EUROPEAN SITUATION OF THE ROUTINE MEDICAL DATA COLLECTION AND THEIR UTILISATION FOR HEALTH MONITORING

EURO-MED-DATA

Final Report

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EXECUTIVE SUMMARY

The Euro-Med-Data (EMD) project was conceived to take part in the collective effort organised on the European Union level in order to establish community health indicators, to develop a community-wide network for health data sharing and to analyse and report on this data.

Its objectives were defined as follows:

- ✓ to inventory the medico-administrative data, routinely collected in 18 European countries at the primary and secondary health care level, as well as at the occupational medicine level (PHC, SHC, OM);
- ✓ to examine this data in terms of data collection process, type of codification, reliability, mobility, mode of concentration, possibility of further analysis and/or reports, type of interpretative framework;
- ✓ to examine the possibilities of transferring this data to a European server and that will handle the problems such as format, language, transfer process, and agreement on designating the person in charge of the data on a local level;
- ✓ to form proposals for feedback of the analysis to the local health care actors;
- ✓ to examine the possibilities for the analysis of the data in order to perform an epidemiological follow-up of public health indicators and health monitoring;

There are indeed, at the present time, very few operational European databases in the field of Public Health allowing one to use epidemiological health indicators in order to:

- ✓ monitor the state of health of European populations;
- ✓ evaluate public health needs;
- ✓ assess the use of health care services;
- ✓ and, more broadly, to analyse and fully exploit what is generally meant by Health Monitoring.

However, every day, in every European country, medical and administrative data is routinely collected for management or therapeutic purposes, or simply as private memory files. The use of this data for public health management as well as for conducting epidemiological studies is often very far from satisfactory. Furthermore, the lack of feedback to the people who deliver health services generates frustration and promotes a lack of collaboration.

The project therefore takes its place in the framework of the hereto accepted 30 other projects. It seems that the EMD project, part of the category of projects linked to a specific collection system, is not redundant but rather complementary in relation to the other project categories, and even to the other ones of the same category.

The specificity of Euro-Med-Data lies in the focus on routinely collected data. As we may distinguish different kinds of morbidity indicators (objective, perceived, expressed, diagnosed,…), it is important to notice their conceptual interrelations, and to clearly assess their respective complementary positions in the HIS. Regarding diagnosed morbidity, it is possible to obtain the data from health providers: the data can be based either on probabilistic samples of practices (the sentinel practices network is one example), or on a continuous basis in an integrated routine system. This latter will be the domain to be investigated by the EMD project in three different settings : primary care, secondary care and occupational health.

1. PRIMARY HEALTH CARE

General practitioners and family physicians form what is commonly called the primary care level.

In several northern European countries, as well as in Italy, Portugal, and Spain, this level plays the role of gatekeeper of the health system. The patient is not authorised to consult a specialised care level (secondary or tertiary care) if he/she has not first consulted a general practitioner with whom he or she generally has a record.

This ‘gate’ system is not present in Belgium, France, Germany, Luxemburg, and Greece. It is therefore difficult to obtain a common denominator to set an epidemiological rate.

The first step of the research has concentrated on the identification of partners throughout the different countries, i.e. medical doctors and other professionals involved in the elaboration and organisation of continuous registration systems for general practice in medicine.

The question of availability of morbidity indicators through these data collections is at the heart of the problem tackled by this analysis.

What are the existing databases in Europe? How are they organised? Can the information gathered by these various bases be aggregated and continuously serve as a source of information on the population’s demands for health care as much as on the answers from the health services?

Despite certain reservations, the Internet survey form (see chapter II) allowed us to gather essential information on twelve databases.

This form was greatly based on work achieved by Dr Job Metsemakers in Holland. In chapter II, one will find a summary of the information obtained, while the entirety of the information collected is available in Access (*.mdb), Excel (*.xls), and text format (*.txt) in the software aid annexed to this report.

The various terminologies and classifications were the subject of a study published on the site and featured in the software and annexed to this report.

After having explored the various databases in a qualitative and quantitative manner, and outlined the content (chapter III), it seemed constructive to give an overview of the different terminologies and classifications currently available in Europe and in use in the EMR’s or other computerised health systems (see chapter IV).

The second step consists in trying to collect data from each participating country to create an international database. This step is quite difficult to address. Although the participants at the first meeting in Brussels have been very enthusiastic, only two have made proposal to exchange information. To build a database in such conditions has no meaning and the research has been continued by editing information already published on the net.

Common grounds on methodology of data retrieval and classification tools are lacking in Primary Care and particularly in General practice at the EU level. Moreover only some private or semi-public organisations are collecting data on continuous basis in primary care. The most important ones are mainly for commercial purposes. Some Member States are producing data trough their own department of public health or through university settings in United Kingdom, France, Suede and The Netherlands. However registration tools are quite different. There is no common standard in the classification field. Some systems are using proprietary classification, other use ICD or Read codes and some are using ICPC in its first version. Sharing morbidity data at the PHC level is consequently not feasible although some data are already published and accessible through web sites.

(do refer to http://www.ulb.ac.be/esp/emd/database_links.htm and http://www.ulb.ac.be/esp/emd/sharing.htm)

The main conclusion is that, even if data gathering in PHC on the basis of the day to day work is in process here and there in Europe in General practice, the utilisation of this data for building up health monitoring indicators at the level of EU is not to be considered yet at the time being.

Before this option could be considered, effort has to be made to disseminate standardised and compatible health information collecting systems based on international classifications. The group "Data quality in Primary care " driven by various European researchers is now taking the relay of the EMD study.

This study concludes by setting up five recommendations on :

- ✓ the development of an Open Source approach for what concerns the electronic medical files software development;
- ✓ to favour the management of individual data in computerised medical files as community health data;
- ✓ to favour implementation of standardisation process in electronic medical record in Europe in order to enhance the quality of data collection
- ✓ promoting European development in the realm of terminologies and classifications;
- ✓ to support the new research group on “Data quality in Primary care”.

2. SECONDARY HEALTH CARE

The secondary health care sector is characterised in Europe by a certain homogeneity for what concerns the medical data collected routinely in the hospitals; this is due to the fact that the national classification systems for hospital data are based on the ICD (International Classification of Diseases), and the consequent proposals resulting initially from Fetter’s works in the USA.

The hospital medical data are collected at the request of the Ministries of Health with epidemiological and/or financial purposes (financing of the hospitals) in all the European countries except Germany where these data are not centralised, but are sent to the sickness-benefit fund of each patient with the aim of financing the care for each patient, and subsequently covering the costs of the hospitals.

To achieve the goals of this study, the methodology used consisted in identifying partners in each country, in preparing a questionnaire concerning the characteristics and the contents of each medical data file, and in making a test of feasibility for the creation of a European database by the aggregation of samples coming from each country.

At the end of this study, we can affirm that the objectives are mainly achieved, with regard to the sector of the secondary care.

Indeed, for all the participating countries (except Liechtenstein), we were able to collect information on the hospital medical data recorded routinely in each country. This information (meta-information) is gathered in summary charts (one by country).

The test of feasibility of the creation and the exploitation of a European database, realised for 11 participating countries, has very encouraging results because it proves the feasibility of the creation of this European database with the help of the installation of various procedures on the one hand, and the definition of certain terms or variables on the other hand. The exploitation of such database currently allows the construction of 37 health indicators covering the following fields :

- ✓ indicators of morbidity,
- ✓ use of the care of health,
- ✓ surgical operations and procedures
- ✓ and quality and performance of the health care.

The conclusions of this test lead quite naturally to proposals on short, average and long term. These should constitute the basis for the continuation of the work in this field of the secondary care, or hospital care.

The short-term proposals take again the coordination of the various projects currently in hand or to come concerning these problems, the methods and the creation of the European data base as well as the creation of a conversion chart for the classifications of pathologies and procedures.

The medium-term proposals relate to the extension of the content of the database in order to increase the number of indicators which result from it, and to the procedures for enlarging this database to include the candidate countries.

Lastly, the long-term proposals concentrate mainly on the evaluation of the possibilities of connection and linking between the primary care database and that of secondary care.

3. OCCUPATIONAL HEALTH

The routine collection of data at work presents certain special features related to the actual context of health in the workplace, namely:

1. The existence of a **proper legislation**;
2. The **division** of labour and, consequently, of health risks;
3. Medical practice at work has a **preventive** mission, sometimes a **therapeutic** mission in the case of health disorders related to the specific exposure and to occupational diseases. It also plays a **rehabilitative** role in cases of accidents at work and occupational diseases;
4. On the European and national level, the organisations centred on the field of health at work are mainly **tripartite structures**: government representatives, employers, and workers.

During the first phase of the EMD study, the characteristics cited above were identified and their influence on the feasibility of a continuous collection of data was underlined.

The second phase focused on: a) the study of European directives relating to the health and security of workers; b) their sectoral application in Member States; and c) the feasibility of their application on the European level.

Globally, the conclusion was that a great number of routine data are available at the local level, but it is currently impossible to use them on a regional, national, and a fortiori an international level given the harmonisation problems.

Except for data on accidents at work and occupational diseases, the examination of these routine databases demonstrates the impossibility of using these databases as comparable international reference databases in the elaboration of a European morbidity data bank. They are too different from each other and their objectives are usually incompatible with the aims of this study.

Finally, a careful analysis was performed on the various indicators for the sector proposed by the ECHI project (Kramers et al., 2001). They were extensively reviewed during the second meeting, on December 5th 2001. This did allow us to formulate recommendations in order to pursue the reflections on indicators of health at work.

- ✓ Short term: some recommendations are made on the possible improvement of the list of indicators, specially for health determinants.
- ✓ Medium term: they concern a better standardisation of data collection, the implementation of additional legislative tools to increase the convergence between countries; a reflection has also to be conducted on the respective advantages of routine and survey data in this field.
- ✓ At longer term, there would be a substantial interest in setting up the statistical tools allowing a linking and a comparison of data on the worker’s characterisation within the firm, on the one hand, and the data on mortality (cause by cause) along with the data related to accidents at work and occupational on the other hand.

"Information gathering requires knowledge of the current organisation of data collection, storage and distribution in Members States, and expertise in data collection and information technology. It also requires an understanding of the core subject matter i.e. health, its determinants and consequences, and health system."

Aromaa Arpo, Health Surveillance,

in: Priorities for Public Health Action in the European Union,
Weil O, McKee M, Brodin M, Oberlé D (eds), march 1999

In summary, it could be said that information in the health field is basically affected by two categories of problems: (1) the insufficient use of available data for planning, implementation, service management, monitoring and evaluation; and (2) the inadequate quality, completeness and timeliness of data produced through the routine health recording and reporting mechanisms.

Selecting and defining national health indicators
Drs Stephen A. Sapirie and Stanislaw Orzeszyna

Strengthening Country Health Information Unit
Division of Epidemiological Surveillance and
Health Situation and Trend Assessment,
World Health Organization, Geneva, September 1995

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1. INTRODUCTION

In recent years, Europe has begun taking the public health dimension of its population more into account.

“Although health issues have been featured in the treaties since the beginning of the construction of Europe, it is only since the ratification of the Maastricht Treaty that that the Community has been able to implement a true public health strategy: five specific action programmes (cancer, AIDS, drug dependence, health promotion and health monitoring) have been adopted and three more have been proposed (rare diseases, injuries, pollution-related diseases) alongside other initiatives (reports on the state of health in the European Community, recommendations on the safety of blood products, etc.). In addition, a number of other Community policies have an impact on health”[1].

In this spirit, the Commission has oriented the future community public health policy towards three strands of action:

- ✓ “**improving information for the development of public health**: based on the activities and outputs of the health monitoring programme, a structured comprehensive Community system should be developed for collecting, analysing and disseminating information on general trends in the population’s health status, health determinants, and on its developments concerning health systems;
- ✓ **rapidly reacting to health threats**: this involves creating a Community monitoring, early warning, and rapid reaction mechanisms to meet the health threats that might arise at any given time (the proposal to create a European monitoring and control network for transmissible diseases already contributes to this objective);
- ✓ tackle the decisive health factors through **promoting health and disease prevention**: this third aspect would comprise, both targeted actions aimed at reinforcing people’s capacity to improve their health including their social, economic and environmental conditions as well as the many activities linked to prevention (vaccination, screening, etc.).”[2]

“**The Community action program on health monitoring** proposed by the Commission in 1995 was finally adopted by the Parliament and the Council of Ministers on June 30th, 1997 (Decision 97/1400/EC). With an allocated budget of 13.8 MECU for the period of 1997-2001, this programme aims at building up a sound community health information system and infrastructure for policy analysis as well as a health monitoring system which makes it possible to:

a) measure health status, trends, and deciding factors throughout the Community;

b) facilitate the planning, monitoring, and evaluation of Community programmes and actions;

c) provide member states with appropriate health information in order to establish comparisons and support national health policies.

by encouraging co-operation between member states and, if necessary, by supporting their action through promoting the co-ordination of their policies and programmes in this field and by encouraging co-operation with non-member countries and competent international organizations.[3]

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[1] http://europa.eu.int/scadplus/leg/fr/cha/c11560.htm

[2] ibid

[3] http://europa.eu.int/scadplus/leg/en/cha/c11702b.htm
http://europa.eu.int/scadplus/leg/fr/cha/c11560.htm

The relevant official documents provide the necessary information on the strands of action that the Commission seeks to develop. These strands involve the establishment of health indicators, data collection, particularly the data needed to ultimately arrive at comparable health indicators, the establishment of a network for the transmission and sharing of health data and indicators, and the development of a capacity to analyse and disseminate health information.

“ESTABLISHMENT OF COMMUNITY HEALTH INDICATORS

Objective: to establish comparable Community health indicators by means of a critical review of the existing health data and indicators, by developing methods for obtaining comparable health data and indicators. Furthermore, its objective is to develop appropriate methods for the collection of the progressively comparable health data required to establish these indicators.

DEVELOPMENT OF A COMMUNITY-WIDE NETWORK FOR HEALTH DATA SHARING

Objective: to facilitate the creation of an efficient and reliable system for transferring and sharing health data and indicators using the telematic exchange of data as a principal means of communication.

ANALYSING AND REPORTING

Objective: to develop the methods and tools necessary for analyses and reports on health status, trends, determinants, and the effect of policies on health as well as developing the tools to support these findings.”[4]

1.1 THE EURO-MED-DATA PROJECT

The Euro-Med-Data (EMD) project was conceived to take part in this collective effort organised on the European Union level. Its objectives were defined as follows:

- ✓ to inventory the medico-administrative data, routinely collected in 18 European countries at the primary and secondary health care level, as well as at the occupational medicine level (PHC, SHC, OM);
- ✓ to examine this data in terms of data collection process, type of codification, reliability, mobility, mode of concentration, possibility of further analysis and/or reports, type of interpretative framework;
- ✓ to examine the possibilities of transferring this data to a European server and that will handle the problems such as format, language, transfer process, and agreement on designating the person in charge of the data on a local level;
- ✓ to form proposals for feedback of the analysis to the local health care actors;
- ✓ to examine the possibilities for the analysis of the data in order to perform an epidemiological follow-up of public health indicators and health monitoring.

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[4] http://europa.eu.int:eur-lex/en/lif/dat/1997/en 397D1400.html

There are indeed, at the present time, very few operational European databases in the field of Public Health allowing one to use epidemiological health indicators in order to:

- ✓ monitor the state of health of European populations;
- ✓ evaluate public health needs;
- ✓ assess the use of health care services;
- ✓ and, more broadly, to analyse and fully exploit what is generally meant by Health Monitoring.

However, every day, in every European country, medical and administrative data is collected for management or therapeutic purposes, or simply as private memory files. The use of this data for public health management as well as for conducting epidemiological studies is often very far from satisfactory. Furthermore, the lack of feedback to the people who deliver health services generates frustration and promotes a lack of collaboration.

In addition, many of the health service providers underline the interest of a European database which would allow for the exploitation of the various files recorded locally and for European comparisons, while also ensuring feedback at different levels: national, regional, and local.

1.2 ORIGINALITY OF THE EURO-MED-DATA STUDY AND COMPLEMENTARITY WITH THE OTHER PROJECTS OF THE HEALTH MONITORING COMMUNITY ACTION PLAN

This project is part of the second series of projects accepted within the framework of the Community health-monitoring programme.

The first series included the following projects:

1. A comparative analysis of *alcohol* consumption and its public health effects in the EU states (Sweden).
2. *Health surveys*: contents and data (Netherlands, Finland)
3. Proposal for a coherent set of health indicators covering most of the dimensions of health.
4. Comparability and quality improvement in European *causes of death* statistics (France).
5. Health Monitoring in *sentinel practice* networks (UK).
6. Monitoring *socio-economic differences* in health indicators in the European Union (Netherlands, Germany).
7. Eucomp – Towards comparable *health care data* in the European Union (Ireland).
8. Integrated approach to establishing *community health indicators* (ECHI) (Netherlands).
9. Establishment of indicators for *mental health* monitoring in Europe (Finland).
10. The state of health in the European Community in the year 2000 (Portugal).

One may classify these projects along these lines:

- ✓ projects linked to a general reflection on the organisation of a health information system: #8;
- ✓ projects linked to one (or more) specific indicator(s): #1, #3, #4, #6, #7, #9;
- ✓ projects linked to a specific collection system: #2 (health surveys), #5 (sentinel practices network);
- ✓ projects aimed at presenting available results: #10.

The second series of projects started immediately after the first. The following are some example of the second series of projects:

11. European food availability databank based on household budget surveys (Dafne III) (Greece).
12. Health indicators in European regions (France).
13. Methodologies for producing EU-wide comparable disease-specific morbidity data (UK).
14. Highlights of health in the applicant countries of the European Union.
15. Rasch conversion of disability data to community indicators: a pilot study (Netherlands).
16. European health risk monitoring (Finland).
17. European situation of the collection of routine medical data (Euro-Med-Data) and its use for health monitoring (Belgium).
18. European physical activity surveillance system (EUPASS) (Germany).
19. European collaboration for the assessment of health interventions (Sweden).
20. European food consumption survey method (Netherlands).

According to the same classification system, one can group the projects as follows:

- ✓ projects linked to a general reflection on the organisation of a health information system;
- ✓ projects linked to one (or more) specific indicator(s): #13, #15, #16, #18, and #19;
- ✓ projects linked to a specific collection system: #11 (household budget surveys), #12 (regional systems), #17 (EMD), #20 (food consumption surveys);
- ✓ projects aimed at presenting available results: #14.

Since then, a third series of projects has been launched:

21. Health surveys in the EU: HIS and HIS/HES evaluation and models (Phase 2) (Finland).
22. Evaluation of national and regional health reports (Germany).
23. Indicators for monitoring and evaluating perinatal health in Europe (France).
24. Human resources in European health systems (Germany).
25. Hospital data (Ireland).
26. Cardiovascular indicators surveillance set in Europe (EUROCISS) (Italy).
27. Indicators for monitoring musculoskeletal conditions (Norway).
28. Establishment of indicators for Diabetes mellitus (Luxembourg).
29. Monitoring public health nutrition in Europe (Sweden).
30. Establishing a coherent set of health indicators for the EU (Euro-REVES 2, phase 2) (France).
31. Child health indicators of life and development (CHILD) (UK).

According to the classification system used above, these last projects are grouped into three categories:

- ✓ projects linked to a general reflection on the organisation of a health information system;
- ✓ projects linked to one (or more) specific indicator(s): #23, #24, #26, #27, #28, #29, #30, #31;
- ✓ projects linked with a specific collection system: #21 (health surveys – phase 2), #25 (hospital data)
- ✓ projects aimed at presenting available results: #22.

Based on the previous analysis, it appears that project #8 (ECHI: Integrated approach to establishing *community health indicators*) holds a very specific position because it aims at organising a conceptual framework to establish a list of the health indicators that the EU should integrate in its Health Information System. The reflection around the current study's results will therefore be based on this team's present achievements.

It also seems that the EMD project, part of the category of projects linked to a specific collection system, is not redundant but rather complementary in relation to the other project categories. This is even the case when compared to the other projects in the same category with the exception of project #25 (Hospital Data). The latter presented unclear objectives for our research team until recently, when they produced their interim report in October 2001. Despite many attempts to communicate and exchange with the team, we were still waiting for answers from them when writing this report. These difficulties led us to fear that we might be doubling our workload, wasting time and effort. Consequently, the European program might lack credibility when contacting the persons in charge of hospital data management in the various member states.

- #5: Health Monitoring in *sentinel practice* networks; this project strongly resembles one of the EMD project's components, i.e. primary health care, as it is founded on the use of general practice networks in order to collect the data pertaining to the first line services or front line services. There are, however, two main differences: project #5 has a partial coverage of the practices and probabilistic methods for its selection, it also only selects a limited number of health problems that can be covered by any annual programme.

- #13: Methodologies for producing EU-wide comparable *disease specific morbidity* data; this project is very close to EMD due to the type of indicators investigated, i.e. morbidity indicators. The distinction lies in the fact that project #13 broadly covers the field of the various sources of information (even including mortality data) rather than being restricted to the routine data such as we strictly defined them in the context of the EMD project[5].

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[5] Cfr. Infra. Chap. 2. definition of the routine data concept.

2 ROUTINE DATA IN THE HEALTH INFORMATION SYSTEMS

In the introduction, we underlined the interest manifested by the European Commission in "improving the information aimed at promoting public health" at the EU level. This can be achieved through establishing a Community health monitoring system "to allow the measurement of a health status, of trends, the evaluation of the Community's other programmes and actions, and to provide member states with information to support their own policies." The programme is likely to support reviews of existing data, the development of data collection, comparison, analysis, and transfer methods.

One can present the HIS structures in different schematic ways depending on the point of view. In any case, it is crucial to create the link between collected data and the objectives assigned to its collection.

According to a classic approach such as in fig 2.1., the central core of the system encompasses the "health status indicators". Around the core, one finds the indicators related to the determinants among which health systems and health services have a special place. This diagram is organised through a conceptual approach, taking the nature of the indicators into account. This approach could also be used to classify the various Community projects on health monitoring.

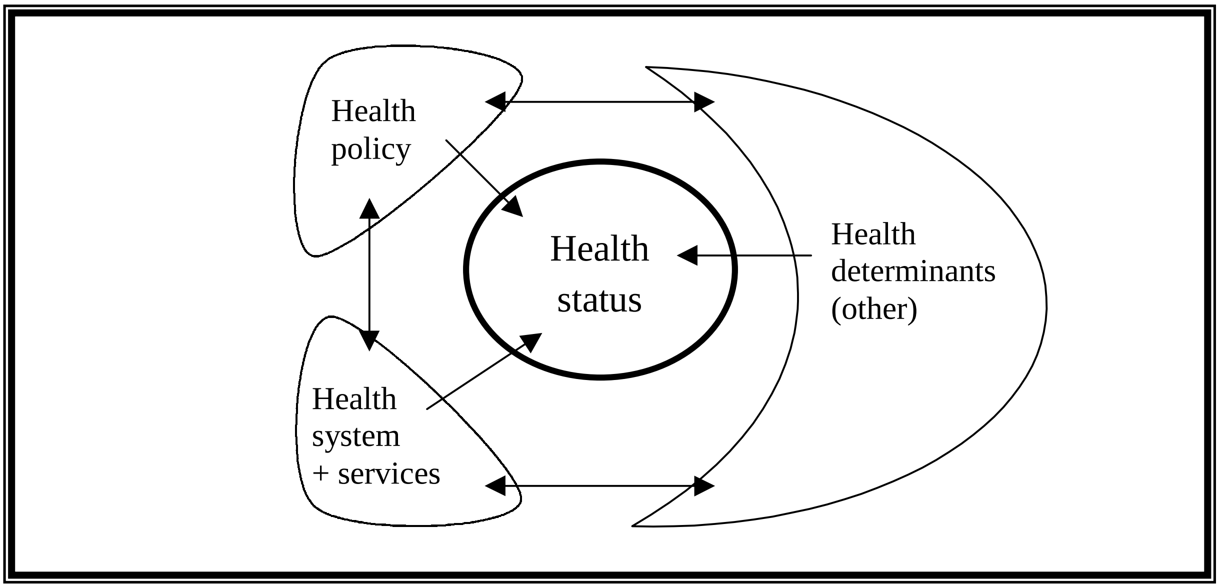

Figure 2.1. Diagram of the HIS and the various health indicators according to their kind

Belonging to the "core", the health status indicators classically comprise mortality, morbidity and, more recently, positive health indicators.

At least two EU projects are dealing with mortality indicators, i.e. project #3 (Proposal for a coherent set of health indicators covering most of the dimensions of health) and project #4 (Comparability and quality improvement in European *causes of death* statistics). Evidently, the collection system for this mortality data is a routine system. The collected data is exhaustive, covers the entire population as well as all lethal phenomena facing the population. According to its clearly defined objectives, the Euro-Med-Data project is not concerned with mortality.

In terms of morbidity data, the problem is considerably more complex. The first and main difficulty is a conceptual one: what morbidity are we dealing with? Various authors (Chen et Bryant, 1975, Lévy et al., 1975, Goldberg et al., 1979) have insisted on the fact that the evaluation of morbidity by practising doctors is only one aspect of morbidity. If one wants to have a general overview of morbidity, one must design a more complex model, such as fig 2.2., modified from Goldberg (1979).

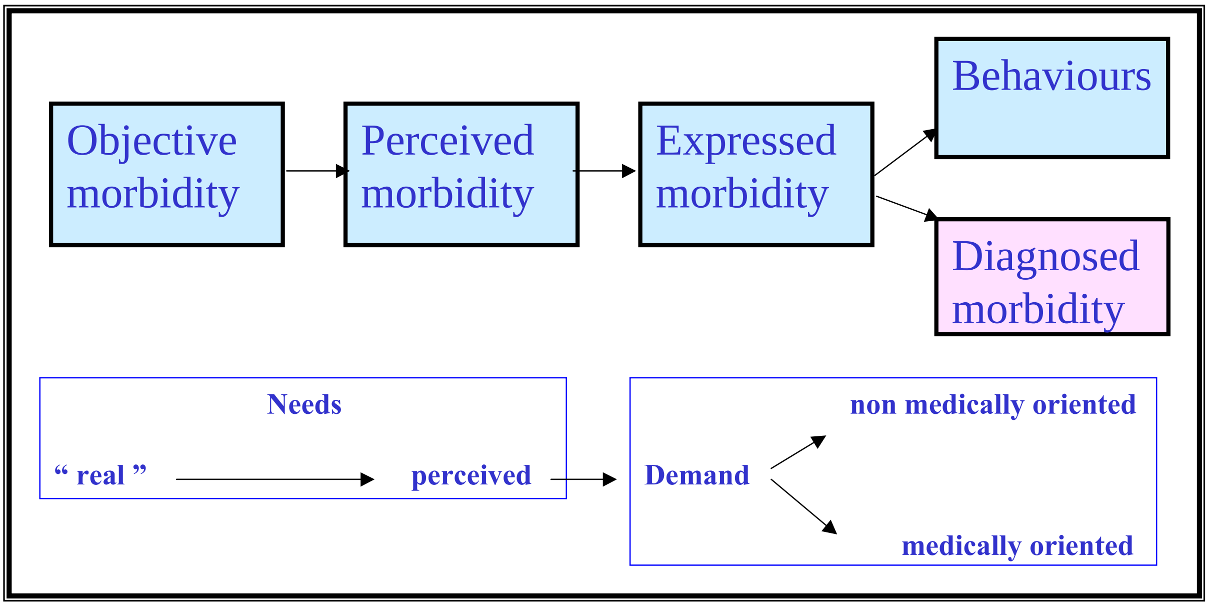

Figure 2.2. Conceptual diagram of the various dimensions of morbidity

The various dimensions of morbidity are linked with different and complementary uses: objective morbidity reflects what one would consider as the "real" health needs, that is to say those that are completely independent from the subjective point of view of both the patient and the examiner. This is the classic incidence and prevalence data concerning the "real" health problems (diseases) as they are described by the medical science at that time. Perceived (or subjective) morbidity, on the contrary, is completely linked to the patient's personal feelings, independently from any objectivation or diagnosis. This clearly reflects the "need that is felt" and hence the potential demand for intervention and for the health system to take charge. Finally, diagnosed morbidity, which only intervenes at the final stages of the process, reflects both the results of the previous steps (hence the need and the demand), as well as the functioning of the health system itself. For this very reason, it is also an indicator of the socio-economic implication of morbidity.

Obviously, it appears that one needs different techniques and procedures to access the data pertaining to these various aspects of morbidity. Objective morbidity data can only be gathered through standardised health examination surveys conducted on representative sample of the population[6]. For perceived morbidity as well as for self-reported morbidity, the only way to collect data is through standardised health interview surveys organised within the same type of representative samples[7]. Regarding diagnosed morbidity, it is possible to obtain the

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[6] One example is given by the NHANES: National Health and Nutrition Examination Survey. http://www.cdc.gov/nchs/nhanes.htm

[7] This is the focus of project #2 (and its continuation, project #21): to study the type of information that could be aggregated at the European level from HIS/HES (*Health surveys* in the EU: HIS and HIS/HES evaluations and models).

data from health providers: the data can be based either on probabilistic samples of practices (the sentinel practices network is one example[8]), or on a continuous basis in an integrated routine system[9].

In recent years, and especially since the exponential development of computer techniques in gathering and storing information, we face a true explosion of local information systems (at the hospital level, practice level, etc.) with not only a local objective but also a intended uses such as financing services, continuous evaluation, research, epidemiological goals, etc.

The EMD project's initial methodological choice has been to focus on the present and potential use for routinely collected data in three different settings: primary health care, secondary health care, and occupational health care. These three settings indeed allow the health personnel to collect medical and administrative data concerning the patients or the workers in their service, and for whom a diagnosis may be established.

It is essential to more clearly define our concept of "routine data"[10], which is so important in the conceptualisation of health information systems (Lippeveld et al., 2000): "Data can be collected through a variety of methods. We have found it useful to classify these methods into two groups: routine methods and non-routine methods."

In one of the rare books published on this topic, Stroup et al. (1994) devote a chapter to the "sources of routinely collected data for surveillance". Beginning historically from the systematic recording of notifiable diseases which was restricted to infectious diseases, and insisting in the interest of gathering existing data in other domains (non infectious diseases, chronic diseases, accidents,…), these authors make the distinction between six categories of sources in the filed of routine data:

- ✓ Notifiable diseases,
- ✓ Vital statistics,
- ✓ Sentinel surveillance, including the sentinel networks,
- ✓ Registries,
- ✓ Health surveys,
- ✓ "Administrative" data collection systems.

When considering this classification, it appears clear how the definition of the routine data concept can vary from one author to the next. If one adopts a more strict understanding, the notion of "routine collection" refers to the systematic character of the collection during the "normal" course of a usual practice.

In order to build on a solid base, the EMD project has been more restrictive even in the choice of a clear and precise definition, and decided to focus mostly on morbidity routine data by studying:

Routinely collected medical data, i.e. data collected systematically within the entire consulting population in the medical practice framework (at three different levels: primary care, secondary care, and occupational medicine), relating mainly to morbidity data or morbidity-related data (such as determinants or risk factors), and allowing the elaboration of health indicators and epidemiological use.

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[8] See project #5 (Health Monitoring in *Sentinel practice* networks).

[9] The term "routine" has a pejorative meaning in French that is not felt in English. In this report, we use it in its most neutral form, meaning that a routine medical record is a record collected systematically for all consulting patients. We therefore make a clear distinction between routine records and records collected through a population survey or records concerning only part of the patient population.

