ANNEX 3a

6th Meeting of the NCA,
4th Meeting of the NWPL

Luxembourg, 7-8 February 2006
DRAFT
Sixth Meeting of the Network of Competent Authorities

Luxembourg, 7 February 2006 (10:00-17:30)
and 8 February 2006 (9:30-16:00)
Room JMO M1

From the afternoon session on 7 February on, the meeting will be held jointly with the Network of Working Party Leaders

1. Adoption of the agenda
2. Adoption of the minutes of the last meeting
3. Prioritizing Indicators and report work (A. Aromaa)
4. Best practice exchange:
   - Health Technology Assessment Network (EUnetHTA)
   - Cochrane Database online (update by SANCO C2)
5. Issues raised by Competent Authorities

Lunch break 12.30-14.15

Start of joint meeting 7 February 14.15-17.30 and 8 February 9.30-16.00

6. Projects 2005 and Workplan 2006 (SANCO C2)
7. Update on New Programme of Community action in the field of Health and Consumer protection 2007-2013 (SANCO C2)
8. Progress report of the Working Parties and Task Forces (10-15’ each)
   - WP on Lifestyle
   - WP on Morbidity and Mortality
     i. Task Force on Rare Diseases
     ii. Task Force on Major and Chronic Diseases
   - WP on Health Systems
   - WP on Health and Environment (Break 15’)
   - WP on Accidents and Injuries
     i. Task Force on Strategic Planning
     ii. Task Force on Work Health
     iii. Task Force on Injury Data Base
- WP on Mental Health

**(February 8)**

9. WP on Indicators / ECHIM

10. Update European Health Survey Systems including situation Eurobarometers (A. Montserrat)

11. Progress of activities at a national level: Summary Country Reports (NIVEL)

12. EU Health Portal, updated progress (*SANCO C2*)

**(Break 11.00-11.15)**

13. Update EUROGLOREH 2007 (*L. Vittozzi*)

14. Update on Proposal for a Regulation concerning Community Statistics on Public Health and Health and Safety (*EUROSTAT*)

15. Confidentiality Of Personal Data: Report of WG (NIVEL)


17. Ehealth Conference (*SANCO C2*)

18. Any Other Business

19. Next Meeting

Circulate:  
- Green Paper Mental Health  
- Injury Communication + Recommendation (Minutes 12/10/05)  
- AIDS Communication  
- Green Paper Nutrition  
- Communication on generic preparedness and response  
- Report to Council by HL Group on patient mobility
• Agenda of the fourth NWPL meeting

DRAFT

Fourth Meeting of the Network of Working Party Leaders

Luxembourg, 7 February 2006 (10:00-17:30)  
and 8 February 2005 (9:30-16:00)  
Room JMO M2

The afternoon session of 7 February and the sessions of 8 February will be held jointly with the NCA

20. Adoption of the agenda
21. Adoption of the minutes of the last meeting
22. Issues raised by Working Party Leaders
23. Reviewing indicators for ECHIM, request from WP on Indicators

Lunch break 12.30-14.15

Start of joint meeting 7 February 14.15-17.30 and 8 February 9.30-16.00

[see agenda of the joint NCA/NWPL meeting]
Minutes of the NCA meeting and joint meeting with the NWPL

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

DRAFT MINUTES

Sixth Meeting of the Network of Competent Authorities

Luxembourg, 7 February 2006 (10:00 am-17:30 pm) and 8 February 2006 (9:30-16:00)

Chair: John F. Ryan (Head of Unit Sanco C/2, Health Information),
Co-chair: Antoni Montserrat (Sanco C/2, Health Information)

List of participants, presentations and other documents and contributions related to the meeting are available at:

Reported by NIVEL Scientific Assistance Office

1. Adoption of the Agenda
Chair opened the meeting. There were no amendments raised to the agenda. The agenda was adopted.

2. Adoption of the minutes of the last meeting
Malta asked to add to the item Confidentiality in the minutes that the ad hoc Working Group on Confidentiality aims to produce a draft statement on Data Protection.
The minutes are considered as adopted and will be published on the SANCO website

3. Best practices
- EUnetHTA (European Network for Health Technology Assessment)
Presentation by Mr Niels Würgler Hansen.
The aim of the project is to establish an European Network for Health Technology Assessment – EUnetHTA.
The Network of Competent Authorities was invited to follow up on the progress of the Health Technology Assessment Network and suggested that a special paragraph may be addressing Health Technology Assessment on the DG SANCO website.

- Cochrane database
The Commission wishes to follow up on developments with the Cochrane Collaboration to find out the practical conditions to get free access through the Health Portal. Some countries already paid free access. The Network of Competent Authorities supported the Commission with this initiative and suggested to do a situation analysis at Member States level, to study elements of costs, and possible scenarios between Member States with different levels of access. It was suggested to raise the issue at the conference in Malaga on eHealth. Exploratory talks will continue, based on situation mapping, and proposals with their financial
implications developed. At the meeting in July an update will be presented together with proposals. The Network of Competent Authorities was asked for a reflection on national level about a national position concerning this issue and to give feedback through the Scientific Assistance Office.

4. Prioritizing indicators
Mr Arpo Arooma presented the approaches taken by ECHIM project (European Community Health Indicators Monitoring) on the prioritisation of the ECHI indicators. ECHIM needs a close collaboration with the Working Parties in the Health Information strand. Priority criteria for indicators are proposed. Priority tasks for ECHIM: assess the current ECHI indicators together with the projects and revise them when needed; assess with Working Parties their proposed indicators; assess with the Member States the need and feasibility of data gathering and indicators; promote use and reporting as well as collection of comparable data.

Some background information was given on the High Committee on Health held in Cardiff. The minutes of that meeting will be circulated. Some concern was expressed about the development of indicators. The Network of Competent Authorities should know about these concerns and contacts the representatives of the Member States in the High Committee on Health. The next meeting is on March 13th in Vienna. The Social Protection Committee of DG Employment has an indicator group. January 25 they had a meeting where health inequalities, healthy life expectancies, patient inclusion and financial sustainability were discussed. The Network of Competent Authorities expressed its disappointment regarding the absence of DG employment in this meeting.

Member States might have difficulty providing resources to provide data for health indicators. There is no objection to the coming legislation of EUROSTAT, but worries about the implementation and the political support. EUROSTAT explained that the basis for the new legislation is not to force Member States into new areas of activities, but keeping what already is available in the field of health statistics. A legal base is developed for the provision of regular data on health.

There was concern expressed that the final report of the ECHI group does not give detailed information and guidelines on any indicator of the short list. The short list was a process of this network and the Working Parties. The list might need more details if necessary; there is clear link between the EUROSTAT activities, the priority list and the legislation needed. EUROSTAT clarified that no matter what demand may come up, it will never be the case that all indicators will be covered by statistics collected by EUROSTAT. The definitions of the ECHI health indicators were given in the ECHI long list and in the WHO/OECD/ECHI – ICHI international compendium of indicators [http://www.healthindicators.org/ICHI/general/startmenu.aspx]

Several Competent Authorities commented on the implementation of the proposed EUROSTAT legislation and the strategies to follow. EUROSTAT explained that now that the list is available the work can go forward on a more detailed level. Only the most important information collected at national level will go in the statistical database for EUROSTAT. There is common agreement about where we want to go. It is not the intention of EUROSTAT, that Member States with more advanced systems will have to implement a lower standard of data collection, but first steps may be taken at a lower level for those Member States where it is needed. There are issues of additional costs that are discussed at EUROSTAT. The new text of the Public Health Programme favours coordination with EUROSTAT.

