

Supporting the Networks of Competent Authorities and the Network of Working Party Leaders (SNAW)

Final Technical Implementation Report

Period: February 2004 – August 2005

Project Number: 2003110 (791053)

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EXECUTIVE SUMMARY

EXECUTIVE SUMMARY FOR EU REPORTS WITHIN THE HEALTH INFORMATION STRAND

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. Priority 2.2.1: Developing and co-ordinating the health information system	
2. <u>TITLE OF PROJECT:</u> Supporting the Network of Competent Authorities and the Network of Working Party Leaders (SNAW)	
3. <u>START DATE OF THE PROJECT:</u> 01- 02 - 2004 (dd-mm-yyyy)	
4. <u>DURATION OF THE PROJECT:</u> 12 (months)	
5. <u>PROJECT LEADER / ORGANISATION</u> (include contact address): Dr. François G. Schellevis NIVEL, Netherlands Institute for Health Services Research PO Box 1568, 3500 BN Utrecht The Netherlands www.nivel.nl	
6. <u>PROJECT NUMBER:</u> 2003110(791053)	
7. <u>SANCO REPRESENTATIVE:</u> Horst Kloppenburg	
8. <u>COUNTRIES INVOLVED</u>	
<u>MEMBER STATES:</u>	<u>CANDIDATE COUNTRIES:</u>
<input checked="" type="checkbox"/> A (Austria)	<input checked="" type="checkbox"/> BG (Bulgaria)
<input checked="" type="checkbox"/> B (Belgium)	<input checked="" type="checkbox"/> TR (Turkey)
<input checked="" type="checkbox"/> CY (Cyprus)	<input checked="" type="checkbox"/> RO (Romania)
	<input checked="" type="checkbox"/> CR (Croatia)

<input checked="" type="checkbox"/> CZ (the Czech Republic)	<u>EFTA/EEA COUNTRIES:</u>
<input checked="" type="checkbox"/> D (Germany)	<input checked="" type="checkbox"/> (IS) Iceland
<input checked="" type="checkbox"/> DK (Denmark)	<input checked="" type="checkbox"/> (LI) Liechtenstein
<input checked="" type="checkbox"/> E (Spain)	<input checked="" type="checkbox"/> (NO) Norway
<input checked="" type="checkbox"/> EE (Estonia)	
<input checked="" type="checkbox"/> EL (Greece)	<u>OTHERS:</u>
<input checked="" type="checkbox"/> F (France)	
<input checked="" type="checkbox"/> FIN (Finland)	
<input checked="" type="checkbox"/> HU (Hungary)	
<input checked="" type="checkbox"/> I (Italy)	
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<input checked="" type="checkbox"/> LT (Lithuania)	
<input checked="" type="checkbox"/> LV (Latvia)	
<input checked="" type="checkbox"/> MT (Malta)	
<input checked="" type="checkbox"/> NL (Netherlands)	
<input checked="" type="checkbox"/> P (Portugal)	
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<input checked="" type="checkbox"/> S (Sweden)	
<input checked="" type="checkbox"/> SI (Slovenia)	
<input checked="" type="checkbox"/> SK (the Slovak Republic)	
<input checked="" type="checkbox"/> UK (United Kingdom)	
9. REPORT STATUS (INTERIM OR FINAL) / Date:	
Final, November 2005	

II CONTENT RELATED INFORMATION

10. CONTEXT/INTRODUCTION (limit 300 words):

Activities carried out under this project aim at supporting the Network of Competent Authorities (NCA) and the Network of Working Party Leaders (NWPL) in their work leading to the operation of a Health Information and Knowledge System for the European Community. For this purpose, NIVEL provides a scientific Secretariat.

The *network of competent authorities* is the interface between scientific expertise and health policy. The *network of working party leaders* represents the scientific expertise in specific fields of public health and is therefore essential for advice on the European Health Information and Knowledge System.

This project is related to the core of the European Commission's activities within strand I of the European Public Health Action Programme 2003-2008. Through its activities this project will contribute to strengthen the cooperation between scientific experts, public health experts, and health policy on the European level.

The project will also enable and facilitate the cooperation between Member States, applicant countries and EFTA-EEA countries with respect to the provision and availability of information relevant for public health on the European level.

11. AIM AND OBJECTIVES OF THE PROJECT:

- a) to have a shortlist of health indicators included in the European Community Health Information and Knowledge System agreed by the Network of Competent Authorities;
- b) to have recommendations produced about the implementation of the shortlist of health indicators into the European Community Health Information and Knowledge System;
- c) to have recommendations developed about the collection of data necessary for constructing the health indicators in Member States, applicant countries and EFTA/EEA countries;
- d) to support adequate functioning of the Network of Competent Authorities, the Network of Working Party Leaders and the European Information and Knowledge Forum in view of the objectives of the Community Action in the field of Public Health, the Commission Services and Member States.

12. KEYWORDS (use maximum 5 MeSH terms):

Public Health, Health Status Indicators, International Health Problems, Public Health Informatics, Information Dissemination.

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

- a) preparation, organisation and follow-up of meetings:
 - 2 meetings of the network of competent authorities;
 - 4 meetings of the network of working party leaders;
 - 1 meeting of the European Information and Knowledge Forum;
- b) coordination of the activities of Working Parties, especially with regard to the implementation of health indicators into the European Health Information and Knowledge System;
- c) collation, description and dissemination of information provided by projects and

<p>working parties for the implementation of health indicators into the European Health Information and Knowledge System and formulating guidelines for the collection of data, if not available, in Member States, applicant countries and EFTA/EEA countries regarding the short listed health indicators;</p> <p>d) producing progress reports describing the stage of implementation of the European Health Information and Knowledge System.</p>
<p>14. <u>OUTCOMES OF THE PROJECT / KEY HEALTH MESSAGES / ADDED VALUE FOR REACHING GOAL OF EU PUBLIC HEALTH PROGRAMME</u> (limit 250 words);</p> <p>a) organisation of the meetings of the network of competent authorities (four), the network of working party leaders (three). The organisation includes the preparation of the meetings (invitations, agenda, content related documents, financial arrangements, minutes and proceedings) in cooperation with the Commission Services;</p> <p>b) for each meeting of both networks production of progress reports on the stages of implementation of the Health Information strand;</p> <p>c) shortlist of health indicators to be included in the European Community Health Information and Knowledge System agreed by the network of competent authorities to be presented for approval to the Programme Committee.</p> <p>d) Ad hoc workgroup on Confidentiality of Person Data</p>
<p>15. <u>CONCLUSIONS</u> (limit 250 words):</p> <p>The support of the NIVEL Secretariat has resulted in:</p> <ul style="list-style-type: none"> - improved communication and information exchange between and within the two Networks (NCA and NWPL) and SANCO; - agreement on a shortlist of health indicators for implementation; - progress towards the implementation of the European Health Indicators Knowledge System - discussions in NCA meetings on national initiatives, national public health policies, implementation and operationalisation of the ECHI indicators, EU public health policy and issues - discussion on progress in Working Parties and synergies and overlap between Working Parties - the establishment within the NCA of an ad hoc work group on Confidentiality of Person Data to develop recommendations regarding this issue related to the use of Health registrations and exchange of these data between Member States
<p>16. <u>PLAN OF DISSEMINATION OF RESULTS:</u></p> <p>The activities of this project are visible through:</p> <ul style="list-style-type: none"> - minutes of meetings, on the Europa website, section Public Health. - presentations and information documents, attached to the minutes and also available on the Europa website - a web board with restricted access for NCA and NWPL members, for dissemination of documents and facilitation of discussion within and between the two groups - progress reports of Working Parties and Country Reports, indicating progress in research and at a national level in the area of Health Information - continuation of the ECHI project in the EU Health Portal <p>Where possible and appropriate, scientific articles will be produced in order to reach other target groups than those directly involved.</p>

17. NEEDS FOR FUTURE POLICY DEVELOPMENT (limit 150 words):

The structures set up for the EU Health Information and Knowledge System, and for the Networks and the Working Parties, need structural, continuous, scientific public health assistance to guarantee progress in the implementation of valid ECHI-indicators and to advocate and monitor the implementation of the EU Health Information and Knowledge System into national public health policy in the Member States. The Networks function as advisory boards towards the Commission services, but need support so that their biannual meetings have added value towards the whole programme and that they are proceeding in the context of a specific public health model. The Working Parties (not supported by this project) are in need of own support as the work done by the Working Party Leaders and other members is completely based on voluntary contribution of their part.

The implementation of the full shortlist of ECHI-II is urgently needed to demonstrate a practical outcome of the Health Information Strand of the EU Public Health Action Programme.

The issue of Confidentiality of person data in Health registries needs special attention in the light of the national legislation of the Member States and the new regulations that are developed with EUROSTAT.

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. During the coming years, these European Health Indicators have to be 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. The ECHIM project (or Working Party 7). Will take over this task. The NWPL brings the 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 will seek 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 (NWPL) 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) 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 (see Terms of Reference, TOR). The work plan of the Public Health Action Programme of the European Commission for 2003 and the TOR refer to the need for a supporting Secretariat. This Secretariat has to provide the infrastructural arrangements and create the conditions for an optimally functioning Network of Competent Authorities. It provides also the necessary infrastructure and creates optimal conditions to use the network for the European Health Information and Knowledge System. According to the TOR, it should support the Commission Services in order to coordinate the cooperation of the Programme Committee together with the Network of Competent Authorities and with the Network of Working Party Leaders, to organise and monitor their actions and annual meetings and to link these actions to the work of the project coordinators.

This final technical report describes the objectives, activities and products or deliverables of the Secretariat for the NCA and NWPL. The project started in February 2004 and the report covers the period up to the end of August 2005. The duration of the project was initially for 12 months. A first extension until March 31, 2005, and a second extension until August 31, 2005 was agreed upon with the Commission Services.

2 OBJECTIVES, TASKS AND WORK PLAN

In February 2004 the project started with the installation of the NIVEL Secretariat. Activities carried out under this project aim at supporting the Network of Competent Authorities (NCA) and the Network of Working Party Leaders (NWPL) in their work leading to the operation of a Health Information and Knowledge System for the European Community.

Objectives

Objectives of the project are:

- e) to have a shortlist of health indicators included in the European Community Health Information and Knowledge System agreed by the Network of Competent Authorities;
- f) to have recommendations produced about the implementation of the shortlist of health indicators into the European Community Health Information and Knowledge System;
- g) to have recommendations developed about the collection of data necessary for constructing the health indicators in Member States, applicant countries and EFTA/EEA countries;
- h) to support adequate functioning of the Network of Competent Authorities, the Network of Working Party Leaders and the European Information and Knowledge Forum in view of the objectives of the Community Action in the field of Public Health, the Commission Services and Member States.

Tasks

To achieve the above mentioned objectives the following tasks were formulated.

Primary tasks

The NCA concentrates in its first year on an agreement on a shortlist of health indicators, to be approved by the Programme Committee. The composition of a shortlist had already been initiated within the framework of the European Community Health Indicator project (ECHI-II). These indicators will be the first to be included into the European Health Information and Knowledge System and will become available through the future EU Health Portal.

The NCA will also prepare recommendations on information systems in Member States, applicant countries and EFTA/EEA countries who are unable to deliver the necessary information. If an indicator is considered relevant for public health policy but no data are available (or expected to be available on the short term), the NCA can recommend the Programme Committee to take necessary measures in Member States.

With regard to the availability of data from existing information sources on indicators (such as WHO [health status, burden of disease], OECD [health system performance], and Eurostat [national health accounts, classic demographic statistics, including cause-specific mortality]), these are taken into account.

The project described here is providing and collating the necessary information for the network to facilitate agreement on the shortlist of indicators and to formulate recommendations on the implementation of these indicators into the European Health Information and Knowledge System.

The NWPL concentrates on the operational definitions of the shortlist of health indicators. These definitions should include additional information for each Member State (including the applicant and EFTA/EEA countries) about at least the current (or in the near future expected) and long-term availability of the necessary data for constructing the indicator, the validity of the information, the comparability of the information on the European level, and the potential relevance for health policy. As the project on European Community Health Indicators (ECHI-II) plays a central role, the preparation of the meetings will take place in close cooperation with the ECHI-II project. The project described here is responsible for preparing proposals for the network on the definition of health indicators (including the above mentioned information), preparing the decision making process by the working party leaders and monitoring the implementation phase.

Secondary tasks

Both the NCA and NWPL have to carry out other tasks that will also be supported by the project described here. These other activities will be included in detail in the networks' annual work plans. The following tasks of the respective networks are to be supported by this project:

NCA

- surveillance of projects within strand I of the Public Health Programme which aim at supporting the implementation of the European Health Information and Knowledge System
- advise on the analysis and reporting on health issues at EU level
- communicating results from the working parties with the aim of improving information flows, preparing decision making by the Member States and achieving the use of common European Health Indicators
- advising working party leaders on complying with the overall implementation strategies
- reviewing major final reports from projects and other public health reports
- advise on the development of the annual work programmes for the European Health Information and Knowledge System
- ensuring information flows between Member States and with the Commission Services
- paying special attention to the needs and obstacles experienced by accession countries and new Member States with regard to their health information systems and participation in the programme's information and knowledge strand.

NWPL

- writing proposals on and assisting in the development of the EU Health Information and Knowledge System
- coordinating the practical work with the appropriate structures in the European Statistical System (especially with Eurostat)
- promoting the dialogue and exchange of ideas, information and results among researchers and policy makers in EU level health information projects
- fostering linkages with other relevant Community projects in health information and knowledge, in particular in the 6th Research and Development Framework Programme
- ensuring information flows between members of the Network and with the Commission Services
- building close links to the members of the Network of Competent Authorities and to those of the Programme Committee.

Original work plan for the project

I. Months 1-3 (February 2004 – April 2004): preparative phase

- a) Set up a project team
- b) Collect and study the relevant background information
- c) Prepare detailed work plan and detailed task descriptions for team members
- d) Establish contacts with officials from the European Commission, working parties, working party leaders, competent authorities and other relevant parties involved in establishing a European Health Information and Knowledge System including Eurostat, WHO, and OECD.

II. Months 4-14 (May 2004 – March 2004) : implementing a shortlist of health indicators

- a) NCA (2 meetings):
 - progress reports on the implementation of activities in the Health Information strand
 - recommendations on implementation of the shortlist of health indicators
 - establishing availability of necessary and comparable information from Member States
 - recommendations on improving information systems in Member States necessary for the shortlist of health indicators
 - recommendations on the implementation of the European Health Information and Knowledge System
- b) NWPL (4 meetings)
 - providing and collating information on the availability, quality and comparability of information of the shortlist of health indicators in Member States

- formulate recommendations on improvement of the availability, quality and comparability of information systems in Member States necessary for the shortlist of health indicators
- c) Site visits to (a maximum of) 6 new Member States in which the availability and provision of information needs local support; the aim of these site visits is to collect detailed information about information systems, availability and quality of data necessary to construct health indicators
- d) European Information and Knowledge Forum (1 meeting)
 - progress report on the implementation of activities in the Health Information strand
- e) Advice on the Working Plan 2005 of the Community Action in the field of Public Health
- f) Preparation of the interim and final report.

3 ACTIVITIES AND TASKS REALISED FEBRUARY – AUGUST 2004

Realized activities are presented following the structure of the work plan part I and II.

Ad Work plan part I

- a) Setting up a Project team at NIVEL premises in Utrecht, the Netherlands : a team was created with a project leader/research co-ordinator, research co-ordinator/public health specialist, senior researcher and junior researcher (all part-time).
 - Weekly meetings with project team: list of tasks and activities developed per member of team
- b) Collecting and study background information:
 - Collection of all interim and final reports of all finished and running projects within Strand I Health Information (hard copy or downloaded electronically)
 - Collection of all background information of projects pertaining to the various Working Parties, organised per Working Party
 - Collection of relevant background documents about EU policy on Public Health produced by EU, WHO regional office, Eurostat and OECD.
- c) Production of detailed internal work plan and task descriptions
- d) Establish contacts at different levels of the Health Information Strand:
 - Regular meetings with SANCO C2 in Luxembourg (every 6 to 8 weeks)
 - to familiarise the Secretariat with the activities and personnel of SANCO C2
 - to discuss preparation of the meetings of both networks NCA and NWPL
 - to discuss progress towards the European Health Information and Knowledge System
 - Setting up a Web Board electronically at NIVEL that should function as a communication and discussion tool for all Working Party Leaders, Competent Authorities and SANCO C2 personnel. It is now up and running and being adjusted following suggestions made by users.
 - Development of country lists of members of Working Parties, NWPL and NCA to facilitate contacts between participants per country.
 - Development of address lists of all participants in the Health Information Strand.
 - Contacts with individual NCA and NWPL for different purposes as follow-up of process within WPs (see further), activities at country level related to the Health Information Strand.

Ad Work plan II

a) Network of Competent Authorities

- Preparation of NCA meetings:
 - Setting the agenda for the NCA meeting in July 2004 in collaboration with SANCO C2
 - Inviting external speakers for the NCA meeting in July 2004
 - Summary of activity report of Working Parties (WPs)
 - Presentation of a Web Board
 - Collection and distribution of background documents produced by the Commission for the WP Morbidity and Mortality and by Eurostat.
- Facilitating the NCA meetings:
 - Production of minutes of the NCA meeting in December 2003, which was held 2 months before the formal start of the Secretariat
 - Taking minutes of meeting in July 2004
 - Introducing agenda items through presentations on the mandate synopsis, the progress report of the WPs and the Web Board.
 - Technical assistance of presentations of other representatives
- Follow-up of the NCA meetings:
 - Production of minutes (December 2003, July 2004)
 - Generating items for the next meeting
 - Improving and updating the Web Board

b) Network of Working Party Leaders

- Preparation of NWPL meetings:
 - Setting the agenda for the meeting in July 2004 in collaboration with SANCO C2
 - Production of a text for the mandate of the NWPL
 - Summary of activity report of the WPs: preparation of template for progress reports
 - Production of a synopsis to discuss the mandates of the working parties
 - Production of a list of projects per country and per WP.
 - Development of a Web Board
- Facilitating the NWPL meetings:
 - Taking minutes at meeting in July 2004
 - Introducing agenda items through presentations on the mandate synopsis, the progress report of the WPs and the Web board.
 - 1. Technical assistance of presentations of other representatives
- Follow-up of the NWPL meetings:

- Production of minutes of meeting in July 2004
 - Generating items for the next meetings
 - Improving and updating the Web Board
- c) Site visits to new Member States: not opportune due to the development of the Eurostat Task Force with new Member States.
- d) European Information and Knowledge Forum: postponed by the Commission
- e) Advice on the Working Plan 2005 of the Community Action in the field of Public Health
- f) Production of the interim report.

4 PLANNED ACTIVITIES SEPTEMBER 2004 – MARCH 2005

1. Preparation and facilitating the NCA meeting in January 2005
 - a. Contacts with CAs: feedback and suggestions concerning draft agenda
 - b. Collection of progress reports of CA concerning national activities
 - c. Contacts with Eurostat, CARD, EU network of cancer registries for contributions
 - d. Report on Dutch registries
 - e. Production of templates for progress reports and executive summaries.
2. Preparation and facilitating the NWPL meeting in January 2005
 - a. Contact with WPL: feedback on agenda
 - b. Collection of progress reports
 - c. Update of template for progress reports
3. Updating the Web Board
4. Transition of tasks of Secretariat to Executive Agency.
5. Draft Final report, inclusive of financial statement.

5 ACTIVITIES AND TASKS REALISED SEPTEMBER 2004 – MARCH 2005

The description of realised activities and tasks follows the structure of the planned activities and tasks for this period, see under chapter 4.

1. Preparation and facilitating the NCA meeting in January 2005
 - a. Contacts with CAs: feedback on agenda, change the agenda accordingly, after consultations with SANCO.
 - b. Collection of progress reports of CA concerning national activities
 - c. Contacts with Eurostat, CARD, EU network of cancer registries for contributions
 - d. Presentation on Dutch registry systems.
 - e. Production of templates for progress reports and executive summaries.
 - f. Production of minutes for the meeting
 - g. Summary of progress reports
2. Preparation and facilitating the NWPL meeting in January 2005
 - a. Contact with WPL: feedback on agenda, change to the agenda accordingly, after consultations with SANCO.
 - b. Collection of progress reports
 - c. Update of template for progress reports
 - d. Production of minutes for the meeting
 - e. Summary of progress reports
3. Updating the Web Board
 - a. Uploading of all relevant information on the web board: draft minutes of meetings, presentations held at meetings, additional document which were distributed at the meeting.
 - b. Access to the board for additional members at their request
 - c. Solving problems related to accessing the board
 - d. Addition of received contact information for WPs.
 - e. Reminding user of the existence of the board
 - f. Placing the templates for the progress reports on the board, for members to download and complete.
4. Transition of tasks of the Secretariat to the Executive Agency

NIVEL has proposed to the Commission to continue the Secretariat's activities until August 2005 within the existing budget limits. As the remaining budget was limited, only the very urgent activities for the meetings of July 2005 could be realised. However, the Executive Agency will not be operational for Strand I until well into 2006. Therefore, there will be no transition of tasks of the Secretariat to the Executive Agency at the end of the project. The Commission is considering how to ensure continuation of the Web board in the intermittent period.
5. Preparation of draft final report, inclusive of financial statement.

6 PLANNED ACTIVITIES MARCH 2005 – AUGUST 2005

1. Preparation and facilitating the NCA meeting in July 2005
 - a. Contacts with CAs: feedback and suggestions concerning the draft agenda
 - b. Collection of progress reports of CA concerning national activities
 - c. Collection of issues from CAs for the meeting
 - d. Evaluation of former 8 community Programmes: overview of lessons learned
 - e. Confidentiality of Person Data:
 - o NCA to be contacted to collect common practices, legislation, regulations
 - o overview document
 - o expert meeting at SANCO with representative CA, EUROSTAT, other experts.
 - f. Best practices to present at NCA
 - g. Adaptation of templates for progress reports and executive summaries.
2. Preparation and facilitating the NWPL meeting in July 2005
 - a. Document about overlap between WP's and health model: to work out ideas together with Pieter Kramers (ECHI-II)
 - b. WP7/ECHIM: tasks, mandate to be presented and discussed
 - c. Allocation of projects to WPs: working out ideas with P.Kramers
 - h. Contact with WPL: feedback on agenda
 - i. Collection of progress reports
 - j. Update of template for progress reports
3. Updating the Web Board
4. Final report, inclusive of financial statement.

7 ACTIVITIES AND TASKS REALISED MARCH 2005 – AUGUST 2005

The description of realised activities and tasks follows the structure of the planned activities and tasks for this period, see under chapter 6.

1. Preparation of the NCA meeting in July 2005
 - a. Contacts with CAs: feedback on agenda, change the agenda accordingly, after consultations with SANCO.
 - b. Collection and summarizing progress reports of CA concerning national activities; presenting summary at NCA meeting
 - c. Contacting the needed EU services for the various items on the agenda:
 - Commission C6 to deal with the Final Evaluation of the former Community Action programmes
 - Commission C5: Report of High Level Group on Health Services and Medical Care Activities and Patient Mobility
 - EUROSTAT: Regulation concerning Community Statistics on Public Health and Health and Safety
 - d. Confidentiality of Person Data:
 - Preparation meeting at SANCO with mr. Stenbeck (CA Sweden), EUROSTAT, mr. Karl Freese (SANCO C4) and SANCO C2.
 - Attendance at PRIVIREAL meeting in Brussels: evaluation of the EU Directive on Person Data (95/46/EC) related to medical research and ethical committees
 - Collection of data regarding the situation in member states through the CAs
 - Presentation of summary of the collected information and introduction to the Directive.
 - Contact with Sweden and Malta to present National cases
 - Contact with the European Network of Cancer Registries (ENCR) and EUROCAT (Congenital Anomalies) to present their experiences
 - e. Adaptation of template for progress reports and executive summaries in collaboration with CA from UK, Germany and Greece.
 - f. Summary of national progress reports and presentation at NCA meeting with focus on health inequalities
 - g. Presentation of summary of progress reports of Working Parties
 - h. Presentation of evaluation of use of Web board
 - i. Summarizing national initiatives related to health inequalities (collected from the progress reports).
 - j. Production of minutes for the meeting
2. Preparation of the NWPL meeting in July 2005
 - a. Contact with WPL: feedback on agenda, change to the agenda accordingly, after consultations with SANCO.
 - b. Production of document of overlap between Working Parties initiated by dr.

- P. Kramers (ECHL-I and II)
 - c. Collection of progress reports
 - d. Update of template for progress reports
 - e. Summary of progress reports
 - f. Production of minutes for the meeting
3. Updating the Web Board
- a. Uploading of all relevant information on the web board: draft minutes of meetings, presentations held at meetings, additional document which were distributed at the meeting.
 - b. Access to the board for additional members at their request
 - c. Solving problems related to accessing the board
 - d. Addition of received contact information for WPs.
 - e. Reminding user of the existence of the board
 - f. Placing the templates for the progress reports on the board, for members to download and complete.
 - g. Access to the board for members of Health Systems Working Party
 - h. Uploading documents for HSWP for the meeting of April 2005

8 FINAL TECHNICAL INFORMATION

Manpower for the execution of the project

Person & professional level	<u>1/2 2004 -1/2 2005</u>			<u>1/2 -1/9 2005</u>		
	Man/days	Unit cost	Total cost	Man/days	Unit cost	Total cost
<u>Scientific Staff</u>						
Supervisor NIVEL	82	518,83	42.544,06	2	539,58	1.079,16
Project leader	124	383,19	47.515,56	30	398,32	11.949,60
Project coordinator	190	356,28	67.693,20	128	370,53	47.427,84
Senior researcher	143	314,42	44.962,06	70	327,00	22.890,00
Senior researcher	198	227,92	45.128,16	-	-	-
<u>Secretarial costs</u>						
Clerical staff member	220	134,15	29.513,00	120	139,56	16.747,20
<u>Other personnel costs</u>						
Communication information officer	134	212,24	28.440,16	12	220,73	2.648,76
Financial officer	92	216,15	19.885,80	30	224,80	6.744,00
Financial/salary administration	46	198,28	9.120,88	15	206,22	3.093,30
Head project administration	20	244,15	4.883,00	8	253,91	2.031,28

Partners involved

No Associated, nor Collaborating partners were involved in this project. The Commission was involved in preparing of the agenda and content of the meetings. Regular meetings were held for that purpose with the Commission services. The Commission chaired the NCA and NWPL meetings. Various project leaders and different departments within the EU were invited as participants or to give presentations during the meetings (see for details Agenda's and Minutes in the Appendices).

Countries involved

All Member States, candidate countries and EFTA countries are members of the NCA and represented as such during the meetings. At the NWPL meetings Working Party Leaders, deputy WPL and WP Secretariats are participating. During this project they came from France, Belgium, UK, Greece, Austria, Finland, Germany, Ireland, Czech Republic, Netherlands, Lithuania.