[10] It is surprising to note how rarely the term "routine" is defined in the various ad hoc glossaries and dictionaries (particularly lacking in Last, J.M. Dictionary of Epidemiology, 2001 and in the recent Glossary of Public Health Technical Terms published by the European Commission, 2001).

From the aforementioned categories, category 2 (vital statistics) has a clear routine approach. Due to the existence of another project devoted to the study of that topic, the EMD project will, not examine that category[11]. Our definition excludes category 3 (sentinel surveillance, including the sentinel networks), which implies a selection of indicators and the gathering of data through a probabilistic sample of practices. It also excludes category 5 (health survey) due to the fact that even when repeated, the surveys do not systematically collect the information from the routine medical activities.

For operational reasons, we also decided not to cover the well-defined and well-studied topic of notifiable diseases (category 1). These collection systems are generally well organised and function properly in most industrialised countries. Examples are given by the MMWR from the CDC-Atlanta[12], or on a worldwide level by the Weekly Epidemiological Report created by the WHO in Geneva[13]. The objective of these systems is more restricted, aiming at careful and sensitive surveillance of contagious and epidemic diseases in order to set up emergency actions, if necessary. This defined objective is well covered by WHO activities and does not appear to belong to the priority thrusts of the Community programme on health monitoring proposed by the Commission (see Introduction, above).

It therefore appears that the EMD project lies at the intersection of the two connotations described above: that of the "administrative" data (category 6; the term medico-administrative data seems to be preferred) and of the registries (category 4)[14] [15], even if we are mainly interested in the first connotation. The following chapters will try to test the availability of such data at the three levels of the health systems (primary health care, secondary health care, and occupational health); they will also test if the use of such routine data is feasible within the framework of the integrated E.C. health information system.

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[11] Comparability and quality improvement in European *causes of death* statistics (project #4, see above).

[12] http://www.cdc.gov/mmwr/

[13] The World Health Organisation (WHO) Weekly Epidemiological Record (WER) serves as an essential instrument for the rapid and accurate dissemination of epidemiological information on cases and outbreaks of diseases under the International Health Regulations and on other communicable diseases of importance in public health, including the newly emerging or re-emerging infections. (http://www.who.Int/wer).

[14] In epidemiology, the term "register" is applied to the data file concerning all cases of a particular disease or other health related conditions in a defined population such that case can be related to a population base. With this information, incidence rates can be calculated. If the cases are followed regularly, information on remission, exacerbation, prevalence, and survival can also be obtained. The register is the document per se and the registry is the system on ongoing registration. {…} Many types of registers – e.g. disease specific, treatment specific, "at risk", local (hospital or clinic-based) – are not population-based. (J. Last, 2001)

[15] We feel that registries do belong to the strict definition of routine data depending on the target population they cover: it is the case if they cover a whole population, but not if they concern only a local sample which would not allow the elaboration of valid or national health indicators.

2.1 A SPECIFIC EXAMPLE: MENTAL HEALTH

Mental health problems are very common in European countries. They have an important load on the socio-economic conditions of the population, due to their impact on employment, working abilities, earnings, but also intra-familial difficulties, including divorces, violence etc. The emphasis has been put specially this year 2001 on the priority to be given to mental health promotion, and subsequently to elaborate indicators in this field.

A project has been set up in the framework of the Community Action Programme on Health Monitoring : Establishment of indicators for *mental health* monitoring in Europe. The interim report started with this statement :
« Agreement is growing that mental health issues need greater visibility in the European context. » (Lehtinen, 2000), and the final report presents a thorough discussion of various indicators, along the lines of the ECHI project (Integrated approach to establishing *community health indicators).*

In order to make a link, both with the ECHI approach and with a project covering a special field of interest, i.e. mental health, we have developed a cross-reflection between the "routine data approach" and the field of mental health (also crossing the primary level and the secondary level of care). These reflections are collected in the Annex 1 .The main findings are as follows.

- ✓ Mental health needs to be recognised as a priority and integrated in the general scope of public health, due to its importance in terms of suffering (mortality, morbidity and consequences on the working and living conditions).
- ✓ There are different concepts which need to be clearly defined in order to avoid discrepancies between countries in the international comparisons: examples are mental health, psychological well-being, psychological distress, mental disorder, mental illness, etc. Theses variations in the definitions will lead to differential classifications in the statistics, but even more to differential attitudes from the patients, conducting to a different use of the specific pathways in the mental health services.
- ✓ The organisation of the mental health and psychiatric sector is very different from country to country. Hence, the different tasks of the services are performed by different structures, with different rhythms and intensities. All this makes the comparison very hazardous between countries. One example is given by the proportional distribution of the psychiatrists and psychologists in the taking in charge of the mental health patients. Institutionalisation or domiciliary treatment is another example of the great variations within EU.

Nevertheless, in this field as in others, indicators founded on medico-administrative routine data should be able to allow comparisons between countries or to follow the trends. Due to the limitations which have been briefly summarised above, and to the very nature of morbidity data collected from within the caring system, one must be very cautious in the conclusions to be drawn from such comparisons.

As they are elaborated on the basis of data linked with the health system functioning, such indicators may only reflect the complex interaction between certain health needs and the available resources, the way they are functioning, their activities, and sometimes their performances. They are unable to reflect directly and with accuracy the actual health status (the "objective" morbidity) of a population, nor the true prevalence of certain mental conditions.

For example, the increasing trend of the demand for mental health consultations which is very generally observed in Europe nowadays, does not imply necessarily an increase in the incidence of the mental conditions noticed at the level of these consultations. Despite this warning, the indicator is not without interest, as it permits to assess some specific trends and hence to anticipate prospectively the demand, which is undeniably a valuable input for planning purposes in this sector.

This is true for all morbidity indicators collected from within the caring system, but, it is even more so than elsewhere in the mental health sector : the nature of the health problems concerned here make them closer to the social problems the patients can face. For this reason, in the perspective of mental health indicators "working on the long term", the question of the broadness of the domain covered by these indicators cannot be eluded.

Beyond the many problems we shall face with the gathering of the routine data gathering at any level of the system (see below chap. 3 to 5), beyond the quality problems linked with the previous ones, the real challenge is here to set up a coherent set of indicators allowing health systems researchers, managers and decision makers to make a good use of the information made available. Therefore, definitions, standards, norms, values and criteria, which all structure the administration of this specialised care in the various countries, should be systematically studied, analysed and compared in such a way that one should be able to enlighten the similarities and the differences, and to allow a sound interpretation of the indicators.

It is noteworthy to mention that three European countries are on the way to set up a national system for the mental health (or psychiatric) health information :

- ✓ in Belgium : the Minimum Psychiatric Summary (RPM) (http://mpg-www.uia.ac.be/mpg/fr/index.html)
- ✓ in France, the PMSI is mainly oriented towards hospital data. (http://www.le-pmsi.fr/commun/glossaire/gloss.html)
- ✓ in UK, the Mental Health Minimum Data Set, also covers ambulatory care episodes when occurring within the NHS (http://www.nhsia.nhs.uk/mentalhealth/dataset/pages/default.asp)
  and the Integrated Mental Health Electronic Record (IMHER) takes part in the national strategy to constitute an individual electronic medical file for each patient (http://www.doh.gov.uk/nhsexipu/strategy/nsf/imhercb.pdf)

The variability of classification systems is great, specially at the primary care level (see below), but even in the hospital settings where the ICD codes are in use, problems arise for the comparison between countries, due to the different versions in use at the same time.

Finally, it appears that some indicators could be provided on the basis of routinely collected data; they concern mainly the supply aspects of the health systems, but some of them also concern its functioning , the demand, the utilisation and the costs associated with their use.

Once again, it should be emphasised that cautious attention has to be paid to the methodological difficulties which have been mentioned above and which jeopardise the proper interpretation of their comparisons. The next sections of this report will focus in more detail on these difficulties, with a specific overview of the constraints one faces in the three different settings : primary care, secondary care or occupational health.

3 CONTINUOUS DATA COLLECTION IN GENERAL PRACTICE IN EUROPE [16]

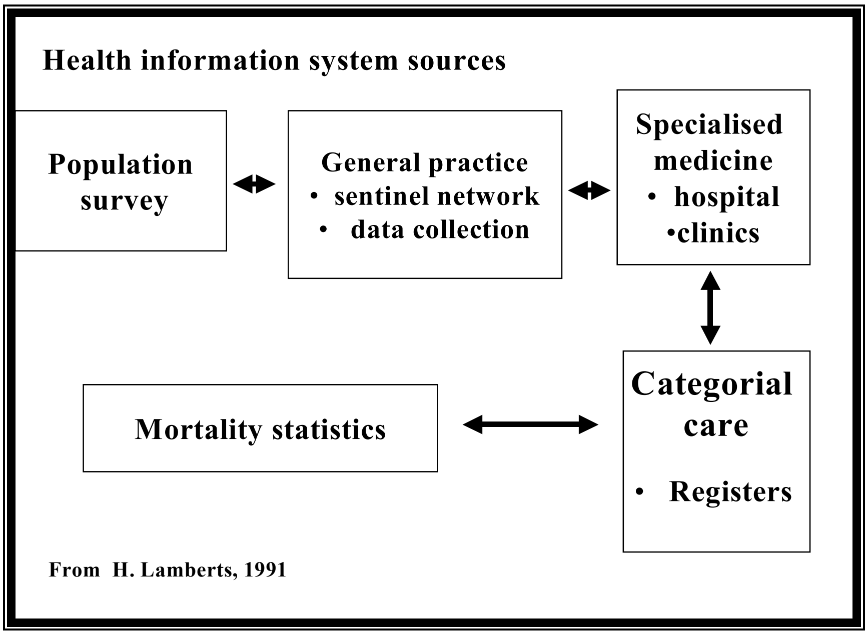
3.1 HEALTH INDICATORS AND DATA COLLECTION IN GENERAL MEDICINE – A GLOBAL OUTLOOK OF THE RESEARCH.

3.1.1 INTRODUCTION

Between the health needs expressed by the population and the actual morbidity data collected in hospitals at the end of a hospitalisation, there is an “information gap” that could be dealt with given the current possibilities of computer sciences.

Traditionally, one may estimate morbidity through hospital diagnoses or even through reported deaths. This morbidity, which is the object of medical procedures, is the base for morbidity indicators and can be used to estimate the health system’s needs.

The felt needs can be analysed by population surveys, but are merely a faint reflection of the demand for care expressed by the population. Besides these surveys, one has recently added the sentinel network of general practitioners (GPs). These networks in General Practice Family Medicine (GP/FM) have allowed, first on paper and then by electronic means, for an estimate on the prevalence of certain problems that are not necessarily featured as hospital diagnoses in the health statistics.



From H. Lamberts, 1991

Figure 3.1. The various sources of health information and the place of GP/FM data collections

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[16] Aknowledgment : thanks to all the participants of the EMD-PHC study.

I would thanks specially Dr Jean-françois Brûlet from France, Dr Nick Booth and Dr Mike Bainbridge from England , Dr Anders Grimsmo from Norway and Dr Erik Falkoe from Denmark, for their friendhip and support during this study. MJ

Whatever the performances and praise deserved by the sentinel networks, they remain completely selective concerning the subjects they analyse, which are always decided by doctors based on their perception of the importance of the problems.

It is therefore information pre-sorted by the providers, which allow for extrapolations for an entire population on highly prevalent subjects. Nonetheless, the sentinel networks could not reflect the entire set of health issues approached by doctors, nor the demand expressed by the population at the health service level.

General practitioners and family physicians form what is commonly called the primary care level.

In several northern European countries, as well as in Italy, Portugal, and Spain, this level plays the role of gatekeeper of the health system. The patient is not authorised to consult a specialised care level if he/she has not first consulted a general practitioner with whom he or she generally has a record.

This ‘gate’ system is not present in Belgium, France, Germany, Luxemburg, and Greece. It is therefore difficult to obtain a common denominator to set an epidemiological rate.

The development of the Electronic Medical Record (EMR) allows the general practitioner (GP) to insert himself/herself in the health information chain[17] (Cf. Fig. 3.1).

3.1.2 GENERAL MEDICINE AND DATABASES

It has been demonstrated that the GP receives and treats, at his/her level, more than 92% of the health problems presented by the consulting population.

The data is retrieved and, if it is adequately classified, it allows for the use of analytical as well as operational data, to be used by the GP.

The processed data can also be utilised when it is transferred from the patient to the hospitals. It can be aggregated and serve in the elaboration of databases that constitute “knowledge reservoirs” for the medical profession[18] (Cf. fig. 3.2)

These databases have been developed in Europe for several years and seem completely distinct in their constitution, content, and homogeneity.

Some of them contain several tens of millions of years/patients in standardised information, which are at the start of intensive investigations. Data mining techniques are applied to these databases.

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[17] Lamberts H, Wood M, Hofmans-Okkes IM (eds). The International Classification of Primary Care in the European Community. Oxford Medical Publication, 1993

[18] Jamoulle M. Information et informatisation en médecine générale. [Computer and computerisation in general practice] in: Les informa-g-iciens.: Presses Universitaires de Namur; 1986:193-209.

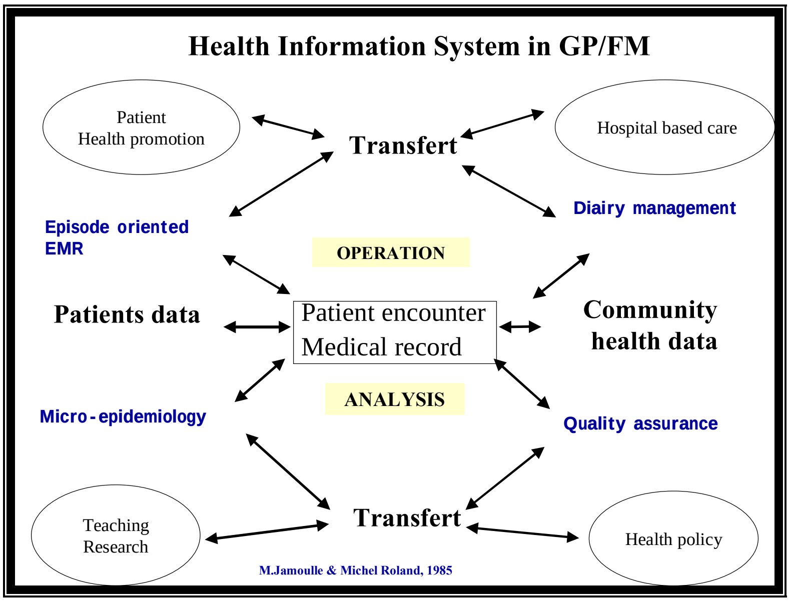

Figure 3.2. Information flow in GP/FM through EMRs use

The question of availability of morbidity indicators through these data collections is at the heart of the problem tackled by this analysis.

What are the existing databases in Europe? How are they organised? Can the information gathered by these various bases be aggregated and continuously serve as a source of information on the population's demands for health care as much as on the answers from the health services?

We will attempt to answer these questions in the following report.

One must nonetheless realise that the degree of GP's computerisation greatly varies throughout Europe. If more than 90% of British general practitioners are computerised and efficiently use an EMR, this is not true when we travel south or if we look at "disorganised" basic health systems such as in France, Germany, or Belgium.

The pivotal position of a GP is nevertheless constantly reaffirmed. Even if hospital and secondary services sometimes have a tendency to be exported towards the primary networks in Germany, Belgium, and France, the GP still remains the intermediary, the advocate and the preferred treatment for most Europeans.

GP's see 75% of their consulting population over a single year, and 95% over a three years period.

They may have a professional information system and be aware of its importance in the emergence and the management of personal health data. If this is the case, they will become unavoidable sources for obtaining an overview of the supply and demand of care and the construction of efficient health indicators[19].

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[19] Grimsmo A, Hagman E, Falkoe E, Matthiessen L, Njalsson T. Patients, diagnoses and processes in general practice in the Nordic countries. An attempt to make data from computerised medical records available for comparable statistics. Scand J Prim Health Care. 2001 Jun;19(2):76-82.

3.1.3 MAKING USE OF ELECTRONIC MEANS

In order to identify a comprehensive view of the European databases that continuously record morbidity in general medicine, one needs to consult many documentary means and new information and communication techniques.

The domain of health information is at the heart of general medicine research on the international level. This chapter's author's (M.J.) position as member of the WONCA International Classification Committee (WICC) and President of the Association of ICPC Users (CISP-Club) allowed for a quick and direct contact with a great number of researching GP's in Europe.

The WICC, CISP-Club and GP WONCA[20] circulation lists, as well as a number of informal contacts, enabled to access information about dozens of data collections throughout Europe.

This is not an exhaustive study – that would certainly require a great deal more time and effort – but the examined bases truly represent the field's tendencies.

It was, for example, impossible to obtain the collaboration of the General Practice of the University of Amsterdam, whose competence on the matter is universally recognised.

Despite certain reservations, the Internet survey form (see chapter II) allowed us to gather essential information on twelve databases.

This form was greatly based on work achieved by Dr Job Metsemakers in Holland (*). In chapter II, one will find a summary of the information obtained, while the entirety of the information collected is available in Access (*.mdb), Excel (*.xls), and text format (*.txt) in the software aid annexed to this report.

Publishing the Internet site http://www.ulb.ac.be/esp/emd also allowed us to edit the tools needed to understand the survey form correctly.

The European geographic regions were thus republished in a specific site (http://www.ulb.ac.be/esp/emd/nuts.htm).

The various terminologies and classifications were the subject of a study published on the site and featured in the software aid annexed to this report.

After having explored the various databases in a qualitative and quantitative manner, and outlined the content (chapter 3.3), it seemed constructive to give an overview of the different terminologies and classifications currently available in Europe and in use in the EMR's or other computerised health systems (see chapter 3.4).

Special attention was devoted to the use of ICPC (International Classification of Primary Care), which serves as a medium for many European studies (see chapter 3.5).

3.1.4 A PROFITABLE EXERCISE

The existence of a considerable diversity between the objectives, the means and the technical contributions of databases led us to attempt, as an assignment, to collect the data on the incidence and the prevalence of two major health problems: zona or herpes zoster (Shingles) and asthma (see chapter 3.6).

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[20] GP WONCA : Circulation list for the "Association Mondiale de Médecine de Famille" (Worldwide Association of General Practitioners/Family Physicians).

Both of these conditions profoundly differ from the conditions generally studied in comparative studies (High blood pressure, Diabetes, etc.) and are approachable and treatable in general medicine. The first, although infectious, is non epidemic in strict terms and has the reputation of offering information easy to trace due to its stable incidence. The latter is a more complex, unwell defined problem, and presenting a variable prevalence.

Analysing the collected data has allowed us to more thoroughly examine the problems concerning the stability and quality of information in continuous recording systems. This exercise naturally compared the prevalence and incidence of the problems between the various databases as well as with the international literature on the subject.

Nonetheless, the true result cannot be found in the available data, but rather in the difficulties and problems that arose when trying to obtain the information. One can therefore note that, in this exercise, the process is the outcome.

This exercise was made possible by the constant e-mail communication between the participants. The exercise was discussed during the final meeting on December 5th 2001, and was the founding principle in the creation of a European research group on the quality of data continuously gathered in general medicine.

The exercise is reproduced in its entirety in chapter 3.6.

3.1.5 THE LONG ROAD AHEAD

The entire communicative process, the two meetings and the exercise led to the conclusion that current continuous databases cannot be used for a European database, nor can they be aggregated to serve as a foundation for European health indicators in present conditions (chap. 3.7).

This is a promising field, but entirely dependant on intellectual and technological developments in the world of new communication and information technologies.

The development of public or dedicated networks is probably the beginning of a new era in this domain and the information generated by the medical exercise can be put to use of both the health decider as well as its actors.

Patients are in the actor’s front row. The use of a public network such as the Internet, will allow the patient’s information to come back to him or her. The coherent management of this information will become synonymous with the quality of healthcare.

During the EMD-PHC group meeting in Brussels on December 5th, Dr Bainbridge (UK), Dr Nardi (It), Nennonen (Fi), joined by Dr Weeks (UK) announced the creation of a **European research group on data quality**. This group will take over the studies begun by the EMD-PHC research.

Supporting this group naturally features at the forefront of our recommendations (chap. 3.8).

The totality of the computer products elaborated through this research, that is to say the Internet site, the answers to the surveys and the communications in both meetings are available on the CD-ROM available on demand.

3.2 THE SURVEY FORM

Throughout Europe, there are numerous databases devoted to the continuous recording of morbidity data in general medicine, and each has its own purpose. In order to obtain a clearer idea of their functioning and their organisation, we developed a survey form. This form was greatly inspired by the work of Dr. Job Metsmakers of the General Practice Department of the University of Maastricht in Holland.[21]

Dr. Mestemakers conducted an extensive study on the situation of databanks in Holland, a country with considerable experience in the matter.

The relevant items were spread over six points. The form was published on the Internet at http://www.ulb.ac.be/esp/phcform.html and was proposed by e-mail to a series of members of the profession.

The number of questions justifies the publication of this form in its entirety and the various chapters that compose this study allow the reader to better understand the complex nature of the problem. Furthermore, certain specific items in the form such as patient, provider, health problem, are terms that are not unanimously understood amongst the researchers.

A hyperlink was created from these terms to the international primary care glossary published by WONCA at http://www.ulb.ac.be/esp/wicc/letter_a.htm.

This links provided the respondents with more details concerning the items. Moreover, in order to help the respondents to understand that this was a study focusing on Europe and to accurately locate their region within Europe, we published an html file that regroups all of the European regions according to the NUT classification (Territorial Unit Nomenclature).

This file is available at the following website: http://www.ulb.ac.be/esp/emd/nuts.htm.

Finally, in order to specify the classifications or terminologies used by the respondents, a special file was published and maintained on the web including hyperlinks to the different classifications and terminologies used in Europe and present on the Internet. http://www.ulb.ac.be/esp/emd/classifications.htm

The survey form (see below) was then edited in an Access database, which is available on the CD-ROM that is available on simple request. The information is also presented in Excel and in text format (*.txt).

We received responses from twelve European morbidity databases. The various databases are listed and detailed in chapter 3.3. Chapter 3.3 will also provide the most important answers from the survey as well as a summary of the interventions from the members of the databases that were active in the meetings held on the 7th and 8th of December 2000 and the 5th of December 2001.

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[21] Job FM Metsemakers Huisartsgeneeskundige registraties in Nederland. Maastricht/Rotterdam, 1999.

3.3 DESCRIPTION OF SOME CONTINUOUS DATA COLLECTIONS SYSTEMS IN GP/FM IN EUROPE.

3.3.1 RESULTS OF THE ENQUIRY

Characteristics of some data collection are described by the authors by filling the enquiry form published on the internet (http://www.ulb.ac.be/esp/emd/phcform.htm) (see also annex)

3.3.1.1 Malta, Odense (Dk) , REAP (Sp)

Items	Malte	Odense (Dk)	REAP (SP)
Contact	JK Soler jksoler@synapse.net.mt	Erik Falcoe E-Falkoe@dadlnet.dk	Luis Palomo luis.palomo@hspa.es
Shorthand of the registration unit	JKS	RUGP[22]	REAP[23]
Firts year registration:	Since 2000	Since 1999	1993-1994
Purpose of the registration unit	To collect data on Maltese General Practice with ICPC-2, using the Transhis Electronic Medical Record software, in collaboration with the University of Amsterdam Department of General Practice. The data will be used for international collaborative studies	Develop and implement methods for continuous data registration from general practise for quality assessment and research	Cuantificar y analizar la morbilidad atendida en las consultas de medicina general en España, así como el patrón de utilización de dichas consultas
Involved doctors	12	13	44
Involved patients	12000	6419	41898
Covered patient number:	NA	9331	68771
Health care financing system:	Fee for service	National Health service	National Health service
Health care insuring system:	Mixed	Public	Public
Name of the software of the registration system:	TRANSHIS	Medex	Manual
Type of classification used in the registration system:	ICPC-2-E / ICD-10 / ATC	ICPC-europe 1993 / ATC	ICHPPC-2-d
Content of the registration system :	Recording Rfe, process and episode title for all episodes presenting to the Family Doctor. Recording drugs prescribed.	Electronic patient record system	

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[22] University of Odense, Denmark

[23] REAP : Spanish GP network

Items	Malte	Odense (Dk)	REAP (SP)
Patient birth date	yes	yes	yes
Patient zip code	yes	yes	yes
Patient birth country	no	no	no
Patient gender	yes	yes	yes
Patient citizenship	no	yes	no
Patient ethnical characteristics	no	no	no
Patient housing conditions	no	no	no
Patient professional status	yes	no	no
Patient social status	no	no	no
Patient identification	yes	yes	yes
Patient educational level		no	no
Type of age group		By 5 years	Other
Reason for encounter	yes	no	yes
Preventive process	yes	yes	no
Diagnostic process	yes	no	
Therapeutic process	yes	yes	no
Referral process	yes	no	yes
Main diagnosis	yes	yes	yes
Allergy	yes	no	no
Drug intolerance	yes	no	no
Risk factors	yes		no
Mortality	yes		no
Problem list	yes	no	no
Family problem list	no	no	no

3.3.1.2 RNH Maastricht (Nl) and Norway

Items	Maastricht (Nl)
Contact	Job Metsemakers mail : job.metsemakers@hag.unimaas.nl
Shorthand of the registration unit	RNH
Firts year registration:	Since 1988
Purpose of the registration unit	The chief goal of the RNH is to establish a computerised anonymous database containing certain patient characteristics and all relevant health problems. The database has been set up primarily as a sampling frame, allowing researchers to identify patients with particular health problems or combinations of problems. Furthermore, the database can be used in education and health care. Finally, the available database can supply data for cross-sectional of longitudinal analyses.
Involved doctors	53
Involved patients	81000
Covered patient number:	100000
Health care financing system:	Mixed (fee+cap)

Items	Maastricht (Nl)
Health care insuring system:	Mixed
Name of the software of the registration system:	MicroHis
Type of classification used in the registration system:	ICPC 1987
Content of the registration system :	Before inclusion in the RNH database it is required that the GP has recorded both socio-demographic patient characteristics and the problem list. Socio-demographic patient characteristics include date and place of birth, sex, educational level, type of health insurance (public, private), type of living arrangement, marital status, place of residence, postal code, date of entry in the system, last update, and finally date of end of registration and reason for ending registration.
Patient birth date	yes
Patient zip code	no
Patient birth country	no
Patient gender	yes
Patient citizenship	no
Patient ethnical characteristics	no
Patient housing conditions	no
Patient professional status	no
Patient social status	no
Patient identification	yes
Patient educational level	yes
Type of age group	Other
Reason for encounter	no
Preventive process	no
Diagnostic process	no
Therapeutic process	no
Referral process	no
Main diagnosis	yes
Allergy	yes
Drug intolerance	no
Risk factors	yes
Mortality	yes
Problem list	yes
Family problem list	no

Remarks on Maastricht database : The problem list holds all relevant health problems. All problems are coded using the International Classification of Primary Care (ICPC), following the criteria of the International Classification of Problems in Primary Care (ICHPPC-2).

Problems are recorded if they affect the present functional status of patients and/or their future functioning. Thus, only permanent problems (no recovery expected), chronic problems (duration longer than six months), recurrent problems (more than three recurrences within a period of six months) and problems with a high impact on daily functioning are recorded. Problems are stated at the highest level of refinement that can be reasonably defended. That is, a condition cannot be given two problem definitions at the same time.

Problems are characterised as active or inactive;. A problem is considered to be active if it has the attention of the general practitioner or the patient at that moment as shown by present treatment (diet, medication, or specific therapy), further diagnostic investigations, regular checks for that problem or a known progressive course for that disease.

