

**METHODOLOGIES FOR PRODUCING EU-WIDE COMPARABLE  
DISEASE-SPECIFIC MORBIDITY DATA: ENHANCEMENT OF THE  
ELECTRONIC INVENTORY OF DATA SOURCES**

**EUMIP (European Union Morbidity Inventory Project)**

**FINAL REPORT – S12.325004**

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## **1. Introduction**

### 1.1 Health Monitoring Programme

The Treaty of the European Union (Maastricht Treaty) of 1992 gave responsibilities regarding public health issues to the European Union, for the first time. Article 129 of the Treaty gave the EU the mandate of ‘encouraging co-operation between Member States (...) and, if necessary, lending support to their action’. The EU was also given the power to spend money on European level health projects. These responsibilities were further strengthened by the Amsterdam Treaty in 1997, article 152 of which states that ‘Community action (...) shall be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to human health’ (see Duncan, 2002).

To respond to these new responsibilities, the Commission established eight Public Health Programmes, which together would represent its Framework for Action in the Field of Public Health. The Health Monitoring Programme (HMP) 1997 – 2001, under which this project received funding, was one of these eight public health programmes. The main objective was to contribute to the establishment of a Community health monitoring system within the following three pillars: i) Establishment of Community health indicators, ii) Development of a Community-wide network for sharing health data and iii) Analyses and reporting. For further information on the HMP, see

[http://europa.eu.int/comm/health/ph\\_overview/previous\\_programme/Previous\\_programme\\_en.htm](http://europa.eu.int/comm/health/ph_overview/previous_programme/Previous_programme_en.htm)

### 1.2 Public Health Programme

A new Public Health Programme 2003-8, with three strands, replaced the HMPs. One of the objectives (Strand 1) is ‘to improve information and knowledge for the development of public health’. This includes ‘improving the system for the transfer and sharing of information and health data including public access’.

### 1.3 First ONS project: Development

In 2000-2001, an HMP-funded project entitled 'Methodologies for producing EU-wide comparable disease-specific morbidity data: Development of an electronic inventory of data sources' was carried out by researchers at the Office for National Statistics (ONS). The project's main aim was to start developing an electronic inventory (implemented in Microsoft Access) of disease-specific morbidity data sources in the 15 Member States (MS) and Norway. The establishment of the inventory was one of the recommendations which resulted from the report on 'Methods of collecting morbidity statistics' that Val Mason and Ann Bridgwood of ONS-UK prepared for Eurostat (Eurostat working document – Population and social conditions: 3/1998/N°9). The report was discussed and endorsed by the Eurostat Task Force (TF) HIS and the Eurostat Working Group on Public Health Statistics (WG PH).

The inventory developed contained information on the following diseases/conditions:

asthma	diabetes
cancer	epilepsy
congenital anomalies	hypertension
communicable diseases	musculo- skeletal disorders
coronary heart disease	mental health disorders
stroke	

and on the following sources and systems of health-related statistics:

births and deaths registration	disease registers
abortion registers	general practice data
hospital inpatients data	hospital outpatients data
surveys	

The final report of this earlier project can be found in English, French and German at [http://www.statistics.gov.uk/events/Eurostat\\_morbidity\\_seminar/papers.asp](http://www.statistics.gov.uk/events/Eurostat_morbidity_seminar/papers.asp).

### 1.4 Aims and objectives of second ONS project: Enhancement

This project took forward the work carried out during the first ONS project. The main aim was to enhance the electronic inventory by filling in gaps in information, checking the

accuracy of the stored information with the providers and developing a system to enable the inventory to be readily updated on a regular basis.

Further aims of the project were:

- to make changes to the database structure in order to increase user-friendliness and to ensure that the database became as widely available as possible.
- to link the three diseases-specific projects funded under the HMP 2000 Work Programme (second round): chronic obstructive pulmonary disease, diabetes and respiratory diseases.
- to enable the enhanced inventory to be used as a source of information to help in the monitoring of the incidence and prevalence of specific diseases for the EU's Action Programme on Health Monitoring in the Field of Public Health.

## **2. Methods**

### 2.1 Collaboration with other HMP projects

The project was carried out in the Health and Care Division of the Office for National Statistics, UK. The project team consisted of Sue Davies (SD project co-ordinator), Katerina Ananiadou (KA project officer), Susan Westlake (SW project officer) and David Dix (project support). They were assisted in their work by a steering group of experts from eight different member states, via one project meeting, HMP meetings and emails.

Eurostat WG PH and TF HIS have also closely followed the progress of the two ONS projects on the inventory.

The first ONS project used mainly questionnaires in order to collect the information needed to populate the inventory. In our project, we tried to minimise the use of questionnaires, but aimed instead at collecting information by alternative means, mainly through collaboration with experts involved in other HMP projects or other experts in relevant diseases and/or data sources in the 15 MS and Norway. This was decided primarily in order to avoid duplication of effort within the HMP, but also in order to reduce as much as possible the number of questionnaires sent out to experts by members of different projects requesting similar information.