The CA represent their countries and report back to their respective Ministries of Health

or Institutes of Public Health. They report to the NCA about national issues related to health information and national public health policy in general. The WPL report to the NWPL about the progress in their respective Working Parties and give feedback to their own WPs.

Achievement of the objectives

Objective	Realized	Deliverables
Project team	Secretariat NCA-NWPL with 4 staff	<ul style="list-style-type: none"> - Own e-mail address - Web board accessible for all members NCA and NWPL, as well as Commission SANCO C2
NCA meetings (2)	NCA meetings: 4	<ul style="list-style-type: none"> - Agenda meetings (3) - Minutes (4) - Template Progress Reports CA - Summary Progress reports CA (3) - Presentation Dutch Health Registry System - NCA-NWPL Web board presentation - Introduction to EU Directive on Person Data (95/46/EC): presentation - Working Group on Confidentiality of Person Data
NWPL meetings (4)	NWPL meetings (3)	<ul style="list-style-type: none"> - Agenda meetings (3) - Minutes (3) - Template Progress Reports NWPL - Summary Progress reports NWPL (3) - Document on overlap between WPs
Site visits to new MS (6)	None	-
EU Information and Knowledge Forum (1)	None	-
Workplan 2005	Workplan 2005	<ul style="list-style-type: none"> - Advice given through NCA-NWPL meetings - Collection of advice through web board
Report (2)	2 reports	Interim, Final report

During the development of the project and the activities of the Network of Competent Authorities, the Commission judged it not opportune any more for the Secretariat to pay visit to the new Member States to introduce the programme and to collect information about the collection of Health Information in these countries.

The organisation of an European Information and Knowledge Forum was postponed by the Commission.

For further comments see also the next Chapter.

9 COMMENTS ON PROCESS AND PROGRESS

The Secretariat: a New Concept in 2004

A Secretariat to support both Networks within the Health Information Strand was in 2004 a new concept for the Commission Services, as well as for NIVEL. It takes time to develop a new concept and to establish it. The Commission Services had to familiarize itself with the Secretariat, its aim, objectives and tasks. The officers who were not directly dealing with the Secretariat seemed to find it difficult to see the relevance of using its possibilities in the work they prepared for the meetings of the NCA or NWPL. After the first NCA and NWPL meetings supported by the Secretariat in July 2004, and during the preparation of the meetings of January 2005, the added value of the Secretariat seemed to become more obvious to the various officers.

NIVEL, being a research institute, had hoped that the project would provide more opportunity to support SANCO C2 in content related issues, related to the development of the European Health Information and Knowledge System. However, very few opportunities arose to this effect during the first months of the Secretariat. Subsequently, at the start, the work content concentrated on administrative secretarial work. Even within this work the Secretariat experienced difficulties in its communication and contacts with Competent Authorities and Working Party Leaders, as it happened that the information flow concerning the same issues and documents related to the NCA and NWPL was sent to them simultaneously by the Secretariat and by the Commission Services. During the second half of the project period, the Secretariat became more involved in the communication between the Commission Services and Competent Authorities (CA) than in the first 6 months of the project.

The above-mentioned problems hampered the development and the use of a Web Board as a way of communication between the Secretariat, NCA and NWPL. Additionally, people need time to start using a Web Board as an active way of communication. In order to make the Web Board a real useful tool in the communication, the Secretariat (or the future Executive agency) should become the central point in the communication between the Commission Services and CA or Working Party Leaders (WPL). The problems in the development of the Secretariat were discussed during the meetings with the Commission Services and the Secretariat, and an evaluation of its use was presented at the meeting of July 2005.

The administrative role of the Secretariat

The Secretariat also had to get acquainted with the working and reporting style of the Commission Services. This resulted in a delay in the production of the minutes of the NCA meeting of December 2003, the meeting that was attended by the Secretariat before its formal start in February 2004. The learning process resulted in a smooth production of materials and minutes of the meetings in July 2004. The meetings of January and July

2005 were an equal success. The Secretariat has now been firmly established and is acknowledged by Working Party Leaders and Competent Authorities alike. There is a steady increase of email contact with the Secretariat and visits to the NCA-NWPL Web board. The CAs became acquainted with the use of the Web board. Materials for the meetings are downloaded from the Web board. Also, the Working Party Leaders made more use of the Web board, especially to contact other Working Parties; the WP on Health Systems, which had no Secretariat yet, used the web board to distribute documents for its meeting. Tasks and responsibilities of the Secretariat are more than before clear to WPLs and CAs and the role of the Secretariat in the process is more recognisable. To facilitate the communication between the Network of Working Party leaders and the NCA, the meetings are organised in such a way that in the morning of the first day of the NCA meeting the WP leaders and the NCA jointly meet. Still, the commission should take more advantage of this joint meeting to facilitate more discussion and feedback between both Networks.

The scientific role of the Secretariat

Next to its more administrative role, the scientific support function of the Secretariat is developing. For example, both networks provide bi-annual progress reports. The Secretariat uses information from these reports to pinpoint potential issues for the meetings. Subsequently, the Secretariat discusses these issues with stakeholders and prepares scientific supportive documents for the meetings. Also, the Secretariat facilitates discussion between members of the Networks in between meetings by providing discussion material. These actions of the Secretariat are aimed at ensuring and consolidating progress in the area of Health Information.

The Secretariat presented an overview of the available health registries in the Netherlands.

One of the major issues brought forward by some CAs was the problem related to the implementation of the Data Directive on Person Data (95/46/EC) with consequences for the use of Health Registries and sharing data between countries. CAs were requested to send information about the situation in their own countries and an evaluation workshop regarding the Directive was attended in Brussels. The issue was extensively discussed at the meeting of July 2005. An ad hoc working group of the NCA was set up with 6 members of the Network and coordinated by the Secretariat. Their first meeting was planned for the fall of 2005.

Contact with SANCO C2

At the start of the project, NIVEL needed to familiarise itself with the working practice of SANCO C2 and vice versa:

- Regular meetings were realised with the officer of the Commission in charge of the NCA and NWPL. But more regular contacts with the other officers of the Commission would have facilitated the processes of familiarization of the Secretariat

with the Commission Services and vice versa. Perhaps this would have resulted also in more content related work for the Secretariat.

- Although preparatory documents were sent, the workload of the Commission officers hindered a proper preparation of the scheduled meetings.
- This last point asks for a good communication between the Secretariat and (one of) the secretaries. The seemingly high turnover over of secretaries at C2 has not facilitated the communication either.
- Since the Summer of 2004, SANCO struggles with serious understaffing problems, which have had its effect on the work of the Secretariat. On the one hand it has not facilitated the interaction with SANCO. On the other hand, to counteract the understaffing, the Secretariat has been able to support SANCO more substantially in the preparation of the NCA and NWPL meetings. In addition, the understaffing problem makes the contribution of the Secretariat more pressing.

Discontinuation and continuation of the project

The proposal for SNAW II was rejected by the Commission as was communicated in July 2004. This hampered a further development of the positioning of the Secretariat as well as the activities undertaken by the Secretariat. This discontinuation of the Secretariat asked for a fluent transition to the future Executive Agency (EA). It was agreed by the Commission Services to extend the actual contract of the Secretariat first to the end of March 2005 and later to the end of August 2005 within the existing budget limits, but it became clear that the Executive Agency would not be in full function by the end of this project and will not be operational for Strand I until well into 2006. Therefore, there will be no transition of tasks of the Secretariat to the Executive Agency due to the time gap. The Commission is considering how to ensure continuation of the Web board in the intermittent period and would like NIVEL to continue its work for as much as possible. As a recognition of the increased importance of the Secretariat in relation to the two Networks and their work, the submission of a new proposal for a Scientific Assistance Office for both Networks integrated in a proposal for scientific assistance to several working parties was considered for financial support in July 2005. Probably this project will be able to start by December 1 of 2005, so that the gap between both projects will probably be limited to three months.

Supporting the Networks of Competent Authorities and the Network of Working Party Leaders (SNAW)

Final Technical Implementation Report

APPENDICES

Period: February 2004 – August 2005

Project Number: 2003110 (791053)

Project Leader: Dr. François G. Schellevis
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Appendix 1: Overview of meetings and visits, in Brussels (one) and in Luxembourg

Date	Purpose	Staff
14-16 December 2003	NCA meeting	Devillé, Schellevis
18-20 February 2004	Regular Meeting Secretariat – Sanco C2 ; ECHI-II meeting	Devillé, Kolthof, Spelten
13 April 2004	Regular Meeting Secretariat – Sanco C2	Devillé, Spelten
27 May 2004	Regular Meeting Secretariat – Sanco C2	Devillé, Spelten, van der Zee
30 June 2004	Regular Meeting Secretariat – Sanco C2	Kolthof, Schellevis,
4-7 July 2004	NWPL and NCA meetings	Kolthof, Schellevis, Spelten
9 September 2004	Regular Meeting Secretariat – Sanco C2	Devillé, Spelten
5-6 October 2004	Meeting WP on Health Systems	Spelten
28 October 2004	Regular Meeting Secretariat – Sanco C2	Devillé, Spelten
21 December 2004	Regular Meeting Secretariat – Sanco C2	Devillé
17-19 January 2005	NWPL and NCA meetings	Devillé, Spelten
24 February 2005	Regular Meeting Secretariat – Sanco C2	Devillé
6-7 June 2005	Regular Meeting Secretariat – Sanco C2	Devillé
13-14 June 2005	Privireal Workshop Data Protection Directive, Brussels	Devillé
3-7 July 2005	NWPL and NCA meetings	Devillé, Spelten

Appendix 2: Agenda & Minutes of NCA meeting December 2003



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Minutes Network of Competent Authorities for Health Information and Knowledge Luxembourg, 15-16 December 2003

Chairman: J.F. Ryan (Head of Unit, DG Sanco C/2, Health Information).

Reported by Secretariat (NIVEL).

1. ADOPTION OF THE AGENDA

The draft agenda was adopted without changes.

2. ADOPTION OF THE MINUTES OF THE LAST MEETING

The minutes were accepted with all amendments received. Copies of presentations will be electronically integrated in the minutes. All minutes of all meetings will be put on the Internet to ensure transparency.

3. PRESENTATION OF THE NEW ORGANIGRAMME OF SANCO C

The new organigramme of SANCO C was presented. The new directorate in Public Health and Risk assessment consists of 7 units (C1 through C7). Most Scientific Committees have moved to the 'Food Authority'.

An **Executive Agency** will be set up in Luxembourg, staffed with 35 people. The director will be nominated in 2004. The Executive Agency will prepare the European Communicable Disease Centre (ECDC), support the project management with evaluations and budget support and (for C2) will help with the Health Portal and the operation of EUPHIN.

4. PRESENTATION OF THE SECRETARIAT OF THE NETWORK

Dr. François Schellevis of the NIVEL Institute (Netherlands Institute of Health Services Research) presents the composition and future tasks of the secretariat.

It was stressed that the secretariat's main tasks will focus on supporting the Commission Services with developing position papers and progress reports for the Network of Competent Authorities. The secretariat will be financed according to the 60/40 rule for one year.

These tasks will be closely linked to the establishment and operationalisation of the short list of European health indicators. They have to take account of the situation in the different Member States, particularly of the need to integrate enlargement countries.

5. DISCUSSION AND ADOPTION OF THE DRAFT MANDATE OF THE NETWORK OF COMPETENT AUTHORITIES

Role of the Network of Competent Authorities

It was emphasised that the Network of Competent Authorities is not a decision making but an advisory body. No voting procedures will take place. All development steps are based on

consensus. Furthermore it provides a platform for information exchange between Member States on their health information and knowledge activities.

Membership

Neither the European Monitoring Centre for Drugs and Drug Addition nor other European agencies are mentioned as members of the Network of Competent Authorities. However the EMCDDA may be specifically mentioned because of its work on data collection in its area of activity.

Relation to the Working Parties

The Network of Competent Authorities is composed of representatives of health ministries of the Member States. Working Parties should feed the Network of Competent Authorities with developments and topics from different angles in their areas of activity. The Network of Competent Authorities should make decisions and set priorities through consensus.

• Members of the Working Parties

Member of Working Parties are project leaders of previous, current and future projects. Up to now only members of financed projects were invited, since the new working groups and projects have not yet been agreed upon. An effort was made to complement Working Parties with experts out of countries not represented in the group of project leaders so far. Special attention will be paid to the enlargement countries. In principle, there is no “closed-door policy”, however, there is a physical and budgetary restraint.

• Link of members of different Working Parties on Member State level

It was suggested to make a list of national members participating in the different Working Parties, to ensure bilateral discussion.

Co-operation on task level

Some delegates questioned the tasks of the Network of Competent Authorities, the relation to the Executive Agency, to the Network of Working Party Leaders and to the Health Portal. The Commission stressed that the Executive Agency will be part of the Commission Services and will be closely linked to DG SANCO/C. The Executive Agency will assist in daily work of implementation of the Public Health Programme.

Co-operation with EUROSTAT

Some representatives questioned the tasks and funding of **EUROSTAT** activities within projects. It was explained that EUROSTAT will in the future focus on fewer activities (i.e. statistics on disabilities will no longer being a priority area). The Public Health programme might complement EUROSTAT's work, especially in developing indicators and working on methodology. Possibilities for joint activities on complementary health statistics are foreseen in the Workplan 2004 in the form of tenders.

6. OVERVIEW OF ACTIVITIES SINCE THE LAST MEETING

Accepted projects 2003

The chairman explained why there had been a delay in the final approval of projects and reports that contracts will not be signed before February 1st, 2004.

Working Parties

Mandates of Working Parties

The Commission Services presented the Working Parties and their mandates. Delegates questioned the format of the mandates and working methods of the different Working Parties.

The Commission will try to use a common template for the mandates of the seven Working Parties so that the format of the different mandates will be harmonized.

The working methods shall be developed by each individual Working Party. According to the subject and priorities, subdivision or the establishment of task forces on an ad hoc basis might be efficient.

Managerial tasks of the Working Parties will be taken up by secretariats which will be established on a basis of project proposals. Proposals for the establishment of a secretariat were received for the Working Parties on Mental Health, Lifestyle and Accidents and Injuries. For the other Working Parties, they shall continue to be operated for the present by the Commission Services.

Working Party on Mortality and Morbidity

This Working Party will not be in competition with the Task Force on Mortality in EUROSTAT. Both groups will work closely together on a complementary basis. In future, there might be an overlap with the Working Party on Mental Health in regard to neurodegenerative diseases.

Working Party on Lifestyles

The Commission Services pointed out that the Working Party addresses lifestyle issues for the whole programme. 'Best practices' should be included in all Working Parties. The paragraph on 'best practices' needs to be rephrased. There is an overlap between Strand I and III in this field. The activities of the Working Party should be integrated with Strand III activities. Working Parties can advise on priorities for projects. A phrase on the inclusion of determinants should be included in the mandate.

Working Party on Health Systems

The Commission presented the Working Party and its mandate. The right balance between prevention and promotion is still a cause for concern. On most indicators information is available (except for patient mobility; this subject is to be addressed at the next meeting).

The remarks from IRL on the horizontal nature of this Working Party will be included as a note. The contribution of health systems to public health is in the mandate. Furthermore, the chairman reports that the Health Council asked to collect information on 'cross border health care' and brings up diverse new topics for the PH Programme. DG SANCO will take this up. Political priorities have to be included.

Working Party on Mental Health/Injury

An outline of the two working parties and their mandates on Mental Health and Injuries was given. SANCO C2 is responsible for health information aspects as well as promotion and prevention in these two areas.

The chairman informed the delegates that minutes of the Working Party on Mental Health will be circulated. Their secretariat is in place.

Workplan 2004

The chairman reported that the workplan 2004 will be published in January 2004 together with the call for proposals and call for tenders in course of the year. Deadline for submissions will be March 2004. Pre-notice of tender-subjects will be published in March 2004.

7. EUROPEAN HEALTH INDICATORS

The Commission introduced the topic, followed by a presentation of Mr. Pieter Kramers on the current list of indicators. He pointed out that availability had not been a prior criterion for indicators to be added to the shortlist.

The delegates' comments on the shortlist of indicators were:

- *selection criteria for the short list* should be made more transparent,
- to keep the focus on the *public health impact* of the system,
- the need to clarify *further procedures and processes* once the shortlist is agreed upon.
- *availability*:
 - < an overview of the available data/indicators is needed (a.o. in EUROSTAT, WHO, OECD);
 - < ongoing developments necessitate reassessing information on availability;
 - < EUROSTAT stressed the importance of clear definitions. A balance should be found between the best definition and available data. A taskforce within EUROSTAT will look at the definitions of the minimal dataset. EUROSTAT has already been provided with some information; coordination is needed to prevent overlap. Separate meetings on the organisation of data collection with the new acceding countries will be set up. User windows and stratification are necessary to increase accessibility to a broad public.
- *responsibilities at national level*:
 - < close collaboration is needed between national and international levels,
 - < teamwork (Network of Competent Authorities /Working Parties) approach per country is needed within the programme,
 - < the shortlist does not impose limitations on national activities,
 - < a dictionary of data was developed for the core list of the Norwegian indicators;
- the '*Health Systems*' indicators:
 - < should focus on 'performance' and 'outcomes',
 - < should make use of rough aggregated data for these indicators,
 - < OECD: the structure used for 'Health Systems' corresponds to the structure used by OECD and EUROSTAT and has an economic perspective (from resources to output). Moving to another model will imply an increase in indicators and correction for 'needs' is difficult and not always routinely available. Information on 'efficiency analysis' is available. OECD has taken up the issue of 'waiting times' and 'quality' ('the right intervention at the right time'), the next frontier in health statistics,
 - < need for further development can be listed once work has started,
 - < to put more emphasis on administrative data which would help the new countries in Eastern Europe. They need advice on the data collection.
- '*communicable diseases*': may consider their own indicators (Strand II);
- WHO: recently WHO and EUROSTAT have started harmonizing hospital mortality statistics ECHI will continue its work concerning 'Health Systems', EUROSTAT data will be used. Comments of the Network of Competent Authorities will be taken into account.

The chairman stated that the comments will have to be discussed at the following ECHI-meeting (February, 2004). Separate meetings with the acceding countries will be organised.

8. DEVELOPMENT OF AN EU HEALTH PORTAL

The Commission clarified that the portal will facilitate communication between the Working Parties. It will have links to the National Institutes of Public Health and to databases of International Organisations. Furthermore the future health portal will make best use of the recently re-organised web site on public health of the EUROPA site.

9. WORKING PROGRAMME 2004 OF THE NETWORK OF COMPETENT AUTHORITIES

Has been postponed because of time limits.

10. ANY OTHER BUSINESS

Next meeting

The next Network of Competent Authorities meeting will probably take place in June 2004 (Note: changed to 5/6 July 2004). Participants will be informed in advance by e-mail, followed by an official letter of invitation.

Evaluation of future projects

The Commission clarified its newly determined policy on the evaluation of projects in the future. Each project submitted under the next call for proposals will be evaluated by one internal staff member of the Commission and one external expert. Both evaluators have to come to a consensus marking. Then the evaluation committee comprised of the senior staff members of the Commission will agree on the ranking of the different projects. The list of projects with the ranks will then be provided to the Programme Committee for an opinion. After an Inter Service Consultation on the approved list of projects, the Commission will conclude the individual grant agreements or will inform the applicants on the refusal decision.

Appendix 3: Minutes of NWPL meeting July 2004

EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Luxembourg

Draft minutes**Network of Working Party Leaders for Health Information and Knowledge**

Luxembourg, 05 July 2004 9.30 h. – 13.00 h.

Chairman: J.F. Ryan (Head of DG Sanco C/2, Health Information).
Reported by NIVEL Secretariat

1. Opening of the meeting

The Commission explained that the purpose of the meeting of the Network of Working Party Leaders is to get an overview of the work within Working Parties and Task Forces, to define common areas of work, to avoid overlap and to discuss common problems. The participants of the Network of Working Party Leaders meeting will be invited to the meetings of the Network of Competent Authorities to ensure the interface function between Member States representatives and those carrying out work on areas of health information in the EU Public Health programme.

2. Adoption of the agenda

The draft agenda was adopted without changes.

3. Mandate of the Network of Working Party Leaders

François Schellevis of the Secretariat presented the draft mandate of the Network of Working Party Leaders. The mandate is a working document to clarify purposes, tasks and organisation of the Network. The Network will act as an interface between the various Working Parties and the Network of Competent Authorities and is a discussion and advice forum. Secretarial support will be given to the Network by the NIVEL Institute and DG SANCO C/2. The draft mandate was approved without modifications and will be made available through the EUROPA website.

4. Progress reports of Working Parties and Task Forces

An overview per Working Party/ Task Force is given by representatives present.

Working Party on Lifestyle

The address of the Working Party website will be added to the Network of Competent Authorities/ Network of Working Party Leaders WebBoard.

Working Party on Morbidity and Mortality

Operational definitions of chronic and major diseases are now restricted to 4 diseases; more definitions will be developed by the Working Party as the work progresses.

Task Force on Rare Diseases

A first draft of the members has been established and circulated to all members of the Task Force.

The mandate will be discussed/adopted at the next Task Force meeting on 14/10/2004.

A proposal for the scientific secretariat of the Task Force has been submitted for funding in the framework of the SANCO 2004 call for proposals.

Working Party on Health Systems (including Task Force on Patient Mobility)

A report on patient mobility will be produced for ministers of Member States in December 2004, as a follow-up to the earlier Commission communication.

The Commission explained that the issue of 'flow of laboratory specimens' belongs to the 2nd Strand of the Public Health Programme. However, the Working Party on Health Systems will take some aspects relevant to this Working Party on board for their next meeting.

Working Party on Health and Environment

The Commission mentioned that the high expectations arising from the WHO Conference in Budapest regarding health and environment monitoring information and indicators might not be in balance compared to the available resources.

Working Party on Mental Health

The Commission mentioned that the 2nd meeting was postponed due to financial limitations. Working Party will collaborate with Working Party on Accidents & Injuries to clarify availability of indicators (particularly suicide).

Working Party on Accidents and Injuries

Ongoing projects can be found on the website. Integration of new Member States is the biggest challenge.

Task Force on Work Health

This Task Force is concerned with injuries caused by work only.

The Commission elaborated that:

- the Commission can pay for a maximum of 20 private experts per meeting and this number is quickly reached by current, previous and future project leaders. Although meetings should be kept to a manageable size, there is in principle 'an open door policy'. Alternative ways to deal with this limitation may need to be considered;
- the Commission explained the difference between 'official Task Forces' (i.e. on Rare Diseases) and the 'Task Forces' mentioned in the presentation of the Working Party on Accidents and Injuries. The latter are 'areas of work' within Working Parties. This is a good method to 'break down the work', followed by a discussion within the Working Party.

The Commission summarized that:

- A procedure to standardize executive summaries of final project reports may need to be developed;
- Coordination of roles and joint activities of Public Health Programme projects and Eurostat (mainly Unit D6: Health and food safety) is important;

- Linkages between the work of Working Parties (identifying common areas of work) is necessary to optimise the work;
- Commission and Working Party Secretariats can work on lists of previous and current projects;
- Applications for Working Party Secretariats are welcome for Working Parties which do not benefit from such secretariats yet (Morbidity-Mortality, Health and Environment, Health systems). Previous successful applications can be made available. Normal rate of funding is 60%.

5. European Community Health Indicators (ECHI): Implementation of available Health Indicators of the ECHI Shortlist

The general strategy on European Community health indicators (ECHI) has been summarized in a specific document elaborated by the Commission.

The strategy regarding the implementation of the ECHI shortlist is presented by the Commission and the current draft of the shortlist is presented by Mr. Nugteren (ECHI team).

Availability of data has been discussed with Eurostat.

Implementation:

- 1st step: implementation of the 45 available indicators within Eurostat (in case improvement is needed, this may follow later);
- 2nd step: implementation of the 36 partly available indicators (develop tools to provide data for the gaps);
- 3rd step: implementation of the 5 not yet available indicators (the 'wish list').

Working Parties will have to focus on the 1st and 2nd step of implementation. The Commission elaborated that in the workplan 2005 particular attention will be paid to areas of work for which data are not presently or only partially available in close collaboration with EUROSTAT (mainly Unit D/6). Working Parties were invited to comment on the workplan and suggest areas of work based on gaps in their work. The shortlist is never definitive; future comments will be taken into account. The future Working Party on European Community Health Indicators is concerned with the operational implementation of the shortlist. This later Working Party will be launched in 2005 after ECHI project has come to an end and delivered its final report (end 2004).

Didier Dupré (Eurostat) explained that at this point compromises between 'wishes' and 'available data' have to be found. Improvement of data will follow the coming years. Different data sources will have to be combined in the future.

6. Webboard for the Network of Working Party Leaders and Network of Competent Authorities

The NIVEL Secretariat presented a web board designed to facilitate communication and information exchange between members of the Network of Competent Authorities and the Network of Working Party Leaders. Information about the present meeting (agenda, document) can be found here. The board can also be used by members to pose questions or engage in a discussion. The board is under construction, suggestions for improvement are most welcome.

URL: <http://board.nivel.nl/nca-nwpl>

Your username is your last name plus the first letter of your first name, e.g. Ryanj.

Your password is ncanwpl

In case of difficulties please contact the NIVEL secretariat by email: nca.nwplsecr@nivel.nl

Any other business

The next Network of Working Party Leaders meeting will last one full day, followed by a full day meeting of the Network of Competent Authorities (to be confirmed: 17/18 January 2005). Participants will be informed in advance by e-mail, followed by an official letter of invitation.

Appendix 4: Minutes of NCA meeting July 2004



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Luxembourg,

Draft minutes

Network of Competent Authorities for Health Information and Knowledge

Luxembourg, 5 July 04 (9.30 h.-13.00 h), 6 July 04 (9.30-17.30 h.)

Chairman: J.F. Ryan (Head of DG Sanco C/2, Health Information).

Interpretation was available in EN, FR, DE, ES, IT

Minutes prepared by NIVEL Secretariat

1. Adoption of the agenda

The order of agenda-items was changed: 6 July started with items 12 through 15.

2. Adoption of the Minutes of the last Network of Competent Authorities meeting

No comments were made on the minutes of the last Network of Competent Authorities meeting (December 2003). Last-minute amendments (made within 2 weeks) will be taken into account. Then the minutes will be final and made available through the Europa website.

3. Progress reports of Working Parties and Task Forces (Summary)

The NIVEL Secretariat gave an overview of the progress made by six Working Parties and the Task Forces on Rare Diseases and Work Health since the last Network of Competent Authorities meeting, based on activity reports completed in advance by the Working Party/Task Force Leaders. A 7th Working Party on European Community Health Indicators will be established next year.

The Commission indicated that within Working Parties, project leaders are brought together to ensure coherency between different projects and to identify work for the following year. Members of Working Parties do not represent their countries and membership is flexible and limited to 20 persons reimbursed as private experts; other participants and observers are not reimbursed. To inform Member States and interested parties, documents related to Working Party meetings and minutes (in four languages) will be available through the Europa website shortly after the meetings.