3.3.1.3 GPRD, DIN, PRIMIS (UK)

Definition	UK GPRD	UK PRIMIS	UK DIN
Contact and source of information	Azeem Majeed a.majeed@ucl.ac.uk	Mike Bainbridge mike.bainbridge@primis.nottingham.ac.uk	Roger Weeks roger@safescript.org
Shorthand of the registration unit	GPRD	PRIMIS	DIN
Firts year registration:	1990	1997	1992
Purpose of the registration unit	To collect information on morbidity, mortality, prescribing, investigations, outpatient referrals and hospital admission in patients registered with general practices that are part of the GPRD. The information is widely used for pharmaco-epidemiology, acute and chronic disease epidemiology, and health services research.	Provision of a) guidance, education, training and support in data quality and information management using GP clinical computer systems b) analysis and feedback of clinical data following national clinical priorities, e.g. heart disease	Medical Research Pharmacoepidemiology Clinical Audit
Involved doctors	300+	100 PCGs[24]	
Involved patients	3 mill	15mill	
Covered patient number:	3 mill	15mill	1mill
Health care financing system:	National Health service	National Health service	National Health service
Health care insuring system:	Public	Public	Public
Name of the software of the registration system:	VAMP Vision	PRIMIS	DINLINK
Type of classification used in the registration system:	OXMIS / RCC5	RCC4 / RCC5	RCC4 / RCC5

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[24] PCGs : primary Care Groups

Definition	UK GPRD	UK PRIMIS	UK DIN
Content of the registration system :	Summaries of medical records of patients registered with general practices that contibute data to the GPRD.	Aggregated data from approx 100 PCGs, covering (now) approx 15 million patients. Clinical data for heart disease, diabetes, asthma, mental health, hypertension, lifestyle factors	Full anonymised clinical data
Patient birth date	no	no	no
Patient zip code	no	no	yes (partially)
Patient birth country	no	no	no
Patient gender		yes	yes
Patient citizenship	no	no	no
Patient ethnical characteristics	no	no	yes (if corresponding Read codes available)
Patient housing conditions	no	no	no
Patient professional status	no	no	no
Patient social status		no	yes
Patient identification	yes	no	yes
Patient educational level	no	no	no
Type of age group	Other	By 5 years	Other
Reason for encounter	yes	no	yes
Preventive process	yes	yes	yes
Diagnostic process	yes	yes	yes
Therapeutic process	yes	yes	yes
Referral process	yes	yes	yes
Main diagnosis	yes	yes	yes
Allergy	yes	yes	yes
Drug intolerance	yes	yes	yes
Risk factors	yes	yes	yes
Mortality	yes	yes	yes
Problem list	yes	yes	yes
Family problem list	no	yes	yes

3.3.1.4 Sentinelles, Prometheus, THALES (Fr)

Definition	France	Paris	Thales (Fr)
Contact	Laurent Letrilliard l.letrilliart@wanadoo.fr	Bernard Ortolan b.ortolan@wanadoo.fr	Raphaël Spira raphael.spira@thales.tm.fr
Shorthand of the registration unit	Sentinelles	Prometheus	THALES
Financing Authority	INSERM-U444[25]	UPML-IDF[26]	CEGEDIM[27]
Firts year registration:	1984	2001	1990
Purpose of the registration unit	Epidemiological sentinel network on entire France. On line database on communicable disease (see Internet site) Primary Secondary care referral pattern study	First steps towards an online retrieval system. Data retrieval and classification network between 300 GPs in the Paris region. Online public anonymised Internet publication and private feed-back to the data producers. Aiming at Epidemiology, Quality assurance and continuous medical education.	Medical softwares surveys in market research, pharmaco-epidemiology, health economics
Involved doctors	1360	300	1200
Involved patients			1.2mill
Covered patient number:			1.2mill
Health care financing system:	Fee for service	Fee for service	Mixed (fee+cap)
Health care insuring system:	Public	Public	Mixed
Name of the software of the registration system:		Prometheus (open source)	DOC'WARE
Type of classification used in the registration system:	CISP-1	CISP-2 / DRC	Proprietary
Content of the registration system :	Communicable disease, Suicide attempts, Hospital referral pattern of the GPs	Aggregated data from approx 300 GPs to be published on an public Internet page. Compared data accessible to each provider on private personal web page	
Patient birth date	yes	age	age
Patient zip code		no	no
Patient birth country		no	no
Patient gender	yes	yes	yes

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[25] INSERM-U444 Unit 444 of the French Institute for Education and medical research

[26] UPML-IDF Stands for Union Professionnelle des Médecins Libéraux - Ile de France (Association of independent Parisian doctors)

[27] CEGEDIM International Company see http://www.cegedim.fr/index2.htm

Definition	France	Paris	Thales (Fr)
Patient citizenship		no	no
Patient ethnical characteristics		no	no
Patient housing conditions		no	no
Patient professional status		no	yes
Patient social status		no	yes
Patient identification		no	no
Patient educational level		no	no
Type of age group		WONCA	other
Reason for encounter		yes (2nd step))	yes
Preventive process	yes		yes
Diagnostic process	yes		yes
Therapeutic process			yes
Referral process			no
Main diagnosis	yes	yes	yes
Allergy			yes
Drug intolerance			yes
Risk factors			yes
Mortality	yes		no
Problem list			yes
Family problem list			yes

3.3.1.5 Marais Breton (Fr), Creta (Gr), Italy

Definition	Marais Breton	Regional Health System of Crete	ITALY
Contact and source of information	Jacques Humbert Jacques.Humbert6@wanadoo.fr	Dimitris Kounalakis dcoun@galinos.med.uoc.gr	Roberto Nardi rnardi@tin.it
Financing source	Public social security funds (CNAM)	Regional Health System of Crete / State	
Shorthand of the registration unit	AVMFMB[28]	ReHS Crete	
Firts year registration:	2001		
Purpose of the registration unit	Study of the management of Emergency in rural practice 2001 and Interface PHC / SHC	Regional Health System of Crete was established three months ago as a small regional ministry of health for Crete. It deals with policy making health monitoring resources sharing etc. It selects health data concerning	

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[28] `AVMFMB:`Stands for `Association Vendéenne des Médecins de Famille du Marais Breton`

		from primary and secondary care and it use them for having health indicators. Currently all data are from HygeiaNet which had limited acceptance by health providers. http://www.rhscrete.gr but will start to work from Jan 2002
Involved doctors	17	
Involved patients	na	
Covered patient number:	na	
Health care financing system:	Fee for service	National Health service
Health care insuring system:	Public	Public
Name of the software of the registration system:	ACCESS	HygeiaNet EPR SyBase SQL server in each primary health care unit
Type of classification used in the registration system:	CISP-2 (=ICPC-2) CIM-10 (=ICD-10)	ICD-9
Content of the registration system :	Comparative study about liberal GP's and hospital practitioner's interventions responding to emergency medical calls. Paper registration, then central computerized registration and coding	Full EPR system with functions for registering patients, 27 visits diagnoses, tests, etc
Ethics	Anonymous registration. Coding central practitioner can identify provider but is not allowed to publish anywhere	
Patient birth date	age	Yes
Patient zip code	no	Yes
Patient birth country	no	Yes
Patient gender	yes	Yes
Patient citizenship	no	Yes
Patient ethnical characteristics	no	Yes Difference between Greek people and not Greek people
Patient housing conditions	no	No
Patient professional status	yes	Yes

Definition	*Marais Breton*	*Regional Health System of Crete*	*ITALY*
Patient social status	no	Yes	
Patient identification	no	Yes The doctor from its insurance book	
Patient educational level	no	No	
Type of age group	WONCA	Other	
Reason for encounter	Yes	Yes	
Preventive process	No	Yes	
Diagnostic process	Yes	Yes	
Therapeutic process	Yes	Yes	
Referral process	Yes	Yes	
Main diagnosis	Yes	Yes	
Allergy	No	Yes	
Drug intolerance	Yes	Yes	
Risk factors	No	Yes	
Mortality	Yes	Yes	
Problem list	No	Yes	
Family problem list	No	Yes	

3.3.2 INVESTIGATED DATA COLLECTIONS IN GP/FM

3.3.2.1 United Kingdom

3.3.2.1.1 Primary Care Information System (PRIMIS) http://www.primis.nottingham.ac.uk/

Dr Mike Bainbridge Nottingham University

Primary Care Information Services (PRIMIS) is a no-charge support service designed to help primary care organisations improve patient care through the effective use of their clinical computer systems.

Working through locally-funded information facilitators, the PRIMIS team will provide:

- ✓ GUIDANCE on how to make the most effective use of clinical computer systems;
- ✓ TRAINING and support in information management skills, data recording, extraction and analysis;
- ✓ ANALYSIS: direct assistance with analyses of data quality, plus a comparative analysis service focused on key clinical topics;
- ✓ FEEDBACK and interpretation of the results of data quality and comparative analyses.

PRIMIS is funded by the NHS Information Authority and is based at the Division of General Practice at the University of Nottingham, with regional centers in Manchester, Guildford and Bristol.

Abstract of the first meeting (http://www.ulb.ac.be/esp/emd/uk_bainbridge.htm);

The effective use of information management and technology is at the heart of the strategy to modernise the NHS, with quality information seen as the key to improving patient care and public health.

While acknowledging the importance of the information contained in primary care records, "Information for Health" points out that the quality and reliability of such information is variable. There is a shortage of local expertise in day-to-day information management, as well as a lack of skills and knowledge for analysing clinical data and interpreting the findings.

To address these problems, in April 2000 the NHS Information Authority launched an important new training and support service to help primary care organisations take full advantage of their clinical computer systems. The no-charge service, known as PRIMIS (Primary Care Information Services), provides training and assistance to information facilitators employed by Primary Care Groups and Trusts (PCG/Ts). These facilitators "cascade" their knowledge and skills to GPs and practice staff in their local health communities to improve patient care through the effective use of quality information.

The PRIMIS service is provided by a team based at the Division of General Practice at the University of Nottingham, and is building on the successful work undertaken by the same team on an extensive pilot project, Collection of Health Data from General Practice (CHDGP), over a three year period.

Working through locally-funded information facilitators, the PRIMIS team will provide:

✓ GUIDANCE on how to make the most effective use of clinical computer systems;

✓ TRAINING and support in information management skills, data recording, extraction and analysis;

✓ ANALYSIS: direct assistance with analyses of data quality, plus a comparative analysis service focused on key clinical topics;

✓ FEEDBACK and interpretation of the results of data quality and comparative analyses;

(This "abstract" written by M.Jamoulle on basis of Internet available information).

3.3.2.1.2 The General Practice Research Database (GPRD)

(see also Azeem Majeed contribution in Exercise on Asthma and Herpes Zoster)

Dr **Louise Wood** BSc (Hons) PhD and Carlos Martinez MD (www.gprd.com)

Abstract of the first meeting (http://www.ulb.ac.be/esp/emd/uk_wood.htm)

The General Practice Research Database (GPRD) is the world's largest computerised database of anonymised longitudinal patient records from general practice, containing more than 30 million years of patient information. It is used by researchers in academia and other organisations, government departments, medicines regulatory authorities and the pharmaceutical industry for studies of clinical epidemiology, drug safety, health outcomes, health service planning, prescribing analysis and pharmacoeconomics.

The GPRD is managed by the UK Medicines Control Agency (MCA) on a self-financing, non-profit making basis. The MCA has made a major investment in redeveloping the database to secure its long-term viability, enable its evolution to support a broader spectrum of public health research and improve benefits for contributing general practitioners. New services, including on-line access to the totality of the raw data via state-of-the-art analytical tools, has been launched in April 2001.

3.3.2.1.3 Doctor's independent Network database (DIN)

(see also Roger Weeks contribution in Exercise on Asthma and Herpes Zoster)

What is Doctors' Independent Network? (http://www.compudata.co.uk/din.html)

- ✓ A learned society of clinicians,
- ✓ Run by doctors for the benefit of all,
- ✓ Nationally organised,
- ✓ Non-profit making - charitable status,
- ✓ Open to all clinicians with a computer interest,
- ✓ A major shareholder in a joint data venture with Industry (CompuData Research Ltd),
- ✓ Financially independent.

Our Data Panel consists at present of more than 300 Torex Meditel practices recruited almost entirely from the best data providers used in the original AAH Meditel - CompuFile data scheme.

The typical DIN panel member has generally had a clinical computing system in place for many years and makes full use of it as general practice adapts to the demands of the new NHS.

They are encouraged to express their health care communication needs, interests and concerns among their professional colleagues through the medium of the DIN Supervisory Board.

Where are DIN members located?

The DIN panel is represented in every part of England, Scotland and Wales. The most Northern practice is Orkney!

How do they provide their data to DIN?

Automatically, without user intervention, over night using DIN RAPID reports. In summary, DIN RAPID :

Provides the GP with a greatly improved Torex Meditel System 5-compatible reports package designed for general practice use.

Is optimised for simple quick extraction of data on a regular basis by modem. By default, the extraction software keeps a record of the date of the last extraction and any subsequent extraction takes all the data added or changed since then.

Is capable of carrying out automatic data downloads daily via modem directly onto the DIN database.

DIN RAPID Reports has been tested by Torex Meditel for compatibility with its System 5 software and have been awarded third party accreditation.

What safeguards does DIN apply to the data?

For the patient:

DIN scrupulously follows the standards laid down by the Committee on Standards of Data Extraction (by organisations external to the practice) of the GPC. This means we extract only these patient identifiers:

- ✓ sex, year of birth;
- ✓ postcode collection now superseded by CACI socio-economic code collection (improving confidentiality);
- ✓ encrypted patient number (DIN doctors hold the decryption key);
- ✓ practice identity number (DIN-specific practice identification).

For the data user:

DIN uses advanced extraction software that works directly on the Torex Meditel data files, not on the indexes. (Other organisations use extraction programs that rely on the index files to the practice's data. These are known to have been repeatedly corrupted in the past).

A comprehensive series of data download trials have demonstrated the extremely robustness of this system and its excellent reliability. After extraction and reading into the DIN database the data follows the same path that it did under the original Torex Meditel regime, i.e. directly to DIN for analysis and onward transmission.

How do we measure data quality?

DIN assesses data quality by individual GP using some of the principles of clinical audit. We currently assess data quality on the following simple criteria:

✓ List size vs. volume of notes recorded;
✓ List size vs. volume of drugs issued;
✓ Percentage of drugs linked to coded reason for prescribing;
✓ Proportion of acute to repeat prescriptions;
✓ Visits and drugs prescribed entered on computer;
✓ Proportion of 'firm' diagnoses vs. symptoms or signs;
✓ Incidence of 'marker' read codes (e.g. a practice with all minor ailments recorded but no recorded cases of appendicitis, MS or psychotic illness would be considered atypical!).

How do we ensure continued data quality?

The DIN Board members have made use of their personal knowledge of the situation at the 'sharp end' of general practice to provide a practical solution. Clinical audit is now an essential activity in General Practice. Compulsory postgraduate education leading to re-accreditation seems inevitable within the next few years. DIN therefore is producing an audit package that allows the GP to do the following:

✓ carry out clinical audit on PCG performance criteria assisted by DIN;
✓ audit his personal performance against either his own or pre-defined nationally accepted targets using clinical ratios;
✓ see how he compares with his partners and other GP's (without identifying them).

This can make PCG[29]-based clinical governance possible for DIN data providers. The GP can set his own clinical standards and can measure changes in practice activity month by month.

How do we reimburse our members for their data?

Indirectly. DIN is prepared in principle to pay members directly for their data but would prefer to use income from the sale of data to provide members with goods and services i.e. quality add-on software. This has the added advantage of not jeopardising reimbursement.

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[29] PCG : Primary Care Group

What services does DIN provide for members?

The FrontDesk 2000 and FrontDesk 6000 Appointments System - designed by GP's and receptionists, all Torex Meditel users and the best available appointments package for Torex Meditel customers. Tested and third party accredited by Torex Meditel, it is provided and supported by DIN at a major discount to its members. Now available in System 5 and System 6000 versions. Data feedback software Free to data-providing practices. The software runs under Windows on any 386 (or more powerful) PC, allowing practices to analyse their own data in a variety of ways including:

- ✓ number of prescriptions issued,
- ✓ number of patients treated,
- ✓ number of days of therapy prescribed,
- ✓ number of prescriptions per patient per year,
- ✓ length of continuous therapy,
- ✓ average daily dose prescribed,
- ✓ intervals between prescriptions.

Practices can choose to receive feedback on any three of the following: Angina prophylaxis, HRT, Hypertension, Lipid lowering drugs, Respiratory, Oral contraceptives, Systemic NSAIDs, Ulcer healing drugs.

3.3.2.2 Nordic countries

3.3.2.2.1 Finland Stakes

The presently available databases are derived from the Care Register, for which social welfare and health care institutions annually provide data on care periods and on operations performed in day surgery. The databases do not contain information about out-patient treatment in specialised or primary health care. The databases are meant for making tentative analyses on various levels concerning social welfare and health care phenomena.

A test in Kotka region in late 2001 in PHC is being performed and at the beginning of next year material would be available, but it is not going to be continuous data collection.

For further information please do refer to Stakes statistical databases. Data are available only from Secondary health Care but the way they are presented is quite interesting. http://info.stakes.fi/nettihilmo/english/hilreinf.htm

Contact: Dr Mikko Nennonen : mikko.nenonen@stakes.fi (see also exercise on Asthma and Herpes Zoster)

3.3.2.2.2 Denmark Odense

Continuous morbidity registration and quality development combined by using the Extended Danish International Classification of Primary Care (a pilot study).

Erik Falkoe

General practitioner in rural practice on Funen since 1975. Part-time researcher at the Research Unit of General Practice.

University of Odense, Dep. of General practice Winslowparken 19 3rd floor Dk-500O Odense e-falkoe@dadlnet.dk

Contribution to the EMD Meeting 8 & 9 December, 2000 http://www.ulb.ac.be/esp/emd/dk_falkoe.htm

- ✓ **Extended Danish ICPC (ICPC-E).** Here a small part of ICD-10, that is relevant to general practise, has been accommodated within ICPC .A useful tool for registration.
- ✓ Continuous morbidity registration and quality development combined by using the Extended Danish International Classification of Primary Care (a pilot study).

  Aim: Describe the disease pattern in general practice using ICPC coding and at the same time making it possible for individual general practitioner (GP) to compare practice pattern with each other and compare their management exemplified by diabetic patients ;

  Method: In a 3 month period in 1999, 14 GPs from 6 practices coded all their patient encounters with diagnosis, using ICPC. Feedback was given to each GP about disease- and contact pattern of their patients and selected parameters as for instance HbA1c, serum cholesterol and blood pressure. A list of identified patients with sub-optimal management was send to the GP as well.
- ✓ **Perspectives**. When using ICPC-E every diagnoses has an ICPC-code as well as a corresponding ICD-10 code in the electronic medical record. This provides good possibilities for research and quality development across the primary- and secondary health sector.

3.3.2.2.3 Norway Trondheim

(see also Anders Grimsmo contribution in Exercise on Asthma and Herpes Zoster)

Data retrieval in general practice in Norway (http://www.ulb.ac.be/esp/emd/no_grimsmo.htm)

Anders Grimsmo

Associate professor, general practitioner Dep of Community Health and General Practice University of Trondheim N-6656 Surnadal Norway Dep Gen Pract Trondheim
+47 71661244 Fax: +47 71660933 E-mail: anders.grimsmo@medisin.ntnu.no

Aim:

The production of regular statistics aimed at better decision support in health care planning and quality development in general practice. This will be statistics about both needs and outcome automatically collected from electronic patient records. The data will be processed centrally and distributed both to different authorities and back to the GPs together with comparable statistics from colleges.

Organisation:

Statistics Norway compiles official statistics in Norway and will be responsible for collecting and processing data and distributing statistics from general practice. The Ministry of Health, The Norwegian Research Council and representatives for local authorities and general practitioners are on the executive committee. First step (2001) is to engage 80-90 general practitioners.

Standardisation:

An official standard for the EPR is developed, but is only partially implemented. All information the GPs need on the bill to collect money from the social security system, are standardised and in place in all EPR software: unique person identifier of the patient, sex, date of birth, address, encounter (date, time, type), diagnoses (ICPC) and many processes. We use ATC-codes for medications, but this is only in use in the newer versions of EPR software. The next to agree upon is a code system for laboratory tests and to establish a unique identifier for all health care personnel and providers.

Structure of data:

All information in the EPR databases are linked to an event. Date and time are parts of the index key in the system. The information is also to some extent episode based, meaning that the Norwegian GPs nearly always (are obliged to) label an event with a diagnosis (ICPC).

Permanence and reliability:

Data collection from general practice in Norway has so far only been done sporadically and usually for specific purposes. But these studies have produced very similar results on comparable issues and over time, supporting reliability.

Quality:

In pilot studies most GPs have reported confidence in the results from their own practice and they also believe that the results can be used for comparisons with others.

Ethics:

The ownership of the information in the EPR is not defined legally in Norway, but is merely the sum of rights and obligations stated in several laws and regulations. The GPs are of course bound to observe professional secrecy, but can give away any patient information for statistical purposes if it is done in a way that the patient can not be identified by it. The authorities can through regulations claim the GPs to hand over information from their practice. But to collect any data from general practice everyone, all authorities included, has to get a legal permission from the Data Inspectorate. This is an independent administrative body under the Norwegian Ministry of Justice, that is set up in to ensure enforcement of the Act relating to Personal Data Registers, etc. The purpose of the Act is to safeguard the protection of individual and social privacy and the Data Inspectorate has interpreted this act very strictly.

3.3.2.2.4 Sweden; Janus, drug treatment and follow up.

Kjell Henriksson
Bengt-Erik Wiholm, Lennart Jacobssob, Lars L. Gustafsson,
Janus Telepharmacology Stockholm County Council and Karolinska Institute, Sweden
Dr Kjell Henriksson Karolinska Institutet PO Box 4135 SE-14104 Huddinge, Sweden
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Abstract of the first meeting ; (http://www.ulb.ac.be/esp/emd/se_henriksson.htm)

Janus decision support system provides producer-independent drug information with recommendations regarding drug prescribing. It is an integral part of the medical record system.

The prescribing module shows present and previous drug therapy and provides alerts for drug interactions and for unsuitable drugs in pregnancy and breast-feeding. Guidelines and recommendations for ”drug of choice” from the regional Drug and Therapeutic Committee and suggestions for therapeutic drug treatment can easily be accessed. The recommendations are evidence based by nature taking locally agreed practice into account and are formulated by expert panels in various therapeutic areas. The prescribing module also provides ready access to appropriate knowledge sources and to the Janus web.

Janus web (www.janusinfo.org) provides independent drug information including abstracts of newly published articles, consensus statements, knowledge sources and regional prescription statistics among other services. It is updated daily.

Ongoing development will allow electronic transmission of prescriptions to any pharmacy, online reporting of adverse effects, and medical follow up modules. These modules are based on requirements from the prescribers and can be collated at different hierarchical levels; one physician, one GP-practice one region etc. Selecting terms from various registers to enhance data quality composes all data. The overall purpose is to contribute to improvement in quality and cost-utility in drug treatment as well as to become a learning instrument in drug prescribing practices.

3.3.2.3 The Netherlands

3.3.2.3.1 LINH ; Netherlands Information Network in General Practice (NIN GP)

Dinny de Bakker, Netherlands institute of primary health care, Nivel,

Dinny de Bakker is research coordinator in the field of general practice at the Nivel institute and project manager of the NIN GP.

NIN GP is a joint project of the Dutch Association of General Practitioners, the Dutch College of General Practitioners, the Centre for Quality of care research and Nivel

Abstract of the first meeting (http://www.ulb.ac.be/esp/emd/nl_debakker.htm):

Aim of NIN GP is to collect nationally, representative data on GP care. The data are used for health services research and quality-of-care research. Continually morbidity specific data are gathered on GP’s patient list, consultations, prescriptions and referrals. Ad hoc extra registrations around specific subjects take place (influenza vaccination, cervical screening, low back pain, diabetes). In NIN GP participate 123 computerised practices from five different GP information systems with 228 general practitioners with in total about 450.000 listed patients. The network mirrors the national distribution of the population according to age, sex, type of insurance, region and degree of urbanisation. Morbidity is classified with the ICPC, prescriptions with the ATC-classification system. Further national coding tables for instance for specialists, consultation type are used. The data are event based. Reliability is ensured by linking as closely as possible to existing registration routines. Therefore the existing GP information systems are the starting point. Minimal adaptations of the software ensure data-integrity. Only anonymous data are extracted from general practice. General practitioners and partners in the project have signed to adhere to the privacy regulations. Patients are informed by a poster and handouts in the practice.

Data are used in several monitoring projects: production data in general practice, influenza vaccination, cervical cancer screening and the introduction of electronic formularies. Other type of studies that take place are state-of-the-art studies (prescribing of Ritalin, repeat prescribing, prescribing of benzodiazepines in general practice), guideline adherence studies (low back pain, diabetes), development of quality indicators, evaluation of policy measures (i.e. reduction of insurance coverage for self care medication).

✓ In 2000/2001 the Second Dutch Morbidity is performed within the framework of NIN GP (in 104 practices) Based on an extensive research program extra data are collected on: morbidity in all consultations during one year (with episode construction), socio-demographic data of all listed patients , experienced health and health behaviour among a sample of patients and doctor-patient communication by video taping one day per GP.

3.3.2.3.2 The Registration Network Family Practices (RNH),

http://www.hag.unimaas.nl/rnh/

Dr Job Metsemakers

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Contribution to the EMD Meeting 8 & 9 December, 2000
(http://www.ulb.ac.be/esp/emd/nl_metsemakers.htm)

Introduction

General practitioners (GPs) possess a wealth of information on the health of their patients. Hence, they are in a unique position to gather information for research, education or management.

Aim

The chief goal of the Registration Network Family Practices is to establish a computerised database containing certain patient characteristics and all relevant health problems excluding minor, temporary illnesses. The database can be seen as a dynamic population sampling frame of chronic and/or severe morbidity, also including risk factors and psychosocial problems. The database has been set up primarily as a sampling frame, allowing researchers to identify patients with particular health problems or combinations of problems. Furthermore the database can be used for longitudinal analysis.

Organisation

On 1 December 2000, the RNH consisted of 55 general practitioners in 21 practices covering approximately 100.000 patients. In all practices computerised health information systems were installed, replacing the hand written records. Totally 5.0 FTE is available for GP’s and the staff.

Classification

The set of patient characteristics to be registered is well defined. There is a clear definition on “a relevant health problem”. All problems are coded using the International Classification of Primary Care (ICPC) using the criteria of the International Classification of Health Problems in Primary Care (ICHPPC-2 Defined), if appropriate.

Structure of the data

On 1 September 2000 patient characteristics and problem lists for 82.411 patients (women 51.2%) had been entered in the database. A total of 341.800 problems have been identified for these patients: 188.219 (55.1%) active and 153.381 (44.9%) inactive.

Quality

Much attention is given to the quality of the data. Training sessions are scheduled before and during the registration. Detailed instructions have been formulated for the general practitioners in a registration handbook/HELP file, which is regularly updated. Furthermore data are checked by computer programmes before addition to the central database.

Use of the Registration Network Family Practices

The database is increasingly being used as a source of information for studies by researchers and students. Researchers find the database a useful tool, but they have to keep in mind that data on the process of care are not directly available. Furthermore, there is a limit to the number of studies which can be performed in the network practices, due to time limitations and the burden on the doctors and patients.

3.3.2.4 Mediterranean countries

3.3.2.4.1 France

3.3.2.4.1.1 Primary and secondary interface in France, the "Marais Breton" registration

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A survey of emergency care. The scope is a semi-rural and tourist region of about 80.000 citizens around the "CHLVO", "Centre Hospitalier Loire Vendée Océan de Challan" in the west of France. The duration is 22 months.

Objectives

A closer analysis of

- ✓ the nature of the perceived needs, i.e. the reasons for calling,
- ✓ the real content of the medical and psychosocial needs,
- ✓ the quality of the answers, from the economical, medical and user points of views.

Human resources

- ✓ 15 GP in charge of 20 to 40.000 persons depending of the season.
- ✓ Emergency "Centre 15" (15 is the main emergency phone nr in France), "SMUR" and emergency service of the "CHLVO"(Centre Hospitalier Loire Vendée Océan), the nursing staff of 9 local hospitals, the medical department of the "SDIS" including 4 fire centres, as well several medico-social actors.
- ✓ A medical doctor is available for the coordination of data collection, anonymisation and classification using ICD-10 and ICPC (French version). He is himself independent of the observed care activities.

Data Acquisition

- ✓ An agreed checklist of process related to emergency activities,
- ✓ Registration of file transmitted in batch to the coordinating doctor,
- ✓ The GPs having initiated a case, will take care of the registration of the follow-up, including data reported from hospitals.

Processing of the data

- ✓ About 5000 emergency reports are expected within 2 years ;
- ✓ The main partner of the project is the AVMFMB, including the coordinating doctor. The project will be achieved in collaboration with the Service des Urgences, the hospital "DIM", the medical "SDIS", the research unit of the Department for General Practice of the University of Nantes ;
- ✓ The methodology and the analysis of the results will be reviewed by an expert in medical statistics, independent of the project.

Expected Results

Identification of potential weak points in the current management of emergencies.

The involvement of all the actors, as well the academics responsible of GP education, should allow to define and to implement optimisations. This taking account of a semi-rural environment.

3.3.2.4.1.2 Prometheus and Episodus, or how to implement medical data collection in the French community setting.

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[4] Public Health School, Free Brussels University

Background

Although private physicians are increasingly using computers in their daily practice, very few data from community medical practice are available in France. Medical data are only valid and reliable if they are coded according to a reference terminological or classification system. The collection of medical data is made difficult, however, by the poor interest of practitioners in the coding task, which is often perceived as time consuming and devoid of direct value to their practice; and also by the lack of standardisation of the various computerised medical record (CMR) systems competing on the market. In that context, two French Regional Unions of Private Physicians (RUPP) have decided to overcome these difficulties by supporting the development of specific open source solutions and tools.

Methods

The Prometheus project, aimed at studying the feasibility of collecting data from the CMR, and conducted in Paris region by the Alpha Medica clinical network in partnership with the Ile-de-France RUPP, is just being implemented. Data on consultation assessment are initially to be collected by 150 computerised general practitioners on a continuous basis during two years, according to different terminological systems, namely the International Classification of Primary Care (ICPC-2), the Braun nomenclature and the International Classification of Diseases (ICD-10). This project involves a couple of software publishers, who have accepted to make at least one of the terminological systems under study available in and exportable from one of their products. After being made anonymous, data collected will be transmitted through Internet to a central server for storage and selective statistical analyses. Apart from being compensated, participant practitioners will be provided on a specific web site with careful real-time feed-back information on their activity and notified if a given health problem appears to be significantly more frequent in their practice, compared to either their own past data or their colleagues current data.

A universal utility called Episodus, able to extract classified data from whichever CMR, is currently under development. It will offer practitioners the opportunity of classifying their data according to any terminological system, and structuring them according to the SOAP scheme. This tool will be experimented soon, in particular in a project of data collection to be conducted in Lyon region by the Rhône-Alpes RUPP since 2002. Data from various heath care providers will be collected by using it, anonymously stored in a central server, and linked into a patient “life line” designed as a global episode-structured record to be shared by health professionals.

Expected results

The registration of data from routine community medical practice may provide health authorities, social insurance managers, and health professionals with (i) useful epidemiological data, including knowledge on the natural history of disease; (ii) objective data on medical activity, to be used in a medico-economic perspective; (iii) meaningful data within the medical record, allowing practitioners to better know their activity, to implement clinical decision support systems, to easily communicate with their colleagues, and to evaluate quality of care given to their patients. Moreover, the availability of a sharable episode-structured record is expected to improved continuity and coordination of care.

The projects being implemented in France should contribute to reach these outcomes. However, their main results must be assessed, in order to propose to community practitioners ever more adapted and user-friendly open source systems necessary to support their interest in the long run. The assessment should include in particular the satisfaction of the participant physicians, the quality, representativeness and confidentiality of the data collected, and the functioning costs of a continuous registration system.

3.3.2.4.1.3 The Sentinel Surveillance of Referral to Hospital in French Primary Care

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Abstract from the first meeting (http://www.ulb.ac.be/esp/emd/fr_letrilliard.htm)

Background

Several pathways exist to get hospitalised in the French free-access health care system. However no data on the referral status are available, even from the national hospital information system called PMSI, regarding the way patients are admitted to hospital. In addition, although complications of hospitalisation are increasingly assessed in the inpatient setting, those arising after discharge have been little studied apart from postoperative nosocomial infections. Our aim was to describe the hospital referral process in primary care in France and to assess complications of all type diagnosed by GPs in the post-discharge period.

Methods

A follow-up outcome study nested within a surveillance system of hospital referrals performed by GPs from the French Sentinel network since July 1997. Data on each referral to hospital are collected by Sentinel GPs and transmitted on a weekly basis via tele-informatics (Internet or Minitel) to the database centre, where a systematic quality control is performed. In particular, reason(s) for referral are entered in a free-text format, and subsequently coded according to the ICPC classification, using an automated tool based on string matching specifically developed to that end. Each reported case of complication that occurred within 30 days of discharge has been investigated through a telephone interview with the GP and the responsible hospital physician. This project was covered by an overall approval of the French Commission Nationale de l'Informatique et des Libertés (CNIL) allowing surveys conducted on the Sentinel system.

Results

Since July 1997, 12 000 referrals to hospital have been individually described by 305 GPs. This system

provides information on the characteristics of patients referred to hospital and on the circumstances of the referral, including the reason(s) for referral. By using the statistical procedures applied on the Sentinel system for the incidence estimation of communicable disease, we could estimate that around 1.3 million hospital admissions result each year from GPs' referrals, which hardly accounts for 10 % of all admissions in French hospitals. Moreover, we observed a seasonal in GPs' hospital referrals, with a regular increase during summer. Ninety-two cases of nosocomial complications have been reported and investigated during the first two years of the project, including 21 nosocomial infections, 31 adverse drug reactions and 40 complications of other type. We estimated at 1.2 per thousand admissions (95%CI, 1.0-1.5 per thousand) the rate of nosocomial adverse events detected in general practice within 30 days of discharge.

Conclusion

The surveillance of hospital referrals is the first attempt on the Sentinel system for systematically collecting data on GPs' clinical practice. It provides epidemiological information to both public health community and participating GPs (through regular feedback procedures). This project, which initially has been funded through a grant from the French Institut National de la Santé et de la Recherche Médicale, will be completed soon.

3.3.2.4.2 Spain

3.3.2.4.2.1 The 'Red de attencion primaria' (REAP) experience in the morbidity record

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Abstract

Forty-four voluntary doctors recorded, in a manual support, the health problems, between 1st may 1993 and 31st April 1994, to analyse the attended morbidity in general practice surgeries in Spain. The registration system was CIPSAP-2 Defined ((ICHPPC-2-d in Spanish) and the analysis unit was the episode.

Recording and validation were realised in a database developed in Clipper. It was checked a sample of 20 random episodes for doctor; the recording of the patients' identification (born date, identity code); the dates of the first examinations, when episodes had changed of heading, when one patient only can have an episode (chronic), and the sex (if the health problems were dependent on the patient sex).