Under the second pillar of the Health Monitoring Programme ‘Development of a Community-wide network for sharing health data’, and because the ONS project spanned several sources and diseases, ONS collaborated closely with the following HMP-funded projects (whose areas overlapped with EUMIP) in order to fill in gaps in information and check the accuracy of the stored information with the providers (co-ordinator’s name and country in brackets):

- Hospital Data Project  
(Hugh Magee, Ireland)
- Establishment of indicators monitoring diabetes mellitus and its morbidity  
(Carine de Beaufort, Luxembourg)
- Cardiovascular Indicators Surveillance Set in Europe - EUROCISS  
(Simona Giampaoli, Italy)
- Health information for primary care  
(François Schellevis, the Netherlands)
- Health surveys in the EU: HIS and HIS/HES evaluations and models  
(Jean Tafforeau, Belgium)
- Rapport sur l’ état de la santé mentale de la Communauté  
(Vivianne Kovess, France)
- Pain and functional limitation (originally: Indicators for monitoring musculoskeletal conditions)  
(Dag Bruusgaard, Norway)
- Indicators for monitoring chronic obstructive pulmonary disease (COPD) and asthma in the EU
- Sentinel Practice networks
- Child Health Indicators of Life and Development (CHILD) and Indicators for Monitoring and Evaluating Perinatal Health in Europe (Peristat)

Since our inventory also contains a section on communicable diseases, the ‘Inventory on Communicable Disease Control in the EU’ contained useful information, though not a HMP project.

## 2.2 Project steering group

Full details of the steering group members are in Appendix 1.

Members of the steering group participated in a meeting in March 2002 that took place in London. A copy of the minutes of this meeting is attached in Appendix 2. The discussion in the meeting focused on progress that had been made until that point, as well as several more specific issues regarding the content and structure of the inventory. At the meeting:

- It was suggested that the inventory should have a name, to be included on some of the pages. ONS later decided to name the project ‘European Union Morbidity Inventory Project’ - EUMIP.
- ONS (KA) presented a revised questionnaire and further changes were made (Appendix 3). It was agreed that enough metadata should be provided to enable a user to decide on the quality of the source. Some information on specific indicators such as incidence or prevalence, and whether data could be stratified by socio-economic status is available. The questionnaires were later sent to experts in different countries, using appropriate HMP contacts, to fill in gaps. Each contact in EUMIP was emailed a web link and instructions for checking their entries, and all replies received were incorporated.
- It was agreed that the ONS project would probably not be able to deliver a complete matrix by the time of its deadline, but that ongoing collaboration with colleagues from the ECHI project was possible and welcome thereafter.

The discussion and recommendations from the meeting were incorporated in the following ways:

### *Hospital Data Project*

The HDP inventory has enabled the addition of some missing information and identification of minor discrepancies. The EUMIP label for hospital admission or discharge data was changed to ‘hospital inpatients’. Information where provided, on linkage of hospital episode data and the disciplines covered by hospital data systems is given.

### *Sentinel Practice Networks*

As SPN differ greatly in size and aims and are not useful for disease prevalence, it was difficult to decide the criteria for inclusion. EUMIP aims to provide information to enable the user to decide if the source is relevant for their purpose.

### *HIS/HES*

Initially, it was decided that EUMIP would provide brief details of each relevant disease-specific survey, where known, and refer users to the HIS/HES website <https://www.iph.fgov.be/hishes/> for further information. Lead Hat Ltd. was contracted for further work to adapt the information held accordingly. After further discussion between ONS and Jean Tafforeau, it was decided that it was better not to give any information but to refer users to the HIS/HES website via a link, so as not to duplicate future maintenance needs, and the EUMIP site was changed again accordingly. However, the HIS/HES database contains only the most recent surveys.

### *Mental Health Indicators*

The main source of mental health data is surveys. The conditions to be included in EUMIP were agreed as depression, anxiety, dementia and Alzheimer's. Depression and anxiety can be estimated through health interview surveys, but dementia and Alzheimer's disease need specific health surveys because of the nature of the disease. However, the relevant working group at the Eurostat Morbidity Seminar recommended that the priority data sources for dementia be primary, psychiatric and residential care use. The mental health indicators project kindly provided EUMIP with brief survey metadata, as originally intended for all surveys, but this was not input because of the HIS/HES decision, above.

### *EUROCISS*

EUMIP has two categories – coronary heart disease (to include acute myocardial infarction, ischaemic heart disease and heart failure) and strokes. This fits with categories used in EUROCISS and ECHI.

### *Musculoskeletal disease*

Data availability is difficult, but it was hoped that asking for data sources for musculoskeletal disease would yield spontaneous information about specific conditions. The relevant working group at the Eurostat Morbidity Seminar recommended that priority data sources be: surveys (if good case definition) for back pain; primary care use for osteoarthritis; hospital care use for rheumatoid arthritis; use of drugs and laboratories and care of fractures for osteoporosis.



### *Respiratory disease*

It was agreed that if, as in France, good data were available from nationally representative surveys on a sub-group of the population (e.g. children), they should be included in EUMIP.

### *Diabetes*

Some contacts were used by ONS.

### *CHILD/PERISTAT*

It was decided not to retain information on pregnancy terminations, as they are not a disease. It is important to include congenital anomalies beyond the perinatal period.

### *Communicable diseases*

It was agreed that minimum information would be given, referring users to the specialised inventory via a link. As the specialised inventory at [hsscd.euphin.org](http://hsscd.euphin.org) is not yet ready, the most up-to-date information is given.

### *International Data Sources*

It was felt to be a good idea to include such sources, but there are a great number. A few of them have been included so far, and it is recommended that this section be enlarged in the next phase of the project.