5. Issues raised by Competent Authorities
Dr Peter Brosch introduces the health related activities under the current Austrian presidency.

**Joint meeting with the Network of Working Party Leaders**

Chair: John F. Ryan (Head of Unit Sanco C/2, Health Information)
Co-chair: Antoni Montserrat (Sanco C/2, Health Information)

5. **Issues raised by Competent Authorities (continued)**

The Networks were informed that Parliament has made amendments to the proposed new public health programme mentioning health inequality.

Dr Mika Gissler gave an update on the upcoming presidency of Finland. At the EUPHA conference, the impact of policies around some of the themes from previous presidencies (such as health inequalities and women’s health) will be discussed. The Commission mentioned that health impact assessment will taken up by the health information strand.

6. **Projects 2005 and Work plan 2006**
Mr John F. Ryan informed the Networks that the projects, agreed for funding for 2005, are in a final stage of contract negotiations. The first 8-9 projects on the reserve list will be funded with the money unused by the agency. The Work Plan 2006 is published at [http://europa.eu.int/eurlex/lex/LexUriServ/site/en/oj/2006/l_042/l_04220060214en00290045.pdf](http://europa.eu.int/eurlex/lex/LexUriServ/site/en/oj/2006/l_042/l_04220060214en00290045.pdf)


The budget will be approximately the same as in 2005, with a small amount taken by the Public Health Executive Agency for administration. The deadline for submission of project proposals is 19 May 2006.

The direct grant agreement with EUROSTAT was discussed. DG SANCO understands that statistical bodies in Member States are not restricted to the national statistical organisations (e.g. registries). The sub delegation of EUROSTAT covers the possibility to support all these kind of institutes that contribute to statistical activities.

7. **Update on New Programme of Community action in the field of Health and Consumer protection 2007-2013**
Mr John F. Ryan gave a brief update on the development of the New Programme in the decision procedure in Council and Parliament.

8. **Confidentiality of Personal Data: Report of WG**
Presentation by Mr Walter Devillé (NIVEL).
Mr Thomas Zerdick of the European Commission DG Justice, Freedom and Security, Data Protection unit, commented on the presentation and on the activities of the Work Group. Regarding personal health data, one should first refer to Article 8 of the EU Directive 95/46/EC about data protection.

Article 8 is a special article because it is about those special categories of personal data ("sensitive personal data"). The processing of these personal data, e.g. data relating to health,
is generally prohibited (Art. 8 (1)). There are however a few exemptions. Article 8 sub 3 only makes the processing of health data legitimate if it is required "for the purposes of preventive medicine, medical diagnosis, the provision of care or treatment or the management of healthcare services, and where those data are processed by a health professional subject under national law or rules established by national competent bodies to the obligation of professional secrecy or by another person also subject to an equivalent obligation of secrecy". Medical research is not mentioned in art 8 sub 3. As a consequence, if Member States wanted to allow for the processing of personal health data the must make use of the exemption provided for in Article 8 (4). It states that Member States have to show grounds of important public interest, and provide for proper guarantees for the processing of these special data. Permission might also be to be obtained by the competent national data protection supervisory authority, under national law.

The Chair would like some more information on the Group that has been set up based on Article 29 of the Directive. Perhaps they can give a presentation at a future meeting of the Network of Competent Authorities. The need for information to explain why there are differences among Member States in the area of data processing was discussed. The Network of Competent Authorities Work Group would like to state that there is no general prohibition by the EU to collect person identifiable health data. Action is needed to facilitate a common interpretation of the Directive. It was questioned whether national data protection authorities have the authority to prohibit data processing based on national legislation, irrespective of the Directive. It was also discussed whether Member States are breaking Article 1 paragraph 2 of the Directive that states that they should not prohibit the free flow of person identifiable data. It was asked who determines whether the collection of person identifiable data is in the interest of public health (e.g. the ministry of health)? It was asked whether countries could have a higher level of protection than the level that the Directive provides for. The problem was pointed out that EUROSTAT provides for a one-way direction of data processing: Member States do not receive anything back; this is perhaps also the case for the European Center for Disease Prevention and Control. Other issues mentioned were informed consent by the patient. Is informed consent sufficient to transfer data between Member States? Not all questions can be answered at this meeting. The Scientific Assistance Office, together with the Commission and Mr Thomas Zerdick will decide how to take this discussion forward.

Mr Zerdick concluded the discussion by stating that "everything is possible" if you know what you want (purpose specification and limitation principle) and if you have legal national framework for the processing of personal data in place. If a Member State has a problem at national level, the national data protection supervisory authority should be addressed to solve it first.

   - Working Party on Lifestyle
     Presentation by Prof. Wilhelm Kirch.
     A succession of different projects on lifestyle related issues have all been brought together in one Working Party, trying to improve links with the policy side on alcohol use, childhood obesity, smoking etc. The health determinants strand performs a lot of work on policy issues. It is therefore important that the Working Party tries to make a bridge between health information and health determinants, trying to steer activities and resources. It would be logical to steer projects in the future in the field where policy developments will be coming up.

   - Working Party on Morbidity and Mortality
Presentation by Ms Dionne Kringos.

- **Task Force on Rare Diseases**
  Presentation by Dr Ségolène Aymé.
The Task Force was complimented for all the work that has been done, the link that has been achieved between all the projects and Non-gouvernemental Organisations’s and hopes to continue to support their work.

- **Task Force on Major and Chronic Diseases**
  Presentation by Mr Enric Duran.
The need was stressed to reach consensus among the projects on a common vision for what is needed in terms of better information. The new strand on diseases in the next programme 2007-2013 will contribute to this. The Scientific Assistance Office will be working on the summaries of the progress that the projects are making. The Morbidity and Mortality Working Party is the largest Working Party. If the Mental Health Working Party is included, it will count about 120 members. The size complicates the management of the Working Party and Task Forces. It was discussed that projects should have a clear focus and output: they should contribute to the health information system. This requires pro-active thinking about the outputs of the current running projects. The Scientific Assistance Office can take a role in this. For this reason new contract forms were designed including blocks with outcome indicators.

- **Working Party on Mental Health**
  Presentation by Kristian Wahlbeck.
In the near future the Mental Health Working Party will be moved to DG SANCO C4 health determinants. It will be transformed in a EU platform for mental health (involving users, international organisations, stakeholders, etc.). This future platform has to link with the Working Parties in the health information structure and ECHIM. The Mental Health Working Party would like to discuss with the Commission the possibility to place the “Orphan projects” in a Task Force on Mental Health within C2. The Working Party was complimented with the work they have done. The Commission will continue to support the work on mental health. A report was given on the discussion of the NWPL morning meeting (7 February) on the Mental Health Working Party (see minutes NWPL meeting). The Working Party will be given the opportunity to decide at their meeting in March whether they want to have a task force on mental health as part of the Morbidity and Mortality Working Party. This will give the opportunity to bring projects on neurological disease together with mental health projects. In June the decision will be accepted. For a small country such as Malta, which has limited resources, a fragmented structure resulting from too many Task Forces will be problematic. The Commission is aware of the large amount of Task Forces and explained that Task Forces are sometimes killed off, leading to a stable total number of Task Forces. Scientific Assistance Office will help with mapping the information system, a point requested by the High Level Committee on public health in Cardiff.