Coverage population was 68.771; attended population: 41.898 (60,92 %); 102.118 episodes and 206.661 consultations.

This recording has not been continued. No similar recording has done either in Spain. No ethical problems has appeared about the utilisation of the information. Limitations of our work are marked for this kind of recording: representativeness of doctor sample, denominator, codification, standardisation of taxes, advantages and limitation of the episode,…Actually, limitations of the information systems in primary health care in Spain, and a poor scientific ambition from the Health Administration and/ or from the Medical Societies to favour representative recording systems of the attended morbidity, with any incentive to doctors and with normalized computer supports.

3.3.2.4.2.2 Regional registration Barcelona

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Unitats Docents de Catalunya Barcelona centre (ICS) (Teaching unit)

Contribution to the Dec 5, 2001 meeting.

(see also the contribution of in exercise on Asthma and Herpes Zoster)

Study design

Prospective study of one year duration

All health care team of two health centres (family doctors, paediatrician, nurses, midwifes, dentist and auxiliary staff)

Registration of all visits during the study period

Health problems gathered based on episodes of care

Quality control

Manuals

Two consensus sessions at the beginning of study

Two audits (4 and 8 months) in order two asses the individual quality of register

Table 3.1. Health centers characteristics

	TOTAL	*TORELLO*	*MANRESA*
Census population:	35,959	15,947	20,012
Health Recorded Population:	32,691	15,492	17,199
Health Care Team:			
Family doctor	15	8	7
Paediatrician	5	3	2
Dentist	2	2	2
Nurses	17	11	6
Midwife	1	1	9
Others	20	11	

3.3.2.4.3 Collection of medical data in Malta

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Abstracts from the first meeting (http://www.ulb.ac.be/esp/emd/mt_soler.htm)

My presentation for the Euromeddata project will give delegates some basic information about Malta, its geography, people, culture, economy and health systems. The Maltese archipelago is situated in the centre of the Mediterranean, and is one of the most densely populated areas in the world. It is also one of the smallest Countries in Europe, with a population of just 380,000. However the Islands have a rich historical background, which is now exploited to enrich the economy with income from tourism. Health care is provided free to all residents by the State, via well-equipped hospitals and health centres, but also by a thriving private system. 290 of Malta's approximately 1000 doctors are full-time primary care physicians, and two thirds of these are private self-employed Family Doctors. Medical data is presently only collected electronically for notifiable diseases, mortality, births, cancers and surgical operations. A system for recording hospital discharges is being implemented. However, the Malta College of Family Doctors is working to collect data from Family Doctors in a longitudinal episode-oriented database built by collating data stored in electronic medical records and classified with ICPC. In this project we are collaborating with the University of Amsterdam Department of General Practice. Some data is also available from data collected by company doctors, who see employees reporting sick from day one of sickness.

3.3.2.4.4 Italy Health Search

(see also Roberto Nardi contribution in Exercise on Asthma and Herpes Zoster)
http://www.healthsearch.it/

- ✓ Goalsgathering reliable data about General Practice in Italy,

  developing epidemiological research and outcomes evaluation in Primary Care,

  getting information about Italian population's health status :
    - scientific community,
    - decision makers,
    - any other interested stake holder within Italian National Health System.

  promoting educational initiatives as well as clinical research activities on collected data, presenting and publishing their results.
- ✓ Structure

  GP Researchers Network,

  National GP Database,

  Health Search School.
- ✓ Institutional framework

  Sponsorships:–GSK–Bayer–Pfizer Italia–Astra Zeneca ;

  National Health Ministry–ISS (Italian Health Care High Institute)–CNR (National Research Council)–Public Health Authorities (Regional and Local) ;

  Partnerships: Universities.
- ✓ Work in progress...

  fostering GP Researchers motivation in data collection and research activities ;

  increasing the number of active researchers ;

  solving technical problems (inhering data collection and transmission) ;

  improving the data collection quality ;

  improving the two ways communication between Researchers and HS National Co-ordination.

3.3.2.4.5 Greece

(see also **Dimitris Kounoulakis** contribution in Exercise on Asthma and Herpes Zoster)

A network for Primary Health Care in Crete, Greece

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Abstract

A recently established network between the University of Crete and several Health Centres serving rural areas of Crete, Greece, had among its main aims the identification of the populations' health problems and needs assessment. A computerised medical records-based

system was developed as part of the HygeiaNet and primary care physicians were asked to record the relevant information for both the different chronic illnesses and other health conditions. Apart from the morbidity data, causes of death were analysed and reported locally.

A Greek health reform attempts to establish clinical governance and clinical effectiveness through regional health authorities. Use of classifications and electronic patient records is reinforced and information data are collected for extracting specific health indicators.

This presentation aims to give an overall picture of the achievements and limitations concerning the health reporting in primary care and at the same time, explore the opportunities, as well as the support, which the current Greek Health Reform is giving the newly established Regional Health Authorities.

References

1. C. Lionis and E. Trell. Health needs assessment in General Practice: The Cretan approach. European Journal of General Practice 1999; 5: 75-77.

2. C. Lionis, I.G. Vlachonikolis, S. Skliros, A. Symeonidis, B.P. Merkouris, E. Kouroumalis E. Do undefined sources of hepatitis C transmission exist? The Greek study in General Practice. J Viral Hepat 2000; 7:218-24.

3. C. Lionis, M. Bathianaki, N. Antonakis, S. Papavasiliou, A. Philalithis· A high prevalence of diabetes mellitus in a Municipality of rural Crete, Greece. Some results from a primary care study. Diabetic Medicine 2001; 18: 768-769.

4. C. Lionis, S. Sasarolis, G I Kasotakis, G M Lapidakis, A I Stathopoulos, Investigation of accuracy of death certificate completion and implications on mortality statistics in Greece. Eur J Epidemiol 2000; 16: 1081

5. Hygeianet. http://www.hygeianet.gr

3.3.2.5 Romania ICPC 2000 - Sentinel dispensaries network for primary care

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Abstract of the first meeting (http://www.ulb.ac.be/esp/emd/ro_marginean.htm)

Objectives

- ✓ development of a tool for collecting data from primary care
- ✓ improving the attitude for research of family doctors

Introduction

Specific research is one of the most important directions the National Society of Family Medicine/GP (NSFM/GP) should act in the near future.

Relevant medical authorities in Romania need valid data about GPs activity.

Therefore the GPs should create some research infrastructure which could be realised through a sentinel stations network at national level.

Problem analysis

As governmental institutions have no financial resources to fund such a project, NSFM /GP finds itself in the position to collaborate in this respect with other organisations. The collected data will be useful in improving CME curricula and in opening the research field to GPs. Valid data will be collected from 1% of population meaning about 100 GPs involved in the network.

Plan

100 family doctors will be trained and organised in a sentinel dispensary network. They will use a computerised medical records for their patients using ICPC-2-E and ICD-10 classifications. Data will be centralised to a national centre (at Department of Family Medicine in the Institute of Public Health Timisoara) and will be worked out by a research groups from SNMF/MG and other specialists.

3.4 TERMINOLOGIES AND CLASSIFICATIONS IN GP/FM DATA COLLECTIONS IN EUROPE

3.4.1 VARIATIONS BETWEEN LARGE DATABASES

Whilst medical training in Europe is relatively homogeneous, the gathering of data by practising doctors is subject to many hazards. We know that the availability of effective and high-quality care for a patient population requires an understanding of the state of health of need of that population. The patient data must be available for analysis in order to determine the tendencies in the disease frequency[30]. Nonetheless, understanding what is related to the world of health care is in no way univocal. Thus, the majority of doctors in northern Europe, under the Anglo-Saxon influence, have recognised the importance of approaching specific problems and the need to place the patient at the centre of the care process. The southern part of Europe, which I consider to begin at the Belgian linguistic border and encompass Germany, is characterised by a "Bismarckian" health system. This system attributes an important place to the individual relationship in the organisation of health care. The doctors in this region have therefore remained more attached to a very individual and medico-centred care system; they use the disease rather than health as a dominant paradigm. The informative systems in Belgium, France, and Germany are therefore conditioned by the individual approach and the non-planning of care systems as well as by a strong individualism from the service providers.

One is therefore not surprised to note that the data banks allowing the continuous recording of comorbidity in general medicine are only developed in northern Europe and particularly in Iceland, England, Denmark, Norway, Finland, and the Netherlands. There is an exception in France where the Thales data bank whose objectives are strictly commercial. The German systems currently being established are directly derived from the hospital milieu.

This explains that the classifications, terminology, and nomenclatures being used are extremely diverse and rarely compatible with each other. There is a tendency to converge towards the family of WHO classifications, which also seems to want to adopt ICPC. However, there is still a large margin between the taxonomists favouring classification systems on the one hand and linguistic engineering on the other hand, which would like to express medical sensitivities through the analysis of free texts.

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[30] SNOMED ® Clinical terms ®. Requirements Analysis. Consultation document DRAFT Version 10 (2000-10-12) published on http://www.snomed.org/snomedct_txt.html accessed December 10th 2001.

3.4.2 TAXONOMY AND LINGUISTIC ENGINEERING, A INEVITABLE ENCOUNTER

The field of knowledge represented by the medicine appears like a terra incognita, travelled by many explorers seeking the Holy Grail. One can distinguish two groups through the works published and the systems put in place.

On one hand, there are the doctors in the field. The taxonomist and nosographists from the word 'go' tempted by a classifying adventure. They are grossly divided into two groups depending on whether they are centred around the problems or around the disease, whether they belong to ambulatory or hospital systems, belonging to the national or international classification that they so often passionately defend and whose visions of the science of medicine complement each other.

Within these groups, some go further than others. When confronted with informatics, they seriously question the actual structure of the patient's meeting and the distribution through time of the problems they encounter. The principal tools of international classification, such as the ICD, ICF, ICPC, the Read codes, Snomed, and UMLS are the structured reservoirs of an evolutionary and complex knowledge for which transcribed terminologies are decisive. In a way, they are the creators of codes and classifiers, occupying the right side of Figure 3.5 and becoming more redundant as they shift towards the left, towards standard terminologies. Some of them have caught sight of the power of the tools developed by the second group.

On the other hand, one finds the defenders of linguistic engineering, physicists, linguists, engineers, and doctors in computer science. They are fascinated by the complexity and the wealth of language and are committed to perfecting its meanings by using the power of computers[31]. The computer language laboratories have invested in the field of Natural Language Processing and are closely followed by the voice recognition enthusiasts. Coming from other disciplines than medicine, adherents of Data Mining, they have the experience of a global processing of information and are supported by a powerful movement present in all industries: Knowledge Management. If one considers Figure 3.5, one notes that these professionals approach the problem from the left of the diagram, which is to say through free text. They do not want to lose any of its wealth or its nuances. Their goal is to perfect computer techniques for the conceptual dissection of the medical language, the semantic and grammatical analysis, and for conceptual tagging. They work on terminologies that they call 'third generation' and organise multinational projects such as GALEN (http://www.opengalen.org/). Some of them have bridged gaps with the practice of medicine in the field where the classification steps is unavoidable to truly grasp reality.

3.4.3 UNDERSTANDING THE DIFFERENCE BETWEEN THE TERMS

It is not easy to grasp the difference between the terms 'terminology', 'nomenclature', 'classification', or 'codes'. The two following figures will help the reader begin to understand the nuances.

One goes from a free text, a simple reproduction of the handwritten text to terminologies, characterised by the use of a controlled and standardised vocabulary. The classifications plan for conceptual categories based on an objective. The codes are used by machines which, if

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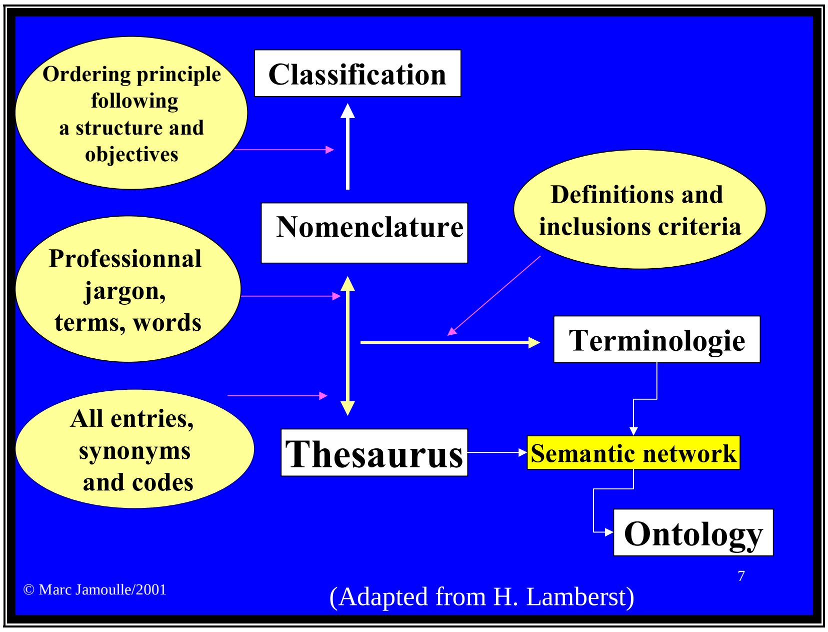
[31] Pierre Zweigenbaum. Encoder l'information médicale : des terminologies aux systèmes de représentation des connaissances. *InnovationStartégique en Information de Santé,* (2-3) : 27-47, 1999.

they have mnemonic capabilities, can be used directly by researchers using the old-fashioned 'paper' method, that is to say without a computer.

Once the terminologies are structured according to a hierarchical system and given a numeric or alphanumeric identifier, they can be called nomenclature (such as SNOMED) and are sometimes called classification (such as ICD or RCC). The terminologies transcribed into one or more classifications are the most interesting tools to collect data through general medicine software programs. In Figure 3.4, one sees a screen showing an example of a terminology transcribed in ICD10 and ICPC-2 (Dutch language, Dr. Lamberts, Amsterdam).

For deeper insight in terminological wealth and definitions please do refer to the work of the third working group of the CEN TC251[32]



Source: Medinfo 2001, Tutorial[33] Adapted from Henk Lamberts [34]

Figure 3.3. Terms and terminology

The terminologies are at the heart of the research of the current research in the realm of medical software program. One distinguishes first generation terminologies (simple lists of standardised terms), second-generation terminologies (complex groups of terms in a hierarchical order and classified on multiple levels), and third generation terminologies. The latter stem directly from linguistic research and truly use the powers of informatics through semantic networks. One will then sooner speaker of ontology. The work of the GALEN[35] group is aimed in this very direction.

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[32] ISO/TC 215/WG3. Health Informatics —Vocabulary on terminological systems. Working document: 2000-10-21 Reference number : ISO/WD nnn-n

[33] Jamoulle M, Booth NW, Bernstein R. Standardisation, structure and exchange of information in primary care : the aim of clinical coding Tutorial presented at Medinfo 2001, London.

[34] Lamberts H, Wood M, Hofman-Okkes IM, (eds.) The International Classification of Primary Care in the European Community: With a Multi-Language Layer. Oxford University Press, Oxford, 1993.

[35] Internet site ; http://www.opengalen.org

One will note the swing to the left in Figure 3.5, Reduction of the redundancy, from free texts to codes. Linguistic engineering occupies the right of the table and the taxonomists occupy the left. MJ, Medinfo 2001, tutorial that demonstrates how information's redundancy is reduced as it progresses towards coding[36]. If a code is exhaustive and exclusive, its redundancy is nil : the loss of a single letter in the code causes one to lose all of the information. The loss of redundancy is achieved to the benefit of a quantification of the data.

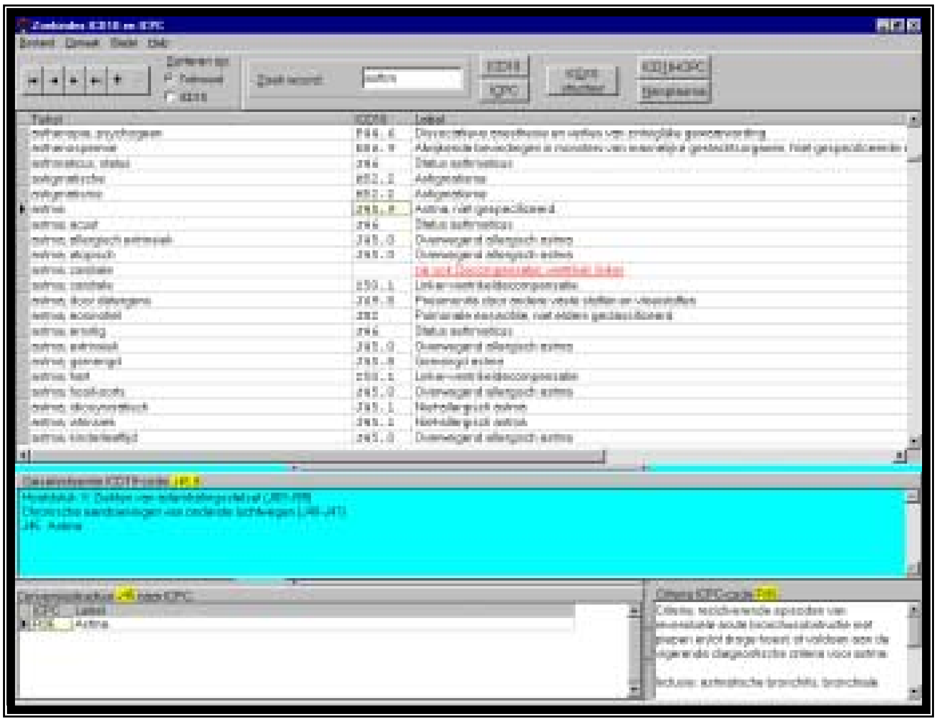

Figure 3.4. Transcribing ICPC/ICD and terminology of 70.000 entries.
(Lamberts, UVA, 2001) The cursor is on Asthma.

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[36] Battail G. Théorie de l'information, application aux techniques de la communication. Masson, Paris, 1997

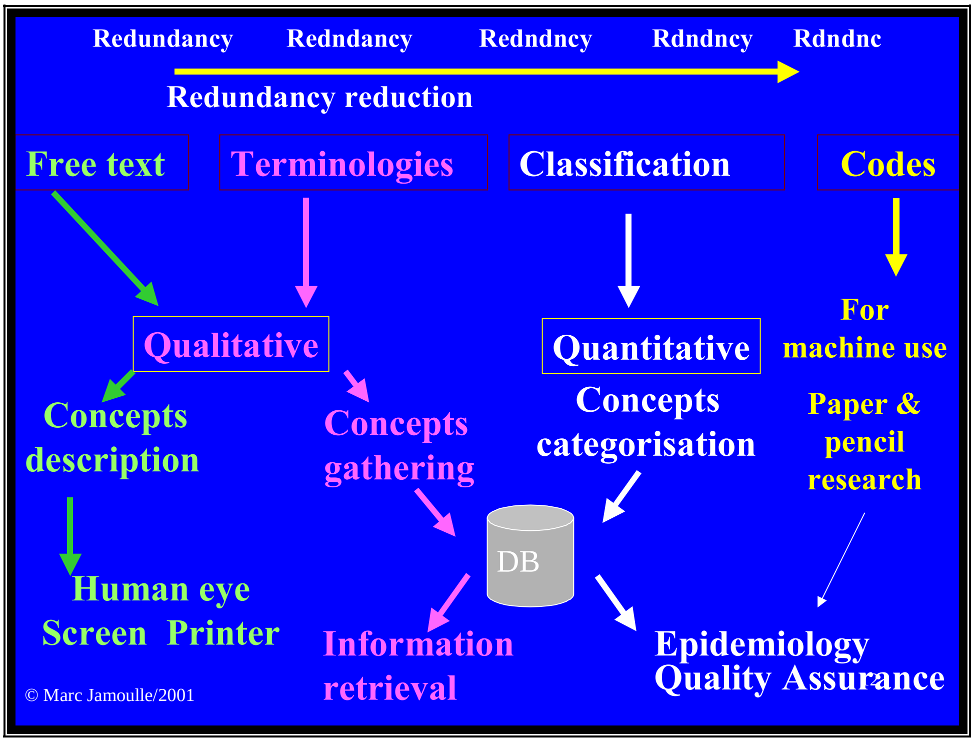

Figure 3.5. Reduction of redundancy, from free text to codes.

Linguistic engineering occupies the right of the diagram and taxonomists occupy the left.MJ ; Medinfo 2001 tutorial

3.4.4 VARIOUS CLASSIFICATION, NOMENCLATURES, AND TERMINOLOGIES USED IN EUROPE

3.4.4.1 The main international terminologies or classifications

3.4.4.1.1 ICD

“The ICD is not very aptly named. It is actually a nomenclature rather than a classification, which stems from more than one organisational principle. The aetiological dimensions (origin of the disease), topographic dimensions (where the disease is found), operational dimensions (test relating to the disease), as well as the ethical and political factors each play a complex, or even contradictory role”[37]. The 10th revision (ICD-10) was published in English in 1992. The translation for ICD-10 is now available in more than 20 languages. ICD-10 consists of several volumes including a tabular list of approx. 17.000 diseases as well as an alphabetical index. It has been revised ten times since it was first published in 1890[38].

ICD-10 is currently present in many countries but is only available in English language for the electronic version. The French translation exists in printed form but the French language electronic version is only available as private copies although the WHO has planned for it in the last five years. Translations into other languages rest upon each individual country. Many countries, however, keep ICD-9 as their health information system due to the upgrade costs

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[37] Geoffrey C. Bowker L’Histoire des Infrastructures Informationelles University of Illinois at Urbana-Champaign bowker@alexia.lis.uiuc.edu http://www.info.unicaen.fr/bnum/jelec/Solaris/d04/4bowker.html accessed December 10th 2001

[38] ICD-10. International Statistical Classification of Diseases and Related Health Problems. Geneva (Switzerland): World Health Organisation; 1992.

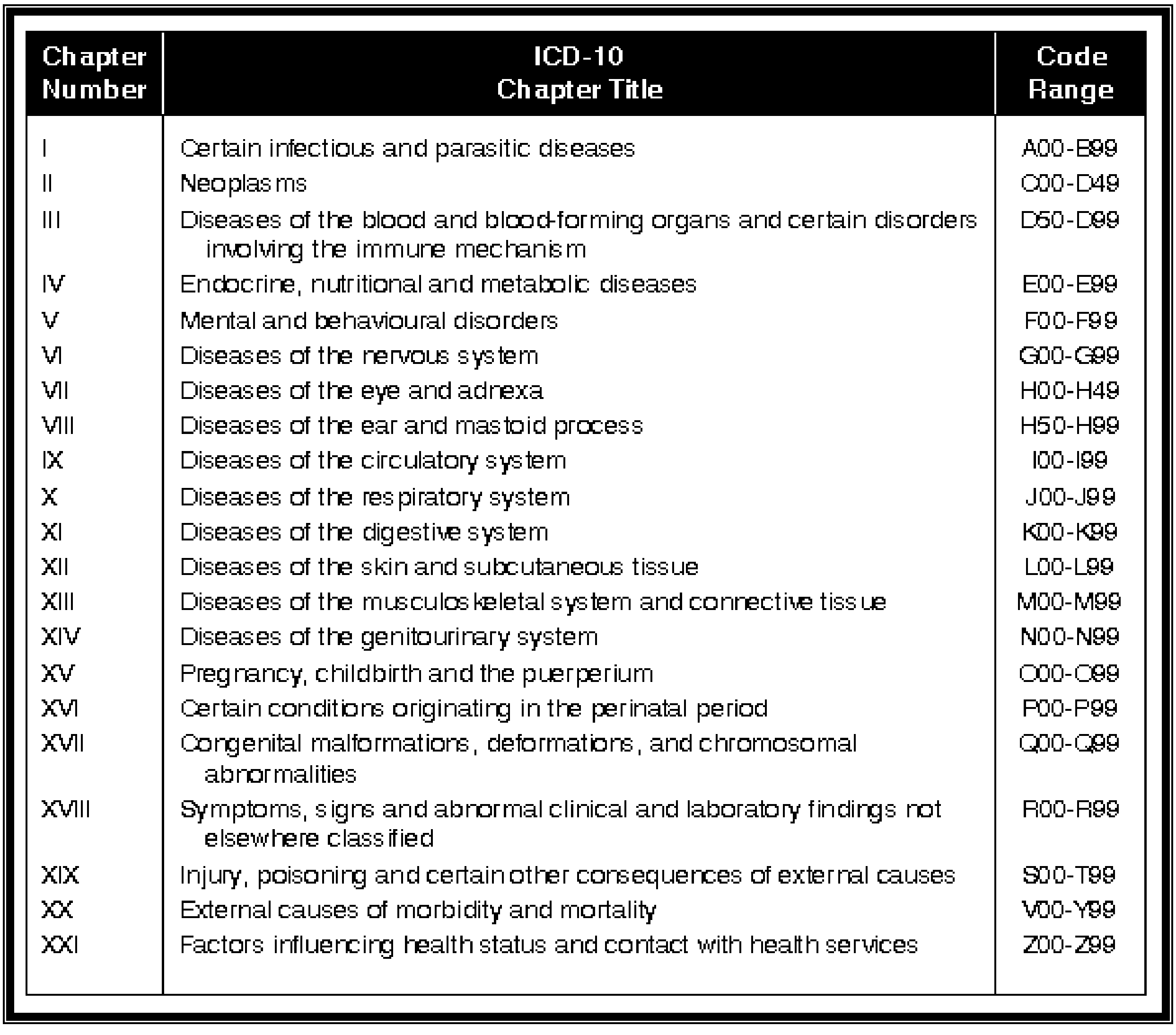
and the absence of an internationally available translation. Nonetheless, ICD-10 will soon become the standard de facto for all of the hospital services for which it is adapted. Nevertheless, certain modifications are underway in each country's national centre without any form of centralised co-ordination. Holland, for example, seems to have taken in ICD-10 such as it was planned for the USA. Each country has its own coding centre that attempts to adapt the tool according to the local requirements.

The main problem for ICD-10 is that disease and medical activity are central to its function. The patient and his/her request for care only play a complementary part. It is therefore a tool with nearly 15.000 items particularly adapted to studying medical production yet detached from medicine's basic objective, which is to respond to a request for care.

The ICD is a historical construction developed since the 19th century using mortality tables. The ICD treats diseases, it is centred on the care provider and is constructed in a linear manner with chapters having been added one after the other through the centuries. (Cf. Figure 3.6 Differences between ICPD and ICD Medinfo 2001, tutorial)

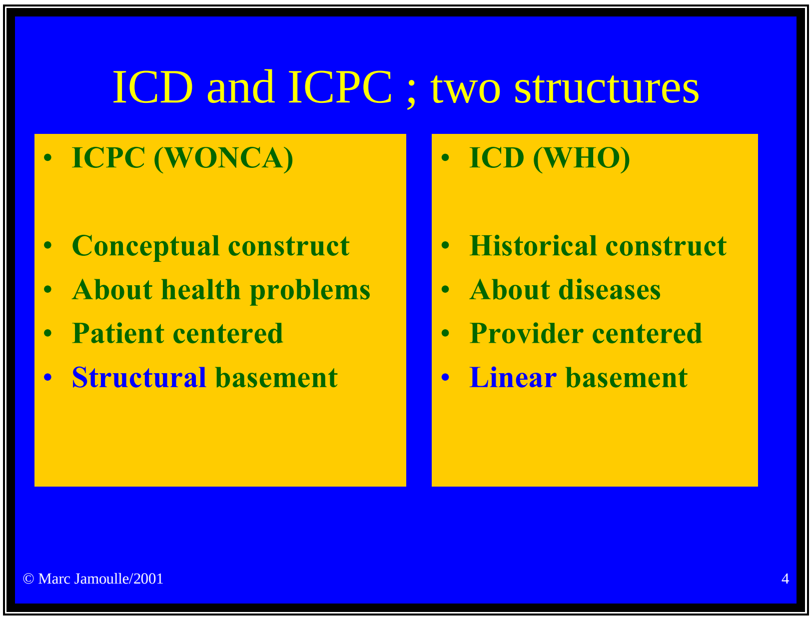
Finally, just as Bowker had emphasized (op. cit), this is in no way a classification but rather a nomenclature. A nomenclature is a classified terminology. ICD's terminological contribution is weak whilst its codification is complex, linear and includes several overlaps.

Table 3.2. The 21 chapters in ICD-10



Chapter Number	ICD-10 Chapter Title	Code Range
I	Certain infectious and parasitic diseases	A00-B99
II	Neoplasms	C00-D49
III	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	D50-D99
IV	Endocrine, nutritional and metabolic diseases	E00-E99
V	Mental and behavioural disorders	F00-F99
VI	Diseases of the nervous system	G00-G99
VII	Diseases of the eye and adnexa	H00-H49
VIII	Diseases of the ear and mastoid process	H50-H99
IX	Diseases of the circulatory system	I00-I99
X	Diseases of the respiratory system	J00-J99
XI	Diseases of the digestive system	K00-K99
XII	Diseases of the skin and subcutaneous tissue	L00-L99
XIII	Diseases of the musculoskeletal system and connective tissue	M00-M99
XIV	Diseases of the genitourinary system	N00-N99
XV	Pregnancy, childbirth and the puerperium	O00-O99
XVI	Certain conditions originating in the perinatal period	P00-P99
XVII	Congenital malformations, deformations, and chromosomal abnormalities	Q00-Q99
XVIII	Symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified	R00-R99
XIX	Injury, poisoning and certain other consequences of external causes	S00-T99
XX	External causes of morbidity and mortality	V00-Y99
XXI	Factors influencing health status and contact with health services	Z00-Z99

ICD alone therefore only partially satisfies the terminological demand from the computer systems that allow standardised information to be stored as readable text. It is furthermore too complex (near 15.000 codes) to be used as classification on a daily basis by non-specialised coders. Its obligatory use by German general practitioners was unanimously criticised.



ICD and ICPC ; two structures

- **ICPC (WONCA)**
- **Conceptual construct**
- **About health problems**
- **Patient centered**
- **Structural basement**

- **ICD (WHO)**
- **Historical construct**
- **About diseases**
- **Provider centered**
- **Linear basement**

Source: Medinfo 2001, tutorial

Figure 3.6. Differences between ICIP and ICD

3.4.4.1.1.1 ICD-10-SGBV and ICD-10-Diagnothesaurus

In the Federal Republic of Germany, use of ICD-10 is obligatory for coding causes of death and mortality statistics since 1998; its is voluntarily used for medical documentation and morbidity statistics in ambulatory medical services since 1996.

A version called “ICD-10-SGBV” came into operation on January 1st 2000. The central part of ICD-10-SGBV is the “ Minimal Standard”, a minimal set of codes that are obligatory for general practitioners, for ambulatory medical specialists, and in Emergency services.

Professor Wolgang Giere of the Johann Wolfgang Goethe-Universität in Frankfurt is the head investigator in the development of “ICD-10-Diagnothesaurus”. This is a validated collection of German language diagnostic terms and expressions coded according to ICD-10-SGBV. Approximately one third of the ICD-10-Diagnothesaurus contains diagnostic expressions that are not present in ICD-10. This also increases the quality and profitability of coding software but disminish the comparability between various countries.

This product is official in Germany. The ICD-10-Diagnothesaurus contains approximately 10.000 diseases coded diseases that are commonly encountered by doctors. Furthermore, a software version with more than 200.000 coded search words was developed and made freely accessible to doctors.