Working Party Secretariats should build on previous work and should identify and follow relevant previous and current projects at the national and international level. Because of practical implications, it is impossible for Member States to be represented during all Working Party meetings. Therefore, better reporting by Working Parties through the Network of Working Party Leaders to the Competent Authorities on the progress made within projects is necessary. A mechanism for this needs to be developed. The Network of Working Party Leaders provides a forum for discussion on crosscutting issues such as gender, age and health impact assessment.

Participation at Working Party meetings

The Commission stated that the participation of new Member States is a big challenge, especially with a limit of reimbursing 20 private experts per meeting. Participants of the new Member States are unlikely to be represented among project leaders and will therefore not readily qualify for reimbursement. Alternative ways to deal with this limitation may need to be considered. A possible solution is to have separate meetings for the Working Party Secretariats and new Member States. This could be included in the contracts of Secretariats.

4. Mandates

It was explained that the mandates should be seen as working documents. They may change over time as the work progresses, so comments can still be made.

Network of Competent Authorities Mandate

The revised mandate of the Network of Competent Authorities was introduced by the Commission and adopted by the Network of Competent Authorities.

Network of Working Party Leaders Mandate

François Schellevis of the NIVEL Secretariat presented the draft mandate. The draft mandate was approved this morning during the first meeting of the Network of Working Party Leaders. The Network of Working Party Leaders will act as interface between the various Working Parties and the Network of Competent Authorities and is a discussion and advice forum.

Mandate of Working Party on Health and Environment

The mandate of the Working Party on Health and Environment was introduced by the Commission. The suggestion to link it more explicitly to the Public Health Programme will be taken into consideration.

The Commission mentioned that there are not enough resources available to fulfil the ambitious plans arising from the WHO Conference in Budapest. Within the Public Health Programme, a balance between different priorities should be guaranteed. Additional financial resources will need to be found.

Synopsis of Working Party mandates

The NIVEL Secretariat presented an overview of similarities and differences between the mandates of the six Working Parties.

5. Presentation of three Networks on Evidence and Expertise

Presentations were given by André Knottnerus and Guy de Backer, (Health Councils Netherlands and Belgium), regarding the European Expertise Network of Public Health, Jane Wallace (WHO) regarding the Health Evidence Network (HEN) and Clive Needle and Caroline Costongs (from EuroHealthNet) regarding the EuroHealthNet and 'Getting evidence into practice'.

The Commission explained that the networks are complementary, but there are more networks in other Member States which may be concerned. The first two networks above represent governmental bodies.

The Community supports initiatives to improve evidence based-approaches through projects financed under the Public Health Programme. The Health Evidence Network project and EuroHealthNet have both received funding from the Public Health Programme. It is not

necessary for the Commission to add another scientific body to the existing Scientific Committees. In addition to official scientific advice in Member States, there are Public Health Regulations, directives and other legal acts based on scientific advice (i.e. Article 152 or Article 100) Directives on blood or tobacco, recommendations on alcohol and young people, cancer screening, electromagnetic radiation protection). Furthermore, every 6 months, with the change of the Presidency of the EU, Council conclusions are formulated (i.e. on Lifestyle, cardiovascular diseases), often based on scientific advice resulting from projects or consensus conferences.

The Commission suggested that a mapping exercise of bodies involved in health evidence/evidence based policy recommendations might be on the agenda for the next Network of Competent Authorities meeting.

6. Structure of the EU Public Health information and knowledge system: An implementation presentation

The document, presented by the Commission, describes the present situation regarding the European Health Information System and the activities to be undertaken over the following years. The document should be seen as a road map, which defines the present situation. The participants of the meeting welcomed the document because it gives a concise description of the 17 major components, and it will aid prioritisation and help to work towards an integrated approach. The Commission added that the document has the status of a working document. Together with the Network of Competent Authorities, a course for the future needs to be set. Important issues that need attention in the coming period are: prioritisation and timescale, urban versus rural indicators, data validation and defining responsibility for data collection. The Commission added that inter-service Task Force (SANCO/EUROSTAT) could be a good approach and stressed that the Executive Agency will manage administrative aspects of the projects only and will not be involved in data collection. The Commission will present a new version of the document at the next meeting.

7. European Community Health Indicators (ECHI): Implementation of available Health Indicators on the Shortlist

THE GENERAL STRATEGY ON EUROPEAN COMMUNITY HEALTH INDICATORS (ECHI) HAS BEEN SUMMARIZED IN A SPECIFIC DOCUMENT DRAWN UP BY THE COMMISSION

The Commission introduced the operationalisation and implementation strategy of the ECHI shortlist. Arpo Aromaa (replacing Pieter Kramers as chair of ECHI –II) presented the state of play of the ECHI shortlist and Eurostat provided a reflection on the data availability of the ECHI shortlist.

The Commission points out that the operationalisation of the European Health indicators is a process and no definite decisions have been made. A start needs to be made with a limited number of indicators, in order to be operational, and then other indicators will be progressively added step by step. Availability of data has been discussed with Eurostat.

Implementation:

- 1st step: implementation of the 45 available indicators within Eurostat (in case improvement is needed, this may follow later);
- 2nd step: implementation of the 36 partly available indicators (develop tools to provide data for the gaps);
- 3rd step: implementation of the as yet unavailable 5 indicators ('wish list').

Working Parties will have to focus on the 1st and 2nd step of implementation. The Commission stated that in the 2005 workplan particular attention will be paid to areas of work for which data are not or only partially available in close collaboration with EUROSTAT (mainly Unit D/6: Health and food safety). Working Parties were invited to comment on the workplan and suggest areas of work based on gaps in their work. The future Working Party on European Community Health Indicators is concerned with the implementation of the shortlist. This Working Party will be launched in 2005 after ECHI project has come to an end and delivered its final report (end of 2004).

8. Intermezzo

Ana Xavier of DG Employment is introduced to the meeting. DG Employment will use the open method of coordination (OMC) to define a policy for Member States on (long term) health care. In the process of the OMC, it will pay close attention to the work of the Network of Competent Authorities, especially the work on indicators, in order to avoid duplication. Therefore, they will attend Network of Competent Authorities meetings.

9. Projects supported in 2003

The Commission presented an overview of all projects supported in 2003 (subject to confirmation) and of projects proposed for 2004.

Draft workplan 2005

The Commission presented its draft work plan for 2005. This draft work plan can be found at the Network of Competent Authorities/Network of Working Party Leaders web board (<http://board.nivel.nl/nca-nwpl>)

Suggestions of participants of the meeting are to focus on facilitation of data collection of the ECHI shortlist and on support for the new Member States, to limit data collection to Public Health (not Health Care), to focus on alcohol (might be more relevant for Strand 3). The classification of diagnostic and therapeutic procedures should be studied on a global level. Comments on the workplan are welcomed before 28 July 2004.

10. Developing links between working parties at a national level

Two presentations were given on developing links between persons involved in EU Public Health projects at a national level with the aim to share experiences within countries. Most countries have similar experiences. The Commission pointed to the lack of contacts with potential new applicants. A criticism is that this programme is run in a closed circle, which might exclude newcomers both in old and new Member States. In this respect, Competent Authorities are meant to be a link between the Member States and the Health Information strand of the Public Health Programme. High Level Health Committee members have been asked to nominate the Competent Authorities; generally speaking, the Competent Authorities have the appropriate expertise to participate in the Network, although membership should be revised on an occasional basis.

The Commission emphasised the need to integrate the indicator work at a EU level, and on a national level as a useful exercise.

The Commission formulated the following suggestions to help the Member States to implement the Public Health Programme on a national level:

1. National or regional conferences; targeted conferences supported by the EC
2. High level committee is regular information point
3. Consider national coordinators
4. Commission information and Press Offices (available in each country), (e.g. former EU against cancer programme)
5. Newsletter from the Health Information Strand

6. Briefings by the Commission High Level Committee could be made available to the Member States; on a regional basis.

The Commission pointed out that the Public Health Programme Committee has a legal status and therefore does not have a mandate per se. References to the relevant legislation can be obtained from the Commission.

11. Interpretation at working party meetings

French authorities emphasised in an official letter that Working Party meetings should also benefit from simultaneous translation. The Commission stated that projects financed by the programme had meetings all over Europe without interpretation. Organisation into Working Parties was meant to bring people from different projects together. They are reimbursed as private experts. The meetings have an informal status. Private meetings with private experts do not qualify for interpretation. By comparison, the Network of Competent Authorities meeting does have a formal status. The Competent Authorities are nominated by the Member States as their representatives. Also, in the past interpreters have been booked for Working Party meetings but were not used, which is embarrassing and costly. The French Competent Authority argued that their request is to do with reaching a level of effectiveness and efficiency in the meetings, that may be hindered by the lack of expression skills in English by some participants and suggested to let the groups decide for themselves.

The Commission proposed to act according to the rules, i.e. no interpretation at Working Party meetings, documents will be translated in four languages (English, French, German and Spanish) and ad-hoc solutions can be considered. The Network of Competent Authorities adopted this proposal.

12. Presentation of the Network of Competent Authorities-Network of Working Party Leaders WebBoard

The NIVEL Secretariat presented a webboard designed to facilitate communication and information exchange between members of the Network of Competent Authorities and the Network of Working Party Leaders. Information about the present meeting (agenda, document) can be found here. The board can also be used by members to pose questions or engage in a discussion. The board is under construction, suggestions for improvement are most welcome.

URL: <http://board.nivel.nl/nca-nwpl>.

Your username is your last name plus the first letter of your first name, e.g. Ryanj.

Your password is ncanwpl

In case of difficulties please contact the NIVEL secretariat by email: nca.nwplsecr@nivel.nl

EU Health Portal

A presentation of the development plan for a EU Health Portal was given by the Commission (see attached documents). Financial support will be made available from the FDA programme. The platform, linked to the Europa website, is meant to be useful for experts and individual citizens alike. With this new Portal, the Commission hopes to turn the page and use the lessons learnt from developing EUPHIN, which is not currently in wide use as regards its HIEMS component. More importantly, with the portal, the Commission hopes to link activities of Member States on a regional/local level. The opening page will be on the language of the country but further down in the portal there will be more specialised information in only a few languages. The portal should focus on Public Health information; some social statistics need highlighting (employment, housing, crime), with limited attention to patient information. There will be no medical information provided. The principle advantage is to put together all the different activities, e.g. about communicable diseases in the EU. For the facilitation of the transfer of data, the EC is introducing a CMS that software will be available from September onwards. The deliverables of a feasibility study are available from the Europa site.

13. Importance and use of the injury database

A presentation was given on the content and use of the injury database plus a perspective of the future use of the database. Discussion focused on general issues with international databases such as timeliness, the source of data, how to define injury, interaction with other sources, variability and comparability of data. It was agreed that injury data from household surveys cannot replace this

information but are additional. Therefore, questions about lifetime-experienced injuries should be kept in household surveys.

14. Any Other Business

Members of the meeting asked for simplification of the new application procedures, which have become too complex and detailed and are burdensome. The Commission agreed that this is an important issue, some information requests may be unreasonable and put too high a pressure on applicants. NGOs have complained in a similar manner.

The Commission will distribute the final draft of the Work Plan 2005 in the coming weeks. The principal elements will be presented to the Programme Committee on 8 July for discussion. Working Parties and Competent Authorities are invited to comment on the Work Plan 2005 (before 28 July 2004). The final version will be ready by October 2004.

The chairman thanked all present for their attendance to the meeting and especially Filomena Lopo for all the secretarial work she has done for this meeting and for SANCO C2 and wishes her good luck in her new job with Eurostat.

Next meeting

17-18 January 2005, to be confirmed.

Appendix 5: Synopsis of (draft) mandates of six Working Parties

Executive summary

May 2004

Attached you will find an inventory of similarities and differences between the (draft) mandates of the six Working Parties (WPs) that have already been constituted. This synopsis has been made for the NWPL and NCA meetings on 5/6 July 2004. We kindly ask you to pay attention to remarkable similarities, differences between the mandates and/or omissions. These can be discussed at the meetings.

Information in this synopsis is based on the version of the mandates available on the Internet on 25 April 2004. The WPs in this document are numbered from 1 to 6:

Nr.	WP	Sources (all from Europe site 25 April 2004)
WP 1.	Lifestyle (and other health determinants)	Lifestyles WP (LWP), dated 16.03.04
WP 2.	Morbidity and Mortality	Draft Mandate Morbidity and Mortality WP, dated 25.11.03
WP 3.	Health Systems	Draft Mandate Health Systems WP, dated 18.03.04
WP 4.	Health & Environment	Draft Mandate Health & Environment –rev2, dated March 2004
WP 5.	Mental Health	Draft Mandate Mental Health WP (MHWP), not dated
WP 6.	Accidents and Injuries	Draft Mandate Accidents and Injuries WP, dated 28.11.03

The synopsis is structured according to the following topics:

- Duration for which the WP has been established;
- Frequency and organisation of meetings;
- Scope ('what aspects are encompassed by the WP');
- Secretariat for the WP;
- Members of the WP;
- Purpose of the WP;
- Tasks of the WP.
- Miscellaneous/additional

Main conclusions:

- Most mandates are very comparable in content: they have similar aims (within their respective fields of attention), have similar organisational structures and have a similar view on the tasks of a Working Party in general.
- Mandates provide very little information on potential overlap between the work of a WP in relation to other WPs. Only one mandate (WP1, Lifestyles) contains a remark about possible overlap with the work of WP4 (Health and Environment): "...except for the elements that will be dealt with in the Health and Environment WP"

Synopsis of (draft) mandates of six Working Parties
May 2004

	WP1 Lifestyle and other health determinants	WP2 Morbidity and Mortality	WP3 Health Systems	WP4 Health and Environment	WP5 Mental Health	WP6 Accidents and Injuries
Duration of establishment	PH programme 2003-2008	PH programme 2003-2008	PH programme 2003-2008	PH programme 2003-2008	PH programme 2003-2008	PH programme 2003-2008
Meetings: frequency	At least 2 per year	At least 2 per year	To be decided, according to need of WP	At least 2 per year	At least 2 per year	At least 2 per year
Meetings: organisation	Secretariat to WP and Commission Services	Secretariat to WP and Commission Services	Secretariat to WP and Commission Services	Not mentioned	Secretariat to WP and Commission Services	Secretariat to WP and Commission Services
Scope	All aspects of lifestyle and influence of socio-economic and cultural factors	An extensive description can be found in the paragraph: 'what dimensions of morbidity/mortality are we dealing with?'	This WP is crosscutting and the scope is therefore difficult to delimit. The Scope is therefore described extensively	All aspects of the relationship between health and environmental factors for information and knowledge aspects	No specific section on scope. Field of activities: mental health and wellbeing	No specific section on scope. Field of activities: injuries and their causes
Secretariat to the WP	Yes	Yes	Yes	Possibly	Yes	Yes
Tasks of secretariat WP	Contribute to organisation of meetings	Contribute to organisation of meetings	Contribute to organisation of meetings Prepare documents		Contribute to organisation of meetings	Contribute to organisation of meetings
		Prepare documents			Prepare documents	Prepare documents
	Focus point for coordination between WP members and internal/external stakeholders	Focus point for coordination between WP members and internal/external stakeholders			Focus point for coordination between WP members and internal/external stakeholders	Focus point for coordination between WP members and internal/external stakeholders
		Take care of overall coordination of related projects under the programme	Take care of overall coordination of related projects under the programme			
Members of the WP	Contract holders and competent shareholders (e.g. International organisations and NGOs)	Current PHP project leaders	Current PHP project leaders	Contract holders and competent shareholders (e.g. International organisations and NGOs)	Contract holders and competent shareholders (e.g. International organisations and NGOs)	Contract holders and competent shareholders (e.g. International organisations and NGOs)
Additional members of the WP		Project leaders from previous PH programmes Other relevant persons on	Project leaders from previous PH programmes Experts or	WP Leader and deputy Relevant Commission Services		National administrators for central injury databases

	WP1 Lifestyle and other health determinants	WP2 Morbidity and Mortality	WP3 Health Systems	WP4 Health and Environment	WP5 Mental Health	WP6 Accidents and Injuries
		invitation	observers on invitation	European Environmental Agency		
Purpose of the WP	Contribute to the development of a sustainable Public Health monitoring system in its field of competence	Contribute to the development of a sustainable Public Health monitoring system in their field of competence	Contribute to the development of a sustainable Public Health monitoring system in their field of competence	Contribute to the development of a sustainable Public Health monitoring system in their field of competence	Contribute to the development of a sustainable Public Health monitoring system in their field of competence	Contribute to the development of a sustainable Public Health monitoring system in their field of competence
	Forum for discussion	Forum for discussion	Forum for discussion	Forum for discussion	Forum for discussion	Forum for discussion
	Promote health by actions in its field of competence				Promote health by actions in their field of competence	Promote health by actions in their field of competence
		Expert group for advising on Community policies and other initiatives; Complete technical and scientific background work for the establishment of indicators	Expert group for advising on Community policies and other initiatives; Complete technical and scientific background work for the establishment of indicators			
		Act according to relevant terms of the European Parliament/Council	Act according to relevant terms of the European Commission	Advising on the creation of Environmental and Health Systems/ coordination with EEA		
	Activities are described in more detail			Activities are described in more detail	Activities are described in more detail	Activities are described in more detail
	Coordinate activities with those of related European and International Organisations	Coordinate activities with those of related European and International Organisations	Coordinate activities with those of related European and International Organisations	Coordinate activities with those of related European and International Organisations	Coordinate activities with those of related European and International Organisations	Coordinate activities with those of related European and International Organisations

	WP1 Lifestyle and other health determinants	WP2 Morbidity and Mortality	WP3 Health Systems	WP4 Health and Environment	WP5 Mental Health	WP6 Accidents and Injuries
Tasks of the WP	Contribute to annual work plan	Contribute to annual work plan and implement through networks	Contribute to annual work plan	Contribute to annual work plan	Contribute to annual work plan	Contribute to annual work plan
	Examine relevant issues in other community policies / coordinate with other priority areas	Examine relevant issues in other community policies	Examine relevant issues in other community policies / coordinate with other priority areas	Examine relevant issues in other community policies / coordinate with other priority areas	Examine relevant issues in other community policies / coordinate with other priority areas	Examine relevant issues in other community policies / coordinate with other priority areas
	Advising on a European strategy in its field of competence	Advising on a European strategy in its field of competence	Advising on a European strategy in its field of competence		Advising on a European strategy in its field of competence	Advising on a European strategy in its field of competence
	Operationalisation of indicators		Operationalisation of indicators	Operationalisation of indicators	Operationalisation of indicators	Operationalisation of indicators
	Contribute to the compilation and development of a health monitoring system and the collection of data	Contribute to the compilation and development of a health monitoring system and the collection of data	Contribute to the compilation and development of a health monitoring system and the collection of data	Contribute to the compilation and development of a health monitoring system and the collection of data	Contribute to the compilation and development of a health monitoring system and the collection of data	Contribute to the compilation and development of a health monitoring system and the collection of data
		Advising Commission Services on PHP projects and reviewing project reports	Advising Commission Services on PHP projects and reviewing project reports			
			Contribute to the coordination of WP-related activities in relevant events		Contribute to the coordination of WP-related activities in relevant events	Contribute to the coordination of WP-related activities in relevant events
	Examine possibilities of common evidence based actions; Evaluate and diffuse best practices			Examine possibilities of common evidence based actions; Evaluate and diffuse best practices	Examine possibilities of common evidence based actions; Evaluate and diffuse best practices	Examine possibilities of common evidence based actions; Evaluate and diffuse best practices
		Develop health information analysis and reporting systems; Contribute to the development of modules for surveys (HIS/HES); Advising Commission				

	WP1 Lifestyle and other health determinants	WP2 Morbidity and Mortality	WP3 Health Systems	WP4 Health and Environment	WP5 Mental Health	WP6 Accidents and Injuries
		about the Commission Eurobarometer Survey				
Miscellaneous/ Additional	Attention for need to reduce economic and social inequalities	Establishment of Task Force (possibly) Listing of relevant projects WP will report on selection of indicators to WP on Community Health Indicators	Listing of relevant projects			Establishment of Task Force (possibly) Datamanagement will be coordinated by the leader of the National Data Administrators Group (due to specifics of injury data management) Organisation chart of WP enclosed

Appendix 6: Mandate of the NWPL

11 June 2004

Draft mandate

Network of Working Party Leaders

in regard to the health information and knowledge strand

1. Purpose of the network

The purpose of the network of Working Party Leaders is to provide a forum for discussion between the representatives of the Working Parties established in the health information and knowledge strand and to advise the Network of Competent Authorities on matters related to the overall development and implementation of the European Community Health Information System based on the European Community Health Indicators (ECHI).

It will advise on the strategic choices and developments in the Health Information and Knowledge Strand. It will assist with the preparation of initiatives on health information and knowledge, in particular regarding the choice of indicators to be developed for monitoring of health status and the strategy to follow regarding operationalisation and implementation of the indicators list, and public health information developed on the basis of these indicators. It will also examine general issues relating to the technical and scientific aspects of the indicators surpassing the domain of a specific Working Party and questions relating to reporting and diffusion of results.

The key function of the network is to ensure an effective interface between the NCA and the various Working Parties with their own specific domain. The network members shall feedback their own Working Party members on the discussions held within the network and the advice given to the Network of Competent Authorities. It will ensure coherency between the Working Parties.

2. Duration and members of the network

This network is to be established for the duration of the public health programme 2003-2008. It shall bring together the Leaders and Deputy Leaders of each Working Party and Task Forces (see list of Working Parties).

Experts from European and International Institutions active in the area of health information such as WHO, OECD, Council of Europe and ILO may participate in the network. EUROSTAT shall also participate to ensure coherency with the European Statistical System.

3. Co-ordination of the implementation actions

This network, which is responsible for providing technical guidelines and advice on the development, operationalisation and implementation of the indicators, shall be closely linked to the Programme Committee and the Network of Competent Authorities. By linking the Network of Working Party Leaders together with the national representatives in the Network of Competent Authorities, synergies during the implementation phase connected to policies and priorities set by the Programme Committee can be ensured. The Network of Competent Authorities will receive regular progress reports from the Network of Working Party Leaders.

In implementing the health information and knowledge strand of the Public Health Programme this mandate does not affect the responsibilities of the Programme Committee as defined in Decision No 1786/2002/EC of the European Parliament and the Council.

4. Organisation of the work of the network

The Network of Working Party Leaders will be assisted by a secretariat. The secretariat will support the Commission in co-ordinating the network meetings and in preparing the relevant documents for these meetings. Furthermore, it shall assist in developing background documents, analytical and progress reports as well as overall European strategies in relation to an effective implementation of the health information and knowledge strand. The Secretariat will be the central focus point for a better co-ordination between the members of the Network of Working Party Leaders and with the Network of Competent Authorities.

5. Tasks of the network

The prime task of the Network of Working Party Leaders is to co-ordinate the work of the Working Parties and to provide technical advice on an operationalisation and implementation strategy in regard to the health information and knowledge strand of the Public Health Programme.

In particular:

- Advising in setting priorities for the selection, collection and validation of health indicators;
- Advising about the possible overlap in content and related indicators between specific working parties;
- Advising on the nature and type of data and information to be collected and transmitted by the structures and/or authorities and the means of transmission;
- Paying special attention to the needs and obstacles experienced by Accession States and Candidate countries with regard to their health information systems and their knowledge strand;
- Contributing to the development of methods to adapt national data to European standards, which allow comparison between different countries concerned, in close co-ordination with the work of the Statistical Programme;
- Advising on the analysis and contributing to reporting on health issues at EU level, including validation;
- Reviewing progress reports from the working parties and task forces within working parties;
- Sharing and reviewing executive summaries of the final reports of the projects of each working party and task force.

The Network of Working Party Leaders shall meet at two annual plenary meetings organised by the Commission Services in Luxembourg in co-ordination with the two annual meetings of the Network of Competent Authorities.

List of Working Parties and Task Forces (update 03 June 2004)

- WP on Lifestyle
- WP on Morbidity and Mortality
 - Task force on Rare Diseases
- WP on Health Systems
 - Task Force on Patient Mobility
- WP on Health and Environment
- WP on Mental Health
- WP on Accidents and Injuries
 - Task force on Work Health

Appendix 7: Template of Progress Reports for WPs, July 2004



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information



SECRETARIAT NCA and NWPL, NIVEL

Email: Secr.NCA.NWPL@nivel.nl
Fax. nr: 0031 - 30- 27 29 729.

Address

Fax

Email

Date

Subject: Summary of Working Party Activities, Sanco C2/ Health Information

Dear,

In February 2004 the Secretariat for the Network of Competent Authorities (NCA) and the Network of Working Party Leaders (NWPL) within Strand I (Health Information) of the EC Public Health Action Programme 2003-2008 was launched. This Secretariat is managed by the Netherlands Institute for Health Services Research (NIVEL). One of the tasks of the Secretariat is to support the European Commission/DG Sanco C2 by preparing the meetings of the NCA and NWPL.

In preparation of/to (?) the next NCA meeting (on the 5th and 6th of July 2004) the Secretariat was asked to collate a summary of the activities carried out by the Working Parties since the last NCA meeting in December 2003.

We therefore kindly ask you, as Working Party Leader of the Working Party on to fill out the enclosed form and return it to the Secretariat as soon as possible (no later than 13 May). Sanco C2 wishes to have a summary of activities of the Working Parties as a recurring item on the agenda of NCA/NWPL-meetings.

For your convenience, this letter and the enclosed form will be send to you electronically and by fax. If possible, we would appreciate it, if you return the filled out form electronically (otherwise by fax).

If you have any questions, please contact Esmée Kolthof by email (Secr.NCA.NWPL@nivel.nl) or by telephone (direct number 0031 30 27 29 841/ 843).

Looking forward to meeting you in July.

Yours sincerely,

Esmée D. Kolthof, researcher
Secretariat for the NCA and NWPL

PLEASE FAX OR EMAIL THE FILLED OUT FORM A.S.A.P. (no later than 13 May) TO:



SECRETARIAT NCA and NWPL, NIVEL

Email: Secr.NCA.NWPL@nivel.nl

Fax. nr: 0031 - 30- 27 29 729.

Working Party on <To be filled out by NIVEL>

Working Party leader <TO be filled out by NIVEL>

(You may enlarge the boxes if needed).

This formed was filled out by

Date

Has your Working Party a work plan to ensure progress between the meetings, and if so, what were the main objectives for the period January 2004 - June 2004 and to what extent have these objectives been achieved?

Objective January 2004-June2004

Has this objective been achieved?

If not, please explain.

1. Yes/No,

2. Yes/No,

3. Yes/No,

4. Yes/No,

5. Yes/No,

What were the main activities that have been carried out by your Working Party since December 2003?

1. Meeting of the Working Party on <To be filled out by NIVEL>

2.