- **Working Party on Health Systems**
  Presentation by Dr Ales Bourek.
The approach of the Health Systems Working Party is necessarily different from the other Working Parties, because some of their issues are quite different such as HTA, patient safety, and eHealth. It will be a challenge to include the projects on eHealth in the Health Systems Working Party. The possibility to split the Health Systems Working Party up in 2 or more groups was discussed.
Informal presentation by Mr Didier Dupré (Eurostat Unit F5).
A joint Eurostat-OECD-WHO collection of the System of Health Accounts has been launched in December 2005 with deadline on 31/03/2006 for provision of the first reference years’ data 2003-2004. The diagnostics classification developed together with the Hospital Data Project (SANCO), EUROSTAT, OECD and WHO for hospital discharges / activity statistics, has now been adopted officially as the “International Shortlist for Hospital Morbidity Tabulation” (ISHMT) by the WHO Family of International Classifications. For more information: http://www.who.int/classifications/icd/implementation/morbidity/ishmt/en/index.html
Meta data is now also available on the SANCO website (http://ec.europa.eu/health/ph_information/dissemination/echi/echi_en.htm). EUROSTAT is launching together with DG Employment an open method of coordination on short and long term care. The Social Protection Committee will now be able to define the first list of indicators. The next meeting of the Subgroup on Indicators of the Social Protection Committee will held on 28 April 2006.

The issue was raised that there are many health systems indicators at the moment not yet available in Member States. There is a need to look more conceptually at the field in all Member States. There is a need to change the strategy regarding the type of projects that are supported. The Commission is currently finalizing the direct financing arrangement with the OECD and is supporting EUROSTAT in their work by sub delegation using the Public Health Programme to provide funding for work linked to public health statistics. It was discussed that a better coordination of the activities with DG Employment E4 (Indicator Sub Group of the Social Protection Committee – ISG SPC) is required. It would be useful if expert groups in collaboration with EUROSTAT would integrate all the existing national models for data collection into one EU wide accepted data model with EUROSTAT. EUROSTAT explained that collecting health care data is particularly difficult because each Member State has its own health system and own data model. It is not a possibility or the intention of EUROSTAT to interfere with their health care systems. It was explained that EUROSTAT uses postharmonization methods. The role of meta-data is important in this area. The main tool for metadata on health care systems was developed by DG SANCO (the EUCOMP tool). Information is available at the DG SANCO website: http://ec.europa.eu/health/ph_information/dissemination/hsis/hsis_en.htm

- Working Party on Health and Environment
No presentation.
If possible, the Commission will try to organise a back-to-back meeting of the Working Party on Health and Environment with DG Environment.

- Working Party Accidents and Injuries
Presentation by Ms. Eleni Petridou.
The Commission has tried to maximize the output from these projects by drafting a White Paper on accidents and injuries involving the public safety side, product and service safety road safety aspects, and aspects of violence. An early draft is available and will be accompanied with a draft Recommendation to be submitted to the Council and to Parliament. Hopefully this coincides with the activities from Austrian Presidency programme.

- Task Force on Strategic Planning
No separate presentation
- Task Force on Work Health
No separate presentation

- Task Force on Injury Data
Presentation by Mr Robert Bauer.
Mr Bauer requested the Network of Competent Authorities to cooperate with the Injury Database National Data Authorities in order to establish or stabilize the Injury Database in their countries. The first European Conference on Injury Prevention and Safety Promotion will be held on June 25-27, 2006 in Vienna.
Mr Bauer mentioned that the coding ICCI (International Classification for Causes of Injuries) has recently been introduced to the Injury Database. The discharge data of hospitals should be coded by the same system.

- Working Party on Indicators / ECHIM
Presentation by Ms Katri Hakulinen.
The Working Party on Indicators was asked to prepare a short paper for the High Level Committee that will meet in Vienna in 13-14March, explaining the philosophy of their work on health indicators. A first selection of 40 indicators is available at the SANCO website, with additional information on the short and long list, at:
http://ec.europa.eu/health/ph_information/dissemination/echi/echi_en.htm

10. Update European Health Survey Systems including situation Eurobarometers
Presentation by Mr Antoni Montserrat.
An update was given on the developments of the EHSS in 2005 and 2006 Important web links:
http://ec.europa.eu/health/ph_information/dissemination/reporting/ehss_en.htm ;
http://ec.europa.eu/health/ph_information/dissemination/reporting/ehss_04_en.htm;
http://www.nut.uoa.gr/Dafnesoftweb/;
An update on the Eurobarometer was given. Important web links:
http://ec.europa.eu/health/ph_publication/eurobaromers_en.htm ;
http://europa.eu.int/comm/public_opinion/archives/eb_special.htm ;
The idea is to use the Eurobarometer more systematically. It is an instrument for opinions of citizens. The limitations of the Eurobarometer are its different biases and competing information. It is often used as basic information on health, without taking the limitations into account, leading to misinterpretation of the results. One of the main advantages is its rapidity. It was suggested to look at alternatives for rapid information tools, such as surveys by telephone.
EUROSTAT informed the Networks on the development of the EHIS but also on ongoing activities such as: The SILC (Statistics of Income and Living Conditions) – EHIS (health status module) harmonization of the MEHM questions. The "Budapest initiative" of UNECEWHO-EUROSTAT on the measurement of health state which will be taken into consideration in the EHIS for international comparisons (US, Canada, Australia, etc.). Current discussions on a European Social Survey (ESS) may be based on an EU sample and with data available within a maximum of 12 months after the definition of the request by the client DG.
Finally Mr Dupré announced the publication of the pocket book "Health in Europe":
The Eurobarometer is extremely useful for opinions and perceptions. The SILC is used to rate the health of the population. The Commission is aware of the limitations and possibilities. The panel of experts on EHSS will meet in April. It was suggested to organize a bilateral meeting between SANCO C2 and Eurostat F5 on statistical data available in EUROSTAT and time schedule for later availability (EHIS, possible European Social Survey), in order to improve their use and limit the use of other sources and define more clearly the interim role of Eurobarometers in the current phase while setting up progressively the EHSS.