3.4.4.1.2 ICF

Although the International Classification of Function, Disability and Health (ICF) is recently published and not used by medical databases, it seems useful to mention it due to complementary potential. Officially launched in Washington in October 2001, ICF finds its place among the WHO Family of Calssification[39].

ICF's purpose is to propose a uniform and standard language as well as a framework for the description of states of health and other conditions related to health. ICF defines the components of health and a number of elements of well being connected to health (such as education or work). The fields covered by ICF can therefore be designated by the terms designating the fields of health or those related to health. These fields be described from various perspectives, such as the organism, the person as an individual or the person as a social being, and according to four basic views:

- ✓ body functions,
- ✓ body structures,
- ✓ activities and participation,
- ✓ environmental factors.

As a classification, ICF systematically regroups the various fields in which evolves any person with a given health problem (for example, what a person can effectively do, or is capable of doing given a particular disease or disorder).

Source: http://www3.who.int/icf/

Figure 3.7. ICF main page

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[39] ICF, see the site http://www3.who.int/icf/

3.4.4.1.3 ICPC

The International Classification of Primary Care is the result of a long conceptual process. Many north European general practitioners contributed to its development since the seventies. From the very start, ICPC is biaxial and conceived in a structural manner. It includes 17 chapters with a localising quality crossed with 7 founding components of the doctor-patient contact. It is oriented towards the patient and covers the patient-doctor cluster. It also allows one to collect data emerging from the first care level and is a means of operational analysis for basic health activities.

Based on a dynamic vision of data processing, it allows one to gather data by episode. Its first aims was research in the field of family medicine and it is now moving towards the collection of data necessary for maintaining personal medical files. Thanks to the development of classified terminologies and to its compatibility with the International Classification of Diseases, it will allow the exchange of information between the different levels of health care.

Table 3.3. Example of CISP-2 features in symptom mode with the ICD-10 transcriptions

A11 TORACIC PAIN NP	R07.3 R07.4
excl: pain attributed to the hart K01, to the thoracic lining L04, to the respiratory system R01	
A13 PREOCCUPIED WITH / FEAR OF A TREATMENT	Z71.1
incl: preoccupied with the consequences of a drug or any other treatment	
excl: side effects of a drug A85, complication from a medical or surgical treatment A87	

The work of the WONCA's (World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians) Classification Committee has now become the authority in the subject. The International Classification of Primary Care (ICPC-1) was published in 1987 and has become a standard. It demonstrated its capacities to process medical information in a dynamic way, whether in clinical research or in a working organisation. Translated into more than 20 languages, ICPC-1 has greatly extended the field of knowledge in the world of family medicine and has been the subject of a great number of publications. The second version, ICPC-2 was published in printed form in 1998[40] and in electronic form in 2000[41]. A bibliography is also kept up to date[42].

The ICPC is in fact 7.000 conceptual categories that can be used as is for "pen and paper" field studies. Coupled with an extended medical terminology, ICPC is obligatory in Holland, Norway and Belgium in general medicine software programs. It is widely used in Europe[43] and is published in most languages. One should also note that ICPC is heavily distributed in eastern European countries as well as in Russian China, and Australia.

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[40] ICPC-2 International Classification of Primary Care, second edition. Prepare by the International Classification Committee of WONCA. Oxford: Oxford University Press, 1998.

[41] Okkes IM, Jamoulle M, Lamberts H, Bentzen N. ICPC-2-E. The electronic version of ICPC-2. Differences with the printed version and the consequences. Fam Pract 2000; 17: 101-6.

[42] ICPC Bibliography updated by F. Mennerat. Internet site of the WONCA International Classification Committee: http://www.ulb.ac.be/esp/wicc/icpc_ref.html

[43] Jamoulle M. use in the European Community WONCA International Classification Committee at the 16th WONCA World Congress of Family Doctors, Durban, South Africa, May 13th to 17th 2001. http://www.ulb.ac.be/esp/wicc/icpc_2001.html accessed December 10th 2001.

3.4.4.1.3.1 The LOCAS

This is a Window software package (DLL) published by Care Edition, a non-profit-making organisation based in Waterloo, Belgium. It contains a French standardised first generation terminology classified in the ICPC allowing for the coding of problems (symptoms a diagnoses) and of procedures (acts) in family medicine and primary care. The system includes a data recovery zone for data that the user might be missing. LOCAS is based on the ICPC will be followed up by LOCAS-2, based on ICPC-2. LOCAS-2 will have a more complex terminological approach. LOCAL is currently used in various software and experimental programs in Belgium and in France.

3.4.4.1.3.2 The Belgian bilingual terminological project

Since ICPC is obligatory in Holland, intensive research was carried out and the Dutch classified terminology elaborated by Prof Lamberts within the framework of the WICC has already been adapted to Flemish. The federal Belgian Public Health minister supports the elaboration of a bilingual French-Flemish terminology that would be strongly recommended in Belgian software programs. A German adaptation is also being considered. The product will be available in late 2002.

3.4.4.1.3.3 ICD-10: extended Danish ICPC

The Danish medical services use two different classification systems for coding diagnoses: ICD-10 for hospitals and ICPC for general medicine[44]. The FynCom organisation[45] developed a conversion between these two classification systems so that general practitioners can use ICPC both to computerised medical files as well as to send an electronic referral to a hospital under an ICD-10 code.

3.4.4.1.4 Dutch ICPC-Works

The Dutch general medicine organisation has published a software package that search for codes using terms as a starting point[46]. In the Netherlands, ICPC is obligatory for all of the electronic medical folders in general medicine. ICPC is a part of basic university education in the country.

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[44] Lorentzen EF. International Classification of Primary Care converted to ICD-10 : Extended Danish ICPC : In : Proceedings of Medical Informatics Europe ’96, 1996 : 188-92.

[45] FynCom 1991-1999 Expectations, Results, Outlook. FynCom, Rugaardsvej 15,2 5000 Odense C, denmark

[46] Westerhof H, ICPC demonstration and search program, version 2, October 1997, revision 2, Netherlands Huisarts Genootschap, 1998

3.4.4.1.5 The ICD-10 conversion algorithm versus that of ICPC

The general practice department of the university of Amsterdam has produced an ICD/ICPC terminology transcribed into several languages[47]. This tool contains 69.323 terms, 11.359 ICD-10 codes, and 726 ICPC codes and allows one to locate codes by entering the selected term (see Figure 3.4). This tool was developed by researchers in the Department of General Practice, based on transcribing work done by the WONCA International Classification Committee. This type of product also exists in Canada (Encode-FM) and in Australia (ICPC-Plus).

3.4.4.1.6 READ CLINICAL CODES

The Read Codes (RCC) is a very extensive list of terms destined to be used by all health professionals to describe the care and treatments administered to their patients.

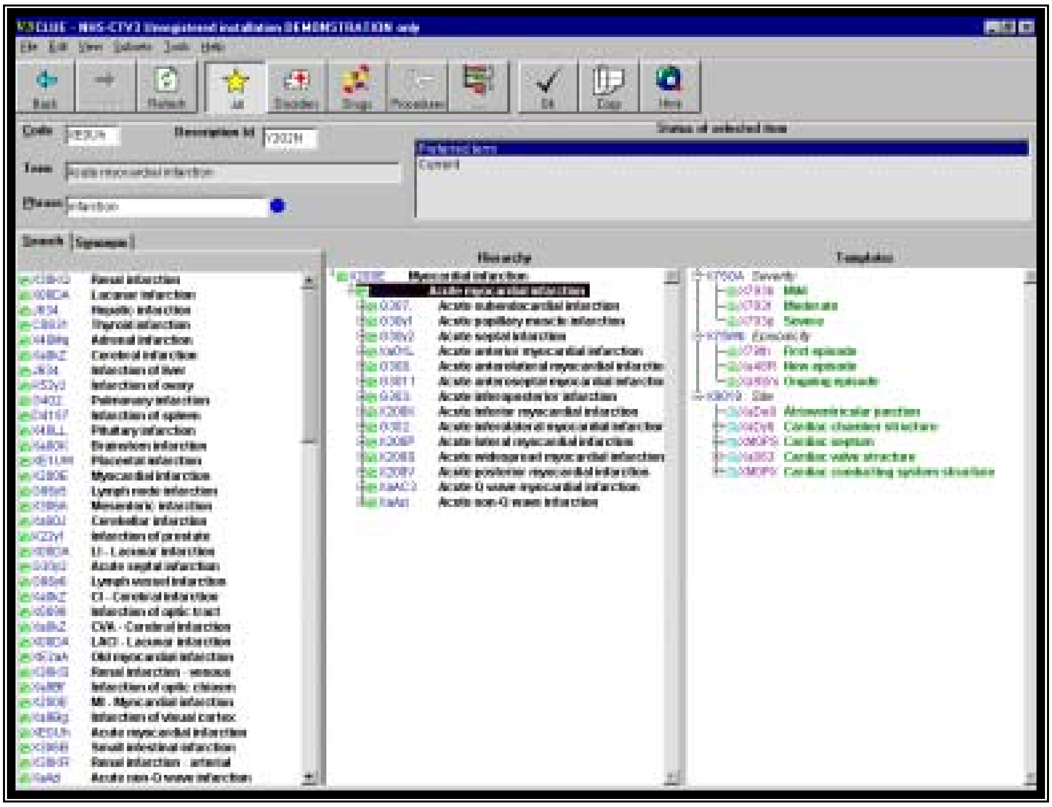

Figure 3.8. NHS Clinical Terms (Read Codes), version 3.
The cursor is set on infarction (Clue software)

They allow one to seize and retrieve data in a clinical natural language in computerised medical folders. The Read Codes are used by a large part of the family physicians in the United Kingdom to record detailed patient care as well as for daily management.

The RCC are mapped to the international classifications such as ICD-9 and ICD-10. Initially developed by Dr James Read, they now belong to the British Ministry of Health. The Read

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[47] Lamberts H, Oskam SK Zoelalgoritme ICD and ICPC versie 1, UVA, Department of General Practice, Amsterdam, 2001

Codes are updated every semester (on a monthly basis for the medications). This task is coordinated by the information department of the NHS (National Health Service) in close collaboration with all of the clinical professions including doctors, nurses, paramedics and pharmacists. The designation NHS Clinical Terms tends to replace that of RCC.

Figure 3.8 shows the terminological entries obtained thanks to the program CIC LOOK Up Engine distributed for free[48].

3.4.4.1.7 SNOMED and SNOMED-CT

SNOMED-RT is the latest version of SNOMED[49] (Systematised Nomenclature of Medicine) is published by the American College of Pathologists (ACP). The existing versions of SNOMED are essentially used by pathologists. In the UK, it is sometimes used in pathology, but in a clinic, the Read Codes are the norm. “SNOMED Clinical Term” (or “SNOMED-CT”) is the name proposed for a new system of clinical coding, which fuses the Read Codes and SNOMED-RT. SNOMED-CT is the result of an agreement between the ACP and the NHS. SNOMED-CT is expected in 2002. It could become the standard clinical terminology for Anglo-Saxon countries. The use of SNOMED-CT could become compulsory in the UK clinical coding systems.

SNOMED is a multi-axial systematic nomenclature/ it allows one to project medical concepts along several orthogonal axes. The variety of these axes distinguishes this nomenclature from a mono-axis classification such as ICD, which is essentially limited to one type of concept: diagnostics. Furthermore, each axis is itself hierarchically structured, with the various levels being linked by relations of specialisation.

SNOMED, which remains today as the only system that still uses a strict hierarchy, is available since 1993 in an enlarged version containing 11 axes or modules with approximately 140.000 terms and with translations into French and Russian (for example)[50].

3.4.4.1.8 UMLS

In 1989 the American National Library of Medicine developed, and now updates, a terminological system called United Medical Language System (UMLS)[51].

The UMLS project, developed by the National Library of Medicine of Bethesda (already one of the founders of MeSH from Medline), dates back to 1986 and aspires to a **unified medical language**. This system is used to translate and conceptualise a medical information source to render it accessible to relevant questioning. This descriptive language analyses the medical language, basing itself on several principles:

1 – The **metathesaurus**: the 2001 edition of the Metathesaurus includes approximately 800.000 concepts and 1,9 million terms stemming from 60 different biomedical dictionaries.

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[48] CLUE Bowser for NHS CTV3, Version: 2.0.0021 available on the Internet site of the Clinical Information Consultancy (CIC). http://www.clinical-info.co.uk/

[49] Côté RA, Rothwell DJ, Palotay JL, Beckett RS, and Brochu L, eds. *The Systematised Nomenclature of Human and Veterinary Medicine: SNOMED International.* College of American Pathologists, Northfield, 1993.

[50] Baumann RP. Données médicales en Anatomie Pathologique- Evaluation d’un grand collectif (530.000 Diagnostics codes en SNOMED). Revue médicale de la Suisse romande, 119, 805-824, 1999

[51] Internet site http://www.nlm.nih.gov/research/umls/

It is itself the melting pot for several distinct assorted thesauri (MeSH, SNOMED, ICD,…) and recognises synonyms, lexical variations and associative concepts; the thesaurus' role ("meta" because it regroups several thesaurus) consists of drawing up a list of all of the vocabulary from available medical expressions.

2 – The **semantic network**: whilst the metathesaurus is an enumeration of all of the existing medical vocabulary, listing almost the entire series of words that might be featured in a medical document, the semantic network is to the UMLS what verbs are to a sentence: it is the compendium of all of the relations that could develop between different concepts.

For example, one can define ties of "belonging" (synonyms: "means the same as"), ties of conceptual association (connected elements: "is related to"), a relationship organising the terms from the generic to the specific ("is a part of") with a notion of inheritance of properties by all of the members of a generic family, or even a tie introducing the time factor ("is temporally linked to")…

3 – Unlike a metathesaurus wherein one term can appear in several places due to different contexts (because the thesaurus creates the semantic context at the root of the term's indexing, creating an environment that is necessarily imperfect because it is incomplete), **a same concept is unique** is unique in a semantic network, equal on that level to the natural language where the concept is defined by the relations that link that same medical expression to the document's other terms.

The ULMS consequently represents the attempt to approach as much possible the natural language ("unified medical language"), to disambiguate and eliminate possible redundancies through a reading of the medical documents in context. This type of project already reveals a type of **semantic program** that would be able to truly "understand" a medical document using concepts that transpire from the text.

UMLS is not yet very common in data collections but it can serve as a base for proprietary dictionaries and this common use could favour coherent analyses.

3.4.4.2 Proprietary dictionaries and terminologies

3.4.4.2.1 Kasugraphy and DRC (Dictionary of Consultation Results)

Based on the studies of the Austrian taxonomist and epidemiologist R.N. Braun and his students[52], Kasugraphy is used by German language researchers (Switzerland, Austria, Germany) as well as French speaking researchers (France). It does not process motives for consultation but rather results formulated at the end of the consultation. Four groups of results can be determined and each can be designated by a letter of the alphabet according to increasing degrees of uncertainty surrounding the case's aetiology. Kasugraphy comprises the definitions of 300 "cases" that are frequent in Western Europe and within the framework of the socially insured. Each of these 300 cases is clearly defined.

The DRC's[53] objective is to describe consultation results stemming from the biomedical norm. In order to accomplish this objective, it defines the semiology of the morbid sates most frequently encountered in general practitioners' daily activities. The Dictionnaire de

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[52] Landolt-Theus P, Danninger H, Braun RN Kasugraphie. Benennung der regelmässig häufingen Fälle in der Allgemeinpraxis. Reihe Praxishilfen – Wissen, Tips und Service für den Arzt, Heft 15. Kirchem Verlag, Mainz. (1994)

[53] Published by the SFMG (Société Française de Médecine Générale), see http://www.sfmg.org/dico.html

Médecine Générale (Dictionary of General Medicine), an extension of Braun's work, is the collective work of the doctors of the SFMG (Association of French General Medicine).

3.4.4.2.2 OXMIS

The OXMIS classification (Oxford Medical Information System) was developed very early on[54]. It is a mix of the ICD, 8th revision and of surgical operation codes applicable in the UK and known at the time as OPCS. OXMIS was used in many incidence and prevalence studies. It was implemented in the British VAMP software program and has become the reference classification for the General Practice Database, hence the question supra.

3.4.4.2.3 VIDAL

In France, VIDAL[55] is synonymous with reference work for prescribed medication. VIDAL is also available in an electronic version and contains an extensive terminology that allows one to manage the information on pharmaceutical leaflets. Recently, VIDAL's terminological banks were merged with a terminological tool classified on ICD-10 and used in France for coding hospitalisation summaries. Furthermore, the VIDAL terminology is actually the subject of a transcription to ICPC. One can therefore appreciate the appearance of a vast terminology on both main international classifications. This becomes all the more interesting when one notes that VIDAL is a part of the Vivendi Universal Publishing group, which publishes reference works on medication in almost 50 countries.

3.4.4.2.4 NAUTILUS

NAUTILUS is a third generation terminological system based on a standardised lexicon and uses a semantic network to develop sentences representative of reality. The NAUILUS[56] data representation technology is inspired by the power of representation in natural languages: just as any medical information can be described by one or more sentences in English, with a relatively restricted vocabulary, NAUTILUS uses a tree structure for terms stemming from the lexicon as a description technique. The Nautilus lexicon is available in Open source through the Odyssey project.

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[54] Perry J, ed. OXMIS problem codes for primary medical care. Oxford: OXMIS Publications, 1978.

[55] Internet site http://www.vidalpro.net/

[56] Internet site http://www.nautilus-info.com/

3.4.4.2.5 CLINERGY

CLINERGY is a third generation terminological system that captures data. This system has been commercialised in the UK. It was constructed from GALEN terminology server comprising an adaptation of a GALEN Common Reference Model transcribed to the Read Clinical Codes. It is destined to be used by primary care doctors and is available as a software component, which can be added to a number of clinical systems offered in the UK.

3.4.4.2.6 Other electronic dictionaries

The computer systems developed in general medicine are innumerable and rare are those that were conceived to include standardised elements. Everyone has thus created his/her own dictionary, progressively expanding it to meet new needs. Some have become very important and have found their place in multi-user systems, such as OXIMIS (mentioned above). The French database THALES functions with such a dictionary proprietary and generally with all of the medical files. The passage from a proprietary product to a standardised product requires a standardisation process that can be costly in time, money, or self-respect.

3.4.5 PERSPECTIVES

3.4.5.1 A WONCA collaborating centre

One notices that international tools clearly dominate the sphere of data collection and medical computer sciences in general. For the taxonomists, a standardisation path was cleared with the creation of a centre that collaborates with the WONCA in northern Europe. The Amsterdam-Newcastle WONCA collaborating centre was created by a joint effort of the general practice department of the University of Amsterdam (Prof Lamberts) and the Sowerby centre for health informatics of the University of Newcastle (SCHIN) (Dr Nick Booth).

The first brought his expertise in transcoding ICD/ICPC/ICF. The second is an expert on Read Codes and is a member of the SNOMED-CT international board.

The Amsterdam-Newcastle group has submitted its first report to the WICC. The ICD-10/ICPC/SNOMED-CT correspondence is particularly difficult but progressing well. The availability of such validated transcription tools is however the only guarantee of having, some day, comparable data in Europe. Below is a significant extract from the report that stresses that there is still a long way to go to reach an operational standardisation.

> *"A main goal still is that ICPC-2-E and its mapping to ICD-10 must be made available in all electronic patient records in family practice. The addition of the four digits of ICD-10 to ICPC-2 is essential to support a world-wide implementation of ICPC-2 in EPRs, at the same time supporting the collaboration between WHO and WONCA by the consequent use of its mapping to ICD-10 and its alphabetical index in the available languages."*[57]

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[57] Okkes I, Booth N, Lamberts H. Report of the Amsterdam – Newcastle WONCA collaborating centre “the international classification of primary care in its relation with other classification systems and nomenclatures relevant for general practice\family medicine” to the WONCA classification committee meeting in Paris, September 7-12, 2001

3.4.5.2 A WONCA-WHO collaboration

The WHO recently expressed a very interesting outlook. During a working session in the spring of 2001 in Copenhagen (Dk), representatives from the WHO classification group met members of the WONCA classification committee. Here are the conclusions that stemmed from their work:

- ✓ One notes the advantages that could result from including ICPC-2 in the family of WHO classifications as a classification for general practice;
- ✓ ICPC-2 includes the classification of reasons for meeting, missing in ICD-10;
- ✓ ICPC-2 complements ICD-10 limitations concerning the description of primary medical services;
- ✓ ICF could usefully complement certain ICPC-2 features;
- ✓ Some ICD-10 features correspond to more than one ICPC-2 code and must be taken into consideration.

There is a clear mutual recognition and a will to supply the international community with a global and coherent coding system.

Finally, in October of 2001, a meeting between the people in charge of the WHO and WONCA centres decided:

- ✓ To proceed with a conscientious analysis of the concepts “reason for meeting, health problem, disorders and diseases “ in the ICD and ICPC and to describe the fields that these two classifications cover within the context of the WHO classifications family;
- ✓ To find a way to create a terminology for classified concepts that ensures a parallel use of both classifications within the WHO classifications family;
- ✓ To propose a transcription between both classification types 1:1 and n: 1 that is to say from from fine granularity to coarse granularity.

3.4.5.3 Towards a European “Open Terminology”

During the most recent Medinfo2001 symposium held in London, a consensus was reached among the attending scientists. This consensus was centred on a proposal by Jean Marie Rodrigues, of the University St Etienne in France[58]. He evoked the imperative need for a reference terminology that would be freely available through the Open source model and which would allow one to coordinate various currently available coding systems through a European, or even worldwide network.

A first argument is the considerable effort such a tool would require, although it is essential if one hopes to transform the clinical data “graveyards” into a consultation tool. Producing such a reference terminology surpasses any single country’s capacities; only a joint international effort could face such a challenge. The correspondence to international classifications, and in particular to the WHO classification family is indispensable. Such a terminology must allow for a faultless application by real clinical services, for specialised as well as for first recourse care, and whose coding needs are distinct. The clinical vocabularies that are currently available, often called clinical terminology, are not really suited to allow for comparisons, multiple uses, and are difficult to maintain. There is a recent development of third generation

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[58] Rodrigues, JM, Rogers R. Co-ordination between clinical coding systems developers and researchers using open reference terminology approach. Is there a need for an international network organisation? Medinfo 2001 workshop, London, 2001

tools such as SNOMED-RT and GALEN. Developing an “Open Terminology”, parallel to the current developments of “Open Health” will become unavoidable in order to face the challenges of trans-European and multilingual data comparisons.

3.5 USE IN EUROPE

3.5.1 INTRODUCTION

One will find below the copy of the file published on the Internet site http://www.ulb.ac.be/esp/wicc/icpc_2001.html This file was presented during the fourteenth WONCA congress in Durban, South Africa in 2001.

Upon consulting the text, one can observe that International Classification of Primary Care (ICPC) has become unavoidable, for research purposes as well as for gathering general medicine data in some European countries. It seemed highly relevant to mention ICPC in this report.

It is important to note that the WHO remained in constant contact with the WONCA International Classification Committee (WICC) throughout 2001.

A first meeting in Copenhagen brought together the members of the WICC and the people in charge of Classification at the WHO gathered. A joint outlook emerged concerning the respective use of ICPC and ICD (International Classification of Diseases).

At the end of the year 2001, a meeting in Washington made this evolution concrete and confirmed our expectation that ICPC will enter into the WHO family of classifications.

This is of major importance because ICPC is the only classification that, on the one hand, includes definitions of morbidity, and on the other hand, also includes a very relevant list of reasons for which patients call on the health system. The ICPC system will have a tendency to develop in European morbidity data banks.

ICPC use is rapidly growing in Europe and is now implemented in many EMR's. It is also used at the national level in Norway, The Netherlands, and Belgium. Listed below are the main initiatives and known research projects and applications in Europe[59]. Research using ICPC has been well developed for many years in The Netherlands and is rapidly growing in France and Romania. It's difficult to give a precise estimate of the use of ICPC in day-to-day practice. ICPC is the de facto standard for Primary Care and for emergency out patient clinics data retrieval. Underreporting of its use is therefore expected. Please consult the ICPC bibliography (http://www.ulb.ac.be/esp/wicc/icpc_ref.html) for a more in-depth understanding of ICPC. Please feel free to contact the author (marc.jamoulle@ulb.ac.be) in order to modify the Internet published text or to add your contribution.

Be Belgium / Dk Denmark / Fi Suomi/Finland / Fr France / Gr Greece / Ma Malta / Nl The Netherlands / No Norway / Ro Romania / Sp Spain / Ch Switzerland

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[59] All information obtained by personal contact with the respective authors

3.5.2 ICPC USE IN THE EUROPEAN COMMUNITY

ICPC use is rapidly growing in Europe and is now implemented in many EMR's. It is also used at national level in Norway, The Netherlands and Belgium. Listed below are the main initiatives and known research projects and applications in Europe[60]. Research using ICPC has been well developed for many years in The Netherlands and is rapidly growing in France and Romania. It's difficult to give a precise estimate of the use of ICPC in day to day practice. ICPC is the de facto standard for Primary Care and for emergency out patient clinics data retrieval. Underreporting of its use is therefore expected. Please have a look at the ICPC bibliography (http://www.ulb.ac.be/esp/wicc/icpc_ref.html) to obtain a deeper understanding of ICPC. Please feel free to contact the author (marc.jamoulle@ulb.ac.be) in order to modify the Internet published text or to add your contribution.

Be Belgium / Dk Denmark / Fi Suomi/Finland / Fr France / Gr Greece / Ma Malta / Nl The Netherlands / No Norway / Ro Romania / Sp Spain / Ch Switzerland

3.5.3 BELGIUM

3.5.3.1 *National level*

ICPC / CISP has been chosen by the Belgian Federal Ministry of Health as a criteria of first importance for the labelling process of Electronic Medical Records (EMR) for general practice in Belgium. ICPC use will not be mandatory but will become a deciding factor in obtaining the Federal quality label for GP's EMR systems. The Federal ministry of health as also given a grant to two university departments of general practice (RUG and ULB) for them to develop and implement a bilingual (French and Dutch) ICPC coded and ICD9 / ICD10 mapped electronic terminology. The Belgian state is considering the purchase of a WONCA licence for ICPC

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3.5.3.2 *ICPC in Belgian national health interview surveys (1997 and 2001)*

The objectives of the national health interview surveys organised in 1997 and 2001 are identification of health problems, description of the health status and health needs of the population, estimation of prevalence and distribution of health indicators, analysis of social (in)equality in health and access to the health services, study of health consumption and its determinants, study of possible trends in the health status of the population ICPC-1 has been in use in the 1997 study and ICPC-2 (French and Dutch version) shall be in use in the 2001 survey performed by the epidemiology section of the Belgian Scientific Institute Of Public Health

Contact ; Dr J. Tafforeau
Mail ; jean.tafforeau@iph.fgov.be

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[60] All informations obtained by personal contact with the respective authors

3.5.3.3 Use of ICPC in Flanders (Dutch speaking part of Belgium)

In 1989 Jan De Maeseneer published his Ph.D. thesis "General practice: an exploration: an exploratory, descriptive study". In this thesis, for the first time in Belgium, ICPC-1 has been used for description of the activities in general practice. In 1992, Anselm Derese published his thesis on the work of trainees in general practice, and used also ICPC-1 for description of the encounters. At the level of the practice-registration, some EMD-software packages are using ICPC-1.

In the year 2000, the Department of General Practice and Primary Health Care, Ghent University, has contributed to the Dutch translation of ICPC-2, published actually as a book (Anonymous. ICPC-2-NL: Nederlandse versie - Utrecht, Nederlands Huisartsengenootschap, 2000).

In March 2001 an educational package has been developed together with the scientific organisation of Flemish general practitioners (WVVH) and the universities. The package follows the implementation-rules for GP-software as they are actually discussed at the level of the federal government. The aim is to train medical students, trainee general practitioners and the GPs themselves in the use of the electronic medical record, using episode based registration and ICPC-2 classification. There is also a link to ICD-10.

In Flanders there is a consensus that in the future all registration in general practice and all GP-software packages will be structured based on ICPC-2, in the framework of episode-oriented registration. Actually the Department of General Practice and Primary Health Care contributes the development of a Flemish thesaurus for the ICPC-2

Contact ; Dr Jan De Maeseneer
Mail ; jan.demaeseneer@rug.ac.be

3.5.3.4 ICPC in day to day care in French speaking Belgium

ICPC is currently included in several EMRs. Various health centres, participating to the Belgian French speaking organisation " Fédération des Maisons Médicales" are using ICPC as a quality assurance and research tool in day to day practice

Contact ; Dr Michel Roland, Fédération des Maisons médicales, Bld du Midi 25, B-1000 Brussels Belgium
Mail : Michel.Roland@ulb.ac.be

3.5.3.5 The CISP-2 (French ICPC-2) book is published in Belgium

The non profit association "Care Editions, asbl", based in Waterloo, Belgium, has recently (Jan. 2001) published the CISP-2 book (M.Jamoulle, M.Roland, J.Humbert, JF.Brûlet. (Eds)). Traitement de l'information médicale par la Classification Internationale des Soins Primaires 2ème version (CISP-2), assorti d'un glossaire de médecine générale, préparé par le Comité International de Classification de la WONCA. Care Edition, Bruxelles, 2000

Contact : This book is available through the website; http://docpatient.net/care

3.5.3.6 The CISP-Club, the club of the ICPC fans

The French speaking association of the users of CISP (French ICPC) is located in France but its president, Dr. Marc Jamoulle, works in Belgium. The CISP Club is a meeting point for researchers in data gathering and coding in Primary Care in the French speaking world. The CISP Club has members in France, Belgium, Tunisia, Rumania and Switzerland. The CISP club is very active though its mailing list, its website and its annual workshop. Please refer to www.ulb.ac.be/esp/cisp for more information.

3.5.4 DENMARK

3.5.4.1 Extended Danish ICPC (ICPC-E).

A small part of ICD-10, that is relevant to general practise, has been accommodated within ICPC .This is a useful tool for diagnosis registration and quality development using the Extended Danish International Classification of Primary Care (a pilot study).

3.5.4.2 Continuous morbidity registration

Aim

To describe the disease patterns in general practice using ICPC coding and at the same time make it possible for individual general practitioners (GP) to compare practice pattern with each other and compare their management as exemplified by diabetic patients. Method: In a 3 month period in 1999, 14 GPs from 6 practices coded all their patient encounters with diagnosis, using ICPC. Feedback was given to each GP about disease- and contact pattern of their patients and selected parameters as for instance HbA1c, serum cholesterol and blood pressure. A list of identified patients with sub-optimal management was send to the GP as well.

3.5.4.3 Perspectives.

When using ICPC-2-E every diagnoses has an ICPC code as well as a corresponding ICD-10 code in the electronic medical record. This provides good opportunities for research and quality development across the primary and secondary health sector

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3.5.5 FINLAND

3.5.5.1 ICPC has been used in research and demonstration projects

From 1985 to 1998. Through these demonstration projects over half of Finnish GPs have tried ICPC. According to a survey among GPs in 1998, ICPC works well in primary health care and is more feasible than ICD-10. In the demonstration projects and in health centres actively using ICPC, over 95 % of the encounters get coded, whereas 50 % or less are coded in centres using ICD-10.

ICPC is used in Finland in 5-10 Healthcare Centres which are responsible for the public primary health care in the areas where they are located. This is only a few percent of the population. The Student health care organisation, which is a private fund which gives health services to the majority of university students in Finland for a very low yearly charge, is using a combination of ICPC and ICD-10 for diagnosis coding.