3.

4.

5.

Has a secretariat for your Working Party been established?

YES / NO

If so, since when?
(month, year)

What activities have been carried out by the Secretariat?

Has a date for the next meeting of your Working Party already been set?
(Please tick a box)

☐ Yes, date

☐ NO

Are there other issues concerning the progress of your Working Party that should be mentioned/discussed during the NCA meeting in July? If so, please explain.

What are the main objectives for the period of July – December 2004?

- 1.....
- 2.....
- 3.....
- 4.....
- 5.....

Do you foresee any problems in achieving these objectives? If so, please explain.

THANK YOU VERY MUCH FOR ANSWERING THESE QUESTIONS.

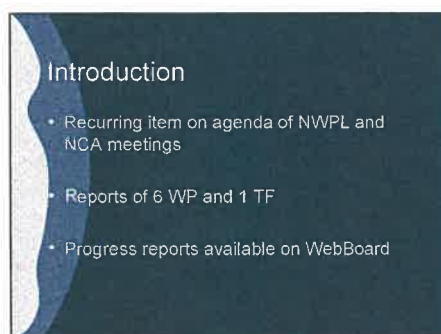
PLEASE RETURN THE COMPLETED QUESTIONNAIRE BY EMAIL TO
Secr.NCA.NWPL@nivel.nl OR BY FAX TO SECRETARIAT NCA and NWPL, NIVEL, **FAX**
NUMBER 0031 30 27 29 729

Appendix 8: Summary of Progress Reports for WPs, July 2004

Dia 1



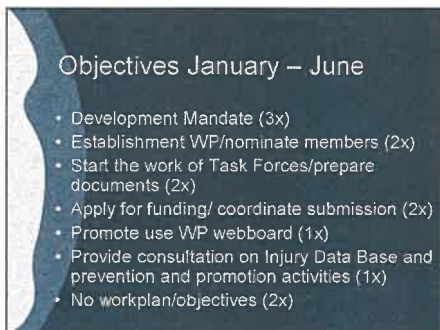
Dia 2



Dia 3



Dia 4



Objectives January – June

- Development Mandate (3x)
- Establishment WP/nominate members (2x)
- Start the work of Task Forces/prepare documents (2x)
- Apply for funding/ coordinate submission (2x)
- Promote use WP webboard (1x)
- Provide consultation on Injury Data Base and prevention and promotion activities (1x)
- No workplan/objectives (2x)

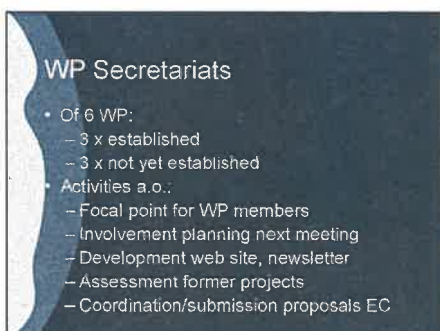
Dia 5



Activities January - June

- WP/ TF Meetings (7x)
- Collaboration/ discussion with others (3x)
- Meeting representatives of Commission to outline future activities (2x)
- WP Webboard (1x)
- Background documents (1x)
- Hand over WP Secretariat (1x)
- Feedback to ECHI project (1x)
- Meeting Data Administrators (IDB) (1x)

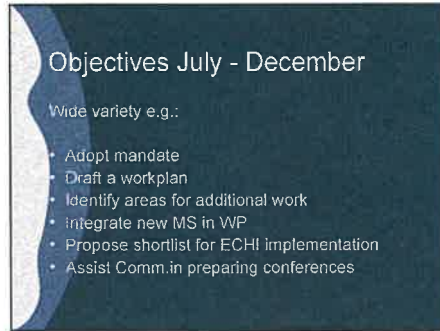
Dia 6



WP Secretariats

- Of 6 WP:
 - 3 x established
 - 3 x not yet established
- Activities a.o.:
 - Focal point for WP members
 - Involvement planning next meeting
 - Development web site, newsletter
 - Assessment former projects
 - Coordination/submission proposals EC

Dia 7

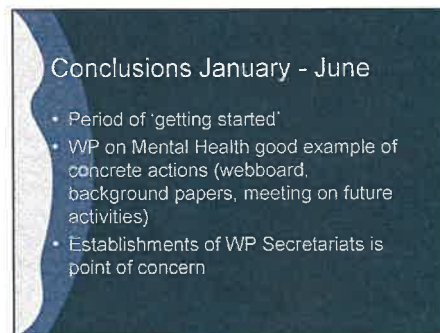


Objectives July - December

Wide variety e.g.:

- Adopt mandate
- Draft a workplan
- Identify areas for additional work
- Integrate new MS in WP
- Propose shortlist for ECHI implementation
- Assist Comm.in preparing conferences

Dia 8



Conclusions January - June

- Period of 'getting started'
- WP on Mental Health good example of concrete actions (webboard, background papers, meeting on future activities)
- Establishments of WP Secretariats is point of concern

Dia 9



Discussion issues

- Establishment of WP Secretariat (3x)
- Permanent communication WP members/ WP Secretariat (2x)
- Absence of work plan (1x)
- Low participation WP meeting by MS (1x)
- Injury Data Base: difference in constructors/ data collectors (1x)

Appendix 9: Template of Progress Reports for CAs, January 2005

EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment

Unit C2 - Health information



NIVEL SECRETARIAT

Email: NCA.NWPLSecr@nivel.nl

Fax. nr: 0031 - 30- 27 29 729.

To XX
CA COUNTRY

Email XX

Date 22 November 2004

Subject: Summary of National Activities CA, Sanco C2/ Health Information

Dear CA,

For the Next NCA meeting, the NIVEL Secretariat is collating co-ordinating activities related to Health Information Strand carried out by the Country Authorities at national level since the last meeting.

We therefore kindly ask you, as Country Authority for Country, to complete the enclosed form and return it to the Secretariat as soon as possible (no later than 6 December 2004). We kindly ask you if possible not only to report relevant meetings, co-ordinating or co-operation activities (also with other international bodies as EUROSTAT, WHO, OECD) related to Health Information at national level, but to also reflect on the actual content-related process within your Country during the previous six months.

As you know, at the request of Sanco C2, this is a recurring item on the agenda of NCA -meetings. The Commission needs this information to further the work in the Public Health area.

If possible, we would appreciate it, if you return the completed form electronically, otherwise by fax.

If you have any questions, please contact us by email (NCA.NWPLSecr@nivel.nl) or by telephone (direct number 0031 30 27 29 841/ 843).

Looking forward to seeing you at the next meeting.

Yours sincerely,

Esmée D. Kolthof, researcher
NIVEL Secretariat

PLEASE EMAIL OR FAX THE COMPLETED FORM A.S.A.P. (no later than 6 December 2004)
TO:



NIVEL SECRETARIAT

Email: NCA.NWPLSecr@nivel.nl

Fax. nr. 0031 - 30- 27 29 729.

Country: Country

CA: Representative

(You may enlarge the boxes if needed).

This formed was completed by

Date

Since July 2004, what were the main policy developments and activities that have been carried out in your country related to the EU Public Health Programme (Health Information Strand and other strands)?

1.

2.

3.

4.

5.

What are the main policy developments and activities in your country related to the Health Information Strand for the next period of January 2005 – July 2005?

1.

2.

3.

4.

5.

Are there issues you would like to raise at the next NCA meeting in January 2005? Please explain.

No / Yes

THANK YOU VERY MUCH FOR ANSWERING THESE QUESTIONS.

**PLEASE EMAIL OR FAX THE COMPLETED FORM A.S.A.P. (6 December 2004 at the latest)
TO THE NIVEL SECRETARIAT: NCA.NWPLSecr@nivel.nl,
FAX NUMBER 0031 30 27 29 729**

Appendix 10: Agenda & Minutes of NWPL Meeting, January 2005



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Luxembourg,

AGENDA

SECOND MEETING OF THE NETWORK OF WORKING PARTY LEADERS

*Luxembourg, 17 January 2005 (10:30-17:30)
and 18 January 2005 (10:00-12:30)*

***Room C5/134 (17 January)
Room JMO M4 (18 January)***

The morning session of 18 January will be held jointly with the NCA

1. Adoption of the agenda
2. Adoption of the minutes of the last meeting
3. Progress report of the Working Parties and Task Forces
 - a. WP on Lifestyle
 - b. WP on Morbidity and Mortality
 - i. Task Force on Rare Diseases
 - ii. Task Force on Major and Chronic Diseases
 - c. WP on Health Systems
 - i. Task Force on Patient Mobility
 - d. WP on Health and Environment
 - e. WP on Mental Health
 - i. Task Force on Evidence
 - ii. Task Force on Future Perspectives in Mental Health Promotion

- f. WP on Accidents and Injuries
 - i. Task Force on Strategic Planning
 - ii. Task Force on Road Safety
 - iii. Task Force on Work Health
 - iv. Task Force on Burden of Accidents
 - v. Task Force on Indicators
- 4. Update on the implementation of the Health Indicators.
 - Presentation by Pieter Kramers
- 5. Issues raised by Working Party Leaders
 - WP secretariats
 - Co-ordination between projects in different WP's
- 6. Presentation of a template for executive summaries of project reports
- 7. Any Other Business
- 8. Next Meeting

Agenda for 18 January, joint meeting with NCA

- 9. (Adoption of the NCA agenda)
- 10. (Adoption of NCA minutes of last meeting)
- 11. Overview projects and tenders 2003-2004 (financed and decided) (Commission Services Working Document) and work programme 2005
- 12. EU Health Portal



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Luxembourg

MINUTES

**SECOND MEETING OF THE NETWORK OF WORKING PARTY LEADERS FOR
HEALTH INFORMATION AND KNOWLEDGE**

Luxembourg, 17 January 2005 (10:30-17:30) and 18 January 2005 (10:00-12:30)

Chair: Horst Kloppenburg (Principal administrator Sanco C/2, Health Information)

Reported by NIVEL Secretariat

1. Opening of the meeting

Chair opens the meeting. Not all participants are present, due to bad traffic conditions (fog).

2. Adoption of the agenda

The draft agenda is adopted without changes.

3. Adoption of the minutes of the last meeting

The minutes were preliminary adopted without changes. Additional comments (from persons not present) should be sent directly to the Secretariat.

4. Progress report of the Working Parties and Task Forces

All progress reports can be found on the NCA-NWPL webboard.

WP on Lifestyle

The WP pays special attention to the final report on their EU Nutrition Health Report, including a workshop, a special issue of the Journal of Public Health and a book. The WP has an interactive website (www.public-health.tu-dresden.de/eu), which will be connected to the Europa Website shortly.

It is discussed whether all WPs and projects should have websites or boards. Some choose not to, because there is already a Europa website and an internal web board. The meeting agrees that it is voluntary to have a website. It is requested that WP/TF websites are linked to the Europa website in order to facilitate locating them. Communication policies may be discussed at a next meeting. The Commission again emphasises that this meeting should not just focus on projects but should take a broader view beyond the scope of the projects. With special attention for cross-cutting issues. Meusel (Lifestyle) and Bourek (Health Systems) will send details on the software they use to the NIVEL Secretariat for distribution among the members.

WP on Morbidity and Mortality

The WP mentions the underreporting of neurodegenerative diseases, which will need more attention in the future. This is also mentioned in the Commission's Workplan 2005. The WP does not have a secretariat. The WP is a very heterogeneous group; this makes the need for a secretariat more pressing.

The development of Health Survey Systems is not a separate TF, but a major point of attention in the WP. The Commission will also give a presentation on this subject for the NCA meeting of tomorrow. Upon questions, Zeitlin confirms that interaction with other WPs is particularly acute for this WP.

- Task Force on Rare Diseases

There is no secretariat because the contract has not yet been signed. Horst Kloppenburg clarifies that the signing of contracts will not happen before mid February because the new budget has only very recently been approved.

The TF is developing an electronic newsletter and has three working groups: on coding, mortality/morbidity and on health care organisation and provision. An international conference will be organised 21/22 June 2005, Luxembourg, 300 participants.

There is a website with fact sheets on diseases in preparation.

- Task Force on Major and Chronic Diseases

The TF is not yet established, needs to appoint a TF Leader. First meeting will be in October.

WP on Health Systems

The WP also has secretarial problems, negotiations with NIVEL about secretarial support, also content related. The timing of calls for proposals and calls for tender needs to be discussed with the Commission. Patient Mobility is the hot topic at the moment: a pre-survey is set up at hospital settings, without primary care information. Attention for stocks and flows as well as motivation. Will be brought to the attention of the High Level Committee on Health. Bourek: 4 Fs are main reasons for patient mobility: fear (of treatment in own country), fate (accident) finance (cheaper elsewhere) or fun. Mobility of professionals is another issue and subject of a tender. Next meeting will be in April. Another issue is how to compare quality of Health Care systems in different MS. Sections are identified that may be comparable. This is also an area of attention for ECHI.

- Task Force on Patient Mobility

Was already included in the presentation of the WP.

WP on Health and Environment

WP organised a conference in which most members participated. WP contributed to the EU action plan on environmental health. Zurlyte will pass the name of the project leader for the TF on Road Accidents on to the Commission. WP has considerable overlap with WP on Accidents and Injuries, this needs to be considered.

Role of Working Party Leader/Working Party. Legal monitoring of projects is not task of Working Parties or Secretariat but of the Commission. Information sharing to stop redundancy and duplicity is task of WP leaders, they have value added role to projects and the general work.

The Commission explains that its work is being hampered by serious understaffing problems.

Fortunately, the NIVEL Secretariat has agreed to continue its work until August. It is unclear what will happen after that. The Executive Agency (EA) will not be operational for this strand until the end of 2006. The EA is an administrative body for the Commission Services for project management and implementation. Documents on the EA are added to the minutes:

(http://europa.eu.int/eur-lex/pri/en/oj/dat/2002/l_271/l_27120021009en00010011.pdf)

WP on Mental Health

Have been active in strand one and three. Were highly visible at a Ministerial Conference, resulting in an action plan (WHO website).

(http://www.europa.eu.int/comm/health/ph_determinants/life_style/mental/ev_20050112_en.htm)

Mental Health is major future health threat, but does not get the attention it needs on a European level. Therefore, the WP has been active on a policy level.

Discussion on the 20 persons limit to attend meetings. WPs and TFs can allocate money within the projects to attend meetings to avoid this limit, but this should be approved in the budget in advance. There will be an application for a secretariat, for two years.

Several projects are about to end, reports will be made available.

A report on the State of the Mental Health in the European Union is distributed at the meeting.

- Task Force on Evidence

Not present

- Task Force on Future Perspectives in Mental Health Promotion

Not present

WP on Accidents and Injuries

The WP is working on data management, a statistical portal and IDB coding manual. The portal should be accessible for non-specialists.

In 2004 there was an IDB partner meeting, EUNESE partner meeting, ECSA Expert Group meeting. Communication via a web board and via two-monthly memos, which are very useful.

The Working Party organises a pre-event to the 1st EU Conference on Injury Prevention Sept 28-Oct 1 2005 in Greece.

- Task Force on Strategic Planning

Focus on actions for a Safer Europe. Concentration on certain topics such as elderly or children, one topic at a time. This increases collaboration with other strands, visibility and funding prospects. An updated report is attached to the minutes. Comments before the end of April at the latest.

- Task Force on Road Safety

Public Health Aspects of Road Safety are presented. Overview of current situation: individual injury risk has not decreased, there is an underreporting of pedestrian injuries, a poor registration of external causes, huge disparities in injury risks between MS and population groups. So far, the role of the PH sector has been weak, partly to do with overlap with ministries of transport at a national level. Challenge for the future is inter-linkage with other WPs.

Possible role of the EC: development of advocacy documents, to introduce road safety in PH policy, cross-sectoral collaboration, improvement of monitoring, the development of population based risk indicators, the inventarisation and standardisation of good policy and programmes, network supporting, promote exchange of experiences, capacity building.

Following discussion on the status of a TF, compared to a WP and a project, it is agreed that Pieter Kramers and the NIVEL Secretariat will make a concept map of all the WPs and TFs indicating possible overlap as well.

- Task Force on Work Health

Not presented due to illness of Wolfgang Boedeker.

- Task Force on Burden of Injuries

Although the EU 25 are among the safest places in the world, prevention of injuries is still an issue. There are differences between the old and new MS. The focus is on the new MS and on cost effective interventions. Furthermore, work is being done in partnership with other WPs.

- Task Force on Injury Indicators

The TF has proposed indicators on: mortality, morbidity, and safety behaviour. Indicators for mortality from alcohol related injuries and mortality by type of injury need to be developed. For morbidity there is a need for hospital discharges due to injuries (by subgroups), proportions by type of injury and disability from injuries. Also, safety behaviour indicators are needed on e.g. helmet use, care restraint use. Some of these indicators should eventually be added to the ECHI list. Hospital data are not

always comparable, but in many countries they are the only source. Eurostat has a TF on the issue of discharge injury data. The Commission suggests close collaboration between this WP and the WP on Health Systems and the ECHI(M) project.

5. Update on the implementation of the Health Indicators

Pieter Kramers presents a short overview. At the ECHI meeting in October 2004 the shortlist was finalised and the January 2005 version is the correct one. Other additions and changes are on the waiting list for the next round. Sections one (46 indicators) and two (31 indicators) are the present shortlist. If you find technical problems in the present list, please give your comments to Pieter Kramers ASAP. This is not yet an implementation, which is being undertaken by Sanco and Eurostat. WP7 will now take over the further development of the indicators. WP7 has to guard the connection between the shortlist and the long-list. It is unclear whether or not all WP Leaders will be invited to attend the future WP 7 meetings, once this WP has been established. The Commission will look into this.

6. Issues raised by Working Party Leaders

- WP secretariats

Contributed by Wahlbeck/Mental Health as an agenda item. The meeting agrees on the need for WP secretariats and it should be a secretariat with content expertise. The division between secretariats and Executive Agency is unclear at present. The Commission adds that secretaries for WPs will not be refused at this stage in favour of the Executive Agency but this could happen in the future. The meeting agrees on the need for secretariats to further the work of the WPs.

- Co-ordination between projects in different WP's

Contributed by Wahlbeck/Mental Health as an agenda item. Pieter Kramers stressed the importance of this point. Once the proposed map (see agenda item 4, under TF Road Safety) has been made, this can be further discussed at the meeting. The item of overlap should be on all WPs' agendas. Individual project leaders may be invited to WP meetings. A task for a secretariat could be the identification of potential cooperation between actual projects.

7. Presentation of a template for executive summaries of project reports

Walter Devillé explains the purpose of the executive summary template: project leaders asked for a structure in order to be able to publish reports on a website, to disseminate information. Members suggest changes to the form.

The adapted form is included in the minutes. For additional suggestions for change, please contact the NIVEL Secretariat.

8. Any Other Business

Ayme: the list of projects (for the meeting of tomorrow) is incomplete. The Commission explains that only the projects actually running and managed by the Commission services are on the list.

9. Next Meeting

4-5 July 5 July will be again a joint meeting with NCA. The subject of overlap / synergy between various WPs will be on the agenda.

JOINT MEETING NWPL / NCA

Chair: Horst Kloppenburg (Principal administrator Sanco C/2, Health Information).

Reported by NIVEL Secretariat

Agenda for 18 January, joint meeting with NCA (morning)

10. Opening of the meeting

Chairman opens meeting and wishes everyone a very happy and productive New Year. John Ryan is not present due to obligations elsewhere. There is interpretation in 5 languages.

11. (Adoption of the NCA agenda)

The draft agenda is accepted without changes.

12. (Adoption of NCA minutes of last meeting)

The draft minutes have been accepted without changes.

13. Overview of projects and tenders 2003-2004 (financed and decided) (Commission Services Working Document) and work programme 2005

Most of the contracts of the projects agreed in 2004 have not yet been signed. Pieter Kramers questions allocation of projects to WP. He will suggest alterations, in collaboration with the NIVEL Secretariat.

The Commission adds:

1. The meeting has been given an overview of the 110 projects running at the moment. The Commission Services are faced with a cumulative number of about 30 new projects per year, each running for two to three years. Suggestions for changes to the document are welcomed.
2. Executive Agency (EA) for PH Programme. The Commission has published a decision establishing the EA and its tasks

(http://europa.eu.int/eur-lex/pri/en/oj/dat/2002/l_271/l_27120021009en00010011.pdf).

The Agency will function as an office for the Commission and should aid the implementation of the PH programme. The role of the Commission controlling the Programme together with the Programme Committee will not change. Transfer of tasks will be progressively: the health information strand will be supported from 2006. The budget for the Agency has to come from the Public Health Action Programme. Job vacancies will be circulated within this group in order to have a good balance of nationalities in the agency.

3. Workplan. The call for proposals has been published. Deadline for applications is extended to 15 April. Croatia can participate on a non-financial basis.

14. EU Health Portal

The EU Health Portal will provide a single point of access to PH, at a Community, national and regional level. Target population are EU citizens. The portal should be operational by December 2005 and will be hosted the Europa website. At present, the advisory board is kept to a manageable size, later a more representative board will be established. The portal will not provide medical information on treatment and medication, and there will be mainly links to health related content. The portal has to be multilingual, and the first few levels may be provided in all the Community languages. This will be considered. An explanatory document can be found on the EU website.

(http://europa.eu.int/comm/health/ph_information/implement/nca/docs/ev20040705_rd26_en.pdf)

15. Progress report of the Working Parties: Summary

All progress reports can be found on the NCA-NWPL webboard. The meeting would like to know if progress has been made in the area of social inequalities and gender mainstreaming. This is a horizontal theme and is considered in all WPs. The future WP on Health Indicators should take these topics, together with age groups and other specific subgroups on board. This could be an issue to consider when the map of WPs and TFs is made.

With regard to the presentation, the meeting suggest short 'highlight' presentations by a few WPs in addition to the summary. The NCA asks for project summaries and lists of members per country. For now, CAs are referred to the minutes and the progress reports, published on the NCA/NWPL web

board. The Commission adds that the Health Portal is a true highlight, based on the work of the WPs. The development of eHealth indicators should be considered. At present, this is not included in the ECHI list. For a comprehensive summary of projects, an executive summary is introduced, this will be discussed later at the meeting of the NCA.

16. Progress of activities at a national level: Summary

Twelve of the 25 MS completed their progress report. All progress reports can be found on the NCA-NWPL webboard. Following comments at the meeting, the template will be revised with the aid of the UK, Greece, and Germany. The form should not use the same focus on each occasion, and be more specific. Some initiatives at country level may be presented as reference or examples of 'good practice'. The candidate countries and the EEA countries will also be asked to complete this report in future. The EMCDDA in Lisbon will also complete the template for the next meeting. WP Leaders add that this report provides WPs with policy information that will be relevant for the WPs.

Chair thanks all present for their active contribution to this joint meeting and he ends the joint session with the NCA members. The exchange of information was agreed to have been useful.

Appendix 11: Agenda & Minutes of NCA meeting, January 2005



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Luxembourg,

AGENDA

Fourth Meeting of the Network of Competent Authorities

*Luxembourg, 18 January 2005 (10:00-17:30)
and 19 January 2005 (9:30-16:00)*

Room JMO M4

The morning session on 18 January will be held jointly with the NWPL (10:00-12:30)

1. Adoption of the agenda
2. Adoption of the minutes of the last meeting
3. Overview projects and tenders 2003-2004 (financed and decided) (Commission Services Working Document) and work programme 2005
4. EU Health Portal

Lunch break and end of joint meeting

Afternoon session (14:15-17:30) and 19 January (09:30-16:00)

5. Progress report of the Working Parties: Summary
6. Progress of activities at a national level: Summary
7. Update on the implementation of the Health Indicators.
 - Presentation by Aarpo Aroma
 - Presentation by Antoni Montserrat
8. Issues raised by Competent Authorities

- Availability person-identifiable data at National level (Malta)

9. European Centre for Disease Prevention and Control (ECDC)

- Presentation by Mr Tapani Piha, Head of Unit SANCO C/6

10. Related health information activities

- Presentation of member of Health and Food Safety Statistics Unit on progress in public health statistics., Eurostat

11. EU Health Survey System and Registries

Presentations and discussion

Presentations by:

- Mr Antoni Montserrat (SANCO) on EU Health Surveys
- Mr Walter Devillé (NIVEL) on Dutch Registry systems
- Representative of CARDS project (CVD)
- Mr Jan-Willem Coebergh Representative of European Network of Cancer Registries (ENCR)
- Injury Data Base; progress (Injury Network – Mr Rupert Kisser)

12. Presentation of a template for executive summaries of project reports

13. Any Other Business

14. Next Meeting



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Luxembourg, 4 February 2005

MINUTES

FOURTH MEETING OF THE NETWORK OF COMPETENT AUTHORITIES

*Luxembourg, 18 January 2005 (10:00-17:30)
and 19 January 2005 (9:30-16:00)*

Chair: Horst Kloppenburg (Principal administrator Sanco C/2, Health Information) / John Ryan (Head of Unit)

Reported by NIVEL Secretariat

The morning session on 18 January was held jointly with the Network of Working Party Leaders (NWPL) (10:00-12:30)

1. Adoption of the agenda

The draft agenda was accepted without changes.

2. Adoption of the minutes of the last meeting

The draft minutes have been accepted without changes.

3. Overview of projects and tenders 2003-2004 (financed and decided) (Commission Services Working Document) and work programme 2005

Most of the contracts of the projects agreed in 2004 have not yet been signed.

Allocation of projects to WPs is questioned. Alterations will be suggested, in collaboration with the NIVEL Secretariat, which will be posted on the webboard.

The Commission adds:

1. The meeting has been given an overview of the 110 projects running at the moment. The Commission Services are faced with a cumulative number of about 30 new projects per year, each running for two to three years. Suggestions for changes to the document are welcomed.
2. Executive Agency (EA) for Public Health Programme. The Commission has published a decision establishing the EA and its tasks

(http://europa.eu.int/eur-lex/pri/en/oj/dat/2002/l_271/l_27120021009en00010011.pdf).

The Agency will function as an office for the Commission and should aid the implementation of the Public Health programme. The role of the Commission controlling the Programme together with the Programme Committee will not change. Transfer of tasks will be progressively: the health information strand will be supported from 2006. The budget for the Agency has to come from the Public Health Action Programme. Job vacancies will be circulated within this group in order to have a good balance of nationalities in the agency.

3. Workplan. The call for proposals has been published. Deadline for applications is extended to 15 April. Croatia can participate on a non-financial basis.

4. EU Health Portal

The EU Health Portal will provide a single point of access to PH, at a Community, national and regional level. Target population are EU citizens. The portal should be operational by December 2005 and will be hosted the Europa website. At present, the advisory board is kept to a manageable size, later a more representative board will be established. The portal will not provide medical information on treatment and medication, and there will be mainly links to health related content. The portal has to be multilingual, and the first few levels may be provided in all the Community languages. This will be considered. An explanatory document can be found on the EU website.