11. Progress of activities at a national level: Summary Country Reports
Mr Walter Devillé introduced the summary.

12. EU Health Portal, updated progress
Presentation by Mr John F. Ryan.
Information is validated and is at the moment in translation. The Portal will be launched at the eHealth Conference in Malaga. The Commission has received good feedback from Member States and Non-governmental Organizations. The remaining Member States can give an easy link to the national entry page. Unlike for Member States, if Non-governmental Organizations do not reply, they will not be included on the Portal. The management of the portal will be up to an editorial board including representatives of Member States and Non-governmental Organizations. The Board will have its last meeting in March. Network of Competent Authorities representatives who want to be present can be invited. After the launch of the Portal, a Formal Editorial Board will be set up. The Board should include representatives from each Member States. The rules on how the Board will work are all stipulated in a formal document. The Scientific Assistant Office will send in March a request to the Network of Competent Authorities members to nominate someone for the Editorial Board. The webmaster of the Portal was introduced. He explained that a lot of technical problems delayed translation into 20 languages. Its development was financed by the IDA programme.

13. Update EUROGLOREH 2007
Presentation by Dr Luciano Vittozzi.
The provisional table of contents was discussed. The publication strategy involves a web report adapted for the general public with special features; a complete report and an executive summary including recommendations addressed to policymakers. A flowchart of the report preparation was discussed. Working Parties will be consulted as a group for the general scheme and content. For the activity of data collection of writing, experts have to be chosen from the Working Parties. The drafting phase should be completed in March 2007. The report should be offered to the Commission by end of the November 2007. Working Parties are formally not involved in the work. Chapter 8 will cover country summaries: countries can comment on their own policies. Executive summary will be translated in Member States (partners of project). The report will be launched during Spring 2008. The format of the chapters was discussed. The structure will be according to a scientific paper. Focus boxes can be created in the main text to address matters that are not evident the statistics. The Working Party leaders and project leaders can give suggestions for the focus boxes. The coordinating TF (ie. from the steering group) will make a selection of topics. The average length of the contributions will be about 20 pages per chapter but 60 pages on health status chapter. The project will be discussed again at the next Network of Competent Authorities meeting. The Network of Competent Authorities should provide the Commission with comments and requests for clarification via e-mail. It is important that the Network of Competent Authorities will inform the project in an early phase if they foresee any problems with this project.
Informal presentation by Mr Didier Dupré. There are two types of consultations in the work of the European Statistical System: there was a consultation with the High Level Committee, and with the Statistical Programme Committee. They gave a favourable opinion, but the problem was to reduce the scale of the proposal. A minimum statistical data set in the field of public health and also an impact assessment is necessary. An analysis of consequences of the project is currently drafted. End February it should be submitted for inter-services consultation. Then the Commission will be asked via a written procedure to adopt it. During the third trimester of 2006, it will be submitted to Parliament and the Council.

15. Presentation of the proposal for a Commission Communication and Council Recommendation on Injury Prevention and Safety Promotion
The proposal for a Commission Communication and Council Recommendation on Injury Prevention and Safety Promotion was informally discussed by the Commission following the presentation of the Working Party on Accidents and Injuries. See agenda point 9 of the minutes.

16. eHealth Conference
Presentation by Mr Artur Furtado.
The eHealth Conference will take place from 10-12 May 2006 in Malaga. It is a thematic conference that is open to high-level official delegations with industry participation on proper invitation. The title of the conference is “Synergies for better Health in a Europe of Regions”. For more information: www.ehealthconference2006.org.
The Network of Competent Authorities confirmed that they are interested to participate at the conference if DG SANCO has the financial resources. The conference has this year a more public health focus. There might also be a session on confidentiality and e-education and learning. The Commission is open for suggestions for the agenda of the conference to strengthen the public health focus. The draft agenda will be circulated to the Network of Competent Authorities by the Scientific Assistance Office, including a request for suggestions, ideas and comments. If SANCO has the resources, the Network of Competent Authorities members will be invited. They can in turn appoint someone else to participate.

17. Any other business.
The Scientific Assistance Office will prepare an evaluation for the organisation of the meeting. The Scientific Assistance Office will also construct a user-friendly map of the structure of the health information strand, including among others the contact details of the Working Parties. The Commission thanked all present for their contribution to the meeting.

18. Next meeting
The next meeting will be held in July.
Minutes of the 4th NWPL meeting:

DRAFT MINUTES

Fourth Meeting of the Network of Working Party Leaders

Luxembourg, 7 February 2006 (10:00 am-17:30 pm) and 8 February 2006 (9:30-16:00)

Chair: Antoni Montserrat (Sanco C/2, Health Information)

List of participants, presentations and other documents and contributions related to the meeting are available at:
http://ec.europa.eu/health/ph_information/implement/nwpl/ev_20060207_en.htm

Reported by NIVEL Scientific Assistance Office

1. Adoption of the Agenda

Chair opened the meeting. There were no additional points raised to the agenda. The agenda was adopted.

2. Adoption of the minutes of the last meeting

The minutes were accepted without changes.

3. Issues raised by Working Party Leaders

The Commission has decided that the main part of the activities of the Mental Health Working Party should be transferred to the unit dealing with health determinants, whereas projects relating to health information will be retained in the health information strand under the working party on mortality and morbidity.

The Commission mentioned three relating problems. The first is the problem of overlap between Working Parties. The second problem is the overlapping activities of projects (e.g. hospital discharges and health surveys are horizontal topics). A third problem is that the mortality and morbidity sector is very big in size. It is therefore necessary to develop an appropriate organisational structure, such as a Task Force. Concerns were expressed that specific areas on mental health determinants might become neglected in the new integration with the mortality and morbidity working party. When considering the overall range of types of information, the suggested mental health indicators are in the area of social conditions, which are not covered by any other Working Party. The observation was made that although it is important in the Task Force on Major and Chronic Diseases to look at epidemiological aspects of diseases, the health determinants of diseases will also be covered in the consideration of mortality and morbidity issues.

Mr Montserrat summarized the discussion by stating that it is agreed that the mental health information projects can be integrated in the working party on mortality and morbidity. The Network was informed that the task force on health expectancies will have its second
meeting in June 2006 to discuss the measurement methods for structural indicators of health, such as DALY’s (disability adjusted life years) and HALY’s (health adjusted life years). The Task force consists out of representatives from Member States, and 2 projects (one from the European Health Expectancy Unit of Inserm in France, and one project on Health Inequalities from the Erasmus Medical Centre in the Netherlands). It is desirable to have a dialogue with the WHO on the use of DALY’s and HALY’s.

The Scientific Assistance Office (NIVEL) mentioned that the Health Systems Working Party is developing a process that should be used for “focussing” activity areas of the Working Party.

The Scientific Assistance Office is collating, on request of the Network of competent authorities, a database organised by country with contact information on all the persons who are or have been involved in a SANCO project within the health information strand. The Network was asked to send the contact information of the project leaders and associated partners of these projects to nca.nwplseer@nivel.nl.

4. Reviewing indicators for ECHIM, request from WP on Indicators (P. Kramers)
Informal presentation by Mr Pieter Kramers.