Helsinki, Espoo and Vantaa the tree largest cities have been interested in ICPC, but for technical reasons the pilot projects have not been very successful. It is important to note that it is not obligatory on a national level to collect any diagnostic information from primary care. The units using ICPC are a substantial proportion of the primary care units collecting diagnostic information systematically.

Contact : Dr Martti Virtanen (martti.virtanen@nordclass.uu.se) or Dr Matti Liukko (Matti.Liukko@Kuntaliitto.fi)

3.5.6 FRANCE

3.5.6.1 The Sentinel Surveillance of Referral to Hospital in French Primary Care

Methods: A follow-up outcome study nested within a surveillance system of hospital referrals performed by GPs from the French Sentinel network since July 1997. Data on each referral to hospital are collected by Sentinel GPs and transmitted on a weekly basis via tele-informatics (Internet or Minitel) to the database centre, where systematic quality control is performed. In particular, reason(s) for referral are entered in a free-text format, and subsequently coded according to the ICPC classification, using an automated tool based on string matching specifically developed to that end. Each reported case of complication that occurred within 30 days of discharge has been investigated through a telephone interview with the GP and the responsible hospital physician. This project was covered by an overall approval of the French Commission Nationale de l'Informatique et des Libertés (CNIL) allowing surveys to be conducted on the Sentinel system.

Results: Since July 1997, 12 000 referrals to hospital have been individually described by 305 GPs. This system provides information on the characteristics of patients referred to hospital and on the circumstances of the referral, including the reason(s) for referral. By using the statistical procedures applied on the Sentinel system for the incidence estimation of communicable disease, we could estimate that around 1.3 million hospital admissions result each year from GPs' referrals, which accounts for 10 % of all admissions in French hospitals. Moreover, we observed a seasonal variation in GPs' hospital referrals, with a regular increase during summer. Ninety-two cases of nosocomial complications have been reported and investigated during the first two years of the project, including 21 nosocomial infections, 31 adverse drug reactions and 40 complications of other type. We estimated at 1.2 per thousand admissions (95%CI, 1.0-1.5 per thousand) the rate of nosocomial adverse events detected in general practice within 30 days of discharge.

Contact Dr Laurent Letrilliard
Mail : l.letrilliart@wanadoo.fr

3.5.6.2 The ICPC in an emergency call centre in Bordeaux

Medical practitioners of "Centre 15 Gironde" has studied the feasibility of using CISP (French ICPC) in an emergency call centre as a coding an assessment tool . A terminological database of the usual emergency term has been extensively developed and tested.

The study has been presented at the recent Congrès de recherche en Médecine générale in Biarritz under the title ;

Maryse Bonnet, Arnaud Castets, Philippe Moreaud, Philippe Souleau, médecins régulateurs libéraux de l'ASSUM 33. Adaptation de la CISP (Classification Internationale des Soins Primaires) au travail de régulation médicale du Centre 15 Gironde (http://www.urmla.org/programme.htm)

Contact Dr Maryse Bonnet or Dr Luc Ribeton
Mail : m.bonnet33@wanadoo.fr luc.Ribeton@wanadoo.fr

3.5.6.3 Classification survey in Paris

Studying ICPC as a coding tool is on the agenda of the URML IDF the French medical professional association "Unions Régionales des Médecins Libéraux de l'Ile de France" That's means that GPs should begin to classify and code data in general practice in 2001 with the help of various members of the CISP Club.

Contact : Dr Bernard Ortolan URML IDF Bld Montparnasse Paris
Mail : b.ortolan@wanadoo.f

3.5.6.4 Episodus in Lyon

The Episodus project is the fruit of research on classifications, semantic, ergonomic medical data gathering and epidemiological treatment of data. Episodus is being developed by the French medical professional association "Unions Régionales des Médecins Libéraux" of Lyon and will be placed under Open Source Licence.

It encompasses the gathering, organisation and treatment of information recorded during the medical consultation. This information, classified primarily with ICPC, is organised into episodes of care. The episodes are entered into a central computer, and are then ready for use in quality assurance by feedback to the practitioner and for epidemiological research.

The practitioner would have many rewards from Episodus to assist his work, the first being the very short time spent for gathering, coding and organising the data, and the second the ergonomic and user friendly software system.

Contact : Dr Jean François BRÛLET Union Professionnelle des Médecins de la Région Rhône-Alpes 20, rue Barrier 69006 LYON
Mail : jean.francois.brulet@freesbee.fr

3.5.7 GREECE

3.5.7.1 Limited use

The use of classification systems is generally quite limited in general practice in Greece. ICPC-1 was translated into Greek in 1992. As a result of the continuing efforts of the Clinic of Social and Family Medicine, University of Crete and the Anogia Health Centre, an electronic patient record database named "Fakelos" was created and used in several primary care centres in Crete and in Greece. ICPC-1 together with ICD-9 is used in this program. Recently, another joint effort of the University of Crete and the Greek Association of General Practitioners aims to translate the ICPC-2-E into Greek. The evaluation of a computer program based on the ICPC-2 and Episodes of Care is also in progress. The objective of this latter effort is for it to be implemented in all Primary Health Centres of Greece. A general conclusion is that the ICPC-2E is the most suitable classification for general practice in Greece. Special cases, like referrals to hospitals and specific diseases, are very well handled with the ICPC-2 to ICD10 conversion.

Contact, Kounalakis Dimitris Mail : dcoun@galinos.med.uoc.gr

3.5.8 MALTA

3.5.8.1 The Malta College of Family Doctors

It has accepted ICPC and ICPC-2 as the standard classification for Maltese General Practice. The College is currently encouraging use of ICPC in electronic medical records. A group of doctors is using TRANSHIS, an ICPC based software in their day-to-day practice.

Contact : Dr. Jean Karl Soler MD "Josephine", St. Catherine Street, Attard BZN 04, Malta. Mail: jksoler@synapse.net.mt

3.5.9 THE NETHERLANDS

3.5.9.1 National level

ICPC has been mandatory in EMRs for several years. In the Netherlands more and more GP's are familiar with and use ICPC. It is obligatory for GP trainees to learn about it. Education materials and examinations for GP qualification are organised around ICPC codes. When research is done in practices it is not difficult to get the data from the GPs and they are willing to code the data in ICPC. For example research to the health effects of the firework-disaster in 'Enschede' had all 40 GP's there code all their consultations. There is ICPC training available across the country. The NHG published a new CD-rom called EVS (electronic prescription system), which is based on ICPC codes and many GP's are happy to use it. See NHG website http://www.artsennet.nl/ (click NHG click EVS) Computer software systems are a major problem. Almost all developers are threatened with bankruptcy and therefore the national GP organisation is considering the development of a non commercial software system. This is still under consideration.. Meanwhile no new updates are available for commercial systems and GPs have to manage with out-dated systems.

Note by Marga Vintges, MD
Mail : marga.vintges@planet.nl

3.5.9.2 The Transhis project, Department of General practice, University of Amsterdam

TRANSHIS is an episode oriented, ICPC based software developed at the Department of General practice of the UVA (Prof Henk Lamberts). TRANSHIS is currently implemented in research centres in The Netherlands, Malta, Poland, Greece, Japan and USA.

Contact : Prof Lamberts, MD, Phd. Meibergdreef 15, AZ Amsterdam
Mail : h.lamberts@amc.uva.nl

3.5.9.3 The Registration Network Family Practices

On 1 December 2000, the RNH (Registration Network Family Practices)(www.unimaas.nl/~rnh) consisted of 55 general practitioners in 21 practices covering approximately 100.000 patients. In all practices computerised health information systems were installed, replacing the hand written records. Classification: The set of patient characteristics to be registered is well defined. There is a clear definition of "a relevant health problem". All problems are coded using the International Classification of Primary Care (ICPC) using the criteria of the International Classification of Health Problems in Primary Care (ICHPPC-2 Defined), if appropriate. Structure of the data: On 1 September 2000 patient characteristics and problem lists for 82.411 patients (women 51.2%) had been entered in the database. A total of 341.800 problems have been identified for these patients: 188.219 (55.1%) active and 153.381 (44.9%) inactive.

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Mail : job.metsemakers@hag.unimaas.nl

3.5.9.4 Netherlands Information Network in General Practice (NIN GP)

Aim of NIN GP (http://www.linh.nl/index.htm) is to collect national, representative data on GP care. The data are used for health services research and quality-of-care research. Continuously, morbidity data are gathered on GP's patient list, consultations, prescriptions and referrals. Ad hoc extra registrations around specific subjects also take place (influenza vaccination, cervical screening, low back pain, diabetes). 123 computerized practices using five different GP information systems participate in NIN GP involving 228 general practitioners with a total of about 450.000 listed patients. The network mirrors the national distribution of the population according to age, sex, type of insurance, region and degree of urbanization. Morbidity is classified with the ICPC, prescriptions with the ATC classification system.

Data are used in several monitoring projects: process data in general practice, influenza vaccination, cervical cancer screening and the introduction of electronic formularies. Other types of studies that take place are state-of-the-art studies (prescribing of Ritalin, repeat prescribing, prescribing of benzodiazepines in general practice), guideline adherence studies (low back pain, diabetes), development of quality indicators, evaluation of policy measures (i.e. reduction of insurance coverage for self care medication). In 2000/2001 the Second Dutch Morbidity study is undertaken within the framework of NIN GP (in 104 practices). Based on an extensive research program extra data are collected on: morbidity in all consultations during one year (with episode construction), socio-demographic data of all listed patients, experienced health and health behaviour among a sample of patients and doctor-patient communication by video taping one day per GP.

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Mail : dinny.debakker@nivel.nl

3.5.10 NORWAY

3.5.10.1 ICPC is in use in GP/FM and Occupational medicine in Norway since 1992.

An official standard for the EMR has been developed, but is only partially implemented. All the information GPs need on the bill to collect money from the social security system, are standardised and in place in all EMR software. These data include: unique person identifier of the patient, sex, date of birth, address, encounter (date, time, type), diagnoses (ICPC) and many processes. In October this year Norway Statistics will run a pilot collecting data from EMR in general practice. The project is a continuation of previous work.

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3.5.11 ROMANIA

3.5.11.1 The Romanian Society of Family Medicine / General Medicine

It has received a copyright license to translate and use the ICPC. The book ICPC-2, with corrections from ICPC-2-E has been translated into Romanian and edited. (http://www.ispt.ro/medinet/ press ICPC-2). ICPC-2 is used in the software MEDINS, made and used in the Sentinel Station Network, GP-Medinet, involving 100 GP's from all around the country. The project began with ICPC-2000 (where the infrastructure was prepared for the Sentinel Station Network) and continues with GP-Medinet Project (2000-2002) with registration of patient data. Doctors began the pilot registration of data on 1 April 2001, and continued until 30 September 2001. Data are transferred monthly by each doctor to a central server using the Internet.

The software Medins use ICPC codes for RFE and symptoms. For diagnosis the codification begin with ICPC codes and is finished with ICD-10 codes (double coding, because ICD-10 is more specific). For procedures internal codes are used which are then translated into ICPC-2 codes.

Contact : Marius Marginean: National Coordinator of Romanian Sentinel Station Network Str.Lidia 37 Timisoara Romania
Mail : mmarginean@mail.sorostm.ro

3.5.12 SPAIN

3.5.12.1 National level

In Spain ICPC is well known both in practice and research. ICPC-1 is still in use in a software program in public health centres. Some researchers have used it in emergency care. The future is problematic because of the strong influence of case-mix classification with ICD-9-CM. There are translations of ICPC 1 and 2, both published by Masson, into Spanish and Catalan. ICPC-1 is used in Andorra.

Contact : Juan Gervas, MD, PHD Equipo Cesca, Madrid
Mail : jgervasc@meditex.es

3.5.12.2 ICPC in Catalonia.

ICPC is the most used classification in Primary Care in Catalonia and all around Spain, but this does not mean that is used very much. ICPC is not widely known and used, and research is still the main reason for use. As the telematics is increasingly available in practices, this situation will change dramatically. The most common software programs for managing patients and health centres use ICPC to classify diseases as well as a translating to ICD-9-CM. This will allow large and comparable databases in the near future.

Contact : Sebastian Juncosa
Mail : sjuncosa@sapcll.scs.es

3.5.13 SWITZERLAND

3.5.13.1 Swiss Medical Association

Dr Brunner, president of the Swiss Medical Association has recently (Feb. 2001) announced that ICPC, ICD10 and ICIDH would be the leading coding systems for EMRs in Switzerland. ICPC is used on a daily base in the outpatient clinic of the Hopitaux Cantonaux de Genève. Dr Laura Pult has recently published a paper on this subject in Médecine et Hygiène, a French medical review. After studying 1600 reasons for encounter annotated in free text, a terminological software has been designed allowing to retrieve easily and in a standard way the reasons for encounter in the emergency outpatient clinic of the Hopitaux Cantonaux de Genève. Feasibility study of the day to day coding is under way.

Contact ; Dr Laura Pult
Mail : laura.pult@dim.hcuge.ch

Dr Vincent Griesser of the Hopitaux Cantonaux de Genève has invited the next CISP Club workshop in Neuchatel in November 2001.

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3.6 EXERCISE ON THE AVAILABILITY OF DATA FROM CONTINUOUS MORBIDITY DATA COLLECTIONS IN GP/FM THROUGHOUT EUROPE[61]

Contribuors : Marc Jamoulle (Be), Vania Siderova (Be), Erik Falkø (Dk), Anders Grimsmo (No), Roger Weeks (Uk), Raphael Spira (Fr), Job Metsemakers (Nl), Sebastia Juncosa (Sp), Azeem Majeed (Uk), Roberto Nardi (It), Dimitris Kounoulakis (Gr), Mike Bainbridge (Uk), Sheila Teasdale (Uk), Lindsay Groom (Uk), Mikko Nennonen (Fi)

3.6.1 INTRODUCTION

GPs are treating at their level more than 90% of patient's health problems in the ambulatory settings. They are particularly well situated to retrieve data on patient's morbidity . Some well designed and well functioning systems are running in various countries, mostly in northern Europe, aggregating data in large databases for specific audit and/or prescription analysis purposes.

In an EU funded research program (please refer to http://www.ulb.ac.be/esp/emd/), the availability of such data to build European health indicators is considered. However, these systems differ consistently in an economical, ethical, and organisational point of view. Quality of data, information structure and classifications systems are also quite different. Nevertheless, we will try to compare data on specific diseases currently seen in GP/FM settings. Learning from the differences could be a factor in progress towards a European morbidity retrieval system.

3.6.2 OBJECTIVES

Test the availability of data gathered in specific morbidity retrieval system in various European systems. This study is the final part the enquiry published on the World Wide web at the following address http://www.ulb.ac.be/esp/emd/phcform.htm. Researchers are kindly asked to answer this questionnaire before data gathering and data transfer. The underlying aim

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[61] exercise prepared by Marc Jamoulle for the dec 5, 2001 Brussels EURO-MED-DATA-phc meeting, updated before the meeting following the email comments

is to assess the comparability of data coming from different systems with different classifications. Are morbidity data useful as health indicators at an European level? This the main research question.

3.6.3 METHODS

Each participating centre or researcher is asked to transfer the data following the description given below to marc.jamoulle@ulb.ac.be preferably in a standard format such as Word doc, RTF or .pdf or Access or Excel. The data should be anonymous (anonymisation should remove all patient or GP identification)

The data will be compared and the comparison will be discussed during the Euro-Med-Data meeting organised in Brussels December 5, 2001

3.6.3.1 Main reasons for choice of Asthma and Zoster

Asthma is a chronic or at least a recurrent condition, potentially severe and life threatening

Herpes zoster causes both Varicella and Shingles. These are acute conditions, with a potential for disability

They are not diabetes, hypertension, or hypercholesterolemia!

They are current health issues in GP/FM

Both are easily recognizable on clinical basis by GPs

Both have good treatments available

3.6.3.2 Data to be retrieved

Name of classification or nomenclature used by the collecting centre

Year/Month (preferably one year)

Geographical area (preferably NUTS codes)

Number of GPs involved in the registration

Number of patient/year

Number of cases/year of both disease items, by age and by sex

If available; number of contacts/GP/year and number of referrals for the specific condition

3.6.3.3 Further discussions

The available data will be discussed in an EMD workshop to be held in Brussels (before the EUPHA workshop) on December 5, 2001

(Annual EUPHA meeting 2001. Health information systems throughout Europe and their interaction with public health policy. Development and actions. Brussels, Belgium. Brussels exhibition centre (expo Heizel) Hall 10, auditorium “2000” 6-8 December 2001).

Researcher or data collection centre representatives are kindly asked to present their contribution at this meeting.

3.6.3.4 Funding

Our EU funded program will refund air plane ticket and hotel night per participating centre if assisting to the EMD workshop.

3.6.4 PEOPLE INVOLVED IN DEC 5, 2001 BRUSSELS EMD-PHC MEETING

Table 3.4. List of participant of the EMD-PHC meeting, Dec 5, Brussels.

12 participants from 8 countries representing 11 different data collection systems in GP/FM in Europe

Country	Name	Institution	Attending	Extracting data on H. Zoster and Asthma
BE	Marc Jamoulle	ESP ULB (MFSP)	Yes	No
BE	Vania Siderova	" "	Yes	" "
DK	Erik Falkoe	Dep Gen pract Odense	Yes	Yes
FI	Mikko Nenonen	Stakes	Yes	Yes
FI	Olli Nylander	Stakes	Yes	" "
FR	Raphael Spira	THALES	Yes	Yes
GR	Dimitri Kounalakis	Integrated Health Telematics Network of Crete	Yes	Yes
IT	Roberto Nardi	Health search (Società Italiana di Medicina Generale)	Yes	Yes
NL	Job Metsemakers	Maastricht RNH	No	Yes
NO	Anders Grimsmo	Dep Gen Pract Trondheim	No	Yes
SP	Sebastia Juncosa	Unitats.Docents.de.Catalunya Barcelona centre (ICS)	Yes	Yes
UK	Roger Weeks	Doctor’s Independent Network	Yes	Yes
UK	Mike Bainbridge	PRIMIS	Yes	Yes
UK	Sheila Teasdale	" "	Yes	" "
UK	Lindsay Groom	" "	Yes	" "
UK	Azeem Majeed	GPRD (ONS)	No	Yes

3.6.5 AVAILABLE CODES FOR THE TWO CONDITIONS

The available codes are listed for the main international classification actually in use. Fourth digit opening are difficult to obtain for ICD10. SNOMED-CT codes will be available in late December 2001. Comparability between databases depend on content of the nomenclatures and classifications in use and it should be noted that code mapping between classifications is sometimes a perilous exercise.

Table 3.5. Two rubrics in the various classifications in use in Europe

	ICHPPC-2-d	*ICPC*	*ICD-10*	*ICD-9*	*Read (V3)*
HERPES ZOSTER	053-	S70	B02	053	XE2x9
ASTHMA	493-	R96	J45, J46	493	H33..

3.6.5.1 Herpes Zoster

3.6.5.1.1 ICHPPC-2-d

Herpes zoster [62]

Inclusion require ; a unilateral eruption over the area of one or more dermatomes; vesicular lesions evolve from papules and may progress to pustules or scabs

3.6.5.1.2 ICPC-2

ICPC-2 as downloaded from the WICC web site [63]

S70 Herpes Zoster

Criteria : grouped vesicular eruptions, unilateral distribution, over area of a single dermatome

Include: post-herpetic neuralgia, shingles, herpes zoster ophthalmicus

Exclude : skin pain S01; localized rash S06

3.6.5.1.3 ICD-9

ICD-9 fourth and fifth digit from "e-mds" website [64]

053 Herpes zoster

053.0 Herpes zoster meningitis

053.1 Herpes zoster, with other nervous system complication

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[62] WONCA International Classification Committee. International Classification of Health Problems in Primary Care, 2nd ed, defined (ICHPPC-2d). Oxford University Press; 1979

[63] ICPC-2-e : Okkes IM, Jamoulle M, Lamberts H, Bentzen N. ICPC-2-E. The electronic version of ICPC-2. Differences with the printed version and the consequences. Fam Pract 2000; 17: 101-6. (downloaded from http://www.ulb.ac.be/esp/wicc)

[64] From the web site E-mds.com Physician in touch http://www.e-mds.com/icd9/493.9/index.html

- 053.10 Herpes zoster, with other nervous system complication, unspecified
- 053.11 Herpes zoster of facial and auditory nerves
- 053.12 Trigeminal neuralgia due to Herpes zoster
- 053.13 Polyneuropathy due to Herpes zoster
- 053.19 Herpes zoster ophthalmica syndrome

053.2 Herpes zoster, with ophthalmic complications

- 053.20 Blepharitis due to Herpes zoster
- 053.20 Dermatitis of eyelid due to Herpes zoster
- 053.20 Herpes zoster ophthalmicus
- 053.21 Keratoconjunctivitis due to Herpes zoster
- 053.22 Iridocyclitis due to Herpes zoster
- 053.29 Herpes zoster with ophthalmic complications, other

053.7 Herpes zoster, with other specified complications

- 053.71 Auricular Herpes zoster
- 053.79 Herpes zoster with other specified complications, other

053.8 Herpes zoster, with unspecified complication
053.9 Herpes zoster, without complication

3.6.5.1.4 ICD-10

B02	Zoster [herpes zoster]
B02.0+	Zoster encephalitis (G05.1*)
	Zoster meningoencephalitis
B02.1+	Zoster meningitis (G02.0*)
B02.2+	Zoster with other nervous system involvement
B02.3+	Zoster ocular disease
B02.7	Disseminated zoster
B02.8	Zoster with other complications
B02.9	Zoster without complication

3.6.5.1.5 READ CODES

NHS Clinical Terms (Read Codes) version 3 from CLUE [65] software
XE2x9 Herpes zoster infection
X70JF Thoracic herpes zoster infection
X70JG Lumbar herpes zoster infection
X009c Acute trigeminal herpes zoster

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[65] CIC Look Up Engine (CLUE), CLUE Browser for NHS CTV3, Version: 2.0.0021, March 2000 Clinical Information Consultancy Web: http://www.clinical-info.co.uk

X20RH Herpes zoster infection of oral mucosa
X00mI Acute herpes zoster pharyngitis
F5016 Geniculate herpes zoster
X0016 Herpes zoster encephalitis
X70JN Multidermatomal herpes zoster infection
A5321 Herpes zoster with keratoconjunctivitis
A5322 Herpes zoster iridocyclitis

Read Version 1 and 2 provided by DIN [66]

V1 V2

Herpes zoster	A44	A53	Herpes zoster -Shingles
Post-herpetic neuralgia	A441	A531	Herpes zoster with other central nervous system complication
Ophthalmic herpes zoster	A442	A532	Herpes zoster with ophthalmic complication
Ramsay-Hunt syndrome	A443	A53x	Herpes zoster with other specified complication
Other herpes zoster	A44Z	A53z	Herpes zoster NOS

3.6.5.2 Asthma

3.6.5.2.1 ICHPPC-2-d

Asthma

Inclusion requires: Recurrent episodes of acute bronchial obstruction with one of the following :

- ✓ Pulmonary function tests showing variable obstruction, relieved by bronchodilatators
- ✓ Two of the following
    - Wheeze
    - Dry cough
    - Prolonged expiratory phase of respiratory cycle

Consider : 466- Bronchitis and bronchiolitis; 492- Emphysema, COPD; 7860 Wheezing; 7862 Cough

3.6.5.2.2 ICPC-2

ICPC-2 as downloaded from the WICC web site

R96 Asthma

Criteria: recurrent episodes of reversible acute bronchial obstruction with wheeze/dry cough; or diagnostic test meeting currently accepted criteria for asthma

Include: reactive airways disease, wheezy bronchitis

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[66] Added by Roger Weeks from Doctors' Independent Network http://www.compudata.co.uk/din.html

Exclude: bronchiolitis R78; chronic bronchitis R79; emphysema R95

3.6.5.2.3 ICD-9

ICD-9 fourth and fifth digit from "e-mds" website

493 Asthma

493.00 Extrinsic asthma

- Allergy-induced asthma
- Bronchospasm due to allergies
- Exercise-induced asthma
- Reactive airway disease

493.01 Asthma with status asthmaticus

493.1 Intrinsic asthma

- Adult-onset asthma
- Endogenous asthma
- Late-onset asthma

493.11 Intrinsic asthma, with status asthmaticus

493.2 Chronic obstructive asthma

- Asthma with COPD
- Asthma with chronic obstructive pulmonary disease
- Asthma with emphysema

493.21 Chronic obstructive asthma, with status asthmaticus

493.9 Asthma, unspecified

- Airway obstruction with asthma
- Allergic bronchitis with bronchospasm, unspecified allergen
- Allergic bronchitis, unspecified allergen
- Allergy-induced asthma, unspecified allergen
- Asthmatic bronchitis, unspecified allergen
- Bronchial asthma, unspecified
- Spasmodic asthma
- Summer bronchitis with bronchospasm

493.91 Asthma - with status asthmaticus, NOS

493.91 Asthma, unspecified, with status asthmaticus

3.6.5.2.4 ICD-10

J45	Asthma
J45.0	Predominantly allergic asthma
J45.1	Nonallergic asthma
J45.8	Mixed asthma
J45.9	Asthma, unspecified
J46	Status asthmaticus

3.6.5.2.5 READ CODES

NHS Clinical Terms (Read Codes) version 3 from CLUE software
H33.. Asthma
X101x Allergic asthma
XE0YT Non-allergic asthma
X1023 Drug-induced asthma
173A. Exercise-induced asthma
X1025 Occupational asthma
H440. Byssinosis
H441. Cannabinosis
Xa0lZ Asthmatic bronchitis
Xa9zf Acute asthma
XE0YW Asthma attack
Xa1hD Exacerbation of asthma
Ua1AX Brittle asthma
X101u Late onset asthma
Xa9zf Acute asthma
X102D Status asthmaticus
Read Version 1 and 2 provided by DIN[67]
V1 V2
H/O: asthma 14B4. |14B4 |H/O: asthma
Wheezing 1737. |1737 |Wheezing
Exercise induced asthma |173A |173A |Exercise induced asthma
Nocturnal cough / wheeze |173B |173B |Nocturnal cough / wheeze
Asthma disturbing sleep |663N |663N |Asthma disturbing sleep
Asthma not disturbing sleep |663O |663O |Asthma not disturbing sleep
Asthma limiting activities |663P |663P |Asthma limiting activities
Asthma not limiting activities |663Q |663Q |Asthma not limiting activities
Asthma management plan given|663U |663U |Asthma management plan given

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[67] Added by Roger Weeks from Doctors' Independent Network http://www.compudata.co.uk/din.html

Asthma severity	663V	663V	Asthma severity
Asthma prophylaxis used	663W	663W	Asthma prophylactic medication used
Emerg asthm adm since lst appt	663d	663d	Emergency asthma admission since last appointment
Asthma restricts exercise	663e	663e	Asthma restricts exercise
Asthma never restrcts exercise	663f	663f	Asthma never restricts exercise
Inhaled steroids use	663g	663g	Inhaled steroids use
Asthma - currently dormant	663h	663h	Asthma - currently dormant
Asthma - currently active	663j	663j	Asthma - currently active
Reversibility trial steroids	663k	663k	Reversibility trial by steroids
Spacer device in use	663l	663l	Spacer device in use
Emerg asthm adm since lst appt	663d	663d	Emergency asthma admission since last appointment
Asthma restricts exercise	663e	663e	Asthma restricts exercise
Asthma never restrcts exercise	663f	663f	Asthma never restricts exercise
Inhaled steroids use	663g	663g	Inhaled steroids use
Asthma - currently dormant	663h	663h	Asthma - currently dormant
Asthma - currently active	663j	663j	Asthma - currently active
Reversibility trial steroids	663k	663k	Reversibility trial by steroids
Spacer device in use	663l	663l	Spacer device in use
Other respiratory procedures	879	879	Other respiratory procedures
Further asthma - drug prevent.	8791	8791	Further asthma - drug prevent.
Physio.-prevent.-pulm.complic.	8792	8792	Physio.-prevent.-pulm.complic.
Asthma control step 0	8793	8793	Asthma control step 0
Asthma control step 1	8794	8794	Asthma control step 1
Asthma control step 2	8795	8795	Asthma control step 2
Asthma control step 3	8796	8796	Asthma control step 3
Asthma control step 4	8797	8797	Asthma control step 4
Asthma control step 5	8798	8798	Asthma control step 5
Other resp. procedures NOS	879Z	879Z	Other resp. procedures NOS
Respiratory procedures NOS	87Z	87Z	Respiratory procedures NOS
Asthma monitoring admin.	9OJ	9OJ	Asthma monitoring admin.
Attends asthma monitoring	9OJ1	9OJ1	Attends asthma monitoring
Refuses asthma monitoring	9OJ2	9OJ2	Refuses asthma monitoring
Asthma monitor offer default	9OJ3	9OJ3	Asthma monitor offer default
Asthma monitor 1st letter	9OJ4	9OJ4	Asthma monitor 1st letter
Asthma monitor 2nd letter	9OJ5	9OJ5	Asthma monitor 2nd letter
Asthma monitor 3rd letter	9OJ6	9OJ6	Asthma monitor 3rd letter
Asthma monitor verbal invite	9OJ7	9OJ7	Asthma monitor verbal invite
Asthma monitor phone invite	9OJ8	9OJ8	Asthma monitor phone invite
Asthma monitoring deleted	9OJ9	9OJ9	Asthma monitoring deleted

Asthma monitoring check done	|9OJA	|9OJA	|Asthma monitoring check done
Asthma monitoring admin.NOS	|9OJZ	|9OJZ	|Asthma monitoring admin.NOS
Asthma	|H43..	|H33	|Asthma
Extrinsic asthma - atopy	|H431	|H330	|Extrinsic (atopic) asthma
Intrinsic asthma	|H432	|H331	|Intrinsic asthma
Status asthmaticus	|H433	|H33z0	|Status asthmaticus NOS
Asthma NOS	|H43Z	|H33zz	|Asthma NOS

3.6.6 PUBLISHED INCIDENCE AND PREVALENCE DATA ON HERPES ZOSTER AND ASTHMA

The aim of the proposed exercise is to compare the data from various continuous collection systems in GP/FM in Europe. In order to be able to compare the obtained result, a research has been performed about the rough data on prevalence and incidence of the two conditions published on Internet and in the literature.

3.6.6.1 Herpes Zoster (Shingles; Zona; Acute Posterior Ganglionitis)

3.6.6.1.1 Incidence and Prevalence Database [68]

ICD Code: 053

Global Incidence and Prevalence

- ✓ **US incidence**: The annual incidence of herpes zoster varies with age and immune status, from a range of 0.4 to 1.6 cases per 1000 healthy people under the age of 20 years, to 4.5 to 11 cases per 1000 among those 80 years of older. The rate of zoster is several times higher among adults with HIV infection or cancer, and 50 to 100 times higher among children with leukemia than among healthy persons of the same age. The approximate number of cases of herpes zoster per 1000 persons seen annually in a general medical practice by age group was reported as follows: ages 0-9 (0.8); ages 10-19 (1.7); ages 20-29 (2.1); ages 30-39 (2.0); ages 40-49 (2.2); ages 50-59 (5.8); ages 60-69 (7.0); ages 70-79 (7.2); ages 80 and older (11.0).
- ✓ Worldwide: The rate of herpes zoster reported in the literature ranges between 1.3 and 4.8 cases per 1000 population per year.
- ✓ **United Kingdom**: This prospective UK study used a General Practice Linkage Scheme with the National Hospital for Neurology and Neurosurgery (NHNN) to ascertain all incident cases of neurological disorders over an 18-month period in an unselected urban population of 100,230 patients registered with 13 general practices in the London area. In three of these practices (27,657 persons), lifetime prevalence was also assessed. Registration of patients began in 1994; this report covers the period from January 1, 1995 to July 1, 1996. This survey does not include the small number of patients who are in

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[68] **Timely Data Resources Inc.** http://www.tdrdata.com/ The Incidence and Prevalence Database. acceded 7-Feb-02 by courtesy of John Borgman

long-stay hospitals for severe neurological problems. The age- and sex-adjusted incidence rate of shingles was reported as 140 per 100,000 per year.