## 2.3 Information Technology

External consultants, Lead Hat Ltd. (<http://www.leadhat.co.uk>), were employed to turn the Microsoft Access® database into an interactive web inventory - the 'European Union Morbidity Inventory Project' (EUMIP) - to make changes to the database structure in order to increase user-friendliness and to ensure that the database became as widely available as possible. A number of meetings were held at ONS between August and October 2003 to develop the inventory, by migrating from Microsoft Access® to a database on a SQL server, with Coldfusion® used as the interface, as requested by the EC. The layout and functions of each page were made as user-friendly as possible. The migration will allow users to have direct access to the most up-to-date version of the inventory. No specific software is needed by users, only an Internet browser.

EUMIP can be updated with new sources and conditions, and amendments to existing ones, via Eumip's administration pages. The majority of updates to EUMIP were made after it was web enabled. This allowed ONS to test the administrative system. Any errors and other

glitches encountered by ONS were reported to Lead Hat and rectified, often following further discussion.

A meeting was held between Sanco (Tapani Piha, Ole Henrikson), their technical representatives from the European Union Public Health Information Network (EUPHIN) and Getronics, and ONS (SW) at the HMP Co-ordinators meeting in Luxembourg in March 2003. The migration from Lead Hat as the site host (<http://ons.leadhat.co.uk/>) to the EU Health Portal was discussed, together with the maintenance of the site. Recommendations were fed back to Lead Hat, for example the administrative section to be password protected to enable remote access, and a delete function to be activated. Technical information, and assistance regarding migration and maintenance of the site, were provided by Lead Hat to Sanco's technical representatives.

A videoconference was held between ONS, Lead Hat, the EC and Getronics on 23.5.03, to further discuss the migration. Lead Hat agreed to provide further technical documentation. ONS asked when the site was likely to go live, as it had been advertised (in presentations given in January and March to European colleagues) as happening around June 2003. Euphin could not host EUMIP, so the Inventory will reside on the EC's Europa website. It will therefore be necessary for the existing Microsoft SQL Server database to be converted to an Oracle database. It was very difficult for Getronics to predict how long this work would take - the best estimate was that it would take about six months. Up to now there had been nothing dynamic on Europa, which usually had static pages. Getronics were at the beginning of working on the EUMIP project.

Close collaboration between IT consultants and the EUMIP administrator is needed. The period between the end of the project in June 2003, and the expected beginning of a maintenance contract in January 2004, is uncertain in terms of hosting of the site, and clerical and IT maintenance of the site. EUMIP is to be used by the EC to test the Public Health Portal as a host.

### **3. Results**

#### 3.1 Achievement of aims

The electronic inventory was enhanced by filling in gaps in information, checking the accuracy of the stored information with the providers and developing a system to enable the inventory to be readily updated on a regular basis.

Changes to the database structure were made in order to increase user-friendliness and to facilitate wide use of the database. The inventory was web-enabled.

The aim to link the three diseases-specific projects funded under the HMP 2000 Work Programme (second round) was furthered. However, little of the information received from the diabetes and cardiovascular diseases projects was useful for EUMIP. Data sources for respiratory diseases other than asthma were not discovered. Attempts were made to contact the HMP project on "Indicators for monitoring COPD and asthma in the EU", but no information was received.

Where provided, information is given to enable the enhanced inventory to be used as a source of information to help in the monitoring of the incidence and prevalence of specific diseases for the EU's Action Programme on Health Monitoring in the Field of Public Health.

#### 3.2 Database structure

##### 3.2.1 The introduction page

The introduction page was designed to take account of recommendations made in discussion with partners. It lists the background and function of the inventory:

## **Welcome to the European Union Morbidity Inventory Project (EUMIP), an inventory of disease-specific morbidity data sources.**

The inventory contains information on data sources for 11 different categories of morbidity for all 15 EU Member States and Norway. If you are aware of any other relevant sources please let us know, either by sending **feedback** or **contacting** us.

This inventory was developed as part of two projects carried out at the **Office for National Statistics** in London, UK:

- *Methodologies for producing EU-wide comparable disease-specific morbidity data: Development of an electronic inventory of data sources (2000-01)*  
This project collected information for the inventory, mainly via questionnaires, and developed the inventory in MS Access.
- *Methodologies for producing EU-wide comparable disease-specific morbidity data: Enhancement of the electronic inventory of data sources (2001-02)*  
This project collaborated further with experts in relevant diseases and/or data sources, and experts in other Health Monitoring Programme (HMP) projects, to expand the inventory. The inventory was also developed into a website.

Both projects received financial support from the Health Monitoring Programme of the European Commission, Directorate-General Health and Consumer Protection. For further details of the HMP go to

**[http://europa.eu.int/comm/health/ph/programmes/monitor/index\\_en.htm](http://europa.eu.int/comm/health/ph/programmes/monitor/index_en.htm)**

The co-ordinator of the HMP projects was Sue Davies (ONS), assisted by Petra Lehmann, Eileen Watson, Dr. Azeem Majeed, Katerina Ananiadou and Susan Westlake. European partners in the projects were Dr Marleen de Smedt, Jean Tafforeau, Henrik Thoning, Niels Rasmussen, Dr. med. Mikko T. Nenonen , Dr Gérard Badeyan, Dr Thomas Ziese, Dr Susanna Conti, Peter Achterberg, Victor Garcia, José António André Giria, and Bengt Haglund.