(http://europa.eu.int/comm/health/ph_information/implement/nca/docs/ev20040705_rd26_en.pdf)

5. Progress report of the Working Parties: Summary

All progress reports can be found on the NCA-NWPL webboard. The members of the meeting would like to know if progress has been made in the area of social inequalities and gender mainstreaming. This is a horizontal theme and is considered in all WPs. The future WP on Health Indicators should take these topics on board, together with age groups and other specific subgroups. This could be an issue to consider when the map of WPs and TFs has been made.

With regard to the presentation, the meeting suggests short 'highlight' presentations by several WPs in addition to the summary. The NCA asks for project summaries and lists of members per country. For now, CAs are referred to the minutes and the progress reports published on the NCA/NWPL webboard. The Commission adds that the Health Portal is a true highlight, based on the work of the WPs. The development of e-Health indicators should be considered. At present, this is not included in the ECHI list.

For a comprehensive summary of projects, an executive summary is introduced, this will be discussed later at the meeting of the NCA.

6. Progress of activities at a national level: Summary

Twelve of the 25 MS completed their progress report. All progress reports can be found on the NCA-NWPL webboard. Following comments at the meeting, the template will be revised with the aid of the UK, Greece, and Germany. The form should not use the same focus on each occasion and should be more specific. Some initiatives at country level may be presented as reference or examples of 'good practice'.

The candidate countries and the EEA countries too will be asked to complete this report in future. The EMCDDA in Lisbon will also complete the template for the next meeting.

WP Leaders add that this report provides WPs with policy information which will be relevant for the WPs.

Chair thanks all present for their active contribution to this joint meeting and he ends the joint session with the NWPL members. The exchange of information was agreed to have been useful.

7. Update on the implementation of the Health Indicators

The Working Party on Indicators will work towards the implementation of health indicators. It will be established as soon as the project application will be approved. The WP has a very specific mission and approach. Collaboration, representation and cooperation (with the other WPs) will have to be considered by Sanco C2.

The circulated shortlist dated January 2005 is the correct one. The meeting underlines the importance of progress towards the actual implementation of the shortlist.

The ECHI Database is of great political and EU importance. It establishes the importance of the Public Health action programme on EU level. Previous documents about the European Health Survey System have been improved, it is strongly advised to (re)read these documents on the Europe website. There is a strong close coordination with Eurostat. For the first time there will be a budgetary sub-delegation from the Public Health programme to Eurostat. It will also be possible to contract other international activities related to health indicators, e.g. with OECD, WHO and Council of Europe.

The database will provide ECHI indicators at a national, sub-national, urban /rural, and regional level. Close cooperation is also needed with the Social Protection Committee. On the list of the Commission that will be presented to the Council, there is one structural indicator on health: Healthy Life Years. Data Presentation System technology from the WHO (new version) might be used for all databases. ICHI (International compendium of health indicators) will be the basis for definitions within the system. The database will be part of EU Health Portal.

The meeting welcomes the progress Sanco has made and the intention to use existing databases. Repetition or the collection of very similar data should be avoided. Also, the use of common definitions is important, e.g. within the whole of the OECD. Quality and comparability need to be guarded since so many different databases and definitions will be used. This will also be an important issue for the future Working Party on Indicators. A road map, already set into action in the workplan 2005, should be further developed to ensure quality and progress and to prevent duplication. Priorities have to be defined in future workplans: e.g. data at primary care level are absent in many countries and data collected by the Social Protection Committee need better coordination. In addition, the Competent Authorities need to be consulted and informed about the process.

8. Issues raised by Competent Authorities

- **Availability person-identifiable data at National level (Malta).**

Data protection issues and national legislation are not always compatible with good quality data. Patient identifiers can help in cross linking and checking the accuracy of the data provided. This is an important issue. It is related to (new) developments in legislation in the different MS. The Commission suggests to discuss data protection and confidentiality at the next meeting. Not only the Eurostat working group on Public Health statistics, but also persons from MS who have worked with these issues should be invited. Competent Authorities are invited to nominate experts to the NIVEL Secretariat.

- **Importance of coordination between Eurostat and DG Sanco (Ireland).**

Mainly raised to emphasise its importance again, this needs to be in writing.

- **Collection of relevant and harmonised health data (The Netherlands).**

The issue is how to get commitment from national governments. Relates to the road map discussion. We need political commitment to get things done. Would like to see this issue on the next agenda of this meeting.

The Commission feels that first the visibility of the Public Health programme needs to be improved. The operationalisation of the key indicators is an important step. Then we can ask for support to better the quality. It will be a coordinated approach by the Commission, not by either Eurostat or Sanco.

9. European Centre for Disease Prevention and Control

The European Centre for Disease Prevention and Control will be established in Stockholm this year, with a mandate that focuses on communicable diseases. Research is, for now, excluded from the mandate. However, this may change in the future as the Parliament aims at a broader scope. The Health Measures (Legislation) Unit is ready to support MS with the legislation concerning the collection of data related to infectious diseases in the public health area.

10. Related health information activities

Mr. Didier Dupré provided an extensive update of activities of Eurostat in all relevant projects on data collection and other activities: Indicator project, EU Health survey, Hospital Data Project.

A main point of attention is the development of an EU Parliament and Council Regulation for Public Health statistics. This legal basis is of interest, this will be a move from a gentlemen's agreement on data collection with MS to a more legal basis. The first regulation will be very general, defining a domain and topics, not variables. Modules that may be integrated into national surveys will be defined. The integration of the ECHI indicator shortlist is of importance in relation to this regulation. The Commission suggested to try to fit in with the umbrella regulation under way. At the suggestion of the meeting, the Commission will put this issue on the meeting of the High Level Committee as well as inform Chief Medical Officers. It needs to be identified if obstruction points exist at national ministries of health. Staying ahead of the developments is a point of attention, members of the High Committee Level need to consult experts regarding data collection issues.

There are two approaches: complete harmonisation or minimal harmonisation. The Commission is trying to achieve more harmonisation within the Public Health Programme, and is getting to the point of a need for a legal basis. You need some sort of obligation to contribute to the Public Health Programme, otherwise people at a national level will re-allocate resources, since these requests are also coming from other sectors such as transport. The question is whether regulations should concentrate on data collection in order to encourage the use of main definitions and agreement. Eurostat needs a solid legal basis established with the Network of Competent Authorities, to improve quality of our statistics in the long term. An improvement of the present situation is also needed for continuation of financing research projects. It seems preferable that Eurostat and Sanco have a joint legal basis.

Other issues raised by the meeting that need to be considered are: data protection regulation, consumer rights, quality guarantees, interference with national legislation, provision of data by important registries that lack a legal basis in their country, regulations should not hamper the evolution of the indicator work. Do recommendations generate more efficient political pressure than regulations? This question needs to be looked into. Coexistence of instruments will be necessary during a longer period: legal regulation framework and recommendations and others.

The Commission thanked all members for their positive messages. The content of the umbrella regulation will be discussed at the next meeting. According to Eurostat, this will be in time to influence this regulation. The Commission is responsible for the draft version of the proposal and there is an obligation to consult experts beforehand as this increases transparency and partnership. The Commission will try to get this also on the agenda of the High Level Committee and of the Chief Medical Officers.

11. EU Health Survey System and Registries

It is not the intention to create a separate European Health Survey. The System will consist of the national health surveys, newly-developed health modules that may be included in other surveys, and ad hoc surveys e.g. the European Environmental Survey. Another objective is to develop an additional instrument to the social instruments in the field of the social survey: self perceived health. There is no intention to substitute more objective measurements, but to complement them with a self perceived health measure, the consumer perspective. This is a good predictor of future health use and mortality, decline of functional ability among elderly and general population. The Euro-barometer is limited, collects opinions, sometimes about health. DG Sanco will develop complementary modules in 2005, one institution per MS will submit a proposal for: the collection of existing complementary modules, a list of institutions that will help in the development, and a pilot survey with some of the special modules. The Commission will send suggestions via Competent Authorities.

For the feasibility study on an EU Health Examination Survey in 2005, a similar procedure will be used. The Commission will provide details for the proposal. There will be a Steering Committee of 12 experts. Two occasions to launch calls for tenders have been refused for legal reasons. Therefore, this is now transformed to a project, not a tender. Funding is 60%, might be possible to go to 80% co-financing. For requirements see call for proposals; the proposals have to include a high participation of new MS. This will be discussed again at the information day on 3 February.

Mr Walter Devillé (NIVEL) on Dutch Registry systems. The Netherlands have more than 120 health related, standardised and validated data-bases that are accessible for external use. The majority collects data on health systems or on morbidity and mortality. Only very few have a legal basis. There are 2 new developments: the continuation of the National Medical Registration (LMR) is under discussion, and the future link of several health (care) registrations with the individual Basic Community Registration by Statistics Netherlands (CBS).

Mr Anselm Gitt, Representative of CARDS project (CVD) focused on the role of the European Society of Cardiology in the implementation of Standards, in the development and execution of the Euro Heart Surveillance Programme since 1988 and in the promotion of use and adherence to guidelines. The Commission suggests to come back to CARDS after the implementation of the survey, e.g. in the meeting of January next year. Suggestions were made for harmonization of the data collection by CARDS with other data-bases and through different data-collection systems.

Ms Paola Pisani, Representative of European Network of Cancer Registries (ENCR). The work of the network is presented with the IARC as secretariat. The last report was presented in 1997 due to a lack of funding since then. The basic activities are resumed through the IARC (routine data collection, dissemination). The link with hospital databases reduces the workload. The Commission emphasises the need for sustainability of projects and initiatives developed by the various projects. It was agreed that a distinction has to be made between original research oriented data-bases and the ones set up in the regular health system.

Mr Rupert Kisser, Injury Data Base; progress (Injury Network). The database gives free access to people authorised through a password. Not all MS are yet providing data. The Network of Competent Authorities is invited to attend the IDB workshop this year

12. Presentation of a template for executive summaries of project reports

Not discussed at the meeting due to lack of time.

13. Any Other Business

A list with the data of the various meetings in 2005 is provided.

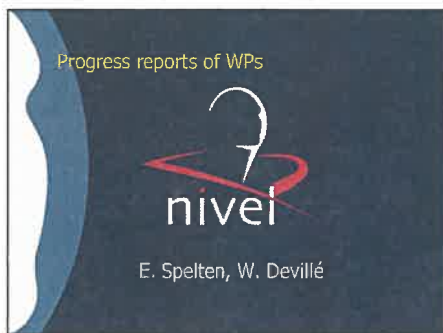
The next meeting will be used to exchange best practices; the Competent Authorities are invited by the Commission to raise issues that occur on a national level and are of interest for other MS.

14. Next Meeting

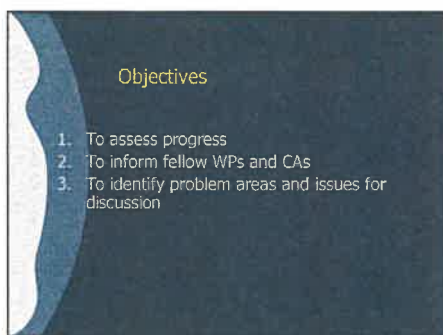
5-6 July 2005, again including a joint meeting with the Network of Working Party Leaders.

Appendix 12: Summary of Progress Reports WPs, January 2005

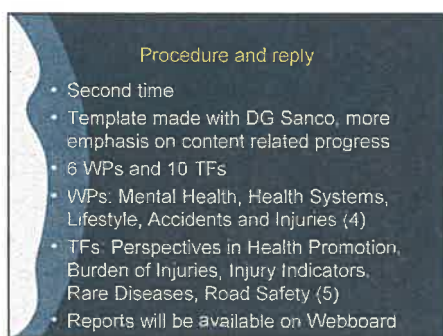
Dia 1



Dia 2



Dia 3



Dia 4

Procedure and reply

- Second time
- Template made with DG Sanco, more emphasis on content related progress
- 6 WPs and 10 TFs
- WPs: Mental Health, Health Systems, Lifestyle, Accidents and Injuries (4)
- TFs: Perspectives in Health Promotion, Burden of Injuries, Injury Indicators, Rare Diseases, Road Safety (5)
- Reports will be available on Webboard

Dia 5

Results

- 7 Workplan, 2 WPs Secr(+ 1 plan), 8 Meetings planned in 2005
- Main activities: meetings, participation, publications, TF activities, development of websites
- TFs: voluntary or still to be established

Dia 6

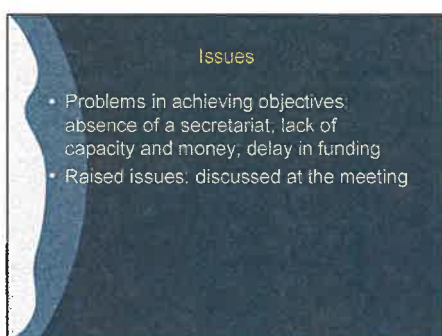
Content Related Results

- EUHKS (3 WPs)
- Surveys
- Professional advice/consultation/recommendations
- Dissemination of information
- Reports/books/other publications
- Project proposals
- Scientific contributions to conferences
- Coordination and presentation of research results

Dia 7

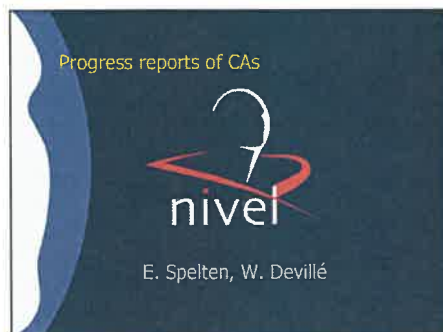


Dia 8

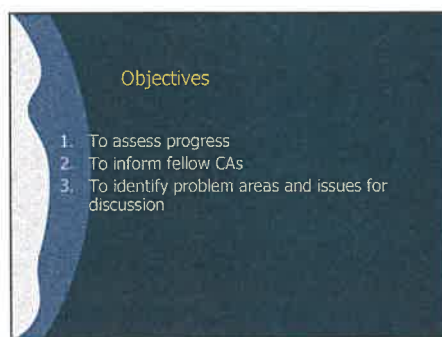


Appendix 13: Summary of Progress Reports CAs, January 2005

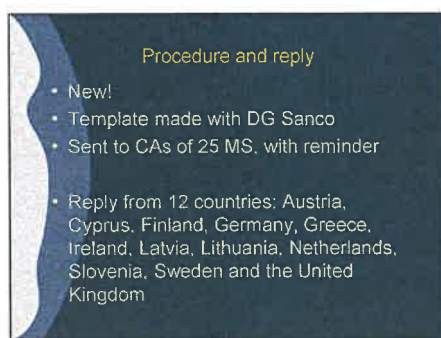
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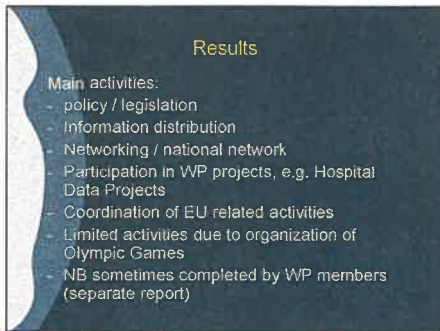
Dia 2



Dia 3



Dia 4

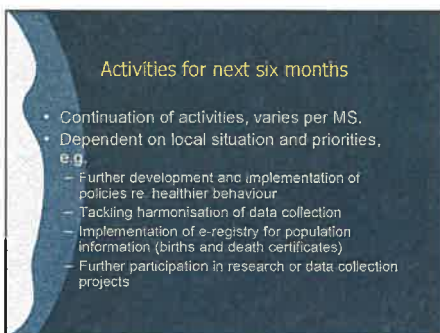


Results

Main activities:

- policy / legislation
- Information distribution
- Networking / national network
- Participation in WP projects, e.g. Hospital Data Projects
- Coordination of EU related activities
- Limited activities due to organization of Olympic Games
- NB sometimes completed by WP members (separate report)

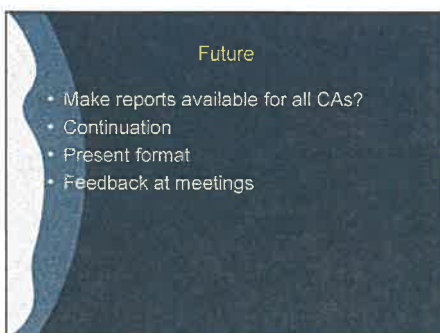
Dia 5



Activities for next six months

- Continuation of activities, varies per MS.
- Dependent on local situation and priorities, e.g.
 - Further development and implementation of policies re. healthier behaviour
 - Tackling harmonisation of data collection
 - Implementation of e-registry for population information (births and death certificates)
 - Further participation in research or data collection projects

Dia 6



Future

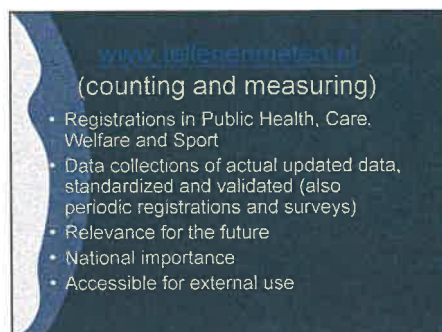
- Make reports available for all CAs?
- Continuation
- Present format
- Feedback at meetings

Appendix 14: Presentation NIVEL on Dutch Registry Systems, January 2005

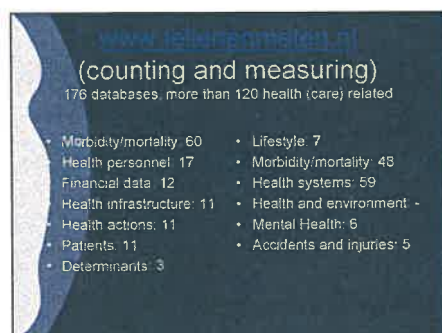
Dia 1



Dia 2



Dia 3



Dia 4

Registration / Content	Continous Mortality Statistics Netherlands
Age	Primary diseases
Cause of death	Secondary diseases, activities in GP practices in a representative sample of GP practices in the Netherlands
Administrative information	Administrative form, questionnaire of patient sample
Registration unit	Personal and professional data GP, contact information patient
Registration period	Administrative form, questionnaire of patient sample
Registration frequency	Quarterly contact search
Registration frequency	Number of contacts per week
Registration frequency	No
Registration frequency	Yearly
Registration frequency	1% sample of population
Registration frequency	Yearly
Registration frequency	Complete sample 1% of population
Registration frequency	Sample is according to age and gender register and information
Registration frequency	Sample is according to need for care with questionnaire
Registration frequency	No
Registration frequency	100%
Registration frequency	2004
Registration frequency	after report 2003 in August 2004
Registration frequency	No
Registration frequency	Yearly changes possible, within limits are collected continuously
Registration frequency	8 August 2002
Registration frequency	6 August 2002

Dia 5

Registration	Content	Population	Medical consumption
Mortality statistics CBS	All diseases ICD	Open population	-
National medical reg (LMR)	All diseases ICD	2 nd care (clin.)	Use hospital care
National obstetric reg	perinatal	1 st + 2 nd care (clin. + outpat.)	Use extra- and intramural care
Dutch Cancerreg	ICD-O	2 nd care (clin. + outpat.)	Use extra- and intramural care
Patientreg Intramural Mental Health care (PIGGZ)	ICD 9CM	2 nd care (clin.)	Use extra- and intramural care
Nursinghome IS	V, VI, IX – ICD	2 nd care (clin.)	intramural care

Dia 6

Registration	Content	Population	Medical consumption
Injury IS	ICD-10	Open population	Use extra- and intramural care
Road accidents reg (VOR)	ICD-10	Open population	-
National Alcohol- and Drug IS	-	1 st care	Use extramural care
Health survey CBS	>25 complaints - 24 chronic dis. - 10 DLA-activ. - 8 functions	Open population	Use health care, medication
EUROCAT	Congenital anomalies	1 st + 2 nd care	Use extra- and intramural care, pregnancies, deliveries

Dia 7

Registration	Content	Population	Medical consumption
National Anatomopath. Archive	SNOMED	1st + 2nd care (clin + outpatient)	Use PA-lab
Reg. Working disabled payment	All diseases	Open population	Inc + prev Working disabled
Cont. Mortalityreg. Huisgen GP (CMR)	All diseases	Primary care	Contact GP, referrals
Cont. Mortalityreg GP and generalists	Changing	Primary care	Contact GP, referrals, specific
National Inf. Network GP (LINH)	All diseases	Primary care	Contact GP, referrals, specific

Dia 8

<ul style="list-style-type: none"> Legal: <ul style="list-style-type: none"> National Drug replacements registration Periodic information insurances working disabled Registration child abuse (law youth aid)

Dia 9

<ul style="list-style-type: none"> legal support: <ul style="list-style-type: none"> screening breast cancer (law screening activities) national medical registration (law hospital care) patient registration intramural mental health care (law hospital care) neonatal screening (law discovery congenital diseases) national registry care services for mental disabled persons (law legal data provision) national registration evaluation side effects (support Board evaluation of medication)

Dia 10



Registrations and ICT

Professional organisations and associations and the government need data that partly originate from registrations of work 'in the field', in order to be able to set a policy and to define their position. Changes have taken place in the registration need during the past few years. In addition to the original product registrations, other registrations have been conducted to help developing health policy and quality policy. After all, the obligation for institutions to justify their social function is growing. Justification means transparency. Registrations can be divided based on the object of registration, permanent versus temporary and locally or regionally versus beyond this level. Coherent, permanent and temporary registrations cannot operate without an infrastructure. Therefore, medical specialists need appropriate software in his practice.

National Medical Registration

The LSV, among others, established the Foundation Medical Registration (Stichting Medische Registratie, SMR) in 1963. The Foundation aimed at making medical data accessible for scientific research. The National Medical Registration (Landelijke Medische Registratie, LMR) was subsumed within the SMR. The foundation of the Foundation Information Centre for Health Care (Stichting Informatiecentrum voor de Gezondheidszorg, SIG), in 1976, caused several national medical registrations to be joined together, one of which was the LMR. In 2000, SIG Health Information (SIG Zorginformatie) merged with the NZi (the former Nationaal Ziekenhuis Instituut, the National Hospital Institute) into Prismant. Prismant is an independent organisation, which, among other things, collects information on illnesses and health, requested and offered care. The LMR is a permanent registration system of medical and administrative data on patients who have been admitted to a hospital in the Netherlands, either for hospital care or polyclinic care. The LMR intends to give medical administrative information on clinical hospital care including day nursing care in the Netherlands, in particular to support the policy of hospitals and specialists who are working within the hospitals. Additionally, the LMR aims to offer mirror information to compare companies and practices; also, to offer insight in the position of the hospital in the care environment and in the developments in the production and consumption of clinical hospital care. The information is also available to other ends, such as scientific research, albeit on specific conditions, like that of privacy and confidentiality. It concerns continuous registration of patients who have been discharged from hospital; in 1998, 120 general hospitals and university hospitals participated in the registration with 1.5 million clinically discharged patients and 0.7 million discharged from day nursing care. The core analysis hospitals and the practice analysis specialists are products people know; these originate from the LMR. Prismant also collects data from hospital information systems (ZIS'en) for the national ambulant care registration (Landelijke Ambulante Zorg Registratie, LAZR). An important part of this LAZR is the information on patients' origins. These data are used to establish the adherence of hospitals and specialisms, for example for the Health Care Charges Board (College Tarieven Gezondheidszorg). The merger of SIG and NZi into Prismant enables linking the LMR-data to the data files containing information for the management of institutions. Every year, institutions receive a Management Information Package (Management Informatie Pakket, MIP). This MIP contains not only the individual data on the institution, but also mirror information. Statistics are made, based on the full data of the institutions, about personnel, finance and production. Integration of the data of LMR and the management contributes to management's and professionals' insight in their own institution and the environment.

Other registrations

Prismant collects and processes statistical data for medical specialists and hospitals, as well as for the sector of nursing homes, mental health care and care for handicapped people. Around 50 different registrations provide information on subjects such as waiting lists, numbers of staff, the costs of labour and statistical facility indicators. Pharmaco-epidemiological and economic research is done together with Pharmo, a cooperation of Prismant and a cooperative of pharmacists (U-expo), among others. Additionally, Prismant is the holder and rewriter of several national specialism-specific registrations, like PALGA (Dutch Pathological Anatomical Computerised Archive, "Pathologisch Anatomisch Landelijk Geautomatiseerd Archief"), the Dutch Gynaecology Registration (Landelijke Gynaecologie

Registratie), Dutch Neonatology Registration (Landelijke Neonatologie Registratie), Dutch Obstetrics Registration (Landelijke Verloskunde Registratie), Dutch Registration Orthopaedic Implants (Landelijke Registratie Orthopaedische Implantaten), Dutch Registry of Implants in Plastic Surgery. Most of the scientific associations conduct many specialism-specific registrations at national level.

Waiting list registration

From 2001, hospitals are obliged to produce waiting list data of the hospital, the outpatient department and the day health treatment department, and to send this information to Prismant. Prismant manages for the NVZ, the Dutch Hospitals' Association, a part of the web site www.nvz-ziekenhuizen.nl, that shows the waiting times. Publication of these data should enable patients and general practitioners to choose the hospital with the shortest waiting time, which should reduce waiting times.

Electronic information

The website www.tellenenmeten.nl provides more information on national registrations in care. Prismant has developed this web site, commissioned by the ministry of Health, Welfare and Sport. This registration description contains data collections that meet the following criteria:

- The data collection concerns registrations in the public health, care, welfare and sports sectors;
- The data collection is continuously registering recent data – based on operational available data – on comparable persons, cases or events, aimed at analysis afterwards.
Random sampling registrations and periodical questionnaires are also covered by this definition;
- The data collection is also accessible to third parties. In addition to the reporting, developing, holding or financing institution, others can receive a variable data set in whatever format and at whatever aggregation level – within the boundaries of the privacy regulations.

Welcome at “Tellen & Meten”

“Tellen & Meten” gives you an accessible survey of the many registrations available on public health, health care, welfare and sport. This data base enables you to find information about these registrations, in order to develop, monitor or implement a policy. “Tellen & Meten” intends to provide insight into the background to the registrations, the creation and the quality aspects. This site does not contain any registrations, but it refers to these.

Definition and delimitation

With registration we refer to a collection of standardized and validated data with a specific aim, updated with a certain frequency. The registration is accessible for third parties within the boundaries of the privacy regulations, and is also relevant in the future.

The definition also covers random sampling registrations and periodical questionnaires. The featured registrations are characterized by a national interest. A registration that is not nationally covered will be of national interest if the collected data are representative for the Dutch situation.

Whom is it meant for?

“Tellen & Meten” is meant for scientific researchers, registration holders, information specialists and policy makers on areas related to health, welfare and sport.

By whom has it been set up?

“Tellen & Meten” has been set up by [Prismant](http://www.prismant.nl), commissioned by [RIVM](http://www.rivm.nl) (National Research Institute of Public Health, Environment and Nature) and the [Ministerie van VWS](http://www.vws.nl) (ministry of Health, Welfare and Sport).