- ✓ **Italy**: According to project HECTOR (Herpes Clinical Trials and Outcome Research), in 1995 the total number of patients suffering from herpes zoster (HZ) was 408 out of 98,508 referral subjects aged 15 and over, corresponding to 4.14 per 1000 per year. According to this estimate about 200,000 new cases of HZ occur annually in people aged 15 and over in Italy. About 42,000 new cases of post-herpetic neuralgia may occur in this age group in Italy each year.

3.6.6.1.2 Research on web sites

- ✓ An infection with varicella-zoster virus primarily involving the dorsal root ganglia and characterized by vesicular eruption and neuralgic pain in the dermatome of the affected root ganglia
http://www.merck.com/pubs/mmanual/section13/chapter162/162c.htm
- ✓ According to estimates by the Centers for Disease Control and Prevention, the incidence of herpes zoster in the United States is 600,000 to 1 million cases yearly **(2.1 to 3.5/1000)**.
http://www.postgradmed.com/issues/2000/06_00/landow.htm

Herpes zoster, more commonly known as shingles, does not exhibit any seasonal pattern because disease results from the reactivation of latent virus and is related to host factors, not to exposure. Prevalence of herpes zoster is primarily determined by the age composition of the population, along with the length of time since primary infection with VZV. Herpes zoster is most common among the elderly and causes significant morbidity in this population as a consequence of postherpetic neuralgia. A 15-year population based study in Rochester, Minnesota between 1945 and 1959 found the annual incidence rate to be **1.4 per 1000 person-years**. Similar rates were found in England. (Weller, 1997) In the US there are 600,000 to 1 million cases of shingles per year. 10-20% of the US population will develop one or more case of shingles in their lifetime, and 50% of people living beyond the age of 80. (CDC online) Herpes zoster seems to have the same relative incidence world wide. Its age of onset, however, may be later for people in tropical countries due to later initial infection with varicella.
http://www.brown.edu/Courses/Bio_160/Projects2000/Herpes/VZV-Pages/VZVEPI.html

3.6.6.1.3 Published papers

- ✓ Arch Intern Med 1995 Aug 7-21;155(15):1605-9

The incidence of herpes zoster. Donahue JG, Choo PW, Manson JE, Platt R.

Channing Laboratory, Department of Medicine, Brigham and Women's Hospital, Boston, Mass., USA.

BACKGROUND: There are few population-based studies of the natural history and epidemiology of herpes zoster. Although a relatively common cause of morbidity, especially among the elderly, contemporary estimates of herpes zoster incidence are lacking. Herein we describe a population-based investigation of incident and recurrent herpes zoster from 1990 through 1992 in a health maintenance organization. METHODS: The health maintenance organization's automated medical records contain clinical and administrative information about care rendered to patients in ambulatory settings, emergency departments, and hospitals.

Cases of herpes zoster were ascertained by screening the medical record for coded diagnoses. The predictive value of a herpes zoster diagnosis code was determined by review of a sample of patient records. Records from all patients with potential recurrences were also reviewed. RESULTS: The overall incidence, based on 1075 cases in 500,408 person-years, was 215 per 100,000 person-years (95% confidence interval, 192 to 240 per 100,000) (1.92 to 2.4/1000) and did not vary by gender. Although the rate increased sharply with age, approximately 5% of the cases occurred among children younger than 15 years. Infection with human immunodeficiency virus was documented in 5% of the persons with incident herpes zoster and cancer in 6%. Four persons had confirmed recurrences of herpes zoster (744 per 100,000 person-years; 95% confidence interval, 203 to 1907); three of these persons were infected with the human immunodeficiency virus. CONCLUSIONS: The recorded incidence of herpes zoster was 64% higher than that reported 30 years ago; the age-standardized rate was more than twofold higher. Immunosuppressive conditions had little impact on overall incidence, although they were strongly associated with early recurrences. http://www4.ncbi.nlm.nih.gov/

- ✓ Pediatrics 1985 Oct;76(4):512-7

Epidemiology of herpes zoster in children and adolescents: a population-based study. Guess HA, Broughton DD, Melton LJ 3rd, Kurland LT.

Medical records were reviewed for all 173 cases of herpes zoster diagnosed among residents of Rochester, Minnesota, less than 20 years of age during the period 1960 through 1981. The incidence of zoster increased with age from 20 cases per 100,000 person-years in those residents less than five years of age to 63 cases per 100,000 person-years in those aged 15 to 19. (0.63/1000)Morbidity was less than has been described in adults, as only two patients required hospitalization and no postherpetic neuralgia or other late complications were diagnosed. The single case of subsequent cancer found in 1,288 person-years of follow-up was not significantly different from the number expected based on cancer incidence in the general Rochester population. The incidence of childhood zoster in patients with acute lymphocytic leukemia was 122 times higher than in children without an underlying malignancy. Chickenpox in the first year of life was found to be a risk factor for childhood zoster, with a relative risk between 2.8 and 20.9. Neither chickenpox in the second year of life nor recent vaccinations were found to be risk factors for childhood zoster. http://www4.ncbi.nlm.nih.gov/

- ✓ J Infect 1999 Mar;38(2):116-20

Herpes zoster and its complications in Italy: an observational survey. di Luzio Paparatti U, Arpinelli F, Visona G. Glaxo Wellcome S.p.A., Research and Development, Verona, Italy.

OBJECTIVES: To estimate the rate of Herpes zoster and its complications in Italy. METHODS: this is an observational, retrospective study carried out by Dermatologists, Geriatric Doctors and General Practitioners. Details on demography, clinical and therapeutic aspects were reported on record forms. The rate of Herpes zoster was only calculated for patients aged 15 years or more, attending General Practitioners because this was the only group where the number of patients at risk was known. The hypothesis that the rate of complications depends on sex, age and number of affected dermatomes was explored through univariate (Chi-square tests) and multivariate (logistic regression) analysis. RESULTS: the number of cases of Herpes zoster examined by General Practitioners was 4.1 persons aged 15 years or more/1000/year. Usually, only one dermatome was affected, most frequently the thoracic one. Overall the rate of complications was 26.1% The rate of complications is significantly higher (P = 0.001) in patients with two or more affected dermatomes, it is positively correlated to age while difference by sex is not significant (P = 0.297). Practically all patients received treatment for their disease. CONCLUSIONS: this is the first epidemiological study on Herpes zoster that has been conducted in Italy. It indicates that annually there are about 200 000 people aged 15 years and over suffering from Herpes zoster in Italy, with a considerable number of cases of post herpetic neuralgia. http://www4.ncbi.nlm.nih.gov/

- ✓ Ann Dermatol Venereol 2001 Apr;128(4):497-501

[Herpes zoster: incidence study among "sentinel" general practitioners.] [Article in French]Czernichow S, Dupuy A, Flahault A, Chosidow O.

Unite de Biostatistique et Informatique Medicale, Hopital Tenon, Paris, France.

INTRODUCTION: Herpes zoster is a frequent disease but its incidence in France is unknown. METHODS: We conducted a postal survey among the general practitioners of the "Sentinel" network. The incidence of acute herpes zoster was extrapolated from the number of cases diagnosed during the year 1998, by the general practitioners who answered the questionnaire. The general practitioners were also surveyed on their prescriptions and attitude. RESULTS: Among the 1,368 "Sentinel" general practitioners, 744 (54.4 p. 100) participated in the survey. The incidence in 1998 was 3.2 cases for 1,000 inhabitants (95 p. 100 confidence interval: 3.0 - 3.4). For acute herpes zoster, 73 p. 100 of the patients have been given an oral antiviral drug, and 63 p. 100 an antalgic. Among the 605 reported herpes zoster cases, 111 (18.4 p. 100) subsequently had chronic pain. DISCUSSION: The estimated incidence is comparable to the incidence from others developed countries. To be interpreted, this estimation has to be discussed according to the sample of population that was studied and the representativity of the "Sentinelles" general practitioners who participated the survey http://www4.ncbi.nlm.nih.gov/

- ✓ Clin Infect Dis 2001 Jul 1;33(1):62-9

Characteristics of patients with herpes zoster on presentation to practitioners in France. Chidiac C, Bruxelle J, Daures JP, Hoang-Xuan T, Morel P, Leplege A, El Hasnaoui A, de Labareyre C.

Department of Infectious and Tropical Diseases-AIDS Reference Center, University Claude Bernard, Lyon, France. christian.chidiac@chu-lyon.fr

There have been many epidemiological studies of chickenpox but only a few of herpes zoster. We report data from an observational study, conducted in France during a 1-year period, of 9038 patients who presented with acute herpes zoster (n = 8103) or postherpetic neuralgia (PHN; n = 935) at the office practices of 4635 general practitioners or dermatologists. The incidence of herpes zoster in France was found to be similar to that in the literature: **from 1.4 to 4.8 cases per 1000 population** per year. The patient profiles and clinical patterns were delineated, as well as the management decisions made according to the type of treating physician. The impact of herpes zoster on quality of life was evaluated on the basis of the Medical Outcome Study Short Form 36 (MOS SF 36) scale, which is widely used for assessing quality of life in the field of health. This study provides reference data on the substantial deterioration in quality of life associated with herpes zoster and PHN http://www4.ncbi.nlm.nih.gov/.

3.6.6.1.4 About Shingles, out of the quoted papers

Table 3.6. Incidence of Herpes Zoster in the quoted studies

Study	*Incidence/ 1000/year*	*Remarks*
CDC USA	2.1 to 3.5	
Minnesota 1945/1959	1.4	
Boston 1992/1995	1.92 to 2.4	
Minnesota 1960/1981	0.63	<20 years
Verona, Italy GPs	4.1	>15 years
France, 1988 sentinel	3.2	
France, 2000, GPs	1.8 to 4.8	
Min/max	0.63 to 4.8	

3.6.6.2 Asthma

Brief Internet and Medline research on Asthma prevalence.

3.6.6.2.1 Incidence and Prevalence Database

✓ Timely Data Resources Inc. http://www.tdrdata.com/ The Incidence and Prevalence Database. acceded 7-févr.-02 by courtesy of John Borgman

ICD Code: 493.9 Asthma unspecified

Includes: Status asthmaticus, bronchial asthma and allergic asthma

Definition: (1) Status asthmaticus -- refers to those attacks in which the degree of bronchial obstruction is either severe from the onset or worsens and is not relieved by the usual therapy in 30 to 60 minutes. (2) Refractory status asthmaticus -- describes those cases in which the patient continues to deteriorate despite aggresive pharmacologic and other medical interventions.

Note: Asthma can occur for the first time at any age including old age. Because of the difficulty in precisely defining asthma, true incidence and prevalence are unknown.

✓ **Diagnosis Statistical Summary see;** http://www.tdrdata.com/IPDSamples.htm - sgeographic

✓ Global Incidence and Prevalence

Global Incidence and Prevalence is a summary of data reported in the abstracts. The geographic summary includes incidence and prevalence statistics for the United States and other countries.

U.S. Prevalence:

The estimated prevalence of asthma in 1994 was reported as follows: All ages, 56.1 per 1000 (14,562,000 patients); under age 18 years, 69.1 per 1000 (4,837,000 patients); 18-44 years, 51.7 per 1000 (956,000 patients); 75 years or older, 47.8 per 1000 (610,000 patients). MALE: under age 45 years, 57.1 per 1000; 45-64 years, 32.3 per 1000; 65-74 years, 39.3 per 1000; 75 years or older, 70.3 per 1000. FEMALE: under age 45 years, 60.0 per 1000; 45-64 years, 68.0 per 1000; 65-74 years, 62.8 per 1000; 75 years or older, 34.1 per 1000.

Int'l Incidence:

UK: in a general practice population of 250,739 patients, the estimated frequency of asthma attacks was 14.3 per 1000 patients per year. FINLAND: new cases of asthma increased between 1986 and 1993 from 1.8% to 4.6% for ages 0-14 years, and from 4.0% to 6.2% for ages 15-54 years; during the same period, new cases decreased from 5.9% to 4.1% for ages over 54 years.

Int'l Prevalence:

Rates of asthma in Japan, per 100,000 inpatients (per day), were reported as follows: 1987, 16; 1990, 16; 1993, 14. Rates of asthma in Japan, per 100,000 outpatients (per day), were reported as follows: 1987, 107; 1990, 111; 1993, 126. In UK: 2-3 million. In Western countries: childhood asthma between 5-20%. Prevalence of asthma in adolescents has been reported as follows: New Zealand (1991), 32 to 38% among persons aged 12 to 15 years; Australia (1992), 16.5% among persons aged 12 to 15 years; Netherlands (1989), 19% among persons aged 10 to 23 years (of whom less than half had been recognized by a doctor); Finland (1991), 2.8% among persons aged 15 to 16 years. The prevalence of asthma in adults in most industrialized nations ranges from 3% to 7%.

3.6.6.2.2 Web sites of some international studies

✓ AIRE, the national patient survey for Asthma Insights & Reality in Europe (1999) (http://www.asthma.ac.psiweb.com/index.html)

This survey found that the **household prevalence of diagnosed asthma was 8.6%** among the 73,880 households reporting in the seven AIRE countries. This means that one or more people had been diagnosed by a physician as having asthma in nearly one out of ten households across the seven European countries.

The survey found significant variation among the seven countries in the household prevalence of current asthma. At one extreme, the household prevalence of current asthma was 15.2% in the United Kingdom. At the other extreme, the household prevalence of diagnosed asthma was 2.5% in Germany. In four out of the seven European countries, the household prevalence of current asthma fell in the range of 4%-6% of households.

The population prevalence of current asthma can be estimated based on the total number of people reported in each household and the total number of people with current asthma in those households. A total of 213,158 people were reported living in the 73,880 households screened for the survey. **The total population prevalence of current asthma was 2.7%** for the seven AIRE countries.

✓ The ISAAC study

http://www.wnmeds.ac.nz/research/Warg/introduction/l4isaac.html

After eight years of work, in collaboration with colleagues in Auckland, London and Münster, 1998 saw the publication of the findings of the International Study of Asthma and Allergies in Children (ISAAC), involving more than 700,000 children in 155 centres in 56 countries.

The key findings include: The highest asthma prevalence in the world is observed in English speaking countries.

New Zealand has a similar prevalence to that in other English speaking countries such as Australia, the United Kingdom, Canada and the United States. There is a strong Northwest to Southeast gradient in Europe, with the highest prevalence in the world being in the United Kingdom and the lowest prevalence being in the Eastern Mediterranean countries such as Greece and Albania. There is also very low prevalence in the former socialist countries of

Eastern Europe. However, the ISAAC study findings indicate that asthma prevalence is uniformly high in all of the English speaking countries, and attention is therefore shifting to factors which are common across these countries.

✓ European Community Respiratory Health Survey (ECRHS)

http://www.ecrhs.org/

ECRHS I

The study was developed in response to the increasing mortality rates associated with asthma in many parts of Europe and elsewhere in the mid 1980's. Also, around this time, evidence emerged of an increase in the prevalence of asthma and allergic disease.

Young adults aged between 20 and 44 years were selected at random from available population based registers to take part in the survey - the database of ECRHS I contains information from around 140,000 individuals. More than thirty centres across Europe each recruited about 300 men and 300 women for a detailed assessment of symptoms (respiratory symptoms, nasal symptoms, asthma), factors known or hypothesised to be of importance for allergy and allergic disease (family size, family history of disease, occupation, childhood and current exposure to pets, exposure to tobacco smoke, dampness, ventilation, use of soft furnishings, use of gas appliances) and use of health services and treatment (including use of inhaled steroids) for respiratory disease.

3.6.6.2.3 Published papers and meta-analysis

✓ Janson C, Anto J, Burney P, Chinn S, de Marco R, Heinrich J, Jarvis D, Kuenzli N, Leynaert B, Luczynska C, Neukirch F, Svanes C, Sunyer J, Wjst M. The European Community Respiratory Health Survey: what are the main results so far? European Community Respiratory Health Survey II. Eur Respir J 2001 Sep;18(3):598-611

Dept of Medical Science: Respiratory Medicine and Allergology, Uppsala University, Sweden.

The European Community Respiratory Heath Survey (ECRHS) was the first study to assess the geographical variation in asthma and allergy in adults using the same instruments and definitions. The database of the ECRHS includes information from approximately 140,000 individuals from 22 countries. The aim of this review is to summarize the results of the ECRHS to date. The ECRHS has shown that there are large geographical differences in the prevalence of asthma, atopy and bronchial responsiveness, with **high prevalence rates in English speaking countries and low prevalence rates in the Mediterranean region and Eastern Europe**. Analyses of risk factors have highlighted the importance of occupational exposure for asthma in adulthood. The association between sensitisation to individual allergens and bronchial responsiveness was strongest for indoor allergens (mite and cat). Analysis of treatment practices has confirmed that the **treatment of asthma varies widely between countries** and that asthma is often undertreated. In conclusion, the European Community Respiratory Health Survey has shown that the prevalence of asthma varies widely. The fact that the geographical pattern is consistent with the distribution of atopy and bronchial responsiveness supports the conclusion that the geographical variations in the prevalence of asthma are true and most likely due to environmental factors.

✓ Basagana X, Sunyer J, Zock JP, Kogevinas M, Urrutia I, Maldonado JA, Almar E, Payo F, Anto JM. Incidence of Asthma and Its Determinants among Adults in Spain. Am J Respir Crit Care Med 2001 Oct 1;164(7):1133-1137

The objective was to measure the incidence of asthma and its determinants in Spain, where the prevalence of asthma is low to medium. A follow-up of subjects participating in the European Community Respiratory Health Survey (ECRHS) was conducted in 1998- 1999 (n = 1,640, 85% of those eligible). Subjects were randomly selected from the general population and were 20 to 44 yr old in 1991-1993. Time of follow-up was on average 6.75 yr (range, 5.3 to 7.9 yr). Asthma was defined as reporting ever having had asthma. The incidence of asthma was 5.53 (95% confidence interval, 4.28- 7.16) per 1,000 person-years (6.88 in females, 4.04 in males). Incidence was highest in subjects who at the baseline survey had bronchial hyperresponsiveness (incidence rate ratio [IRR], 3.85), in those with positive IgE against timothy grass (IRR, 3.16), and in females (IRR, 1.80). These results persisted after adjusting for respiratory symptoms at baseline. There was no significant association ($p < 0.2$) with high total serum IgE, atopy defined by reactivity to any allergen, smoking, occupational exposure, or maternal asthma. A sensitivity analysis using four definitions of population at risk yielded incidence rates varying from 5.53 to 1.50. In this population of subjects without self-reported asthma or asthma-type symptoms at baseline, bronchial hyperresponsiveness and IgE reactivity to grass appeared as the main determinants of new asthma.

✓ Cuijpers CE, Wesseling GJ, Swaen GM, Sturmans F, Wouters EF.Asthma-related symptoms and lung function in primary school children. J Asthma 1994;31(4):301-12

Department of Epidemiology, University of Limburg, Maastricht, The Netherlands.

The aim of the present study was to determine the prevalence of **asthma-related symptoms** in a group of primary school children, by means of a questionnaire completed by their parents, and their lung function using spirometry and the forced oscillation technique (FOT). Also investigated were diagnostic labeling and medical prescription. We approached 535 children, from two primary schools in Maastricht, the Netherlands. Completed questionnaires were received from 482 children (90%). Valid lung function values were obtained in 470 of these children (98%). The lifetime prevalence of **wheeze and attacks of shortness of** breath with wheeze was 29% and 19%, respectively. The period prevalence of wheeze was 15%, 13% reported chronic cough, and 10% attacks of shortness of breath with wheeze. The **doctor-diagnosed asthma** and bronchitis **prevalence was 6%** and 19%, respectively. Of the children diagnosed as having asthma, 69% used anti-asthma medication; none of the children diagnosed as having bronchitis used anti-asthma medication. A symptom-based asthma prevalence of 11% was calculated. Statistically significant differences in spirometric and FOT indices were found between the children with and without complaints. In conclusion, among the 482 investigated children a relatively high prevalence of unrecognized or misclassified, and therefore undertreated, asthma-related symptoms was found. These observations were confirmed by the lung function data, in that we found significant differences in spirometric and FOT indices between children with and without complaints.

✓ Van der Wal MF, Uitenbroek DG, Verhoeff AP. [Increased proportion of elementary school children with asthmatic symptoms in the Netherlands, 1984/85-1994/95; a literature review.] Ned Tijdschr Geneeskd 2000 Sep 9;144(37):1780-5

Afd. Epidemiologie, Documentatic en Gezondheidsbevordering, GG&GD Amsterdam.

OBJECTIVE: To investigate whether the prevalence of asthmatic symptoms among children in the Netherlands has changed. DESIGN: Literature study. METHOD: Investigations into the prevalence of children with asthmatic symptoms were collected from Medline, Embase and various libraries if they had been performed between 1984/'85 and 1994/'95 and had used the so-called WHO or Region list. 23 studies were selected with data on 76,353 elementary school pupils. Linear regression analysis, weighed for the number of children, was used to determine if the proportions of children with **asthmatic symptoms** had increased over the years. RESULTS**: In 10 years the prevalence of recent shortness of breath had increased by 107% (from 4.16 to 8.63%**), that of recent **wheeze** by 16% (from 10.64 to 12.35%), that of recent **attacks of breathlessness with wheezing** by 17% (from 5.29 to 6.19%), and for **chronic cough** by 259 (from 1.05 to 3.77%) to 272% (from 3.14 to 11.68%). The prevalence of doctor-diagnosed asthma had increased by 120% (from 2.82 to 6.19%). CONCLUSION: There had been a pronounced increase in the percentage of primary schoolchildren with asthmatic symptoms between 1984/'85 and 1994/'95. The prevalence of doctor-diagnosed asthma increased faster then did key symptoms of asthma. Publication Types: Meta-Analysis.

- ✓ Timonen KL, Pekkanen J, Korppi M, Vahteristo M, Salonen RO. Prevalence and characteristics of children with chronic respiratory symptoms in eastern Finland. Eur Respir J 1995 Jul;8(7):1155-60

Dept of Environmental Epidemiology, National Public Health Institute, Kuopio, Finland.

The objective of the present study was to assess the prevalence of asthma and asthma-related symptoms in Finland. We also wondered whether chronic cough may be an indicator of occult asthma. Prevalence and characteristics of children with doctor-diagnosed asthma and chronic respiratory symptoms were investigated in 7-12 year old school children from eastern Finland by using a questionnaire on respiratory symptoms. In addition, skin-prick tests, flow-volume spirometry, and serum total immunoglobulin E (IgE) measurements were performed in children reporting chronic respiratory symptoms. The **parent-reported prevalence of doctor-diagnosed asthma was 4.4%**, of **wheezing** 5.4%, of **attacks of shortness of breath with wheezing** 4.6%, and of **dry cough at night** 12%. Children with dry cough only (n = 195) had less frequent parental asthma, self-reported allergies, daily respiratory medication, and moisture stains or molds at home than asthmatic children (n = 180), but these findings were more frequent than among asymptomatic children (n = 2,169). The prevalence of at least one positive skin-prick test result was 79% among the asthmatic children and 55% among children with dry cough only. There were no differences between the two symptom groups in serum total IgE levels and spirometric lung functions, except in maximal mid-expiratory flow (MMEF) values, which were significantly lower among children with asthmatic symptoms. The present results support the hypothesis that chronic cough may be an indicator of occult asthma. Therefore, to improve the sensitivity of respiratory questionnaires designed to detect asthma, they should also include questions on chronic cough Publication Types: Multicenter Study

- ✓ **Upton MN** , **McConnachie A**, **McSharry C**, **Hart CL**, **Davey Smith G**, **Gillis CR**, **Watt GCM**, Intergenerational 20 year trends in the **prevalence** of **asthma** and hay fever in adults: the Midspan family study surveys of parents and offspring *BMJ* 2000;321:88-92 (8 July)

Department of General Practice, University of Glasgow, Glasgow G12 0RR,

Objective: To estimate trends between 1972-6 and 1996 in the **prevalence** of **asthma** and hay fever in adults.

Design: Two epidemiological surveys 20 years apart. Identical questions were asked about **asthma**, hay fever, and respiratory symptoms at each survey.

Setting: Renfrew and Paisley, two towns in the west of Scotland.

Subjects: 1477 married couples aged 45-64 participated in a general population survey in 1972-6; and 2338 offspring aged 30-59 participated in a 1996 survey. **Prevalence** were compared in 1708 parents and 1124 offspring aged 45-54

Main outcome measures: **Prevalence** of **asthma**, hay fever, and respiratory symptoms.

Results: In never smokers, age and sex standardised prevalence of asthma and hay fever were **3.0%** and 5.8% respectively in **1972**-6, **and 8.2%** and 19.9% in **1996**. In ever smokers, the corresponding values were **1.6%** and 5.4% in **1972**-6 **and 5.3%** and 15.5% in **1996**. In both generations, the **prevalence** of **asthma** was higher in those who reported hay fever (atopic **asthma**). In never smokers, reports of wheeze not labelled as **asthma** were about 10 times more common in 1972-6 than in 1996. **With a broader definition of** asthma (asthma **and/or wheeze), to minimise diagnostic bias, the overall** prevalence **of** asthma **changed little**. However, diagnostic bias mainly affected non-atopic **asthma**. Atopic **asthma** increased more than twofold (**prevalence** ratio 2.52 (95% confidence interval 1.01 to 6.28)) whereas the **prevalence** of non-atopic **asthma** did not change (1.00 (0.53 to 1.90)).

Conclusion: The **prevalence** of **asthma** in adults has increased more than twofold in 20 years, largely in association with trends in atopy, as measured indirectly by the **prevalence** of hay fever. No evidence was found for an increase in diagnostic awareness being responsible for the trend in atopic **asthma**, but increased awareness may account for trends in non-atopic **asthma**.

✓ **Dickinson JA, Meaker M, Searle M, Ratcliffe G** Screening older patients for obstructive airways disease in a semi-rural practice *Thorax* 1999;54:501-505 (June)

Central Surgery, King Street, Barton on Humber, North Lincolnshire DN18 5ER, UK

BACKGROUND—Obstructive airways disease in older patients is reported to be not only common, but frequently overlooked and untreated by general practitioners. This study examines the value of screening elderly patients in a large semi-rural general practice for potentially treatable asthma and chronic obstructive pulmonary disease (COPD).

METHODS—A random sample of 353 patients aged 60-75 years attended a nurse run screening clinic for pulmonary function testing, serial peak flow recording, and completion of a symptom questionnaire. Patients with a low forced expiratory volume in one second (below the fifth centile of their predicted value) or >15% mean diurnal variation in peak flow were referred to a doctor's clinic for further diagnostic assessment and/or to discuss possible treatment where appropriate

RESULTS—Fifty eight patients (16.4%) had obstructive airways disease, **the prevalence of asthma being 6.5%** and that of COPD 9.9%. Of these, 30 had no previous diagnosis of airways disease and were not on treatment; eight of them had significant airways reversibility and 10 were current smokers. No newly diagnosed patients had severe disease as measured by pulmonary function or quality of life assessment, and six patients accepted treatment.

CONCLUSION—Few older patients benefited from a screening programme for obstructive airways disease in a semi-rural general practice.

✓ **Magnus P**, **Jaakkola JJK**, Secular trend in the occurrence of **asthma** among children and young adults: critical appraisal of repeated cross sectional surveys *BMJ* 1997;314:1795 (21 June)

Objectives: To review repeated surveys of the rising prevalence of obstructive lung disease among children and young adults and determine whether systematic biases may explain the observed trends.

Design: Review of published reports of repeated cross sectional surveys of **asthma and wheezing** among children and young adults. The repeated surveys used the same sampling frame, the same definition of outcome variables, and equivalent data collection methods.

Setting: Repeated surveys conducted anywhere in the world

Subjects: All repeated surveys whose last set of results were published in 1983 or later.

Main outcome measures: Lifetime and current prevalence of asthma and current prevalence of wheezing. The absolute increase (yearly percentage) in the prevalence of asthma and wheezing was calculated and compared between studies.

Results: 16 repeated surveys fulfilled the inclusion criteria. 12 reported increases in the current prevalence of asthma (**from 0.09% to 0.97% a year**) and eight reported increases in the current prevalence of wheezing (from 0.14% to 1.24% a year). Changes in labelling are likely to have occurred for the reporting of asthma, and information biases may have occurred for the reporting of wheezing. Only one study reported an increase in an objective measurement.

Conclusions: The evidence for increased prevalence of asthma and wheezing is weak because the measures used are susceptible to systematic errors. Until repeated surveys incorporating more objective data are available no firm conclusions about increases in obstructive lung disease among children and young adults can be drawn.

- ✓ Azeem Majeed and Kath Moser, Prescribing for patients with asthma by general practitioners in England and Wales 1994–96. ONS Office for National Statistics
- ✓ The objective of this study was to examine trends in the management of asthma in general practice, and in particular, to examine trends in the use of inhaled steroids and inhaled bronchodilators between 1994 and 1996. The data for the study came from 288 general practices, total list size 2.1 million, about 4 per cent of the population in England and Wales, on the General Practice Research Database. Between 1994 and 1996, the percentage of asthmatics being prescribed inhaled steroids, either alone or in combination with bronchodilators, increased in all age groups. The largest increase in the use of combination treatment was seen in children under five years of age. The use of bronchodilators alone in
- ✓ patients with asthma fell in all age groups but particularly in children. The results suggest that the management of asthma in primary care is changing, with an increase in the percentage of asthmatics who are being prescribed combination treatment with bronchodilators and either inhaled steroids or inhaled cromoglycate.