**The 11 categories of morbidity** in this database are: Asthma, Cancer, Communicable diseases (including Hepatitis, HIV/AIDS, STDs and Tuberculosis), Congenital anomalies, Coronary Heart disease, Diabetes, Epilepsy, Hypertension, Mental Health disorders, Musculo-skeletal disorders and Stroke.

**The 8 types of morbidity data sources** included are: Disease Registers, Epidemiological Studies, General Practice, Health Publications, Hospital Inpatients, Hospital Outpatients, International Sources and Surveys.

There are **three different ways to search** - please use the **SEARCH** menu on the left to choose your method. International sources can ONLY be accessed through the Sources search.

### 3.2.2 Menu Bar and Searches

To the left of page is a menu bar:

**EUMIP** Introduction, Reports,  
**Search Map**, Sources, Conditions,  
**About Us** Contacts, Feedback, Privacy

The site can be searched in three ways – by country, source or condition. Instructions are provided on-screen. Searching by *source*, a table shows the availability of each source in each MS.

The information can also be accessed via a map.

By clicking on a *country*, e.g. Italy, the following is displayed:

### **Italy**

Please click on the link(s) below to view data

Data are collected for the following conditions in Italy

- Asthma
- Cancer
- Communicable diseases
- Congenital anomalies
- Coronary Heart disease
- Diabetes
- Epilepsy
- Hepatitis
- HIV/AIDs
- Hypertension
- Mental Health disorders
- Musculo-skeletal disorders
- Sexually Transmitted diseases
- Stroke
- Tuberculosis

Data are collected from the following sources in Italy

- Disease Registers
- Epidemiological Studies
- General Practice

Hospital Inpatients  
Hospital Outpatients  
Organisations (Births and deaths  
registration information is given under  
results for organisations in EUMIP)  
Surveys

The other alternative searching method is via *condition*. For example, here is one of the results for cancer in the UK:

## **SOURCE: DISEASE REGISTERS**

### **CONDITION: CANCER**

#### **ICD Codes**

ICD9 140-239, ICD10 C00-C97,D00-D48

#### **A. Data collected on this condition or group of conditions**

Yes

#### **B. Compulsory notification of this condition or group of conditions**

No

#### **C. Proportion of cases with this condition or group of conditions reported**

Cancer is not a notifiable disease; coverage is very high, but not 100%.

#### **D. Availability of national data for this condition or type of conditions. If available, type of data collection procedure used to collect this national data**

There are national and regional cancer data available. Regional cancer registries collate data on cancer patients from a wide range of sources and those in England and Wales send a subset of the data to agreed standards to ONS (see I below).

#### **E. If there are no national data available for this condition or type of conditions, do regional data allow the calculation of national estimates**

N/A

#### **F. Coding system used to code this condition or type of conditions, e.g. ICD9, ICD10, READ codes, etc.**

1971-78 ICD8; 1979-94 ICD9; 1995 onwards ICD10.

#### **G. Frequency of data collection**

Continuous.

#### **H. Accessibility of the data**

Cancer data available through the regional cancer registries and the National Cancer Intelligence Centre at the Office for National Statistics, London.

Data on consultations of general practitioners are available from the General Practice Research Database, Medicines and Healthcare Products Regulatory Agency, and through other agencies. They are available in computerised format. Studies must be approved by the GPRD Scientific and Ethical Advisory Group. There is a data charge payable.

### **I. Specification of the way the data are collected**

Data are collected continuously via 12 independent regional registers (9 registers in England, 1 in Wales, 1 in Scotland and 1 in Northern Ireland). Those in England and Wales submit a standard data set to the Office for National Statistics. They collect data on a voluntary basis on data on cancer incidence in residents of their region.

The registries cover the whole population. Hospitals and other sources supply the 12 independent registries with data on cancer patients. All registrations are entered on the National Health Service Central Register.

### **J. Any important publications regarding the collection of data for this condition or group of conditions**

Cancer 1971-1997 CD-ROM. Office for National Statistics.

The following publications are available on the National Statistics website at

<http://www.statistics.gov.uk>:

Cancer Survival Trends in England and Wales, 1971-1995: deprivation and NHS Region. The Stationery Office.

Cancer Statistics - Registrations of Cancer Diagnosed in 1999, England. National Statistics.

Cancer Trends in England and Wales 1990-1999. The Stationery Office.

### **K. Website address if available**

<http://www.statistics.gov.uk>

<http://www.velindre-tr.wales.nhs.uk>

<http://www.show.scot.nhs.uk/isd/cancer/cancer/htm>

<http://www.qub.ac.uk/nicr/intro.htm>

### **L. Future changes**

Unknown

### **M. Other morbidity data sources**

Unknown

### **For further information**

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<http://www.gprd.com>

<http://www.statistics.gov.uk>

### 3.2.3 Administration pages

Administration pages are only available to the administrator. They contain:

- Registrations – date registered, name, job title, organisation, work sector, country;
- Visitors – total number, number per date, date visited, percentage per date;
- Page View – total number of pages viewed, number per date, percentage per date,
- Section Views – total number of pages viewed in each section, pages viewed in each section as a percentage of total pages viewed;
- Metatags – these allow search engines to easily index EUMIP using specific keywords, with a description of the site;
- Feedback - Dates, email addresses of senders, and messages left;
- Add/Edit Sources/Conditions - all the sources and conditions are listed by country and may be edited or deleted, and new ones may be added;
- Add/Edit Contacts – contacts are listed in three ways (country, condition, source) to increase ease of use, and may be edited or deleted, and new contacts may be added.