The ECHIM (EC Health Indicators Monitoring) project has 2 major goals: 1. Working towards implementation of indicators; 2. The further development and improvement of the indicators list. Important issues are:

How do we arrive at a situation where data will be collected on all the indicators? How should this be realised in working together with SANCO and EUROSTAT? The new EUROSTAT regulation might facilitate it. Another important issue is why should we invest in further development of the list when the existing list has not even been implemented yet? The development of new and improved indicators is what happens in the Working Parties. The Network of working party leaders should discuss how the list can be improved in order to be able to come up with a new list within a few years. The Working party on Indicators would like to bring the process of indicator development and improvement into life again, so that in the long run the Health Information Surveys can be improved. The Working parties are requested to examine the current short and long list, the ICHI website (http://www.healthindicators.org/ICHI/general/startmenu.aspx), and to identify which areas are not well defined, redundant or lacking. Working parties are asked to work on the technical improvement of indicator instruments and to prioritize the indicators in their field. Perhaps Working parties can incorporate this as a standard point on the agenda of their meetings. The members of the Network agreed that it is of importance to take advantage of the work performed by the projects and to work on the development of instruments for indicators as well as to improve the current list of indicators. Several Working parties and Task forces pointed out that they are already making effort on this. The working party on Indicators needs to develop a mechanism that prevents that the short list is growing too much (e.g. by applying a Delphi procedure) and assures a good balance between all the fields in the short list. The Working party on Indicators would like to have an overview of all the information strand projects.

Concerns were expressed about the stability of indicator implementation. Given the (financial) implications for countries, it would be desirable that DG SANCO takes a more formal stand on which specific health issues they want to focus in the upcoming period. Concrete information is e.g. needed on the definition of indicators and on the methods for collecting data. Another issue that was brought up that it should be decided which elements need to be included in the mechanism as part of the monitoring system. Every indicator that is proposed for the list should include elements such as: definitions, how to measure it, etc. The discussion therefore needs to go beyond the stage of which indicators should or should not be
included in the list. If gaps in knowledge are identified, it would be possible to finance projects to fill the technical gaps. The basic idea is that projects should contribute to a common effort for health information. The Secretariat ECHIM will meet on 14 and 15 February 2006 and the Working Party on Indicators will have a meeting in May. All Working Party leaders are always invited to join the meeting. Examples of types of problems experienced in the short list are different sources providing conflicting information and resource problems. A solution for missing sources that is sometimes applied is to ask projects to propose modules for health surveys. In the long list, which includes about 400 indicators, data sources are for a large part missing. It should be decided which sources are appropriate to use for data collection on indicators. It was commented that instead of including new and more indicators on the list, focus should be placed on the existing indicators and try to define and include them in the national data sets. Programmes, such as centres of reference, should use the indicators to show countries that their activities are reflected in the outcomes. The Commission concluded that this discussion will be forwarded to the Working Party on indicators.

*Joint meeting with the Network of Competent Authorities*
[see minutes of the Sixth NCA meeting]
SAO Presentation during joint NCA/NWPL meeting: MMWP Progress Report

Structure MMWP (1)

Projects on disease morbidity information
- Rare
- Reference centres
- Collaborating departments
- Gynaecological and obstetrical
- Multi-morbidity
- Public and private
- Personal health

Projects on morbidity inventories
Projects on improving health surveys
Projects on causes of death
Cross-cutting projects

Structure MMWP (2)

Task Forces

Task Force on Major and Chronic Diseases
Task Force on Rare Diseases

Workshop on the European Health Survey System
Task Force on Health Expectancies
(cross-cutting with WP Health Indicators)

New MMWP projects 2005 (1)

- Scientific Assistance Office (NIVEL, NL)
  - objective: To provide structural and scientific support to the MMWP and Task Force to ensure their effective management
- Eur. Collaboration on Dementia (ALZHEU, EU, Lux.)
  - objective: To evaluate the effectiveness of care for neurological and neuro-psychiatric disorders and to assist in the formulation of future policies in the field of dementia
- Eur. Core Indicators in Diabetes Mellitus (CIBIO, NL)
  - objective: To set up a database to collect best and worst practices on health status and care delivery for DM in the EU and future MS in order to promote the sharing of good DM health data and DM care organisation in the EU and internationally
- Eur. Autism Information System (The Hope Project, IRL)
  - objective: To improve the quality of life of children affected by ASD by setting up a surveillance system to improve data availability on ASD and by contributing to the accessibility of information about AS to appropriate treatment and care services

New MMWP projects 2005 (2)

- Eur. Global Oral Health Indicators Development II (CBO, NL)
  - objective: To develop (and promote the use of) the recommended common oral health indicators and tools for routine monitoring
- Eur. Collaboration on Dementia (ALZHEU, EU, Lux.)
  - objective: To evaluate the effectiveness of care for neurological and neuro-psychiatric disorders and to assist in the formulation of future policies in the field of dementia
- Eur. Core Indicators in Diabetes Mellitus (CIBIO, NL)
  - objective: To set up a database to collect best and worst practices on health status and care delivery for DM in the EU and future MS in order to promote the sharing of good DM health data and DM care organisation in the EU and internationally
- Eur. Autism Information System (The Hope Project, IRL)
  - objective: To improve the quality of life of children affected by ASD by setting up a surveillance system to improve data availability on ASD and by contributing to the accessibility of information about AS to appropriate treatment and care services

Working Party Meeting, December 2005 (1)

- Establishment Scientific Assistance Office
- New MMWP developments in Work Plan 2006
- Work programme: European Centres of Reference for rare diseases
- Development of a new system for routine collection of primary data
- Indicators women’s health
- Women’s specific causes of death (e.g. suicide, smoking related deaths)
- Exchange of best practices, promoting of patients and carers, and related training in countries (e.g. MS, Poland)
- Discussion: Report Major and Chronic Diseases in the EU 2006
- European Health Status Report 2007

Working Party Meeting, December 2005 (2)

- Discussion: relation projects-ECCHI list
- Disease and condition information sheets

European Health Survey System Framework
- Core modules: health status
  - self-assessment (disability)
- HIS technical group meeting September 2006: national, regional and health injuries and health; work and postal health care payments

Annex 3a Sixth meeting of the NCA/Fourth meeting of the NWPL

Luxembourg, February 7-8, 2006
Network of Working Party Leaders / Competent Authorities

Interim Report Dec.05-Nov.06
Annex 3a: Sixth meeting of the NCA/Fourth meeting of the NWPL

Working Party Meeting, December 2005 (3)

• Eurobarometer surveys
  - implemented 25 MS and candidate countries:
    - AIDS prevention, medical errors, tobacco consumption, mental well-being, health behaviour
  - Results:
  - Discussion Negative and Positive points

• Presentation Task Forces:
  - 2nd Meeting TF Major and Chronic Diseases: 12 December
    Enric Duran, Simona Giampaoli, TF Leader and Deputy
  - 3rd Meeting TF Rare Diseases: 14 December
    Ségolène Aymé, Helen Dolk, TF Leader and Deputy

Project progress related to:

EU Health Surveys Information Database (EUNSID):
- List national HIS performed 2004-2006 completed, incl. database
- EU-wide harmonization: Croatia, Cyprus, Norway, Poland
- next HES identified (e.g., Scot., Irl., Can.) will be included database in 2006
  - Preparatory work HES methodology questionnaire

Cancer Registry Based Project on Haematologic Malignancies (HAEMACARE):
- Start October 2005
- January 2006, 3rd meeting project partners, panel of experts and data analysis
- HAEMACARE is proposing to all European population based cancer registries the adoption of internationally agreed classification of haematologic malignancies
  - project website under development