Searching and finding

Via 'Direct zoeken' (direct search) you can search the whole web site using one single word.

Via '[Zoeken](#)' (searching) you can do an advanced search or combine search terms. '[Registraties](#)' (registrations) and '[Organisaties](#)' (organisations) present all information in alphabetical order.

Registration

You will find the registration underneath:

Registration / description of questionnaire	
Registration / questionnaire	Zorginformatiesysteem GGZ Nederland (Zorgis)
Characteristics	
Aim of registration	Information supply for policy, planning and research on mental health care. Zorgis has especially been set up to provide GGZ-institutions with mirror information on their performance. The system supports benchmarking in the GGZ.
Contents	Data on registration, waiting times, diagnosis and problems, legal status and provision of care are collected per client. The need for and the use of mental health care can be followed longitudinally in Zorgis.
Geographic area	The Netherlands
Research method	Data originate from the registration systems of institutions and are registered digitally.
Keywords	Clients, mental health care, psychiatric patient, patient characteristics, mental health care institution, psychiatric hospitals, Zorgis.
Extra keywords	
Registration unit	Data are registered per client. Per client, consecutive registrations are gathered. Per registration, the care provided is recorded. Registration has a nationally unique, but anonymous client identification, which makes it possible to follow clients in time and at several care providers.
Data groups	Client characteristics, registration data, care provision, legal status, medication (care of addicts).
Definitions & descriptions	Zorgis holds around 50 data items that are all defined in a code book.
Classifications	All data are classified. DSM-IV and ICD-9CM or ICD-10 are the classification systems used for diagnosis.
Reporting	Continuous registration in mental health care institutions. Monthly report.
Scope	Zorgis is aimed at the member institutions of GGZ Nederland (around 150)
Periodicity	Continuous
Legal basis	No.
Quality aspects	
Exhaustive sampling	Exhaustive, except for the non-respons, all institutions are involved.

Representativity	Data are not raised to sector level; in the reports information will be provided to enable this.
Process description registration	Data are automatically taken from the registration systems of the institutions. Trusted Third Party (TTP) will anonymise the data before they are stored in the national data base.
Codebook	Institutions have a codebook defining all data involved and assigning a classification to these, if needed.
Availability of data	
First year	Continuous
Most recent year of data	2003
Publication date	The first normal output of Zorgis appeared in March 2003
Access to data	Third parties can request for data, provided the request is not in conflict with the management and privacy regulations. Please submit requests to GGZ Nederland
Finished	No
Data available	No
Counter for amendment proposals	Responsible institution for registration (GGZ Nederland) or registration processor (Prismant)
Details	
Date description	3 March 2003
Amended date description	3 March 2003

Explanation of the registration descriptions

Name registration / Questionnaire

Name under which the registration or the questionnaire is known. An addition to the name can be given in order to make the name understandable to outsiders.

Characteristics

Object

Object of collecting or processing the data - short description or summary.

Content

Description of the area of attention for which the data, the output, are valid. Area of attention means: the population that is subject of the registration and that is represented by the registration. The character of the data that are collected.

Geographical delimitation

Which geographical area concerns the registration, i.e. is it a national, regional or local registration? The registration concerns which area or which local situation.

Research method

Which research method is used to collect registration data, i.e. survey by telephone, questionnaire, registration in institutions etc.).

Keywords

Which keywords or expressions characterise the registration's content right.

Registration unit

On what kind of registration unit are data being collected, i.e. persons, institutions, things or events.

Groups of data

The data or groups of data to be differentiated between within the data collection.

Definitions / Descriptions

Definitions and / or descriptions of concepts from the registration as used in this registration description.

Classifications

Classifications, lists of codes or schedules for calculation as applied to the registration. The full name, as well as the abbreviation, in brackets, is given.

Communication

Who communicates the information; who are the reporting persons?

Extent

Number of reporting persons who deliver the information, plus the number of registration units, on which the reporting persons deliver information. This is indicated for the most recent year, or concerning sentinels, for two measurements. Do not count the reporting persons who deliver no data, or data that cannot be used ('non-response').

Periodicity

How often are data collected, i.e. continuously, once a year, etc.

Legal basis

Is there a legal basis for the registration? This means that reporting persons are by law obliged to deliver information. This is indicated by: "this registration has a legal basis", "name law" and "title article", if needed. Also, several registrations are done to support the application of certain laws. This is indicated by: "there is no legal basis, but the data are used to generate information in the Law "name law" and, if needed, "title article".

Quality aspects

Exhaustive / Sampling

Are all units involved in the observation or is it a sample? If a sample is used, please state which sampling method and how many reporting persons and units are in the sample; the number of units given under EXTENT are the reporting persons or units that have delivered data that can be processed.

Representativity

Are the delivered numbers calculated towards the complete population, if a sample is taken and / or not all contacted participants have delivered useable data? If so, how is this done?

Process description registration

Is there a description of the way the data are collected and processed, i.e. procedures on data collection, training of field workers and quality controls? Is this description available?

Codebook

Is there a codebook available? Is it also in electronic format available? Availability data.

Availability of data

Period

Here the first year on which data are available and accessible in machine readable format is mentioned. If the registration is finished, the last year of registration is also given.

Most recent data year / Most recent measuring date

The year or date of measurement of most recent data is given here.

Date of publication

The date of publication is given here. This date indicates when the most recent data have become available to third parties, for instance through publication.

Access to the data

What are the conditions for third parties to receive the data and what procedure is used? At which aggregation level are the data available? Is there any indication of the costs involved?

Counter for amendment proposals

Can third parties influence the registration's content? For example: is it possible to add a module with questions once? Can proposals for changing the registration's or questionnaire's content be presented?

Finished?

Is the registration finished yes / no?

Any more data needed? After finishing

If yes, is it possible to acquire data yes / no (as applicable).

Details

Here, important amendments made during the registration are mentioned, as well as any details regarding the registrations' exhaustiveness, quality, etc.

Date description / Amended date description

Date that the registration description is checked and / or corrected, or created by the registration holder.

Appendix 15: (Draft) Agenda & Minutes of NWPL Meeting, July 2005



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG
Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

DRAFT

Third Meeting of the Network of Working Party Leaders

*Luxembourg, 4 July 2005 (10:30-17:30)
and 5 July 2005 (10:00-12:30)*

Room JMO M1

The morning session of 5 July will be held jointly with the NCA

4 July 2005 (10:30-17:30)

1. Adoption of the agenda
2. Adoption of the minutes of the last meeting
3. Progress report of the Working Parties and Task Forces (10-15' each)
 - a. WP on Lifestyle
 - b. WP on Morbidity and Mortality
 - i. Task Force on Rare Diseases
 - ii. Task Force on Major and Chronic Diseases
 - c. WP on Health Systems
 - i. Task Force on Patient Mobility
 - d. WP on Health and Environment
 - e. WP on Mental Health
 - i. Task Force on Evidence
 - ii. Task Force on Future Perspectives in Mental Health Promotion
 - f. WP on Accidents and Injuries
 - i. Task Force on Strategic Planning
 - ii. Task Force on Road Safety
 - iii. Task Force on Work Health
 - iv. Task Force on Burden of Accidents
 - v. Task Force on Indicators
4. Financial procedures (Commission C1)

- Application procedures and processing
- Project management, signatures
- Timing of calls for proposals and calls for tender .

5. Reflection document on overlap between WPs and assignment of projects.

- Presentation by Pieter Kramers / NIVEL Secretariat

6. Issues raised by Working Party Leaders

7. Any Other Business

8. Next Meeting

Agenda for 5 July, joint meeting with NCA

9. (Adoption of the NCA agenda)

10. (Adoption of NCA minutes of last meeting)

11. Final Evaluation of eight Community Action Programmes on Public Health

- Presentation Commission C6

12. List of projects and tenders 2004

13. NCA-NWPL Web board: evaluation of use

14. Update on the implementation of the Health Indicators

- Presentation Reporting Tool (A. Montserrat)
- ECHIM (A. Aromaa)



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Luxembourg, 7 July 2005

DRAFT MINUTES

THIRD MEETING OF THE NETWORK OF WORKING PARTY LEADERS FOR HEALTH INFORMATION AND KNOWLEDGE

Luxembourg, 4 July 2005 (10:30-17:30) and 5 July 2005 (10:00-12:30)

Chair: John Ryan (Head of Unit) Horst Kloppenburg (Principal administrator Sanco C/2, Health Information)

List of participants/cancellations, other documents and contributions related to the meeting are available on:

Reported by NIVEL Secretariat

1. Opening of the meeting

Chair opens the meeting.

2. Adoption of the agenda

The draft agenda is adopted with one addition: John Henderson would like more information on the Sanco (Health and Consumer Protection) Website. Added to agenda item 11: AOB.

3. Adoption of the minutes of the last meeting

The minutes were accepted without changes.

4. Progress report of the Working Parties and Task Forces

All received progress reports can be found on the Network of Competent Authorities-Network of Working Party Leaders webboard.

Working Party on Lifestyle

Presentation by Wilhelm Kirch. Website: www.public-health.tu-dresden.de/eu. The Working Party will change its focus from nutrition to physical activity and nutrition with focus on the Health Information strand. Overlap with Health Determinants will be considered. A presentation was held at the ENSP (European Network of Smoking Prevention). A 2nd workshop on monitoring physical activity and nutrition will be held at the EUPHA (European Public Health Association) Conference. In future, the Working Party will focus on information on smoking, physical activity alcohol consumption and drug substance abuse. Projects in progress are Dafne V (Data Food Networking), Epic Elderly, Age and Nutrition and World Health Organisation-HIPP (health care in prison). Bilateral meetings were held to integrate new projects in the Working Party at the World Health Organisation in Copenhagen and at Erasmus University in the Netherlands. The Commission will check links between the Working Party website and the Europa website.

John Henderson raises concerns about the limited scope of the HIPP (Health care In Prison) project. There is too much emphasis on physical health and other issues, e.g. mental health, substance abuse,

are ignored. The Commission will forward the proposal to John Henderson for comments. Pieter Kramers expresses concern about data collection through Epic Elderly and its potentially crosscutting relation to the Working Party on Mortality and Morbidity.

The Commission remarks more generally on the venue of Working Party meetings. Members of staff are only able to attend if meetings are held in Luxembourg. There are approximately 100 health information projects and 10 tenders and at present 4 officials to follow all this.

Working Party on Mortality and Morbidity

An informal presentation is given by Jennifer Zeitlin. The Working Party has submitted a proposal for a Secretariat, it is still a very heterogeneous group, which is affected by the lack of a secretariat as well as the staff shortages at Directorate General Sanco (Health and Consumer Protection). No meeting was held since January, but a new meeting is planned for November.

Task Force on Rare Diseases

Presentation by John Ryan. The Task Force has held a meeting, has produced a newsletter (<http://www.orpha.net/actor/orphanews>) and has a website (<http://www.drftf.org/>) linked to the Sanco (Health and Consumer Protection) website. A European Conference was held in June. The development of a possible reference centre for rare diseases have been discussed. Coding and classification of rare diseases is worked on in close collaboration with the World Health Organisation and NLM (National Library of Medicine). Rare diseases with high priority are also considered. The next meeting will be held in December, tied in with the Working Party meeting on mortality and morbidity.

Task Force on Major and Chronic Diseases

Toni Montserrat gives a brief summary of the progress made. Autism is a new area, and controversial. More attention is focussed on neurological diseases, and on psychiatric mental disorders (e.g. Alzheimer) and cancer. The heat wave of 2003 is also taken into account. The issue is excess mortality and what the effect of waves is (heat and cold). A system of alarm is needed to produce the necessary information on all effects of mortality. The Task Force is also working on the EHSS (European Health Survey System) and the SILC (Survey on Income and Living Conditions) survey is launched, first results will be available in 2006. Non-Governmental Organisations ask to become members of the Working Party or Task Force.

Working Party on Health Indicators

The discussion also involves the new Working Party on indicators. On 19 October 2005, the first meeting of this Working Party will be held. The operationalisation of the European Community Health Indicators list still resides with the Working Party on mortality and morbidity. The first list of the 40 indicators for which operationalisation is available, are visible on the website of Sanco (Health and Consumer Protection). A Health for All-like database will be ready by the end of July 2005. The European Community Health Indicators list online has improved the visibility of the work of the Strand. A structural indicator will be the indicator on healthy life years, intended to monitor gains of healthy life and good quality health, i.e. without disability. The first results will be on the website in July 2005 and are comparable to the Eurobarometer 58. The Health Indicators needs to improve the European Community Health Indicators list on the basis of information of the Working Parties. It is a continuation of work.

EHSS (European Health Survey System) is seen as an important development, however, by residing it with Working Party on mortality and morbidity, other Working Parties may not be sufficiently aware of this important data source being built. It is suggested that one way to solve the problems is to consider this issue in relation to the composition of Working Party. The Commission adds that the composition of the Health Indicators is still under discussion. It is agreed that a better structure with respect to the positioning of the EHSS (European Health Survey System) is needed. The Commission suggests including EHSS as a structural item on the agenda of the Working Parties.

Working Party on Health Systems

Presentation by Ales Bourek. A meeting was held with attention for safety improvement, patient choice and mobility. The Working Party has given attention to its goal and has checked for duplication

with World Health Organisation/Eurostat/Organisation for Economic Co-operation and Development. The scope of the mandate of the Working Party was discussed in relation to the new Health Indicators. The goal of the Working Party on Health Systems can be found on the webboard and members of the meeting are invited to comment on this working document. Different data sets were also considered. Pieter Kramers stresses that it is important to define what information you want to measure, to check if the data are available and to then adequately measure and analyse, and finally to make it available for policy development. The Commission agrees and adds that the Public Health Programme is not directly contributing to political debates but should analyse what information is needed to achieve solid judgement.

Task Force on Patient Mobility

No separate presentation

Working Party on Health and Environment

Presentation by Ingrida Zurlyte. The ENHIS (Environment and Health Information System) project is still ongoing. There is a website in line with the European Union Health Information and Knowledge System project and linked to the health portal. Contributions are made to European environment and health action plan, electro-magnetism is a new subject. In the health action plan, the nature of physical stressors considered, is explained. The Working Party will be contacted by the Working Party on Lifestyle to prevent overlap on for example nutrition. No meeting was held, but a new meeting is being planned. More in general, the Network of Working Party Leaders meeting agrees that is important to define project areas at the beginning of projects, to prevent overlap as well as to avoid unnecessary consultation of experts.

Working Party on Mental Health

Task Force on Evidence, ii. Task Force on Future Perspectives in Mental Health Promotion.

Presentation by Kristian Wahlbeck. The Working Party was highly visible at the World Health Organisation Ministerial Conference on Mental Health. A draft green paper is being produced for Commission Services. Mental Health is highly visible at the political agenda and will be an item for the Finnish Presidency (follows the present UK presidency). Two final reports were produced: of the mental health economics report and of the POMONA project (on the health of people with intellectual disabilities in the European Union Member States). The Working Party collaborates with European Community Health Indicators and Monitoring and European Health Survey System. There is discussion on the best publication channels, special issues of scientific journals are one option, but also status reports could be disseminated more effectively. A discussion on better visibility of results, more understandable messages and means of dissemination could be an issue for the next Network of Working Party Leaders meeting.

The Task Force Evidence has experienced increased awareness of their subject area. They have produced a common framework, a checklist, a background paper and a glossary. A draft of the paper and the glossary will be forwarded to Nivel and then placed on the Network of Competent Authorities-Network of Working Party Leaders. (<http://board.nivel.nl/nca-nwpl>). The other Task Force is dormant.

Working Party on Accidents and Injuries

Presentation by Stephanie Anast. The Working Party has had a meeting and has produced a document on Actions for a Safer Europe. There is a long-term strategic plan to work on Delphi technique surveys. The Working Party has produced a newsletter, there is a website and there will be a pre-event of the European Conference on Injury Prevention in October 2005 (see Network of Competent Authorities-Network of Working Party Leaders Webboard for an announcement). A pilot of the statistical portal on accidents and injuries is under development by the secretariat and the Injury Database (IDB) has been relaunched.

Task Force on Communication

The Task Force has focussed on internal and external communication of the Working Party. A draft report has been completed and will be put on the Network of Competent Authorities-Network of Working Party Leaders Webboard

Task Force on Strategic Planning

Dormant

Task Force on Burden of Injuries.

The Task Force has produced a brief report on the Burden of Injuries in the European Union. The emphasis is on fatal injuries. The draft of the report will be available on the Network of Competent Authorities-Network of Working Party Leaders Webboard.

Task Force on Road Safety

Presentation by Rupert Kisser. The presentation of the report was already given at the last meeting. In the report, recommendations are given for action at European Union level. It is important to provide other sectors with Public Health arguments.

Task Force on Work Health

Presentation by Wolfgang Boedeker. The presentation refers to Work Health and the European Network of Work Health Prevention. Activities of Strands 1 and 3 are merged. A policy-oriented report was produced. Attention is given to Work Health Prevention of the new Member States and the Candidate Countries. A meeting was held with European Institutions (World Health Organisation, Copenhagen. Erasmus University, Rotterdam). The Task Force aims at building a Consortium of health promotion experts, social insurances and work inspectorates.

Eleni Petridou will forward their list of indicators to Pieter Kramers as member of Working Party 7 and former chair of European Community Health Indicators I and II.

Task Force on Indicators

Dormant

Questions are raised related to the number of Task Forces and the number of projects of this Working Party. It remains unclear how this relation is in the Working Party. The Commission points to the voluntary work in most Task Forces.

Jennifer Zeitlin suggests producing a list of projects with their finalisation and, if possible, a brief list of indicators resulting from the projects. This could be added as a question to the next progress report. Nivel will look into this, if their funding is approved and extended. At the moment, the Nivel secretariat will stop its work at the end of August 2005.

The Commission refers to a recently published report, a list of projects and classification, including orphan projects, e.g. some e-health projects. Members of the meeting are asked to comment on the report.

A table with planned meetings is circulated. Wilhelm Kirch adds that the Working Party on Lifestyle will meet at 12/13 September. The Commission promises to take major public holidays into account when planning meetings. The Commission publishes a yearly list with the public holidays of the 25 Member States.

5. Financial Procedures

Reimbursement of Conference visits and scientific events in non-European Union countries is discussed. The Commission explains that reimbursement is structurally not possible due to the legal basis: focus on promotion of European Union Public Health field.

The Executive Agency is on the verge of becoming operational. The Agency will function as an office for the Commission and should aid the implementation of the Public Health Programme. The role of the Commission controlling the Programme together with the Programme Committee will not change. Transfer of tasks will be progressively: the health information strand will be supported from 2006.

The draft Workplan 2006 will be circulated through the Secretariat soon after the meeting. Comments can be sent to the Commission.

John Henderson asks if there are intentions for simplification of the calls. John Ryan will look into this and this will be added to the minutes and drawn to the attention of the Programme Management (SANCO C1). Concern is expressed about a discriminatory element for smaller organisations and independent organisations that do not have assistance. The Commission states that this issue has been raised before. A change has been proposed to allow "cope founding" but was rejected, which envisaged care founding for Non-Governmental Organisations.

6. Reflection document on overlap between Working Parties and assignment of projects.

Presentation by Pieter Kramers. The document provides a theoretical basis for the Working Party structure and can therefore help to address issues of overlap between Working Parties. Also assignment of projects to Working Parties could be more solidly based if the presented model would be used. Some questions for assignment and possible relocation are made in the document. And some suggestions for allocation to the Working Party on health indicators have been made. A number of Working Party leaders have already commented on the document via the Network of Competent Authorities-Network of Working Party Leaders Webboard and via email. It is suggested to add a question on crosscutting issues to the template of the next progress report. NIVEL will look into this.

The Commission adds that the expansive growth of Task Forces adds to the workload of the Commission. Seven Working Parties produce 14 meetings per year plus two Network of Competent Authorities and Network of Working Party Leaders meetings is 18. Every Task Force is an extra meeting. There has been severe criticism; the Commission has been accused of suffering from "meetingitis". An additional problem is how to highlight the results of the meetings, this is not always obvious. One suggestion done by the meeting is to tie meetings to Conferences as this adds to the visibility of results. The earlier made comments on reimbursement problems and problems for the Commission to attend meetings outside Luxembourg are reiterated. The Commission adds that maybe there should be clearer rules about the timeline for Task Forces and the number of Task Forces. Also, the addition of Task Forces does not change the contractual obligation of the Working Party.

7. Issues raised by Working Party Leaders

Staffing problems of the Commission. Frederic Sicard has still not been replaced. The Government of the selected candidate refused the application. Therefore, some Working Parties and Task Forces have temporary allocation to members of C2. Horst Kloppenburg is responsible for Working Party on Lifestyle, John Ryan for Working Party on Health and Environment.

8. Any Other Business

John Henderson: Sanco (Health and Consumer Protection) Website needs more navigation facilities, maybe Google is an option.

- Jurgens Schefflein (summary of presentation)

Mental health is very visible on the European Union agenda. The green paper on mental health will be available before the workplan and will thus be taken into account. The ministerial Conference covered the health sector as well as other Directorate Generals (education, work places).

It is a good idea to join forces and to create synergy on issues related to risky lifestyles that have an effect on (un) intentional injuries.

9. Next Meeting

To be confirmed

Joint meeting with Network of Competent Authorities

10. (Adoption of the Network of Competent Authorities agenda)

One agenda item was added as item 5 bis: presentation of the Cochrane library.

11. (Adoption of Network of Competent Authorities minutes of last meeting)

The minutes were accepted without changes

12. Final Evaluation of eight Community Action Programmes on Public Health

Presentation by John Ryan.

The previous Public Health Programme was evaluated by an external evaluation company (Deloitte and Touche). For the first time, all eight action programmes have been put in one report. The main conclusions can be found in the executive summary.

The evaluation calls for increased investment of national authorities. The diversity of the eight programmes had been difficult to manage. There was a dichotomy between the research perspective and European Union policy. Criticisms were: focus was on disease rather than health determinants; lack of coherence between the eight programmes, size of budgets and ambitions vary. There were very few real bridges, sometimes at a project level. Community added value: network, best practice exchanges. Recommendations for the future: more action orientated, more concrete, more direct impact on national level, importance of more long-term investment in Health Information Systems, European Union agencies may be set up for specific fields instead of continuing the project approach, small stakeholders should be given the means to participate

The Commission asks all members of the meeting to give feedback on the documents to the Commission. The Commission is aware of the fact that this document is outdated since a new programme is already in use. However, the evaluation will be used for the new programme.

The Commission suggests Working Parties to put this document on the agenda of their meetings, to take out the key messages. Exchange of best practices, training and expertise development are underused parts of the programme. In the work plan 2006 this will be the focus in the area of palliative care.

The Network of Competent Authorities suggests to put the evaluation of the Health Monitoring Programme on the agenda for the next meeting.

Comments on mistakes or misunderstanding in the report can be forwarded to the Commission on paper; the Commission will then forward them to the external agency.

More discussion on legal matters related to data collection will follow later today with the presentation of Eurostat.

13. List of projects and tenders 2004

The Commission circulates a draft document for comments and corrections. At present there are almost 90 running projects (including, tenders, jointly run projects and sub-delegation). The Commission is proposing to accept 22, which will give a total of over 100 projects. Classification in the seven Working Parties is not always straightforward. The Commission has experienced difficulties with e.g. gender issues, patient mobility and e-health. Most were classified in Working Party on Health Systems, but this is only a proposal. Please give the Commission feedback on the classification, they will look at reclassification. At the same time the scope of Working Party 7 will be discussed, there is a reasonable consensus that the Working Party on health indicators should have an umbrella function.

With respect to reimbursements, there is good news: increase in reimbursed participants for Working Party meetings from 20 to 25. Including attendance to Working Party meetings in project proposals is another way to secure reimbursement. The participation of completed projects may be relevant for particular projects, but not for all. The creation of Task Forces does not solve the reimbursement possibilities.

The Commission experiences staffing problems at the moment. Therefore, some Working Parties and Task Forces have temporary allocation to members of C2. Horst Kloppenburg is responsible for Working Party on Lifestyle, John Ryan for Working Party on Health and Environment. The Executive Agency is on the verge of becoming operational. The Agency will function as an office for the Commission and should aid the implementation of the whole Public Health Programme, including Consumer Protection in the new Programme from 2008 on. The role of the Commission controlling the Programme together with the Programme Committee will not change. Transfer of tasks will be progressive: the health information strand will be supported from 2006.

The first European Community Health Indicators and Monitoring/Working Party on Health Indicators meeting will be in October, a timetable of all meetings for the rest of the year will be circulated.

Consumer protection programme and health programme are separate, but from 2008 these will be joined, once the programme has been approved.

Information is lacking on which national institutions collaborate within the various projects. Could there be a national link?. The Network of Competent Authorities asks to facilitate co-ordination at

country level by providing per Member State a list of participants in projects. This should be on the agenda of the next meeting, to see what progress has been made.

14. Network of Competent Authorities-Network of Working Party Leaders Web board: evaluation of use

Presentation by Nivel.

The board as an information exchange point has been established a year after its start. Some points still need clarification, e.g. can the agenda be found on the webboard or on the Europa site? And what about documents for the Network of Competent Authorities and Network of Working Party Leaders meetings? The website is the primary information tool. Definitive documents are published at the European Union website. Provisional drafts and discussion documents are published on the web board. Names of all Competent Authorities and regional contacts should be on the board. NIVEL will take care of this. In the future, the board could be used more as a discussion forum.

14bis. Cochrane library presentation

Presentation Nick Royle.

The Cochrane Library is a set of databases concerning systematic reviews of clinical trials resulting in evidence based health information. The library is used by health workers, policy makers, citizens, internationally. A number of countries provide free access for their citizens. For more information: www.cochrane.org or nroyle@cochrane.org. The Commission suggests to study the possibility to access the Library via the Portal.

15. Update on the implementation of the Health Indicators

Presentation Reporting Tool by Antoni. Montserrat

The Commission and the Network of Competent Authorities are happy about the fact that the first European Community Health Indicators (ECHI) indicators are now available on the Europa website. This provides concrete evidence of results. In addition, attention has been focussed on the development of the healthy life years indicator, a structural indicator. The further development of the European Community Health Indicators list (now via European Community Health Indicators and Monitoring) and the operationalisation of indicators is an ongoing process that will involve interaction with the authorities of the Member States and discussion with the Competent Authorities and the Working Parties, based on a consensual approach. There will be no demand at national level for new resources. Financial resources have to come from the Public Health Programme funds

Informal presentation of European Community Health Indicators and Monitoring 2005-2008 (Working Party 7) by Arpo Aromaa. At the moment there is an informal list of members. The Commission invite new Member States to be represented. Working Parties should become conscious about their contribution to the central European Community Health Indicators system without interfering with other Working Parties on Health Indicators.