Details of the EUMIP contact/administrator will be added, when the administration has been decided by the EC, before the site goes live. Users are invited to register for access to the final reports for both ONS projects, so that the administrator can determine the level of interest. Users are invited to comment on the website, and these comments may be used to improve the site. The add/edit pages also provide the option to delete entries.

#### **4. Discussion and recommendations**

##### 4.1 Challenges faced

1. Developing the Access database into a web product took longer, and was more complicated, than expected. This meant that less time was available for filling gaps and updating.

2. When collecting information for updates, some emails bounced back as people had moved jobs and many had no reply or needed reminders. This required further investigation and resolution, to prevent potential user frustration. ONS colleagues kindly translated information from other languages, for instance information on websites used in our investigations. Despite these efforts, some gaps or potential inaccuracies remain.



3. It was established that most of the information in the Access database concerning 'diseases' (among the sources category) referred to 'disease registers'. ONS and Lead Hat re-categorised the information as appropriate.

4. ONS spent much time on collecting and inputting brief details about surveys but these were replaced by a link to the HIS/HES database (see 2.2). As a result, Lead Hat Ltd. twice carried out extra work to redesign and link the survey section.

#### 4.2 Main recommendations

We recommend that:

- Money is set aside from the budget for the new EU Public Health Programme to keep EUMIP up to date. Also that responsibility for maintenance of the site be given to an appropriate working party in DG Sanco, as it will be hosted on the EC website, and that links with ECHI 2 (another HMP project) be maintained.

*Resources and commitment for updating are needed from the EC and MS. It is vital that this is provided as otherwise over time the investment in all original HMP projects is eroded and in due course will be considered wasted as inventories etc. become out of date.*

- There is free access to the site via the Internet, hosted by the EC.
- EUMIP be kept up to date by
  - (i) acting on, and verifying with an MS official, email feedback containing updates of information stored in EUMIP, such as contact details. Critical feedback may also be used to further develop and improve EUMIP.
  - (ii) carrying out an annual update via a central contact point in each MS. We suggest that this central contact be given the names of all the contacts in EUMIP for their MS, and be asked to check with them each year whether there have been any changes to the information stored in the inventory which need to be fed back to the EC.

- (iii) continuing to use the results of other projects to fill gaps in information, e.g. on asthma.
  
- A larger map be included to incorporate the applicant and EFTA-EEA countries. The necessary program links also need to be made, including an ‘add country’ facility in the administrative program. A future contract could also cover the collection and inclusion of information on disease-specific morbidity data sources from the new countries - Hungary and Iceland have already provided some information.
  
- Brief metadata for older surveys and mental health surveys that are not included in the HIS/HES database be included in EUMIP.
  
- Improvements be made to the website and its architecture. In testing and updating the website, ONS and Lead Hat realised that many improvements were needed in order to make the website perform more appropriately and be more user-friendly. The web-enabled version of the inventory has developed a long way, but the range of queries being asked of the inventory has reached the limits of the original inventory design. Examples of improvements needed are:
  - (i) Restructuring of the site, to incorporate improvements e.g. the facility to link diseases to organisations, epidemiological studies and health publications needs to be provided, and contact details more appropriately linked.
  - (ii) It would be useful to have a ‘date of update’ in each entry, so that users would know how current the information is.
  - (iii) A means of archiving feedback that has been dealt with by the administrator.
  - (iv) Criteria of relevance for health publications need to be decided.
  - (v) A variety of text accents such as é and ö have rarely been used but are available, so should be made use of in future.
  - (vi) A few spelling errors need to be corrected.

#### 4.3 Recommendations from the Eurostat Morbidity Seminar held in London in January 2003

Tapani Piha stated that EUMIP should be made available on the web as soon as possible. Questions from the floor were asked about the updating, and completion of gaps in, various inventories and databases. Sanco will now invest more time and money in the co-ordination of, and interaction with, projects.

It was pointed out that it was very difficult to rely on any one source for morbidity data, and therefore the key was the provision of a summarised picture. On the other hand, given that this was supposed to be the beginning of a development phase, it was also stated that it was important not solely to concentrate on data availability problems and consequently to rule out some data sources, but rather to look at how data sources and analysis might be improved over a period of time to make better use of systems which were already in place.

The matrix approach developed in ECHI 2 is needed for sources, showing a disease entity (groups of diseases) by possible source, with a separate matrix for each country. The sources appropriate for each disease need to be prioritised, but priorities will depend on the health system in place in each MS. Other variations by MS may be more transitory e.g. factors affecting current availability, such as funding of registers.

## **5. Dissemination**

ONS (KA) gave a presentation in March 2002 of work carried out so far, and identified a number of potentially useful HMP funded projects. The main output from this project is the EUMIP online inventory. Both this report and the report from Phase 1 will be available from EUMIP online.

A presentation of the beta version of EUMIP was made by Susan Westlake at the Eurostat Morbidity Seminar in London in January 2003, and at the HMP co-ordinators meeting in Luxembourg in March 2003. EUMIP will be housed in the EU Public Health Portal, with public access.

It is recommended that EUMIP continue to be disseminated at relevant conferences, journals etc.

## 6. References

Duncan, Ben (2002). Health policy in the European Union: how it's made and how to influence it. *British Medical Journal*, 324, 1027-1030.