European Cancer Health Indicator Project (EUROCHIP-2):
- Enlarged the network to all MS and candidate countries (30)
- Activated groups of experts in all countries
- Checked availability cancer health indicators
- National Groups in Eastern Europe found increased cervical cancer mortality trends: 2500-3000 avoidable deaths annually
  - projects proposes to re-activate cc screening programmes
- Is considering pilot studies (breast, colon cancer) to identify causes of big differences in survival rates in Europe (several countries have showed interest)
- Is considering to set up a large dietary intervention in Europe based on Mediterranean diet in the fight against the risk of cancer

Main Objectives 2006

• Start of activities SSO for a better exchange of information between projects
• Development of a dedicated MMWP/TFMCD Website
• Contribution of projects to the Report on ‘Major and Chronic diseases in the European Union 2006’
• Contribution of projects to the Report ‘European Health Status Report 2007’
• Propose a calendar of diseases action for future EU Presidencies
• Contribution to the health modules on the Eurobarometer 2006 and 2007
• Contribution to the health modules on the European Health Interview Survey
• Contribution to the EU Health Portal

(71x348) of the NCA, NWPL, MMWP, TFMCD, HSWP

Project progress related to:

European Cardiovascular Indicators Surveillance Set (EUROCISS):
- Inventory in 18 countries on data sources, data collection methods, available indicators
  - Summary tables: www.cuore.iss.it/eurociss/en/eurociss.htm
- Developing a Manual of Operations for implementation AMI/ACS and Stroke population-based registers and of CVD surveys
- In cooperation with EUROCHIP-2 action plan promoting healthy diet

Contact MMWP

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Interim Report Dec.05-Nov.06
SAO Presentation during joint NCA/NWPL meeting: HSWG Progress Report

EXECUTIVE SUMMARY

-Austria data model was chosen as a basis of the common data model for its excellence, transparency and relative simplicity and highest ability to provide information, despite of the need of a higher need of transformation of data from other countries.

-For each involved country, a data specification of a ‘hospital episode’ can be set up which can be translated into the data model running in the EU-25. Because the Austria model (CEEQNET) differs between health insurance companies and statistical authorities:

-These differences could be a potential source of significant decrease of precision of performance and quality measurement and need to be investigated carefully focusing on separation between acute and “other” procedures. The dimensions used in data collection are defined in detail in future, especially the core definition of appropriate quality and efficacy measurement (e.g. all procedures representing total hip replacement).

CEEQNET

• Developed a consensus based protocol on reviews which resulted in a European Review Protocol for health promotion (still under validation).
• Developed a 1st project coordination meeting in Vienna 2005
• 1st meeting to be held in February 2006
• HSWG deputy leader

SAO

• EU Public Health Outcome Research and Indicators Collection (EUPHORIC)

- Project progress related to:

EU Public Health Outcome Research and Indicators Collection (EUPHORIC)

- Completed fist phase of project: Survey development
- Produced a list of 66 outcome indicators in 9 pathologies/procedures categories: cardiovascular disease and surgery, cancer, infectious diseases, other chronic disease, orthopaedics, transplantations, emergency, neuro/traumatology
- Questionnaires to gather information about existing databases and registers on the selected self-identified procedures available in participating countries have been filled in by all the partners on the selected pathologies/procedures available in participating countries
- First results will be published Spring 2006

Health Care Conference, Vancouver, Canada (October 25-28, 2005)

• CEEQNET presented at 22nd ISQua International Society for Quality in Health Services and Medical Care in London, June 2005
• Setting up of a conference and expert group for values, data collection and the development of a framework for mapping exercise on patient safety, activities in most EU countries, available through project website
• Combined workshop on patient safety together with WHO Europe in Copenhagen, September 2005
• Activities for drafting the Work packages responsible for developing databases on 1. Indicators/outcomes for patient safety, 2. Instruments for external evaluation, 3. Instruments for patient safety for internal evaluation of health services

Interim Report Dec.05-Nov.06
**PREAMBLE**

Empowering the patient economically and information-wise promotes the shift from the passive role of patient to an active role of client (with a much wider possibility of choice) and eventually to a position in which he is able to influence the improvement of the quality of care. Both of these goals can be reached also with the help of data, information and knowledge management...

**HSWP (matrix approach)**

<table>
<thead>
<tr>
<th>Focus Area</th>
<th>High Level Focus</th>
<th>Specific Focus</th>
<th>Deliverables</th>
<th>Mandate</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1H</td>
<td>Focus Area 1</td>
<td>Specific Focus 1</td>
<td>Deliverable 1</td>
<td>Mandate 1</td>
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<tr>
<td>F1V</td>
<td>Focus Area 2</td>
<td>Specific Focus 2</td>
<td>Deliverable 2</td>
<td>Mandate 2</td>
</tr>
</tbody>
</table>

**OUTPUTS**

- time lag in Hungary, where initial Hungarian authorities get authorized for a contract amendment (initially through Mr. S. Zenner and later through Mr. van Welssenaers). Our latest request, delivered through Mr. M. Van Popper, has been considered as an amendment to the project agreement. As of February 2006 we still have no response and though the new Hungarian partner is already collaborating since July 2005, CEEQNET has no formal recognition for him, so we are unable to contract Hungarian hospitals in order to start working with their data.

**FURTHER STEPS:**

- Complete definitions of dimension objects (in English glossary).
- Identify significant measures obtained through data collection, participating hospitals, and key stakeholders.
- Deliver basic multilingual HSWP work methodology.
- Deliver results to all stakeholders, including further expert workshops.
- Integrate new dimensions: Operational efficiency, Secondary diagnosis, Complexity.

**URGENTLY NEEDS TO BE RESOLVED**

**Health SYSTEMS**

The health system of the European Union is more than the sum of the 25 Health Systems of the Member States.

<table>
<thead>
<tr>
<th>Area</th>
<th>Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>MANDATE</td>
<td>Objectives of eHealth Services for better health outcomes and economic effects</td>
</tr>
<tr>
<td>SCORE</td>
<td>Defining focus areas – Delphi / conferencing</td>
</tr>
<tr>
<td>PROFILES</td>
<td>Identifying cross-overs, interactions, strategies, networking</td>
</tr>
<tr>
<td>PROJECTS</td>
<td>Research, Development of eHealth strategy, EU eHealth projects, ENSP/WHO, TFOs, Networking, Professional, newsletter, Task forces on eHealth</td>
</tr>
</tbody>
</table>

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**Interim Report Dec.05-Nov.06**
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### HSWP (matrix approach)

<table>
<thead>
<tr>
<th>Task</th>
<th>Description</th>
<th>Status</th>
<th>Next Step</th>
</tr>
</thead>
<tbody>
<tr>
<td>Task 1</td>
<td>Description 1</td>
<td>In Progress</td>
<td>Next Step 1</td>
</tr>
<tr>
<td>Task 2</td>
<td>Description 2</td>
<td>Completed</td>
<td>Next Step 2</td>
</tr>
</tbody>
</table>