Chair thanks all present for their active contribution to this joint meeting and ends the joint session with the Network of Working Party Leaders members.

Appendix 16: (Draft) Agenda & Minutes of NCA Meeting, July 2005



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Luxembourg, 10 June 2005

DRAFT AGENDA

Fifth Meeting of the Network of Competent Authorities

*Luxembourg, 5 July 2005 (10:00-17:30)
and 6 July 2005 (9:30-16:00)*

Room JMO M1

The morning session on 5 July will be held jointly with the NWPL (10:00-12:30)

5 July 2005 (10:00-12:30)

1. Adoption of the agenda
2. Adoption of the minutes of the last meeting
3. Final Evaluation of eight Community Action Programmes on Public Health - (Commission C6)
4. List of projects and tenders 2004 (SANCO C2)
5. NCA-NWPL Web board: evaluation of use (NIVEL)
6. Update on the implementation of the Health Indicators
 - Presentation Reporting Tool (A. Montserrat)
 - ECHIM (A. Aromaa)

Lunch break and end of joint meeting 12.30

NCA only**Afternoon session 5 July (14:15-17:30) and 6 July (9.30-16:00)**

7. Progress report of the Working Parties: Summary (NIVEL)
8. Progress of activities at a national level: Summary Country Reports (NIVEL).
9. Report on the High Level Group on Health Services and Medical Care activities and Patient Mobility (Commission C5)
10. New Programme of Community action in the field of Health and Consumer protection 2007-2013 (Commission C5)
11. Regulation concerning Community Statistics on Public Health and Health and Safety (EUROSTAT – M. Desmedt)
12. Confidentiality of personal data (outside official statistics)
 - Introduction (NIVEL)
 - Introduction to Data protection directive (95/46/EC)
 - PRIVIREAL results (PRIVIREAL) (www.privireal.org)
 - The Swedish example (research, registries and surveys)
 - Experience from EUROCAT

6 July 2005 (9:30-16:00)

13. Draft Workplan 2006 (SANCO C2)
14. Report E-health Conference, Norway Tromsø (<http://www.ehealth2005.no/>) (SANCO C2)
15. EU Health Portal, updated progress C2 (Z. Podniece)
16. Issues raised by Competent Authorities
17. Any Other Business
18. Next Meeting



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment
Unit C2 - Health information

Luxembourg, 10 July 2005

DRAFT MINUTES

FIFTH MEETING OF THE NETWORK OF COMPETENT AUTHORITIES

Luxembourg, 5 July 2005 (10:00-17:30) and 6 July 2005 (9:30-16:00)

Chair: Horst Kloppenburg (Principal administrator Sanco C/2, Health Information) / John Ryan (Head of Unit)

List of participants/cancellations, other documents and contributions related to the meeting are available on:

Reported by NIVEL Secretariat

The morning session on 18 January was held jointly with the Network of Working Party Leaders (10:00-12:30)

1. Adoption of the agenda

One agenda item was added as item 5 bis: presentation of the Cochrane library.

2. Adoption of the minutes of the last meeting

The minutes were accepted without changes

3. Final Evaluation of eight Community Action Programmes on Public Health

Presentation by John Ryan

The previous Public Health Programme was evaluated by an external evaluation company (Deloitte and Touche). For the first time, all eight action programmes have been put in one report. The main conclusions can be found in the executive summary.

The evaluation calls for increased investment of national authorities. The diversity of the eight programmes had been difficult to manage. There was a dichotomy between the research perspective and European Union policy. Criticisms were: focus was on disease rather than health determinants; lack of coherence between the eight programmes, size of budgets and ambitions vary. There were very few real bridges, sometimes at a project level. Community added value: network, best practice exchanges. Recommendations for the future: more action orientated, more concrete, more direct impact on national level, importance of more long term investment in Health Information Systems, European Union agencies may be set up for specific fields instead of continuing the project approach, small stakeholders should be given the means to participate.

The Commission asks all members of the meeting to give feedback on the documents to the Commission. The Commission is aware of the fact that this document is outdated since a new programme is already in use. However, the evaluation will be used for the new programme.

The Commission suggests Working Parties to put this document on the agenda of their meetings, to take out the key messages. Exchange of best practices, training and expertise development are underused parts of the programme. In the Workplan 2006 this will be the focus in the area of palliative care.

The Network of Competent Authorities suggests to put the evaluation of the Health Monitoring Programme on the agenda for the next meeting.

Comments on mistakes or misunderstanding in the report can be forwarded to the Commission on paper; the Commission will then forward them to the external agency.

More discussion on legal matters related to data collection will follow later today with the presentation of Eurostat.

4. List of projects and tenders 2004

The Commission circulates a draft document for comments and corrections. At present there are almost 90 running projects (including, tenders, jointly run projects and sub-delegation). The Commission is proposing to accept 22, which will give a total of over 100 projects. Classification in the seven Working Parties is not always straightforward. The Commission has experienced difficulties with e.g. gender issues, patient mobility and e-health. Most were classified in Working Party on Health Systems, but this is only a proposal. The Commission asks for feedback on the classification, they will look at reclassification. At the same time the scope of Working Party 7 will be discussed, there is a reasonable consensus that Working Party 7 should have an umbrella function.

With respect to reimbursements, there is good news: increase in reimbursed participants for Working Party meetings from 20 to 25. Including attendance to Working Party meetings in project proposals is another way to secure reimbursement. The participation of completed projects may be relevant for particular projects, but not for all. The creation of Task Forces does not solve the reimbursement possibilities.

The Commission experiences staffing problems at the moment. Therefore, some Working Parties and Task Forces have temporary allocation to members of C2. Horst Kloppenburg is responsible for Working Party on Lifestyle, John Ryan for Working Party on Health and Environment. The Executive Agency is on the verge of becoming operational. The Agency will function as an office for the Commission and should aid the implementation of the whole Public Health Programme, including Consumer Protection in the new Programme from 2008 on. The role of the Commission controlling the Programme together with the Programme Committee will not change. Transfer of tasks will be progressive: the health information strand will be supported from 2006.

The first European Community Health Indicators and Monitoring/Working Party 7 meeting will be in October, a timetable of all meetings for the rest of the year will be circulated. Consumer protection programme and health programme are separate, but from 2008 these will be joined, once the programme has been approved.

Information is lacking on which national institutions collaborate within the various projects. The Network of Competent Authorities asks to facilitate co-ordination at country level by providing per Member State a list of participants in projects. This should be on the agenda of the next meeting, to see what progress has been made.

5. Network of Competent Authorities-Network of Working Party Leaders Web board: evaluation of use

Presentation by Nivel.

The web board as an information exchange point has been established a year after its start. Some points still need clarification, e.g. can the agenda be found on the webboard or on the Europa site? And what about documents for the Network of Competent Authorities and Network of Working Party Leaders meetings? The website is the primary information tool. Definitive documents are published at the European Union website. Provisional drafts and discussion documents are published on the web board. Names of all Competent Authorities and regional contacts should be on the board. NIVEL will take care of this. In the future, the board could be used more as a discussion forum.

5bis. Cochrane library presentation

Presentation Nick Royle

The Cochrane Library is a set of databases concerning systematic reviews of clinical trials resulting in evidence based health information. The library is used by health workers, policy makers, citizens, internationally. A number of countries provide free access for their citizens. For more information:

www.cochrane.org or nroyle@cochrane.org. The Commission suggests to study the possibility to access the Library via the Portal.

6. Update on the implementation of the Health Indicators

Presentation Reporting Tool by Antoni Montserrat

The Commission and the Network of Competent Authorities are happy about the fact that the first European Community Health Indicators (ECHI) indicators are now available on the Europa website. This provides concrete evidence of results. In addition, attention has been focussed on the development of the healthy life years indicator, a structural indicator. The further development of the European Community Health Indicators list (now via European Community Health Indicators and Monitoring (ECHIM)) and the operationalisation of indicators is an ongoing process that will involve interaction with the authorities of the Member States and discussion with the Competent Authorities and the Working Parties, based on a consensual approach. There will be no demand at national level for new resources. Financial resources have to come from the Public Health Programme funds.

Informal presentation of European Community Health Indicators and Monitoring 2005-2008 (Working Party 7) by Arpo Aromaa. At the moment there is an informal list of members. The Commission invite new Member States to be represented. Working Parties should become conscious about their contribution to the central European Community Health Indicators system without interfering with other Working Parties.

Chair thanks all present for their active contribution to this joint meeting and he ends the joint session with the Network of Working Party Leaders members.

7. Report on the High Level Group on Health Services and Medical Care activities and Patient Mobility

An informal presentation was given by Nick Fahy of C5 on all areas that are of concern to the High Level group. *Cross-border health care*: guidelines are in development; a conference will be organised in October. *Health impact assessment of health systems*: difficult to assess indirect impact on health status, there is a need for the development of new methodologies. *Information and E-health*: focus lays on the information needs for consumers; coherence will be sought with Network of Competent Authorities and Working Party on Health Systems. *Health professionals*: mechanisms are studied for information exchange about professional performance; a shortage in more economically developed countries leads to their drawing on resources in already under-resourced countries. *Centres of reference for highly specialised care serving more than one Member State or for rare conditions*: efforts should be made to move expertise between Member States; models should be developed and a call for pilot projects will be put on the call for proposals of 2006. With respect to patient safety, the emphasis is on a reduction of adverse effects through procedures to ensure safety. This should improve good health care in general. End of 2005 a proposal will be submitted to the Council regarding a proposal for an European Network of Technology Assessment. A report from the High Level Group on health technology assessment can be circulated. Issues raised at the meeting are about the level and coding of patient data that needs to be exchanged, should there not be agreed on a minimum? Electronic collection of patient data will also be discussed at the meeting of the Working Party on Health Systems and the e-health Working Party of Directorate General IMSO, November/December this year.

The Commission points to a pre- announcement of e-health conference, funded by Commission.

8. New Programme of Community action in the field of Health and Consumer protection 2007-2013

Informal presentation by Nick Fahy. The new programme is available on the Europa website

http://europa.eu.int/eur-lex/lex/LexUriServ/site/en/com/2005/com2005_0115en01.pdf

The key element is that it is an integrated programme, based on the two previous programmes in both groups. Reasons for a joint programme are: (i) many overlap areas, (ii) overhead minimization (iii)

mainstreaming health and consumer issues across all community policies (iv) dealing with health threats. Health objectives will be: surveillance of and response to health threats, promoting health, prevention, cooperation between health systems, health information.

For the time being, the Public Health activity is still a separate activity, established in Luxembourg. Further changes in the Commission have not yet been considered. There will be consequences, e.g. because of European Centre for Disease Control being established in Sweden. An Agency might take over the Consumer side, as well as programme management.

Not losing the dynamic in the health systems needs to be an issue at the next meeting, candidate countries should also be involved.

9. Regulation concerning Community Statistics on Public Health and Health and Safety

Presentation by Marleen Desmedt from Eurostat

The structure, legal framework and work of Eurostat within the European Statistical System is presented. A Working group 'Public Health Statistics' supervises the collection of these data within DG6 'Health and food statistics'. A proposal for a Regulation to establish a legal framework for the statistical activities was submitted to the Working Group last May, titled: "Public Health and Health and Safety at Work". The content of the proposal is presented. It relates to point 10 in the minutes of the previous meeting. Now there has been wider consultation. Concern was expressed about the formalisation of European Community Health Indicators list. The Commission agreed with Eurostat that this proposed regulation is the optimum way to follow.

The members of the meeting express their concern about the proposal and ask for more consultation at a national level. At present there is limited support in countries for this proposal. There is worry about the pace of the revision. Also, there is a slight fear that the statistical root is going to decide the process without giving weight to the public health perspective. The Commission agrees that linkage between Eurostat, the Competent Authorities and the Working Parties needs to be reinforced. The Commission adds that European Union court decisions have prompted the drafting of the new proposal. In order to progress, a legal basis is needed, it was requested by the Member States as a result of these court decisions. The legal basis is needed for the obligation to secure data collection in all Member States. A legal basis exists for personal data/ health data, but not for health statistics. Eurostat adds that they are aware that annexes are at different levels of implementation. This is not a problem. The Statistical Programme Committee (SPC) is a body of people from Member States representing the whole official statistical system of the country. There is an obligation to consult with the national authorities in Member States. Link with Working Parties and European Community Health Indicators is important. This item will again be on the agenda of the next Network of Competent Authorities meeting. Please feel free to suggest items for the next meeting, possibly via the Network of Competent Authorities - Network of Working Party Leaders web board.

10. Confidentiality of personal data

An introductory presentation was held by Walter Devillé of NIVEL on the data protection directive (95/46/EC). Presentations on their national system of data collection were given by Magnus Stenbeck for Sweden and Renzo Pace Asciak for Malta. An informative presentation on 20 years of experience with collecting person identifiable data was given by Vera Nelen of Eurocat and finally, David Townsend presented the Privireal project studying the implementation of the European Union Directive in the Member States from a legal point of view. (www.privireal.org). Email privireal@sheffield.ac.uk, d.townend@sheffield.ac.uk. It was felt that the presentation on Privireal was interesting but fell somewhat outside of the realm of this meeting, which is on health statistics and research.

The data protection directive is a binding directive on harmonizing confidentiality of person identifiable data and therefore all countries are bound by it. Nevertheless, some national systems have been in force for a long time, new Member States are developing new legislation and some tension between these systems and the directive was noted at the meeting.

The Swedish example was considered to be a good example of a combination of medical secret and consent for research purposes. This system was used to get the right balance with the implementation

of the directive: mandatory participation and strong data protection Data Protection Authority is holder responsible for data. The presentation on the Maltese system centred on the national Data Protection Act and the issue of aggregated data or identifiable data, which direction to take.

A number of general questions were raised during the meeting concerning supply of data to third parties, use for other purposes than research, guidelines about coding and recoding with hospital data, guidelines about contacting patients, anonymisation, registration of foreign nationals that fall ill in your country, sharing of data between different authorities. Difficult cases were mentioned such as contacting people long after they f.i. had a serious illness, or continuing to contact parents of stillborn children. It was agreed that national data should not travel without good cause and should be anonymous. It is suggested that a statement should be made by the Network of Competent Authorities.

At the request of the Commission, a Working Group was established at the meeting to prepare issues that need to be discussed in the future. The Working Group consists of the Competent Authorities of Finland, Malta, Sweden, Spain, France and Estonia. Time frame: priority list of issues over the summer holidays, short draft document for the next Network of Competent Authorities meeting, maybe consult with Karl Freese of C4. At the next meeting, we could concentrate on specific issues rather than general ones. Meetings of this Working Group cannot be reimbursed.

If you have any other specific questions, please send them to the Network of Competent Authorities - Network of Working Party Leaders Secretariat who will then forward the questions to the relevant presenters.

11. Draft Workplan 2006

The status of the presented draft workplan was not readily apparent to the members of the meeting. It is in a pre-draft stadium for everybody to comment on. Following the discussion at the meeting, the slides with keywords have been sent by the Commission to all members of the Network of Competent Authorities and Network of Working Party Leaders meeting, asking for comments and input for the Workplan 2006 through the Secretariat. The Work plan will be drafted by September, sent to the Competent Authorities for final comments.

12. Report E-health Conference, Norway Tromsø

Not presented due to the absence of John Ryan. More information can be found on <http://www.ehealth2005.no/>

1. European Union Health Portal, updated progress

Presentation by Zinta Podniece

The European Union health portal is directed at citizens. At the end of the year, the portal should be fully functional. The Network of Competent Authorities will be given access to the prototype for comments, for improvement towards the end of this year.

One problem is translations in all languages, new languages will not be realised by the end of this year, will be March 2006. News items do not fall under translation requirements. Questions are raised about which information to include, who decided? At present there is a temporary editorial board. In future there will be one representative from each Member State included, as well as portal correspondents from each Member State. Could be the same person. At least three reimbursed meetings per year will be held. In the next phase, a number of issues raised at this meeting will be taken into account, e.g. need for a good Public Health input and focus, criteria for inclusion of links to other sites, link with eHealth Action Plan, access to the Cochrane library, medical advice, health inequalities as an issue, chat-function, restricted access in relation to the function of the board as an expert system, updating policy.

The Commission adds that they want to consult Member States in September or October on recommendations on injury prevention. A representative from each Ministry of the Member States is needed.

14. Progress report of the Working Parties: Summary

Presentation by NIVEL

Concern that this agenda item was discussed outside the joint meeting with the Working Parties was expressed at the meeting. This does not facilitate information exchange, which should be the main purpose of both meetings. The Commission explains that due to limited availability of external speakers, the agenda had to be changed at the last minute. However, this will be a point of attention for the next meeting.

Working Party 7/European Community Health Indicators and Monitoring will deal with cross-cutting issues and orphan projects; all Member States should be represented in the Working Party. Competent Authorities express the need to be kept current on national participants in the projects/Working Parties.

15. Progress of activities at a national level: Summary Country Reports

Was not presented due to lack of time. Summaries of links to national documents and of how Member States are addressing health inequality were distributed. The received progress reports and the summary can be found on the Network of Competent Authorities - Network of Working Party Leaders Webboard.

16. Issues raised by Competent Authorities**Health Inequality (United Kingdom)**

Hugh Markowe briefly introduces the issue of health inequalities, which will receive elaborate attention during the United Kingdom presidency:

<http://www.dh.gov.uk/PolicyAndGuidance/International/EuropeanUnion/EUPresidency2005/fs/en>

Country reports (GE)

Efforts were made to improve the country reports: who is receiving the information and for what purposes is it used. The commission receives the reports to be kept informed about the national activities and to disseminate information with colleagues. The reports are available through the web board.

17. Next Meeting

6-8 February 2006

Appendix 17: Template of Progress Reports for WPs



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment

Unit C2 - Health information



NIVEL SECRETARIAT

Email: NCA.NWPLSecr@nivel.nl

Fax. nr: 0031 - 30- 27 29 729.

To: **XX**

Date: 2 June 2005

Cc: **DeputyWP**

Subject: Summary of Working Party Activities, Sanco C2/ Health Information

Dear Working Party Leader and Deputy,

For the Next NCA and NWPL meeting, the NIVEL Secretariat is again collating a summary of activities carried out by the Working Parties and Task Forces, since the last meeting.

We therefore kindly ask you, as Working Party Leader of the Working Party on **nameWP**, to complete the enclosed form and return it to the Secretariat as soon as possible (no later than **15 June**). We kindly ask you not just to focus on activities such as held meetings, but to also reflect on the progress your Working Party has made in your area of research during the previous six months.

As you know, at the request of Sanco C2, this is a recurring item on the agenda of NCA/NWPL-meetings.

Please return the completed form electronically.


If you have any questions, please contact us by email (NCA.NWPLSecr@nivel.nl) or by telephone (direct number 0031 30 27 29 841/ 843).

Looking forward to seeing you at the next meeting.

Yours sincerely,

Esmée D. Kolthof, researcher
NIVEL Secretariat

PLEASE EMAIL THE COMPLETED FORM A.S.A.P. (no later than 15 June) TO:

	NIVEL SECRETARIAT Email: NCA.NWPLSecr@nivel.nl Fax. nr: 0031 - 30- 27 29 729.
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Working Party on **Working Party on Accidents and Injuries**
 Working Party Leader: **name**

(You may enlarge the boxes if needed).

This form was completed by: Dr. Rupert Kisser
Date: 30th of June 2005

What were the main activities* that have been carried out by your Working Party since January 2005?

1. Meeting of the Working Party at0

2. Revision of task force report (2nd version) by addressing comments given till Dec. 2004 = Final Version

3. Adoption of report by the Working Party on Accidents and Injuries on Feb 1 and 2, 2005

What were the main objectives* for the period January 2005 – July 2005, and to what extent have these objectives been achieved?

Objectives January 2005 – July 2005	Has this objective been achieved? If not, please explain.
1. Final report	Yes
2. Adoption of report	Yes
3.	

Please describe the progress* which has been made by your Working Party since January 2005.

1. Report accepted by EC/DG Sanco.

2. Decision on Inclusion of RTI into the Injury Data Base – Monitoring System

3. PHP-Project on “vulnerable road users” planned under work plan 2004

Are there issues concerning the progress of your Working Party that should be raised at the NWPL meeting in July 2005? If so, please explain.

Yes

Pass (main) recommendations of the task force report to responsible Working Parties

What are the main objectives* for the period of July 2005 – January 2006?

1. Prepare an advocacy document for the improvement of traffic safety, using PH arguments

2. Organise meetings between transport and public health sectors (within EC-DG's, on NGO level)

3. Decision on future of the task force on road safety (next WPAI-Meeting)

Do you foresee any problems in achieving these objectives? If so, please explain.

Lack of funding & capacity

Does the Working Party have a Work Plan?

Yes but accomplished

What is the date of the next meeting of the Working Party?

.....0

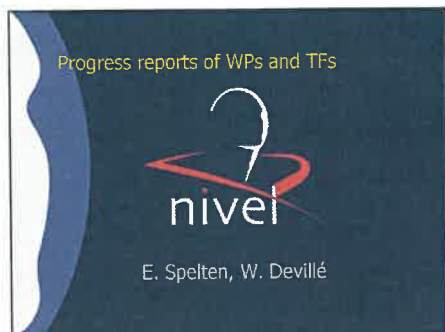
Please provide a summary of the projects that are were finalised in the previous period and their major findings.

THANK YOU VERY MUCH FOR ANSWERING THESE QUESTIONS.

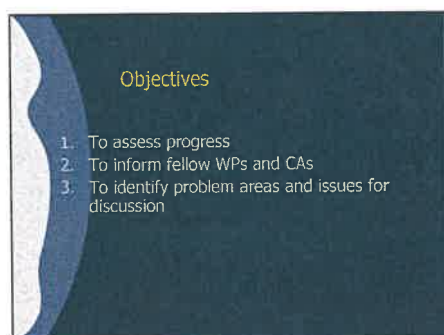
PLEASE EMAIL THE COMPLETED FORM A.S.A.P. (15 June at the latest) TO THE NIVEL SECRETARIAT: NCA.NWPLSecr@nivel.nl.

Appendix 18: Summary of Progress Reports WPs July 2005

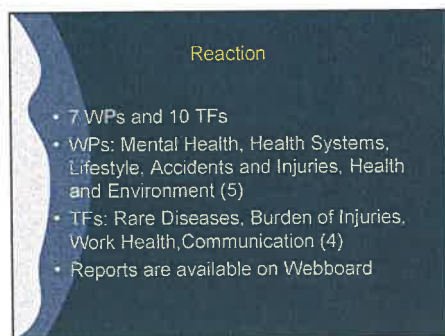
Dia 1



Dia 2



Dia 3



Dia 4

General Results

- Progress: most objectives and plans have been realised or are well under way.
- TFs focus on their (limited) mission.
- Summary of highlights from progress reports of WPs and TFs

Dia 5

WP Lifestyle


- Focus shift from nutrition to physical activity and nutrition
- Special Issue and Conference
- Collaboration with WHO
- Contribution to ENSP (smoking prevention)
- Projects: Dafne, Epic Elderly, WHO HIPPS
- Future: smoking cessation, nutrition, physical activity, PR

Dia 6

WP Mortality and Morbidity

- Building EHSS
- (New) topics: Autism, Neurological diseases/brain diseases, Alzheimer
- Proposal for Secretariat
- No meeting, next meeting planned

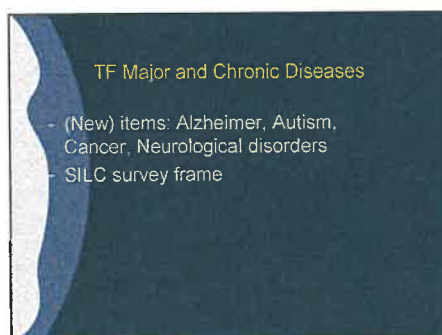
Dia 7



TF Rare Diseases

- Coding and classification in close collaboration with WHO
- Reference centres for rare diseases has been discussed
- Rare diseases with high priorities
- PR: TF Meetings, newsletter, website, also on Sanco website.
- Organisation of European Conference on RD

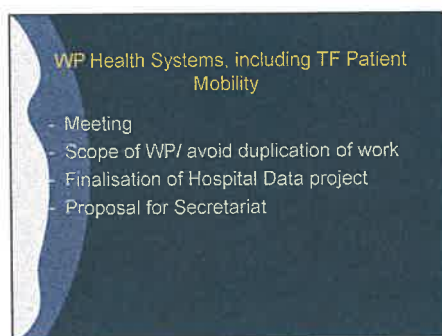
Dia 8



TF Major and Chronic Diseases

- (New) items: Alzheimer, Autism, Cancer, Neurological disorders
- SILC survey frame

Dia 9



WP Health Systems, including TF Patient Mobility

- Meeting
- Scope of WP/ avoid duplication of work
- Finalisation of Hospital Data project
- Proposal for Secretariat

Dia 10

WP Health and Environment

- ENHIS project, ongoing
- Website, link with Sanco website
- European health and environment action plan, electro-magnetics
- No meeting, next meeting planned

Dia 11

WP Mental Health

- WHO Ministerial Conference on Mental Health
- Draft green paper
- Mental Health: issue for Finnish Presidency
- Final report: mental health economics and POMONA
- Collaboration with ECHIM and EHSS

Dia 12

TF Evidence

- Common framework
- Checklist
- Background paper
- Glossary

Dia 13



WP Accidents and Injuries

- Strategic document: Actions for a Safer Europe,
- Comments on WHO document: injuries in the WHO Europe region
- Meeting

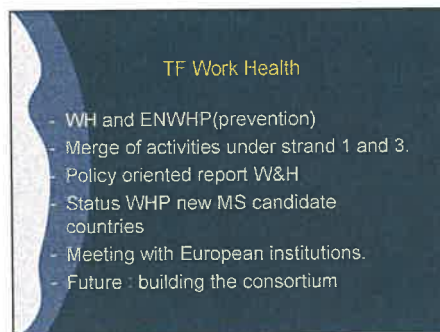
Dia 14



TF Communication

- Focus on communication strategy for WP AI
- First draft report will be available on the webboard shortly for comments

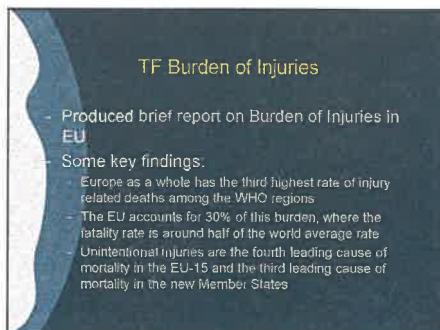
Dia 15



TF Work Health

- WH and ENVHP(prevention)
- Merge of activities under strand 1 and 3.
- Policy oriented report W&H
- Status WHP new MS candidate countries
- Meeting with European institutions.
- Future : building the consortium

Dia 16



TF Burden of Injuries

- Produced brief report on Burden of Injuries in EU
- Some key findings:
 - Europe as a whole has the third highest rate of injury related deaths among the WHO regions
 - The EU accounts for 30% of this burden, where the fatality rate is around half of the world average rate
 - Unintentional injuries are the fourth leading cause of mortality in the EU-15 and the third leading cause of mortality in the new Member States

Dia 17



TF Road Safety

- Report on Road Safety, recommended actions on EU level:
- Provide other political sectors with Public Health arguments (Collaboration with DG Tren)
- Improve surveillance of road traffic injuries by health information system
- Provide administrations with policy recommendations
- Run campaigns on vulnerable road users and risk prone adolescents

Appendix 19: Template of Progress Reports for CAs



EUROPEAN COMMISSION
HEALTH AND CONSUMER PROTECTION DG

Directorate C: Public Health and Risk Assessment

Unit C2 - Health information



NIVEL SECRETARIAT

Email: NCA.NWPLSecr@nivel.nl

Fax. nr. 0031 - 30- 27 29 729.