## 7. Appendices

### Appendix 1

HMP steering group members:

Peter Achterberg, RIVM, The Netherlands

Katerina Ananiadou, ONS, UK (succeeded by Susan Westlake, ONS, UK)

Gérard Badeyan, HCSP, France

Sue Davies, ONS, UK

José Giria, Ministry of Health, Portugal

Bengt Haglund, Centre for Epidemiology, Sweden

Thomas Ziese, Robert-Koch Institut, Germany

Niels Rasmussen, National Institute of Public Health, Denmark

Jean Tafforeau, Scientific Institute of Public Health, Belgium

Henriette Chamouillet, European Commission – DG SANCO

Marleen De Smedt, European Commission - ESTAT

### Appendix 2

#### **Minutes of Partners' meeting Office for National Statistics, London 18 & 19 March 2002**

#### *Present:*

Peter Achterberg, RIVM, The Netherlands

Katerina Ananiadou, ONS, UK

Gérard Badeyan, HCSP, France

Sue Davies, ONS, UK

José Giria, Ministry of Health, Portugal

Bengt Haglund, Centre for Epidemiology, Sweden

Thomas Ziese, Robert-Koch Institut, Germany

#### *Apologies:*

Niels Rasmussen, National Institute of Public Health, Denmark

Jean Tafforeau, Scientific Institute of Public Health, Belgium

Henriette Chamouillet, European Commission – DG SANCO

Marleen De Smedt, European Commission - ESTAT

## Overview of aims of the project

SD welcomed all participants and started the meeting with a brief overview of the aims of the project (see slides). The project officially started on 1 November 2001 and will end on 31 October 2002, with the final report being due by 1 February 2003.

KA then began a presentation of the work that has been carried out so far. This has mainly focused on establishing links with other HMP projects (disease- and source-specific ones), as well as work on revising the questionnaire used in the first phase of the project and the structure of the inventory. Liaising with other HMP projects is considered important, in order to avoid duplication of effort, and also for validation purposes. KA then talked about each of the projects identified as (potentially) useful to the ONS one, inviting the participants to discuss issues as they came up during the presentation rather than at the end.

## **Links with other HMP projects**

### Hospital Data Project

The first project to be discussed was the Hospital Data Project (HDP) of which JG is a partner. The inventory produced by HDP has enabled the addition of some missing information, and identification and resolution of some minor discrepancies. An interesting finding was that most countries report that their basic unit of analysis for hospital data is discharges rather than admissions; however, it is the latter that is used to label the source in the ONS project. Participants agreed that this should be changed to reflect the fact that most hospital data are based on discharges. Also, this is the source from which the correct diagnosis will be obtained. Other points discussed were: including information on linkage of hospital episode data and including information on whether all disciplines are covered by the hospital data systems. In France, for example, psychiatric hospitals are not covered.

### Sentinel Practice Networks

In this context, the issue of primary care data in general was raised. This topic was discussed rather extensively, since it was generally agreed that primary care data is a difficult area, since countries differ a lot between each other on their primary care system. One of the points discussed was whether we should include sentinel networks in our inventory. PA explained that sentinel networks differ a lot in terms of size, aims, etc between themselves, and it may be hard to define a criterion on which ones we would like to include. TZ added that sentinel networks also tend to change their focus regularly (eg a network may concentrate one year on influenza, another year on hypertension). They can be used as an early warning system, but are not good for disease prevalence. ONS should speak to François Schellevis and/or Douglas Fleming about how the definitions of sentinel networks fit into the purpose of the morbidity inventory. One option may be to restrict our coverage to those networks which might give comparable national/regional data.

### HIS/HES

This project has produced a detailed inventory of health surveys in the EU. The main point for discussion was how much of this information we would like to include in our inventory in

terms of which surveys to include, but also how much detail to include on each survey. There was agreement that we wouldn't want to replicate work carried out by another project. PA suggested that we only include disease-specific surveys, as this is the scope of our project. It was suggested that we establish from the list of questions included in the HIS/HES database which ones can provide data for specific diseases and then focus on these surveys only. It was agreed that we then only provide minimal, high level information (e.g. timeliness, sample size) about each survey, referring the user to the HIS/HES inventory instead for further details, through a link.

### Mental Health Indicators

KA said that this project did not seem very useful to us, since it mainly developed a list of indicators in the area of mental health and provided very little information on sources. GB mentioned that a new mental health project has now started and that it would be useful to make contact with them. PA said that the main source for mental health data is surveys and that sometimes a mental health (eg anxiety) instrument may be used in a more general health survey. He also raised the issue of which diseases exactly we would like to include under the label mental health, and whether we need to include the neurological ones as well (eg Parkinson's, epilepsy). This led to a discussion on which specific diseases to be included; TZ mentioned that there is disagreement even among experts about definitions of some diseases. PA suggested that we include the ones in the ECHI list. These are depression, anxiety, dementia/Alzheimer's.

### EUROCISS

The discussion centred on the question of which diseases to include in the inventory; EUROCISS includes heart failure, in addition to the diseases of the ONS inventory. Heart failure is also on the ECHI list. It was felt that if heart failure was included we would not find any new data sources as they would be the same as for IHD. It was suggested that we split CVDs into two categories, one covering AMI, IHD, heart failure and one for strokes. This fits more or less with the current situation in the inventory. One of the sources that EUROCISS investigated was Longitudinal Studies. This matches more or less the Epidemiological Studies source of the ONS inventory.

