issue considerable and timely thought.

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