To XX
CA COUNTRY

Email XX

Date 31 May 2005

Subject: Summary of National Activities CA, Sanco C2/ Health Information

Dear CA,

For the Next NCA meeting, the NIVEL Secretariat is again collating co-ordinating activities related to the Health Information Strand that have been carried out by the Country Authorities at national level since the last meeting.

The aim of this exercise is to update the Commission and other MS, to share good and innovative practice and to enable us to summarise the direction of Health Information activities across the EU. The form has been adapted in collaboration with Hugh Markowe (UK), Susan Gregory (GR) and Barbel Kurth (DE)

We therefore kindly ask you, as Country Authority for Country, to complete the enclosed form and return it to the Secretariat as soon as possible (no later than 15 June 2005). Please describe, if possible, major activities and important publications you wish to share, **related to Health Information** at national level, during the previous six months. Responses may be brief as long as they are understandable for colleagues outside your country. The use of web links in the document where helpful, is encouraged. The progress reports will be published on the web board, so that all MS have access to the information provided. The progress report addresses a few background questions and a specific focus.

If you wish to give a brief oral update at the coming NCA meeting to highlight a specific substantive activity, please inform the Secretariat when submitting this progress report.[Drafting note: not absolutely clear whether this is the same request as in the final box of the questionnaire. I have assumed – perhaps wrongly – that the final box is a request for any **substantive** agenda items whereas the option offered here is the opportunity for a brief “news” item rather than a trigger for a substantive discussion. If so perhaps this could be clarified by offering the chance in the question in the box to highlight either type]

As you know, this is a recurring item on the agenda of NCA –meetings at the request of Sanco C2. The Commission needs this information to further the work in the Health Information Strand of the Public Health area.

We kindly ask you to return the completed form electronically, if possible, otherwise by fax.

If you have any questions, please contact us by email (NCA.NWPLSecr@nivel.nl) or by telephone (direct number 0031 30 27 29 841/ 843).

We are looking forward to seeing you at the next meeting.

Yours sincerely,

Evelien Spelten, senior researcher
NIVEL Secretariat

PLEASE EMAIL OR FAX THE COMPLETED FORM A.S.A.P. (no later than 15 June 2005) TO:



NIVEL SECRETARIAT

Email: NCA.NWPLSecr@nivel.nl

Fax. nr: 0031 - 30- 27 29 729.

Country: Country

CA: Representative

(You may enlarge the boxes if needed).

This formed was completed by

Date

Since January 2005, what were the major activities that have been carried out in your country related to the Health Information Strand of the EU Public Health Programme?

1.

2.

3.

What are the important publications in your country related to the Health Information Strand since January 2005?

1.

2.

3.

Since January 2005, were there any other major activities that have been carried out in your country related to the EU Public Health Programme?

1.

2.

3.

Health inequalities will be one of the main components of the health part of the coming UK presidency. Can you refer to important recent publications or major substantive activities related to this subject in your country that are underway or planned?

1.

2.

3.

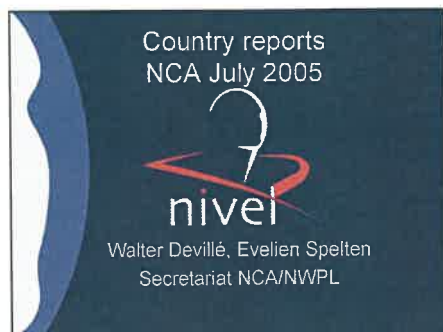
Are there issues you would like to raise at the next NCA meeting in July 2005? Please explain.

THANK YOU FOR ANSWERING THESE QUESTIONS.

PLEASE EMAIL OR FAX THE COMPLETED FORM A.S.A.P. (15 June 2005 at the latest) TO THE NIVEL SECRETARIAT: NCA.NWPLSecr@nivel.nl,

Appendix 20: Summary of Progress Reports CAs July 2005

Dia 1



Dia 2

MAJOR ACTIVITIES HIS	
AUSTRIA	<ul style="list-style-type: none"> • WHO European Centre for Environment and Health coordinates a project "Implementing Environment and Health Information System in Europe, EHIS1" • Establishment of Environmental Health Information System Supporting Policy Making - EHIS2 • The EUPHIX project (European Public Health Information, Knowledge & Data Management System)
BELGIUM	<ul style="list-style-type: none"> • End of field work for the Health Interview Survey 2004 • Establishment of a new legal entity for cancer registration
BULGARIA	Development of Health Information Standards
FINLAND	<ul style="list-style-type: none"> • Start of ECHIM / WP 7 - secretary in May 2005 (lead by the National Public Health Institute KTL of Finland) • Activities related to mental health working party including the Ministerial Conference in Helsinki January 2005 • National preparation on the Proposal for a Regulation (EC) of the European Parliament and of the Council concerning Community statistics on public health and health and safety

Dia 3

MAJOR ACTIVITIES HIS	
FRANCE	<ul style="list-style-type: none"> • The implementing measures of the Public Health Policy Law (adopted on 9 August 2004) are in process • The National Institute against Cancer was officially set up. See website: http://www.institutnationalcancer.fr/
GERMANY	<ul style="list-style-type: none"> • Meeting of the German representatives of the Programme Committee, the NCA and the members in the Working Parties for establishing a national network
GREECE	<ul style="list-style-type: none"> • A Network has been launched which concerns Safety Promotion and Prevention of Accidents • Network Promotion of Mental Health and Prevention of Mental Illness • Gd is currently under discussion "For Quality and Safety of Health Services, and the National Health Information System."
HUNGARY	<ul style="list-style-type: none"> • Launching the Internet-based Hungarian Health Datawarehouse (MCA) • English version of downloadable Hungarian Health DataBase made available at the National Center for Epidemiology website (currently under construction) • A national indicator list and dictionary is being developed

Dia 4

MAJOR ACTIVITIES HIS	
LATVIA	<ul style="list-style-type: none"> • Creation of Injury Database • Participation in eHealth session with report "The role of state institutions in facilitation of data exchange and implementation of eHealth" during The 2nd International Conference "Public Health 2005" • Development of Health Statistics and Medical Technologies State Agency's home page • Participation with report "Medical Staff Manpower Reform in Latvia" in meeting Past Trends Assessment and Future Forecasts of Health Workforce
LITHUANIA	<ul style="list-style-type: none"> • Annual collection of administrative data for 2004 related to health status and health care system
MALTA	<ul style="list-style-type: none"> • Expansion of IDB to all primary health centres. Work is ongoing to include the main public hospital Accident and Emergency department
NORWAY	<ul style="list-style-type: none"> • NoHealth, the database and presentation programme, called Norwegian in Norwegian, is available on the internet in English • A new system for notifying outbreaks or suspected outbreaks of infectious disease over the internet • Municipal Health Profiles

Dia 5

MAJOR ACTIVITIES HIS	
PORTUGAL	<ul style="list-style-type: none"> • Adoption of statistical concepts on health. Published by the IRE (National Institute for Statistics)
SLOVENIA	<ul style="list-style-type: none"> • Improving safety and confidentiality of health and personal data processing, related to the new ZJOP (Personal Data Protection Act) • IT of national health data bases and other IT for health data, some of them will be presented at "e-health for better Health in Slovenia" • Activities for implementation of DRGs in hospitals • 21th international conference of Patient Classification Systems International – PCSI "Casemix in a Patient-oriented Health Care"
SWEDEN	<ul style="list-style-type: none"> • Preparation of the National Public Health Report 2005 • Preparation of the first National Public Health Policy Report on the 11 goal areas of the public health policy • Preparation of Environmental Health Report
UK	<ul style="list-style-type: none"> • A Public Health Information and Intelligence Task Force has been established in England (May 2005) • Development of a Core set of Mental Health Indicators for Scotland

Dia 6

IMPORTANT PUBLICATIONS	
AUSTRIA	<ul style="list-style-type: none"> • Austrian Health Report 2004 • Austrian Report on Infectious Diseases • 7th Environment Control Report 2004 • Women's Health Report 2005 • WHO HIT update on Austria • First Austrian Quality Report • Public Health in Austria
BELGIUM	<ul style="list-style-type: none"> • 4 scientific publications
BULGARIA	<ul style="list-style-type: none"> • 3 publications on health information in Bulgaria in Social medicine, informatics and healthcare management, 2005
FINLAND	<ul style="list-style-type: none"> • National health report • Launch of Indicator bank • Atlas of Mental Health (STAKE5)
FRANCE	<ul style="list-style-type: none"> • 5 websites with weekly issues of publications on public health • Publication based interview survey 2002-2003: Prevention, perceptions and behaviours • Data about social and health situation in France 2004 (finance act for national health and pensions organization)

Dia 7

IMPORTANT PUBLICATIONS	
GERMANY	• 2 public health reports on Breast Cancer and Diabetes
GREECE	• Bill "For Quality and Safety of Health Services, and the National Health Information System"
HUNGARY	• Comprehensive Public Health Report • Regional public health reports for the 7 statistical regions • public health report in preparation on health of the population and any changes
IRELAND	• Public Health Information System (PHIS) • Health Statistics Report for 2005 • Data and Statistics Strategy • Regional Population Projections • Annual and Quarterly Reports on Vital Statistics
LATVIA	• Public Health Analysis, Latvia 2005 • Statistical Overview on Health and Health Care, Latvia 2004 • The reform of human resources of the health system in Latvia: estimation of present situation and future requirements

Dia 8

IMPORTANT PUBLICATIONS	
NORWAY	• Norwegian Recommendations on Nutrition and Physical Activity • 4 dissertations; and one scientific publication
PORTUGAL	Health In Portugal – Basic Statistics 2002
ROMANIA	• The activities for creating a site for the National Centre of Surveillance and Control of the Communicable Diseases • informative brochures on communicable diseases, death causes, and mean health status indicators
SLOVENIA	delay in publishing Health Statistics Yearbook of Slovenia
SWEDEN	• Public Health Report • Environmental Health Report • Public Health Policy Report
UK	• Clinical and Health Outcomes Knowledge Base • Association of Public Health Observatories "Progress and Prospects 2004/5" • "Indicators of Public Health - Lifestyle and its impact on health" • interactive web tool

Dia 9

EU Public Health Programme	
AUSTRIA	• combat against air pollution by PM10 • OECD System of Health Accounts • Contribution to the Open Method of Coordination in acute health and long term care / reporting duties to the EU-Social Protection Committee
BELGIUM	• Launching of the Eurostat project for the elaboration of standard modules for the future Core European Health Interview Survey • Launching of the DG Sanco project for the inventory and the evaluation of the European health surveys (European Union Health Surveys Information Database)
BULGARIA	• Project "Health Information Standards" – a conference- 26/04/2005 • A Roadmap to e-Health of the accession countries – a conference- 07/06/2005
FINLAND	• Preparatory work for the information system on health of children and the young • Preparation of the Government's Social and Health Report

Dia 10

EU Public Health Programme	
GERMANY	<ul style="list-style-type: none"> Draft of a national prevention law, which is currently discussed in the parliament http://www.bmja.bund.de/download/gesetze/entwurf/PravG/PravG_2005a/05a001n1.pdf Official publication of Gesundheitsziele de (a programme of health targets on national level)
HUNGARY	<ul style="list-style-type: none"> Call AND 2005 Work plan translated into Hungarian and published on the Ministry of Health website Financial back up in the ministry budget for co-financing EU Public Health Program presented in medical conferences Training about writing EU grant proposals under the "Functioning as a Member State" program
IRELAND	<ul style="list-style-type: none"> Health Service Reform Programme: New agency: Health Information and Quality Authority (HIQA) CARDS project: development of a template of standards for demographic and socio-economic components of health information systems A Public Health Observatory is being developed

Dia 11

EU Public Health Programme	
LATVIA	<ul style="list-style-type: none"> Participation in Technical meeting Causes of Death Statistics (TM COD) in Bonn 2nd European Commission "Help – for a life without tobacco" campaign participation in Stockholm Europe 2005 Conference Latvian Health Protection State agency had been submitted to EU Public health programme 2005 for funding Participation with report "Data Collection System in Latvia" in EC project's ISARE 3
NORWAY	<ul style="list-style-type: none"> A new national health survey end of 2005 two proposals: Feasibility of a European Health Examination Survey and European Urban Health Information System
SLOVENIA	<ul style="list-style-type: none"> population register began, without reporting of birth and death preparing the Slovene edition of updated ICD-10, version for 2006 Work on HIS module translation and implementation (Phare projects)
SWEDEN	<ul style="list-style-type: none"> The government has decided to relocate the Public Health Institute to northern Sweden Startup of the European Institute for monitoring communicable diseases in Stockholm March 2005

Dia 12

HEALTH INEQUALITIES	
AUSTRIA	<ul style="list-style-type: none"> Austrian Health Report 2004 Regional Health Information System "REGIS"
BELGIUM	<ul style="list-style-type: none"> Call "Society and future" of the Belgian Science Policy department
BULGARIA	<ul style="list-style-type: none"> A Paper on Nation's Health in the Beginning of 21-st Century. An Analysis of the Healthcare Reform in Action
FINLAND	<ul style="list-style-type: none"> TERO - programme (Reducing health inequalities) TEROKA - project (Partnership to reduce inequalities in health) 11 scientific publications
FRANCE	<ul style="list-style-type: none"> call for tender is launched concerning research about social health inequalities Social differences in mortality: increase for men, stability for women the regional programmes for access to prevention and care
GERMANY	<ul style="list-style-type: none"> National report on poverty and wealth EU-Project: "Closing the Gap: Strategies for Action to tackle Health Inequalities in Europe" Internet-Portal: "Gesundheitsförderung bei sozial Benachteiligten"

Dia 13

HEALTH INEQUALITIES	
HUNGARY	planned a first thematic public health report on health inequalities
IRELAND	National Anti-Poverty Strategy (NAPS) and the National Cardiovascular Information Systems (NCIS) Working Group • difference highest and lowest socio-economic groups in relevant mortality data and low birthweight data
LATVIA	• 'Closing the gap-Strategies for action to tackle health inequalities in Europe' • dissertation
LITHUANIA	3 scientific publications
NORWAY	• national expert group • national conference the Directorate for Health and Social Affairs and the Norwegian Healthy Cities Network • one dissertation
ROMANIA	• Roma Health Mediator Program • community nursing network

Dia 14

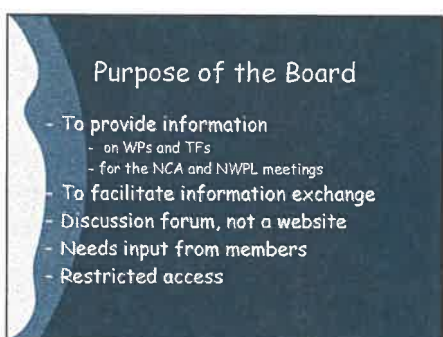
HEALTH INEQUALITIES	
SWEDEN	• The National Social Report 2006 • The Public Health Report focuses on social inequalities in health • The Public Health Policy Report follows many indicators within this field
UK	• Health Inequalities will be one particular focus of activity in relation to the health agenda. The official website • strategy backed by 12 Government Departments 'The strategy, Tackling Health Inequalities: A Programme for Action' •

Appendix 21: NCA-NWPL Web board: presentation of use

Dia 1



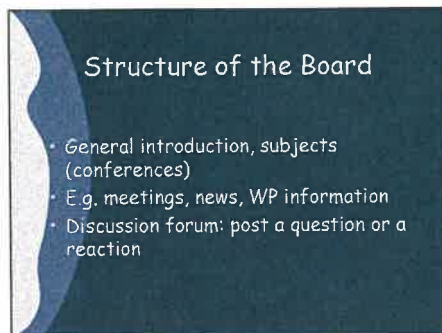
Dia 2



Dia 3



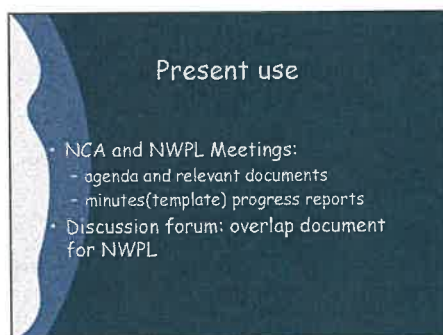
Dia 4



Structure of the Board

- General introduction, subjects (conferences)
- E.g. meetings, news, WP information
- Discussion forum: post a question or a reaction

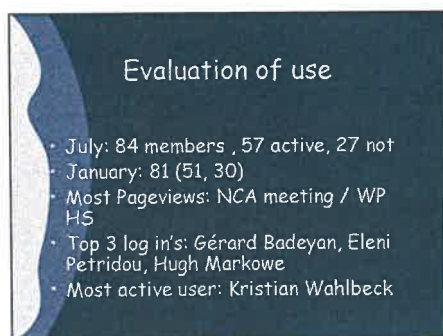
Dia 5



Present use

- NCA and NWPL Meetings:
 - agenda and relevant documents
 - minutes(template) progress reports
- Discussion forum: overlap document for NWPL

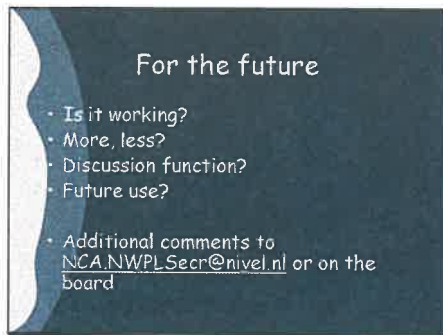
Dia 6



Evaluation of use

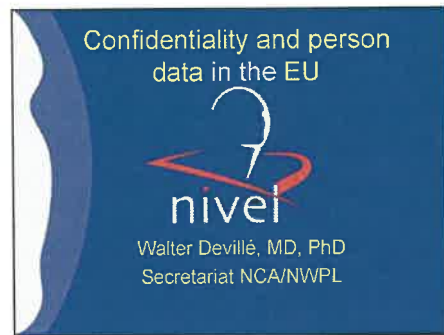
- July: 84 members , 57 active, 27 not
- January: 81 (51, 30)
- Most Pageviews: NCA meeting / WP HS
- Top 3 log in's: Gérard Badeyan, Eleni Petridou, Hugh Markowe
- Most active user: Kristian Wahlbeck

Dia 7

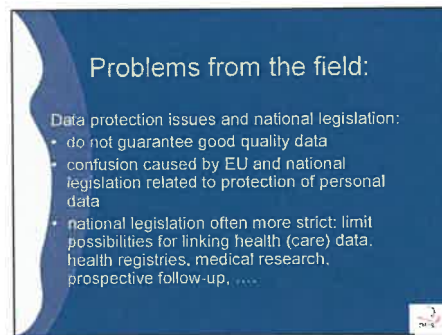


Appendix 22: EU Directive on person data : introduction

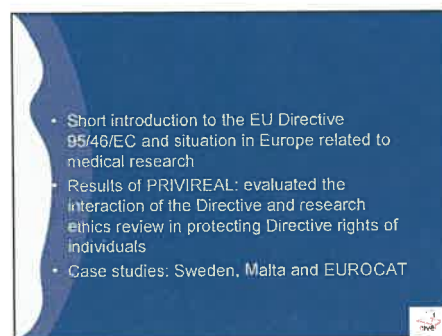
Dia 1



Dia 2



Dia 3



Dia 4

Legislation

- Within ESS: dealing with confidential data national authorities official statistics and EUROSTAT
- National production of data: EU Directive 95/46/EC
 - on the protection of individuals with regard to the processing of personal data
 - on the free movement of personal data

(The Data Protection Directive and Medical Research Across D Beylerveld et al Europe 2004)

Dia 5

Exemptions for Medical Research (1)

- Further processing for scientific purposes
- Identifiable for no longer than necessary. Special safeguards for longer periods
- Explicit consent to the processing of health data

Dia 6

Exemptions for Medical Research (2)

- Processing of health data for health care purposes
- Processing of health data for substantial public interest
- Exemption from information to be given to the person
- Exemption from the data subject's right of access to data

Dia 7

National implementation(1): provisions for national identification number or general identifier	
No	Austria, Cyprus, Czech Republic, Germany, Greece, Slovenia, Bulgaria,
Yes	Belgium, Denmark, Estonia, Finland, France, Latvia, Lithuania, Malta, Netherlands, Poland, Spain, Sweden, UK, Norway, Iceland
?	Hungary, Ireland, Italy, Luxembourg Portugal, Slovakia, Romania,

Dia 8

National implementation(2):informed consent necessary or alternatives available?	
Medical research always requires consent	(Finland), (Netherlands)
Probably sufficient to use alternatives even when not impracticable or inappropriate	Austria, Cyprus, Czech Republic, Denmark, Germany, Ireland, Italy, Latvia, Luxemburg, Malta, Poland, Portugal, Sweden, (UK), Bulgaria, Romania, Iceland
Probably necessary to get consent when not impracticable or inappropriate	Belgium, Estonia, France, Greece, Hungary, Lithuania, Slovakia, Slovenia, Spain, Norway


Dia 9

Problems confronted in practice: ENCR(1)	
<ul style="list-style-type: none"> Increasingly problems: <ul style="list-style-type: none"> new MS, not notifiable disease: France, Italy, Netherlands, Spain and UK. despite specific legislation: Germany, Czech Republic, Malta Less/ no problems: Denmark, Finland, Norway, Sweden, Poland, Slovenia 	

Dia 10

Problems confronted in practice: ENCR(2)

- No access to death certificates
- Impossible to use identifiable data, follow-up to ascertain cases, survival
- Informed consent needed for registration
- Informed consent needed for research
- Encryption / pseudonomization
- Cancer registration not supported by law
- Difficulties in transposing Directive to national laws / interpretation of local Data Protection Acts




Dia 11

Problems confronted in practice: confusion by legislation, the example of UK(1)

- Balance confidentiality ↔ use of identifiable health information
- Common law: exceptions straightforward
- Data Protection Act ('98):
 - Additional protection
 - Identifiable living individuals
 - Registered data controller
 - Information Commissioner: supervision
 - Exceptions for explicit consent
- Confusion and uncertainty: exemptions consent versus sufficient information

United Kingdom: data protection and confidentiality
Harwood & Coleman in Ethical eye - biomedical Research



Dia 12

Problems confronted in practice: confusion by legislation, the example of UK(2)

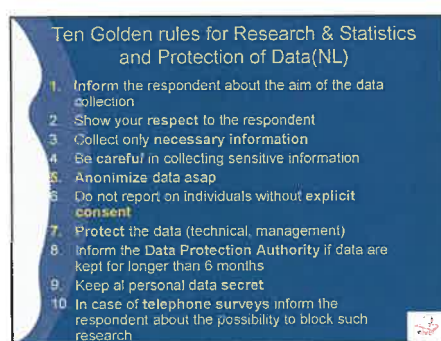
- Interpretation of more stringent safeguards
- Solution?: Health and Social Care Act 2001
 - Certain classes id. data without consent
 - Patient Information and Advisory Group
 - But Section 60: "transitional"
 - concerns compliance European Convention Human Rights
 - Safeguards: yearly review regulations, consultation relevant interest groups, no processing confidential information if alternatives
- Impact: continuing reluctance data providers



Dia 13



Dia 14



Appendix 23: Draft template for executive summaries for EU reports

DRAFT TEMPLATE FOR EXECUTIVE SUMMARIES FOR EU REPORTS WITHIN THE HEALTH INFORMATION STRAND

I. TECHNICAL INFORMATION

1. <u>AREA OF ACTIVITIES / WORKING PARTY:</u>	
2. <u>TITLE OF PROJECT:</u>	
3. <u>START DATE OF THE PROJECT:</u> __ - __ - ____ (dd-mm-yyyy)	
4. <u>DURATION OF THE PROJECT:</u> ____ (months)	
5. <u>PROJECT LEADER / ORGANISATION</u> (include contact address):	
6. <u>PROJECT NUMBER:</u>	
7. <u>SANCO REPRESENTATIVE:</u>	
8. <u>COUNTRIES INVOLVED</u>	
<u>MEMBER STATES:</u> <input type="checkbox"/> A (Austria) <input type="checkbox"/> B (Belgium) <input type="checkbox"/> CY (Cyprus) <input type="checkbox"/> CZ (the Czech Republic) <input type="checkbox"/> D (Germany) <input type="checkbox"/> DK (Denmark) <input type="checkbox"/> E (Spain) <input type="checkbox"/> EE (Estonia)	<u>CANDIDATE COUNTRIES:</u> <input type="checkbox"/> BG (Bulgaria) <input type="checkbox"/> TR (Turkey) <input type="checkbox"/> RO (Romania) <input type="checkbox"/> CR (Croatia) <hr/> <u>EFTA/EEA COUNTRIES:</u> <input type="checkbox"/> (IS) Iceland <input type="checkbox"/> (LI) Liechtenstein <input type="checkbox"/> (NO) Norway

<input type="checkbox"/> EL (Greece) <input type="checkbox"/> F (France) <input type="checkbox"/> FIN (Finland) <input type="checkbox"/> HU (Hungary) <input type="checkbox"/> I (Italy) <input type="checkbox"/> IRL (Ireland) <input type="checkbox"/> L (Luxembourg) <input type="checkbox"/> LT (Lithuania) <input type="checkbox"/> LV (Latvia) <input type="checkbox"/> MT (Malta) <input type="checkbox"/> NL (Netherlands) <input type="checkbox"/> P (Portugal) <input type="checkbox"/> PL (Poland) <input type="checkbox"/> S (Sweden) <input type="checkbox"/> SI (Slovenia) <input type="checkbox"/> SK (the Slovak Republic) <input type="checkbox"/> UK (United Kingdom)	OTHERS:
9. REPORT STATUS (INTERIM OR FINAL) / Date:	

II. CONTENT RELATED INFORMATION

10. CONTEXT/INTRODUCTION (limit 300 words):

11. AIM AND OBJECTIVES OF THE PROJECT:

12. KEYWORDS (use maximum 5 MeSH terms):

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

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

15. CONCLUSIONS (limit 250 words):

16. PLAN OF DISSEMINATION OF RESULTS:

17. NEEDS FOR FUTURE POLICY DEVELOPMENT (limit 150 words):