### Musculoskeletal diseases

Projects with which KA and SD had not liaised that much – for different reasons – were discussed next, starting with the musculo-skeletal project. The interim report of this project had just become available on the CIRCA website but prior to that no links had been made. Given the fact that this is considered a difficult area in terms of data availability, it was agreed that we should ask for information for musculo-skeletal diseases and not for specific conditions (e.g. arthritis). PA mentioned that experts will probably then provide information on specific diseases spontaneously, where it is available.

### Respiratory diseases

A new HMP project on respiratory diseases has just started and it will collect information on asthma and COPD data sources; a potential difficulty could be timing, since the new project has only just started. It was agreed to make further contact with the co-ordinator of the project (Enric Duran) in order to find out whether they will be collecting the information we are interested in and to obtain names of contacts in the other member states. It was felt that there were relatively large amounts of epidemiological research available in this area, hence

comparative studies would be available as a data source, if not national data. It was agreed that if, as in France, good data were available from nationally representative surveys on a sub-group of the population (e.g. children), these surveys should be included in the inventory.

### Diabetes

The diabetes project is currently collecting information on data sources for various diabetes indicators. SD and KA have already liaised with Carine de Beaufort and she will be sending information soon.

### CHILD/PERISTAT

Finally, the CHILD and PERISTAT projects were discussed, because of their possible overlap with the ONS project in the areas of congenital anomalies and pregnancy terminations. KA and SD asked the partners' advice on whether to retain information on pregnancy terminations, since the inventory's content is defined as disease-specific morbidity sources. The general consensus was not to include abortions; however, given that the information on abortions is already there, we would first wish to find out whether another project (possibly PERISTAT) aims to collect information on this area. Pieter Kramers (ECHI project) would be advised that someone needs to cover abortions. It was thought important to include congenital anomalies beyond the perinatal period.

### **Communicable diseases**

The next issue discussed concerned communicable diseases, as an inventory of communicable diseases has been developed with EU funding and is currently available on the HSSCD website (a part of EUPHIN). Jean Tafforeau, in his comments to the documents circulated before the meeting, had suggested that we do not include communicable diseases at all, in view of the above inventory, but just provide a link to the relevant website. It was agreed that a minimum of information should be provided, referring the user to the specialised inventory for more information, via a link. ONS would check with the Commission when the HSSCD was last updated.

### **International data sources**

KA then asked the partners views on including information on international (in addition to national) data sources, such as IARC on cancer data or EUROCAT on congenital anomalies. It was thought that it was a good idea to include such sources; however, a potential difficulty is that there may be too many such sources for the inventory to include, as there is a large number of international networks collecting data on specific diseases. It was suggested that ONS talk to Arun Nanda about WHO sources.

### **Questionnaire**

SD and KA presented the partners with a revised version of the questionnaire that they had been working on and pointed out the changes they had made, using the General Practice section as an example. BH remarked that the very first question of each section could be changed from 'Does your country collect X data' to 'Is X data being collected in your country'; this will then not imply that the only data sources we are interested in are official ones. There are many smaller institutes or organisations that can provide data on specific diseases; the difficulty is setting a criterion on which ones we would like to include. PA

suggested that very small or very old studies are not included, but it was generally agreed that enough meta-data should be provided in the inventory for the users to be able to decide on the quality of the source. GB suggested that background summary information on the health system of each country should also be included. Other partners were of the view however that this may too difficult a task, and may also be replicating information to be included in a relevant HMP project. KA mentioned that there is some background information on morbidity data providers (including for example National Statistical Institutes, Public Health Institutes, etc), births and deaths data in the relevant section of the inventory. It was also suggested that a question on the suitability of a source for providing information on specific indicators (incidence, prevalence) and whether data could be stratified by socio-economic status be included in the revised questionnaire. Since most of the gaps in the inventory were for specific diseases it was suggested that ONS contact the appropriate HMP projects to obtain good contacts. Questionnaires sent to ministries tended to 'fall into a hole'.

### **Inventory structure**

The front page menu was considered to contain too many 'buttons'; it was suggested that only two buttons be included, one for sources and one for diseases. It was also agreed that an additional front page should be produced, with some explanatory notes on the inventory, what information it includes and does not include and how to navigate. KA pointed out that, at the moment, the information under 'diseases' only refers to disease registers. This would be changed by adding disease registers to the list of data sources. SD and KA were of the view that most of the information should be accessed from the sources menu, as the inventory is meant to be one of data sources. A disease menu could then contain only summary information on the different sources available in different countries for each disease, with a link to the relevant part of the sources section. Contact details should be linked to the sources. A printout of the information contained in the inventory would be sent back to the expert who provided the information for checking. ONS would send a preliminary revised structure to the partners for comments. It was suggested that the inventory should have a name which could be included on some of the pages.

### **Links with ECHI project**

SD gave a short presentation on the ECHI-2 project and how it relates to the ONS one (see slides). The issue of a matrix of diseases vs data sources was discussed. It was agreed that the ONS project would probably not be able to deliver a complete matrix by the time of its deadline, but that ongoing collaboration with colleagues from the ECHI project after the deadline is possible and welcome. Input would be needed from other disease/source-specific projects.