### HSWP progress report

**Thank you for your attention**

**Have a great day**

- Thanks to all WP leaders for their inputs and help
- Thanks to the Scientific Assistance Office
- Thanks to the SANCO Luxembourg Office
- Ciara - "welcome back on board"

Looking forward to more intense collaboration with the Network of Competent Authorities
**SAO Presentation during joint NCA/NWPL meeting:**

*Progress of activities at a national level: Summary Country Reports*

### National Progress Reports

**NCA 7-12 2005**

Walter Devillé, MD, PhD
Secretariat NCA/NWPL

**ISSUES**

- Major activities Health Information
- Major activities EU Public Health
- Mental health (see overview)
- Adult-onset diabetes (see overview)
- Women’s health (see overview)
- Important publications (see overview)

### Major activities Health Information & Public Health

- **France**
  - Efforts to build national expert group tasks WP on indicators
  - Contribution Subgroup Indicators within Social Protection Committee of DG JUMP, conference needed with EMCDDA
  - Participates in ENHIS (WHO/ECEH), ENHIS2 and EUHIS prevention programme “FIT FOR HEART AND BRAIN”
  - Continuous campaign on healthy lifestyle development, National Action Plan for accident prevention
  - Injury prevention priority for national health promotion

- **Bulgaria**
  - Investigation on existing hospital information systems
  - Development of strategy on e-health
  - National Discussion Forum on “Information and communication technologies in healthcare”

- **Finland**
  - The leadership in ECHIS project
  - Mental health issues: green book and indicator work

- **Greece**
  - The report concerning the indicators to follow the objectives fixed by the Public Health Policy Law is now available. This report describes in detail the indicators. We are at present collecting the data corresponding to these indicators.

- **Latvia**
  - Use of eMDDS software and training continues

- **Cyprus**
  - Important publications (see overview)

- **Malta**
  - Work on Injury Register’s (IDB) implementation is ongoing
  - Ending of the pilot project and information of participants and public about results of research and POP (persistent organic pollutants) in breast milk of mothers

- **Hungary**
  - Joint UNECE/Eurostat meeting on the measurement of health status (the Budapest Initiative)
  - Eurostat projects on the translation and pilot of the ECHIS European Health Status Module were completed
  - Tobacco
    - Nationwide organisation of “World No Tobacco Day”
    - Conference on the methodology of helping quit smoking
  - 5th National Health Information Forum - results of the National Health Interview Survey 2003, underway in Hungary, health and sustainable economic development, regional data, first feed-back on the use of regional health statistics
  - Joint UNECE/Eurostat meeting on the measurement of health status (the Budapest Initiative)
  - Eurostat projects on the translation and pilot of the ECHIS European Health Status Module were completed
  - Tobacco
    - Nationwide organisation of “World No Tobacco Day”
    - Conference on the methodology of helping quit smoking
  - 5th National Health Information Forum - results of the National Health Interview Survey 2003, underway in Hungary, health and sustainable economic development, regional data, first feed-back on the use of regional health statistics
  - Joint UNECE/Eurostat meeting on the measurement of health status (the Budapest Initiative)
  - Eurostat projects on the translation and pilot of the ECHIS European Health Status Module were completed
  - Tobacco
    - Nationwide organisation of “World No Tobacco Day”
    - Conference on the methodology of helping quit smoking

### Major activities EU Public Health

- **Latvia**
  - Bill “For Quality and Safety of Health Services, and the National Health Information System” founding of an independent National Health Information Institute
  - Networks for Mental Health and for Accidents & Injuries are now well established
  - Centre for the Control of Infectious Diseases and Prevention of Illness. It is hoped that this will enable the establishment of cancer and other registries
  - A major programme “Systelis” is underway which concerns the networking of all public services in the health sector with high speed connections for internet, networking and telephony

### Major activities Health Information

- **Austria**
  - European eHealth Consumer Trends Survey EU project
  - Building Casuality in Larger Europe

- **Bulgaria**
  - European eHealth Consumer Trends Survey EU project
  - Building Casuality in Larger Europe

- **Finland**
  - European eHealth Consumer Trends Survey EU project
  - Building Casuality in Larger Europe

- **France**
  - European eHealth Consumer Trends Survey EU project
  - Building Casuality in Larger Europe

- **Greece**
  - European eHealth Consumer Trends Survey EU project
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- **Latvia**
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- **Malta**
  - European eHealth Consumer Trends Survey EU project
  - Building Casuality in Larger Europe

- **Hungary**
  - European eHealth Consumer Trends Survey EU project
  - Building Casuality in Larger Europe
Major activities Health Information & Public Health

Lithuania
- Analysis of the data of health behaviour survey carried out in 2004 within the framework of the International Fisal Health Monitor.
- The health interview survey carried out in September - October 2005 for the first time in the framework of the National Statistical Programme.
- Lithuanian Health Programme started in 1998: the National-wide Consensus conference assessing the interim results.

Latvia
- The Challenge of the Gradient. The Norwegian Directorate for Health and Social Affairs' plan of action to reduce social inequalities in health will start in 2006 and to be based in the Ministry.
- The risk of introduction of highly pathogenic avian influenza to Norway: a joint risk assessment regarding the risk of the introduction of the HPAI virus to Norway.
- Tobacco: Focus on COPD in 2006.

Major activities Health Information & Public Health

UK
- Tackling Health Inequalities Summit
- Workshop on sumit on health inequalities: Platform and impact of health inequalities - what can the information tell us?
- Launch Scottish Public Health Observatory (ScotPHO) website
- Patient Safety Summit

Major activities Health Information & Public Health

Austria
- Mental Health Advisory Board MCH
- Vienna meeting MINDFUL
- Conference "Social Inclusion and fundamental rights in mental health" (March 2006) (consultation process Green Paper)

Mental Health

Latvia
- Mental Health Government Agency published its annual statistics yearbook "Mental Health and Learning Disability
- Public Health Report on Diabetes (published) and Overweight (published) (in press) (in German)

Austria
- informal meeting ministers for Equal Opportunities (01-06)
- new guidance Making it possible: Improving mental health and well-being in England

Lithuania
- Health Behaviour among Lithuanian Adult population, 2004
- Health Statistics of Lithuania, Health in the Baltic countries
- Public Health Report on Lithuanian

Belgium
- Mental Health Promotion Action Plan (Wales)
- Mental Health of Children and Adolescent Survey 2004
- The Centre for Public Mental Health (CPMH)
- Mental Health Information Project

Diabetes

Austria
- Conference Type 2 diabetes (February 2005) report basis for discussion Health Council
- Conference "Diabetes mellitus – a challenge for health policy"

Finland
- STAKES Diabetes in Finland (in Finnish)
- STAKES Diabetes in Finland (in German)

France
- Health report on the health of middle-aged women and men (in press) (in German)

Women’s Health

Austria
- informal meeting ministers for Equal Opportunities (01-06)
- female migrants, victims of traditionally-based violence
- priorities: cardio-vascular disorders, smoking/lung cancer, osteoporosis, endometriosis

Finland
- Health report on the health of middle-aged women and men (in press) (in German)

Germany
- Health report on Diabetes (published) and Obesity (published) (in German)