### **Dissemination**

SD went through an earlier presentation of Tapani Piha's, responsible for the EUPHIN system of the European Commission (see slides). The issue of hosting the database within EUPHIN-HIEMS was discussed; it was thought that at this stage there is not enough information available on the technical aspects of this process; one option was that it be hosted at the ONS website, to which the EU site could have a link. This relates to the issue of the regular update of the inventory, which was an underlying theme throughout the meeting. For all projects, huge commitment and resources are needed. Recommendations to the



Commission on how updates can be effectively carried out will be included in the final report.

### **Next steps**

Finally, SD went through the proposed programme of work for the next seven months (see slides). Future work would also include the suggestions raised by partners during this meeting. SD noted that only one partners' meeting had been budgeted for in the project. Therefore most future liaison with the partners would take place via e-mail.

SD also informed the participants that the EUROSTAT morbidity seminar has been postponed until after the summer.

Katerina Ananiadou & Sue Davies  
ONS  
3 April 2000

### **Appendix 3**

Example of a revised questionnaire:

## **METHODOLOGIES FOR PRODUCING EU-WIDE COMPARABLE DISEASE-SPECIFIC MORBIDITY DATA: ENHANCEMENT OF THE ELECTRONIC INVENTORY OF DATA SOURCES**

### **QUESTIONNAIRE**

#### **In case of any queries, please contact:**

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**Email: [sue.westlake@ons.gov.uk](mailto:sue.westlake@ons.gov.uk)**

**Many thanks for completing this section:**

**Date:** \_\_\_\_\_

**Name:** \_\_\_\_\_

**Title** \_\_\_\_\_

**Institution:** \_\_\_\_\_

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1. Information about *General Practice data* in the UK comes from various sources. There are the General Practice Research Database (GPRD), the Weekly Returns Service, and the Morbidity Statistics from General Practice. GPRD is a database of anonymised medical records of over 2 million patients in over 280 GP practices in England and Wales. It represents around 4% of the population and contains information on treatment patterns and prescribing patterns. The Weekly Returns Service contains 85 practices. The main focus is on the numbers of people reporting illness. A mean weekly incidence rate for each disease and in each age group is used to derive an annual rate. The registered population of the practices is representative of the national population. The Morbidity Statistics are statistics from General Practice from surveys of morbidity in GP practices. GPs in 60 practices who were caring for a population of nearly half a million people throughout England and Wales took part in the study. It contains information on the reasons for which people consult in general practice. Also noted were the diagnosis for each encounter.

1a. Are General Practice data collected in your country?

Yes  No

→ If yes, please go to Question 1b → If no, please go to Question 2

1b. Are the collection of General Practice data compulsory?

Yes  No

→ If yes, please go to Question 1c → If no, please go to Question 1c

1c. Are the General Practice data collected nationally, or only for one or more regions?

National  Regional

→ If yes, please go to Question 1e → If no, please go to Question 1d

1d. If the data are collected for only one or more regions, is it possible to use the regional data to calculate national estimates of General Practice data?

Yes  No

→ If yes, please go to Question 1e → If no, please go to Question 1e

1e. What proportion of General Practices contribute data towards your system (if possible, please give as percentage and absolute number)?

1f. What is the size of the population coverage?

**1g.** How often does your country collect General Practice data?

**1h.** Do the General Practice data include information on the following diseases:

- |   |         |        |
|---|---------|--------|
| - Diabetes                                      | Yes [ ] | No [ ] |
| - Coronary Heart Disease                        | Yes [ ] | No [ ] |
| - Hypertension                                  | Yes [ ] | No [ ] |
| - Stroke  | Yes [ ] | No [ ] |
| - Asthma  | Yes [ ] | No [ ] |
| - Muskulo-Skeletal Disorders<br>(eg Arthritis)  | Yes [ ] | No [ ] |
| - Mental health<br>(eg Depression and Dementia) | Yes [ ] | No [ ] |
| - Epilepsy                                      | Yes [ ] | No [ ] |
| - Cancer  | Yes [ ] | No [ ] |
| - Communicable diseases                         | Yes [ ] | No [ ] |
| - Congenital anomalies                          | Yes [ ] | No [ ] |
| - COPD  | Yes [ ] | No [ ] |
| - Heart failure                                 | Yes [ ] | No [ ] |

**1i.** What is the accessibility of the data, i.e. how do people get the data in terms of

- contact points or organisations
- charges / costs
- availability of computerised data
- availability via the Internet
- any restrictions or special criteria for access

**1j.** Please specify the way General Practice data are collected in your country including information on:

- the size of the population under surveillance in respect to the national population
- which age-groups are included
- method of data collection,
- method of data analysis and dissemination (including frequency and timeliness)
- data validation procedures and overall quality
- the disease classification system used (eg READ, ICD)

**1k.** Are there any routine publications in your country based on General Practice data?

**Yes**  **No**

→ If yes, please go to Question 1l      → If no, please go to Question 1m

**1l.** If yes, which diseases do these publications focus on?

**1m.** Please list any other important publications regarding General Practice data or the collection of General Practice data in your country.

*If possible, we would be very grateful if you could send us a copy of any relevant publication.*

**2.** Are there any major changes planned in your country regarding the collection of data from General Practice?



Please append any reports, publications, papers, or any other reports you feel may be of use to us. Please also let us know the names and contact details of any of your colleagues, or people working in other institutions, who may be able to help us with our study.

THANK YOU VERY MUCH FOR YOUR HELP WITH THIS QUESTIONNAIRE!

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