Lebanon
- Preparing of a symposium on "Women's health"

Malta

Slovenia
- Health Statistics Department of Health Statistics and Medical Technologies State Agency is working Register of Patients of Diabetes Mellitus.
### Annex 3a Sixth meeting of the NCA/Fourth meeting of the NWPL

#### Women's Health

<table>
<thead>
<tr>
<th>Country</th>
<th>Summary</th>
</tr>
</thead>
</table>
| Latvia  | - Participation in the EC project REPROSTAT  
- Participation in the EC project PERISTAT  
- Maternal and infant Health Care 2004  
- Participated of the EC three years project “Promotion of breastfeeding in Europe: Pilot Testing the Blueprint for Action” |
| Greece  | - Rapport 2004: Voices of Women in the Barents region  
- The Norwegian Mother and Child Cohort Study |
| Slovenia | - Analysis of maternal mortality in Slovenia, report |

#### Major Public Health publications

<table>
<thead>
<tr>
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</table>
- English updated summary of First Austrian Report on Men’s Health  
- Austrian Report on Drug situation 2005  
- First Austrian Diabetes report  
- Austrian Women’s Health Report 2005  
- Injury data base – basis for annual reports about Burden of Injuries |
| Bulgaria | - National Health Data Dictionary  
- The electronic data interchange - Methodology of financing of healthcare facilities in 2008  
- Optimization of the project “Health data record” |
| Cyprus  | - Health and Hospital Statistics 2004  
- Demographic Report 2004 |

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</table>
- Health Behavior among Estonian Adult Population, 2004  
- Health in Baltic Countries 2004 |
| France  | - Health status in France in 2003  
- Perceived Health, self-reported morbidity and health care utilization DREES Studies at Reutelèse  
- Tobacco addiction, alcohol abuse and overweight Jean-Louis  
- Are health and activity measures comparable in the European surveys? IRDES Questions d’économie de la santé  
- Bulletin épidémiologique hebdomadaire:  
- about musculoskeletal condition  
- deals with the surveillance and alert system |
| Germany | - Health reports on Physical Activity, Sleep Disorders, Demenence, Poverty and Health |
| Hungary | - Yearbook of Health Statistics 2004  
| Norway  | - Public Health Analysis in Latvia 2003  
- Data Presentation System’s new 2005 version (similar to HFA-DB) |
| UK  | - Cancer Atlas of UK and Ireland  
- Focus on Health  
- The first annual report of the new Welsh Health Survey  
- The health and social care information centre  
- London Health Observatory Ethnicity and Health report  
- Tackling health inequalities: Status report on the Programme for Action  
- Yearbook of Health Statistics 2004  
- Aging, Health Status And Determinants Of Health Expenditure (AHEAD), Health and Morbidity in the Accession Countries, Country Report – Hungary  
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- Aging, Health Status And Determinants Of Health Expenditure (AHEAD), Health and Morbidity in the Accession Countries, Country Report – Hungary |
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- Optimization of the project “Health data record” |
| Cyprus  | - Health and Hospital Statistics 2004  
- Demographic Report 2004 |

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Interim Report Dec.05-Nov.06
Confidentiality and person health data in the EU

Walter Devillé, MD, PhD
Secretariat NCA/NWPL

Legislation

- Within ESS: dealing with confidential data at national authorities level, 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

Problems from the field:

Data protection issues and national legislation:
- confusion caused by EU and national legislation related to protection of personal data
- national legislation often more strict: limit possibilities for linking health (care) data, health registries, medical research, prospective follow-up, ...
- do not guarantee good quality or valid data

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

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

Problems confronted in practice: ENCR(1)

- Increasingly problems:
  - 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

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

Network of Competent Authorities 07-2005

- Sweden: good example balance mandatory participation and strong data protection
- Issues:
  - registration data
  - guidelines coding and recoding, anonymisation
  - guidelines contacting patients
  - registration foreign nationals
  - sharing data between different authorities
  - supplying data to third countries
- ad hoc Work Group: CA of Finland, Sweden, Malta, France, Spain, Estland and the Secretariat

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Ad hoc NCA Workgroup on Confidentiality of person data

- meeting November 3 in Utrecht, NL
- Interpretation of Directive in relation with:
  - the processing of personal identifiable health data for public health information purposes / health statistics (Art. 1, 7, 8)
  - flow of data between MS
- check with Commission:
  - legal check of interpretation
  - existence of WP mentioned in Directive
- Development of feedback form for NCA concerning national implementation of the Directive and problems related to it per WP domain of interest

Article 1 Object of the Directive

Member States shall ensure that the processing of personal data is carried out in accordance with this Directive and that the fundamental rights and freedoms of natural persons, and in particular their right to privacy with respect to the processing of personal data, are protected.

Interpretation

The Work Group shares the opinion that article 1 contains the data protection philosophy of the Directive.

The Work Group means that as a consequence of this article MS cannot use fundamental rights and freedoms of individuals as an excuse to restrict or prohibit the free flow of personal data between MS.

The Work Group questions whether as a result of article 1 paragraph 2, it is mandatory for MS to have national data laws that facilitate the collection of person identifiable health data.

Article 7 Member States shall provide that personal data may be processed only if:

a) the data subject has unambiguously given his consent;

Interpretation

Keeping in mind that the Work Group considers health monitoring as a task performed in the public interest, the Work Group draws two conclusions from article 7 sub a:

- Processing of personal identifiable health data is not prohibited. The Work Group wonders what falls under “processing data” : collecting, keeping and using the data?
- Informed consent is not mandatory for the collection of personal identifiable health data if health monitoring is defined as in the public interest. This requires that necessary national legislation on collection of health data with identifiers exists.

Article 8 The processing of special categories of data

(1) Member States shall prohibit the processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, trade-union membership, and the processing of data concerning health or sex life.

(2) Paragraph 1 shall not apply where:

a) the data subject has given his explicit consent to the processing of those data, except where the laws of the Member State provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject’s giving his consent;

Interpretation

- The Work Group shares the opinion that as a result of article 8 paragraph 1 the Directive does not prohibit the processing of person identifiable health data, in fact, it allows it, but it cannot be concluded that the Directive recommends or prescribes it.
- Due to the referral of article 8 paragraph 3 to paragraph 1 without mentioning any informed consent requirements, the Work Group concludes that informed consent is not mandatory for the processing of person identifiable health data.
- The Work Group questions whether as a result of article 8 paragraph 3, it is mandatory for MS to have national data laws that facilitate the collection of person identifiable health data.
- The Work Group wonders if the processing of personal data for health statistics purposes is covered by Article 8, paragraph 3.

New literature:

1. Consent, confidentiality and the Data Protection Act
   Amy Iversen et al., BMJ, 21 January 2006, p. 165-169
2. Commentary: Evidence will help achieve consensus
   Peter Goldblatt, BMJ, 21 January 2006, p. 169
3. Personal data for public good: using health information in medical research
   Academy Medical Sciences (www.acmedsci.ac.uk) January 2006
Next steps:

1. Feedback from Data Protection Party
2. Collection information at national level: who?
Annex 3a Sixth meeting of the NCA/Fourth meeting of the NWPL
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