3.6.6.2.4 About asthma, out of the quoted papers

Table 3.7. Some expressions about asthma incidence in the quoted studies

☐ ***Frequency of asthma attacks***
☐ ***Incidence of asthma***
☐ ***New cases of asthma***
☐ ***Rates of asthma (in and outpatients)***

Table 3.8. incidence of asthma (%) in the quoted studies

UK		1,43
FI	1986-1993	4
SP	1998-1999	5,53

Table 3.9. Some expressions about asthma prevalence in the quoted studies

☐ ***Household prevalence of current asthma***
☐ ***Prevalence of asthma***
☐ ***Prevalence of asthma related symptoms***
☐ ***Prevalence of attacks of shortness of breath with wheeze***
☐ ***Prevalence of recent shortness of breath***
☐ ***Prevalence of childhood asthma***
☐ ***Prevalence of current asthma***
☐ ***Prevalence of doctor's diagnosed asthma***
☐ ***Prevalence of parent related doctor's diagnosed asthma***
☐ ***Prevalence of reporting ever having had asthma***
☐ ***Prevalence of potentially treatable asthma***
☐ ***Prevalence of asthma and wheezing***

Table 3.10. Published prevalence of asthma (%)

USA	1994	5,6
Industrialised countries		5
AIRE (Household)		8,6
AIRE (current asthma)		2,7
NL	1994	6
NL (School children)	1984	4,16
NL (School children)	1994	8,63
FI (School children)	1995	4,4
UK (School children)	1972	3
UK (School children)	1996	8,2
UK (old pt. rural practice)	1999	6,5

3.6.7 CONTRIBUTION OF THE PARTICIPANTS

3.6.7.1 Department of general practice, Odense University(Dk)

3.6.7.1.1 Erik Falkoe contribution (Dk)

✓ Which classification used by the collecting centre; ICPC-1

Year/Month

3 month for contacts/diagnoses

1-2 years for processes and drugs

Geographical area-NUTS codes: Fyn(Denmark)

Number of GPs involved in the registration

- 6 surgeries with 14 doctors (included 2 trainees and 2 part-time locums)

Number of patient/year

  - Study population 12648 people (M:6.003-F:6.645)
  - consultation in 3 month: 9451(M:3630,F:5821)

- Number of cases/year of both items, by age and by sex Patients in the population in 3 month
  - With asthma; 106
  - Herpes Zoster ;9
- Number of contacts/GP/year Consultations in 3 month with;
  - astma : 166
  - herpes Zoster:9

✓ Number of referrals for the specific condition: na

Table 3.11. Asthma and Zoster distribution, Odense database, Dk

	ASTMA			*ZOSTER*		
AgeGroup	**All**	**M**	**F**	**All**	**M**	**F**
0-9 years	46	30	16			
10-19 y	14	5	9	1		1
20-29 y	17	3	14			
30-39 y	15	12	3			
40-49 y	7	2	5	2		2
50-59 y	2	2		1	1	
60-69 y	3	2	1	3	1	2
70-79 y	2		2	2	1	1
80- y	106			9		

3.6.7.1.2 Comments: Erik Falkoe, Odense University

The doctors are using the same software. Part of a working group with the leader of Fyncom, Tove Lehrmann. In the field of information technology (IT) this region (FYN) is a front runner and acts as a development and trial area within electronic communication in the health care sector.

3.6.7.2 Department of general practice, Trondheim

3.6.7.2.1 Anders Grimsmo contribution

✓ Which classification used by the collecting centre; ICPC-1

✓ Year/Month 1 year for astma (1998), 7 years for herpes (1992-1998)

✓ Geographical area-NUTS codes: Suldal (Rogaland), Surnadal (Møre og Romsdal), Rindal (Møre og Romsdal), Saltdal (Nordland), Alstadhaug (Nordland), Hammerfest (Finnmark)

✓ Number of GPs involved in the registration ; 1992-1998:164 1998: 71

✓ Number of patient/year

Study population 34271 people per 01.10.98 (M:17262-F:17009)

consultations during 1992-1998: 1077966 (M:442552,F:633495, Missing:1919)
consultations during 1998: 147064 (M:63479,F:83585, Missing: 0)

- ✓ Number of contacts/GP/year; asthma : 11,6 herpes zoster: 0,4
- ✓ Number of referrals for the specific condition : na
- ✓ Number of cases/year of both items, by age and by sex (Number of persons):

Herpes Zoster

Table 3.12. The incidence of new cases of herpes zoster per 10.000 people per year (1992-98)

	0-5y	6-12y	13-15y	16-19y	20-29y	30-39y	40-49y	50-59y	60-69y	70-79y	> 80y	Total/2
Total/2	31	44	24	47	76	36	53	124	215	330	544	113
Men	30	42	23	45	84	29	47	96	156	278	478	90
Women	32	45	23	50	67	44	59	155	274	372	580	136

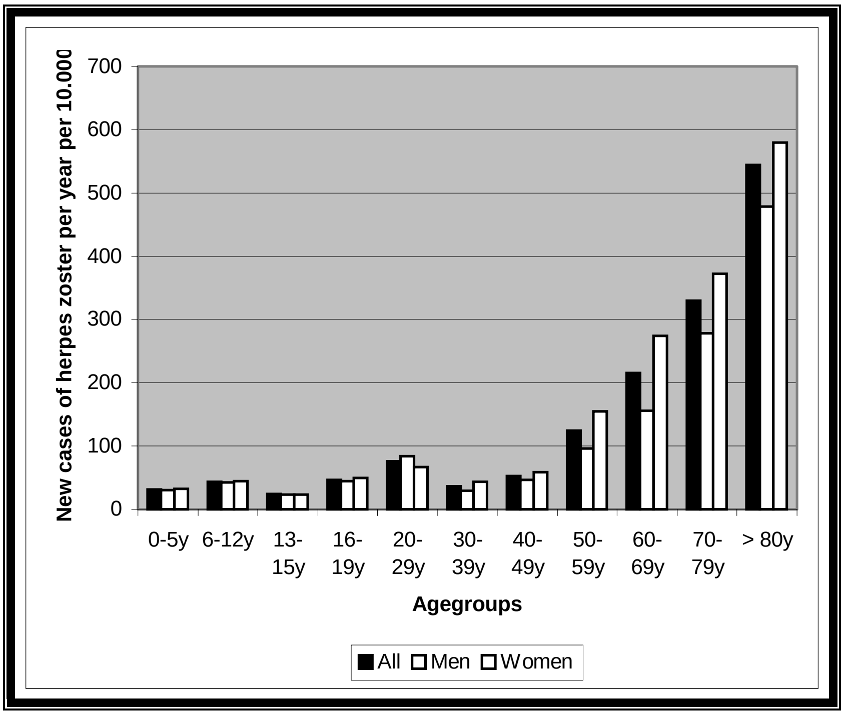

Figure 3.9. The incidence of new cases of herpes zoster per 10.000 people per year (1992-98)

Table 3.13. Shingles distribution, 1992-1998, Norway (6 regions)

Herpes 1992-1998	0-5 y	6-12 y	3-15 y	6-19 y	20-29y	0-39 y	0-49 y	0-59 y	0-69 y	0-79 y	80 y -	Total
Female	3	5	1	3	11	7	10	20	26	36	40	162
Male	3	5	1	3	15	5	8	14	15	22	18	109
Total	6	10	2	6	26	12	18	34	41	58	58	271

Asthma

Table 3.14. People with asthma in Norway

	All	*Men*	*Wo men*	*0-5y*	*6-12y*	*13-15y*	*16-19y*	*20-29y*	*30-39y*	*40-49y*	*50-59y*	*60-69y*	*70-79y*	*> 80y*
Study population	34271	17262	17009	2762	3283	1239	1814	4909	4736	4843	3920	2729	2512	1524
Total no. encounters 1998	147064	63479	83585	8427	5604	2080	5086	18501	20798	20689	19922	14942	16659	14356
Patients registered with asthma at least once (1992-98)														
No. persons	1700	836	864	212	207	80	102	200	150	164	139	158	186	102
% of population	5,0	4,8	5,1	7,7	6,3	6,5	5,6	4,1	3,2	3,4	3,5	5,8	7,4	6,7
Patients with asthma visiting the doctor during one year (1998)														
No. persons	397	178	219	49,0	54	15	20	28	31	33	47	38	60	22
% of patients with asthma	23,4	21,3	25,3	23,1	26,1	18,8	19,6	14,0	20,7	20,1	33,8	24,1	32,3	21,6
Encounters for asthma (1998)														
No. encounters	822	389	433	97	106	45	33	42	58	54	123	86	142	36
% of all encounters	0,6	0,6	0,5	1,2	1,9	2,2	0,6	0,2	0,3	0,3	0,6	0,6	0,9	0,3
Encounters per patient	2,07	2,19	1,98	1,98	1,96	3,00	1,65	1,50	1,87	1,64	2,62	2,26	2,37	1,64

The number people and percentage of population with at least one encounter for asthma from 1992 to 1998, the number and percentage of these asthma patients seeing a GP during one year (1998) and the number of encounters per patient and percentage of all encounters.

Table 3.15. Prevalence of asthma in Norway: Number patients with asthma per 1.000 people, men and women in different age-groups registered in general practice

	0-5y	*6-12y*	*13-15y*	*16-19y*	*20-29y*	*30-39y*	*40-49y*	*50-59y*	*60-69y*	*70-79y*	*> 80y*	*Total/2*
Total/2	77	63	65	56	41	32	34	36	58	74	67	50
Men	90	78	85	37	37	24	25	27	62	80	86	48
Women	63	47	44	78	45	41	43	46	54	69	57	51

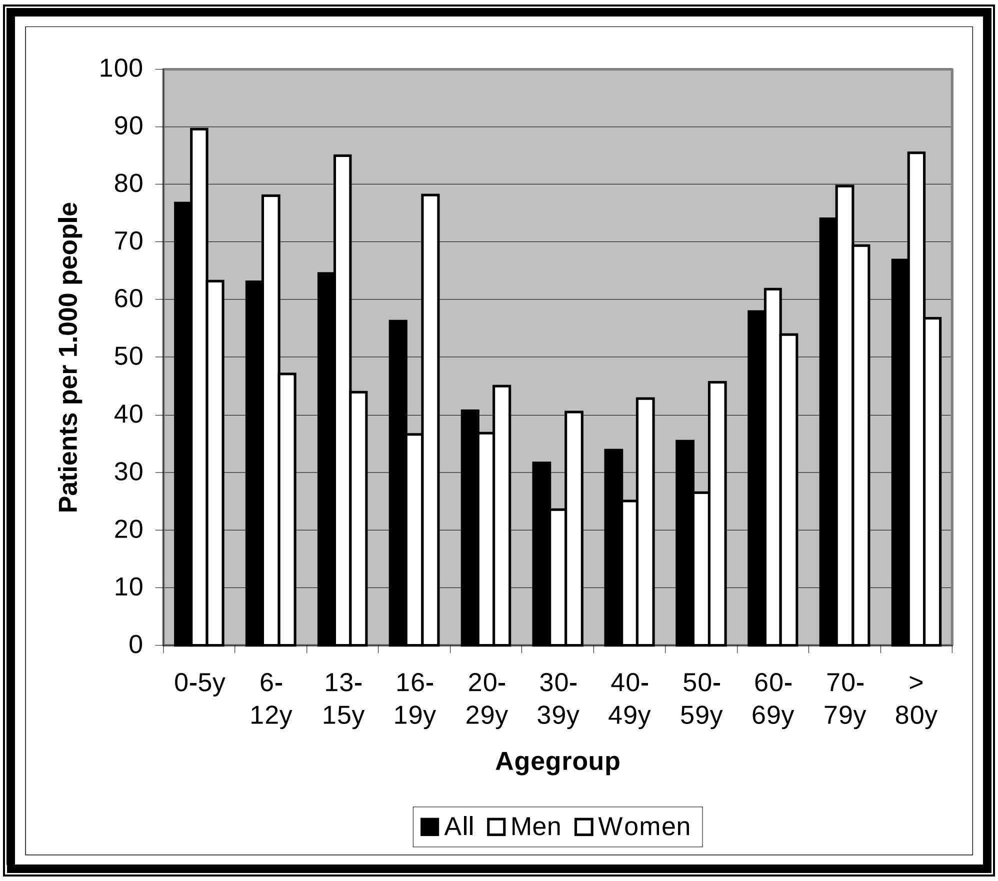

Figure 3.10. Prevalence of asthma in Norway: Number patients with asthma per 1.000 people, men and women in different age-groups registered in general practice.

Table 3.16. Incidence of asthma in Norway: incidence of new persons getting asthma first time per 1.000 people during one year (1998)

	0-5y	*6-12y*	*13-15y*	*16-19y*	*20-29y*	*30-39y*	*40-49y*	*50-59y*	*60-69y*	*70-79y*	*> 80y*	*Total/2*
Total/2	9	4	4	4	2	3	3	4	6	6	3	4
Men	11	6	3	1	1	2	1	2	7	8	4	4
Women	6	2	5	8	4	4	4	6	5	5	2	4

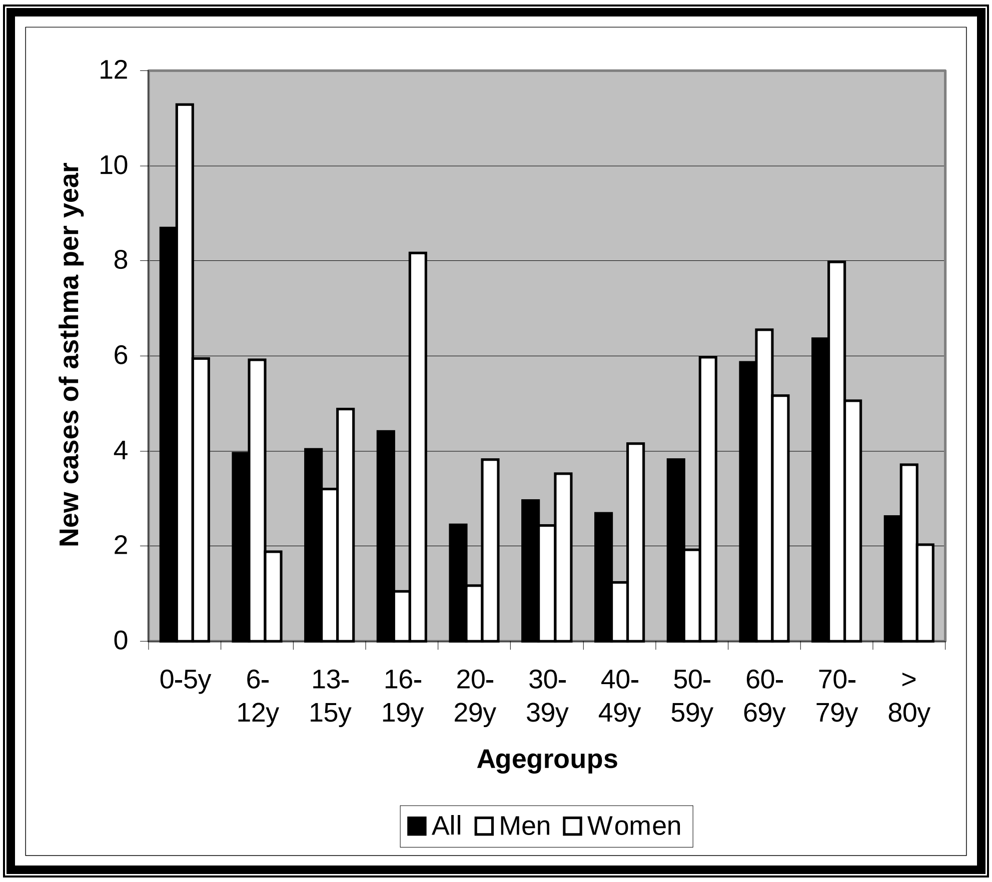

Figure 3.11. Incidence of asthma in Norway: incidence of new persons getting asthma first time per 1.000 people during one year (1998).

Table 3.17. Asthma distribution, 1998, Norway (6 regions)

Asthma 1998	*0-5y*	*6-12 y*	*13-15 y*	*16-19 y*	*20-29 y*	*30-39 y*	*40-49 y*	*50-59 y*	*60-69 y*	*70-79y*	*80 y -*	*Total*
Female	24	19	4	15	21	20	24	30	19	28	15	219
Male	25	35	11	5	7	11	9	17	19	32	7	178
Total	49	54	15	20	28	31	33	47	38	60	22	397

Census Norway, 2000

Table 3.18. Norway, Populations by Gender and Age in 2000

Age	Male	Female	Total	Age	Male	Female	Total
0-4	148463	140146	288609	45-49:	155137	149589	304726
5-9	156080	147444	303524	50-54:	157554	150914	308468
10-14	145251	138139	283390	55-59:	122435	120388	242823
15-19	135358	128930	264288	60-64:	91083	94799	185882
20-24	139379	133995	273374	65-69:	78541	87105	165646
25-29	164363	159769	324132	70-74:	73730	89322	163052
30-34	176510	169441	345951	75-79:	64311	90121	154432
35-39	167894	160635	328529	80 plus:	67801	132754	200555
40-44	161928	156398	318326				
				TOTAL:	**2205818**	**2249889**	**4455707**

Source: U.S. Bureau of the Census [69]

3.6.7.2.2 Comments: Anders Grimsmo , Trondheim

I have the material to answer many questions about asthma and herpes zoster in general practice, but your request is not very precise, which also can be seen in the figures sent by Erik Falkoe. It would not be very convenient to discover that arriving in Brussels since we then might not have access to the data or time to recalculate. But maybe time is too short to do anything with it. Here are some of my comments:

✓ "Number of GPs involved in the registration"

Some of the GP's in the material have left or are new in the practices during the period of registration, meaning that the number of participating GP's is quite larger than the number of positions for GP's (especially in remote areas in Norway). What denominator are you thinking of, and do you then mean the average number participating doctors or positions?

✓ "Number of patients/year"

Do you mean (average number) patients on the list, active patients or with at least one encounter during the period? The length of the registration period will here make a big difference depending on how you are counting persons and the type of contacts (direct/indirect) you are including.

✓ "Number of cases/year of both items, by age and by sex"

Do you mean all cases or only new cases (incidence)? This makes a very big difference for asthma, hardly any for herpes Zoster. If you want to know the prevalence for asthma, you need probably a 5 year material to get registered or to accumulate all persons in the practice/study population with that problem (mild and/or recurrent cases), and then another year counting only new cases to find the incidence. Else the figure only will give an indirect picture of health care utilization (time intervals of contacts combined with percentage of the population seeing the doctor), which don't make much sense to compare.

What age groups do you want by five or ten years or others?

✓ "If available; number of contacts/GP/year"

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[69] **Timely Data Resources Inc.** http://www.tdrdata.com/ The Incidence and Prevalence Database. acceded 7-Feb-02 by courtesy of John Borgman

Again, all contacts or only direct contacts? Should house calls and emergency calls (out of office hours) be included? What about contacts with other staffs (the secretary, the nurse, the midwife) in my practice (about 1/3 of the patient contacts)?

Anyway, I have tried to copy Erik Falkoe the way I believe he has thought, and my results are attached. You then see some of the problems mentioned above.

Additional comments

The division into age groups for the young ones, as you see, is grounded on the school system in Norway and may be different from other countries. In the tables the term "Total/2" to the left means both sexes together that age group. It would be the same as average if both sex groups were of equal size. "Total/2" to the right in the tables mean the whole population. "Norway" is short for the six regions mentioned initially.

Herpes zoster causes in more than 90% of the cases only one encounter. The number of contacts therefore is equal to the incidence (table 2)

Notice that during one year (1998) only about one quarter of the people who at least once have gotten the diagnosis asthma (1992-98) attend the doctor under the heading asthma (table 4). Does that mean that for many people asthma is only sporadic or causes very little interference of daily life, or is the problem asthma often taken care of seeing the doctor for other main reasons?

Figure 3.9 and 3.10 nicely show the biphasic distribution of asthma being frequent in very young and old people. What I have not seen before is the sharp rise in incidence of asthma among teenage girls. It is opposite for the boys. Is that a artefact or have other found something like this?

Anders Grimsmo will not assist to the meeting.

http://home.online.no/~agrimsm/anders/index.htm

3.6.7.3 General practice database (GPRD) UK

3.6.7.3.1 Contribution of Azeem Majeed (ONS)

Herpes Zoster

• ***Classification used***	ICD9 Codes
• ***Year***	1991-1992
• ***Geographical Area***	England & Wales
• ***Number of GPs***	60 General Practice
• ***Number of patients***	502,482

Table 3.19. Period prevalence of Herpes Zoster infection per 1,000 people in England & Wales in 1991-92.

Period prevalence based on proportion of population consulting during one year.

Age group	*0-4*	*5-15*	*16-24*	*25-44*	*45-64*	*65-74*	*75-84*	*85+*	*All ages*
Males	0.9	2.6	2.3	2.7	5.3	9.9	13.2	16.0	4.1
Females	1.1	2.8	2.5	3.1	7.4	13.5	14.2	14.2	5.6

Source: Fourth National Survey of Morbidity in General Practice

Asthma

• ***Classification used***	Read Codes
• ***Year***	1998
• ***Geographical Area***	England & Wales
• ***Number of GPs***	211 General Practice
• ***Number of patients***	1.4 Million

Table 3.20. Prevalence & treatment of asthma in males in England & Wales in 1998

Crude rate ** Age standardised rate

Age group (years)	*0-4*	*5-15*	*16-24*	*25-34*	*35-44*	*45-54*	*55-64*	*65-74*	*75-84*	*85+*	*Rate**	*ASR***
Prevalence / 1,000	97.0	132.1	72.8	55.3	47.2	44.5	59.2	80.7	89.4	61.8	72.3	73.2
% prescribed bronchodilators only	32.0	26.4	36.1	35.5	28.1	24.6	17.7	15.4	17.2	20.1	26.6	27.4
% prescribed corticosteroids only	5.4	5.7	4.1	5.7	6.9	8.6	6.6	6.3	6.1	6.4	6.0	6.2
% prescribed cromoglycate only	0.3	0.6	0.3	0.3	0.3	0.5	0.4	0.2	0.1	1.1	0.4	0.4
% prescribed bronchodilators and corticosteroids	62.3	67.2	59.4	58.4	64.7	66.3	75.3	78.1	76.6	72.4	66.9	66.0

Source: UK General Practice Research Database

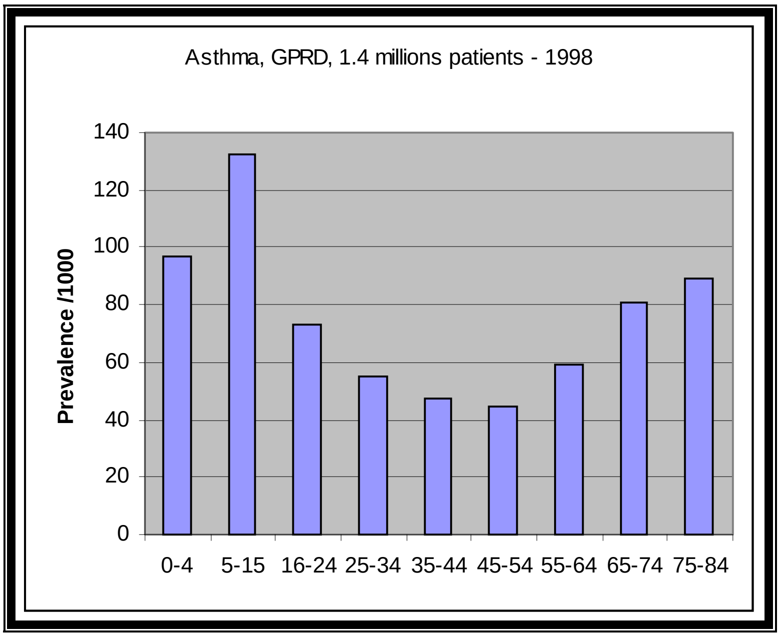

Figure 3.12. Prevalence of asthma in males in England & Wales in 1998

Table 3.21. Prevalence & treatment of asthma in females in England & Wales in 1998
* Crude rate ** Age standardised rate

Age group (years)	*0-4*	*5-15*	*16-24*	*25-34*	*35-44*	*45-54*	*55-64*	*65-74*	*75-84*	*85+*	*Rate**	*ASR***
Prevalence / 1,000	62.5	104.1	85.2	65.3	62.4	64.8	79.9	88.0	80.0	52.2	76.2	76.5
% prescribed bronchodilators only	33.2	28.7	34.1	31.2	25.4	19.9	16.2	16.0	18.2	22.8	24.9	25.7
% prescribed corticosteroids only	4.5	5.4	5.0	5.6	7.8	8.2	8.3	7.0	7.8	6.2	6.6	6.6
% prescribed cromoglycate only	0.3	0.5	0.2	0.1	0.3	0.3	0.3	0.3	0.1	0.0	0.3	0.3
% prescribed bronchodilators and corticosteroids	61.9	65.4	60.6	63.0	66.5	71.5	75.2	76.5	73.9	70.9	68.1	67.4

Source: UK General Practice Research Database

Census United Kingdom, 2000

Table 3.22. UK, Populations by Gender and Age in 2000

Age	Male	Female	Total	Age	Male	Female	Total
0-4	1824016	1731549	3555565	***45-49***	1874120	1872829	3746949
5-9	1972203	1874794	3846997	***50-54***	2015893	2027553	4043446
10-14	2003629	1894185	3897814	***55-59***	1601789	1639085	3240874
15-19	1907776	1802706	3710482	***60-64***	1395011	1460316	2855327
20-24	1819688	1732845	3552533	***65-69***	1213166	1333768	2546934
25-29	2039049	1964979	4004028	***70-74***	1040873	1267117	2307990
30-34	2342132	2279742	4621874	***75-79***	813648	1164554	1978202
35-39	2401950	2339491	4741441	***80 plus***	773403	1678454	2451857
40-44	2086634	2058492	4145126				
				TOTAL	**29124980**	**30122459**	**59247439**

Source: U.S. Bureau of the Census

3.6.7.3.2 Azeem Majeed comments, General Practice Research Database (GPRD)

Period prevalence of Herpes Zoster Infection

The source of the information on the period prevalence of Herpes Zoster in primary care for the United Kingdom is the Fourth National Survey of Morbidity in General Practice, carried out between September 1, 1991 and August 31, 1992. The fourth national morbidity survey was a one-year prospective cohort study of 502,482 patients registered with 60 general practices in England and Wales. The main objective of the survey was to examine the workload and pattern of disease in general practice in relation to the age, sex, and socio-economic status of patients. Sixty general practices in England and Wales took part in the survey. The study population comprised a 1% sample of the general population.

Prevalence & Treatment of Asthma

The source of the data on the prevalence and treatment of asthma in primary care for the United Kingdom is the UK General Practice Research Database (GPRD). The GPRD contains information entered prospectively by general practitioners onto their practice computers from early as 1987 for a limited number of practices and from the early 1990s for most of them. It contains anonymised information on demographic characteristics, medical diagnoses, information on all significant consultations, prescriptions and events leading to withdrawal of a drug, investigations, hospital referrals, admissions and treatment outcomes. The UK Office for National Statistics publishes an analysis of disease prevalence and treatment rates, based on this data, every two years. The most recent analysis (*Key Health Statistics from General Practice 1998*) was published in 2000 and contains trend data for the period 1994-1998. The full text of the document is available free of charge as a PDF file, and also as spreadsheet files, from URL below on the UK National Statistics website:

http://www.statistics.gov.uk/products/p4863.asp

UK : Doctor's Independent Network(DIN)

3.6.7.3.3 Contribution of Roger Weeks

I have received a dynamic excel table of which some figures have been printed out

Herpes Zoster

Table 3.23. Herpes Zoster in the year 2000

New Cases By GP/Year and Month				
Practices 001 to 180				
Pracnum	8			
Year	***InitMth***	***GPCode***	***Cases/Yr***	***Contacts/Yr***
2000	1	008CK	1	1
		008MJ	2	3
		008MS	1	1
	2	008CK	3	3
		008MJ	1	1
		008MS	1	2
	3	008CK	2	2
		008MJ	1	1
		008MS	2	2
	4	008CK	2	2
	5	008CK	1	1
		008MJ	1	1
		008MS	1	1
	6	008CK	1	1
		008MS	2	2
	7	008CK	1	1
		008MS	1	1
Total			24	26

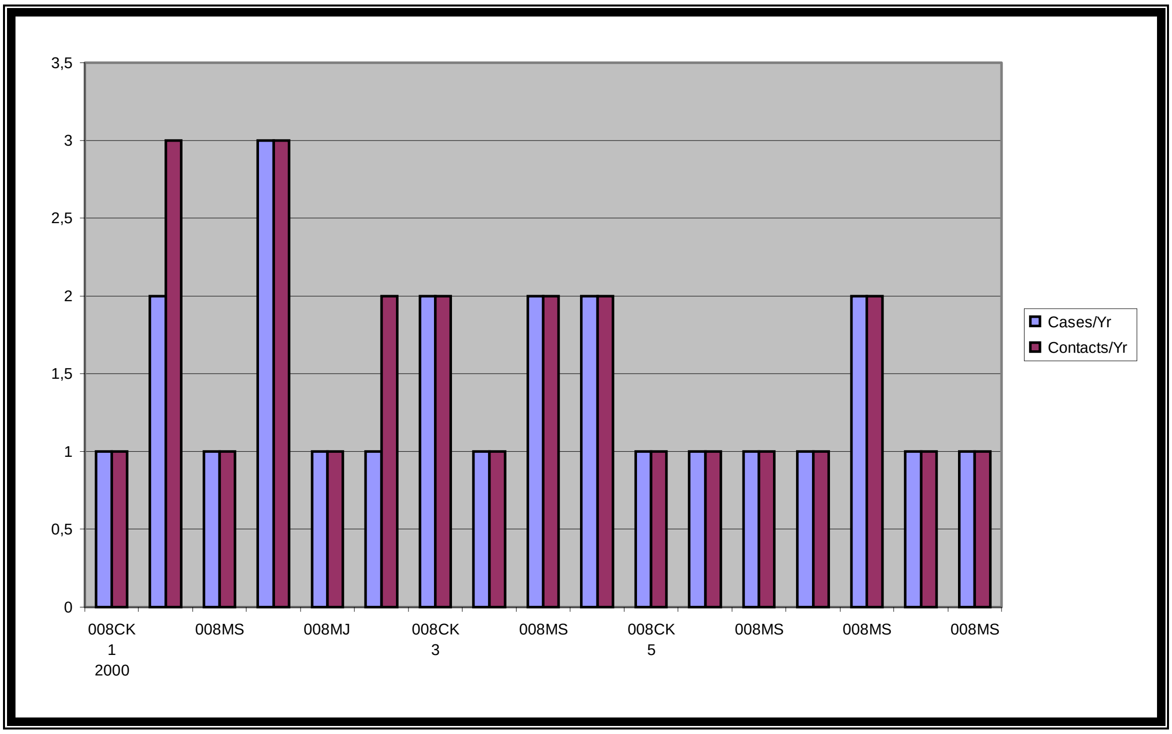

Figure 3.13. Herpes Zoster in the year 2000

Asthma

Table 3.24. Asthma contacts by age groups in the practice n°3 in 1994 (DIN)

Cases and Contacts By Pactice/Year By Age Group and Sex

Practices 001 to 140

	Cases/Yr		*Contacts/Yr*		*Total Cases/Yr*	*Total Contacts/Yr*
Age Group	*F*	*M*	*F*	*M*		
05 to 9	2	5	3	6	7	9
10 to 14	5	8	8	11	13	19
15 to 19	9	10	11	17	19	28
20 to 24	13	14	13	16	27	29
25 to 29	2	4	2	5	6	7
30 to 34	11	2	16	2	13	18
35 to 39	2	2	3	2	4	5
40 to 44	10	3	11	3	13	14
45 to 49	6		11		6	11
50 to 54	8	12	8	15	20	23
55 to 59	2	2	4	2	4	6
60 to 64	2	7	3	11	9	14
65 to 69	8	10	10	10	18	20
70 to 74	6	14	6	17	20	23
75 to 79	7	13	8	24	20	32
80 to 84	5	7	5	8	12	13
85 to 89	5	4	9	4	9	13
90 plus	4	4	8	4	8	12
Total	107	121	139	157	228	296

Table 3.25. Asthma contacts by age groups in 140 practices 2000 (DIN)

Cases and Contacts By Pactice/Year By Age Group and Sex

Practices 001 to 140

Pracnum All

	Cases/Yr		*Contacts/Yr*		*Total Cases/Yr*	*Total Contacts/Yr*
Age Group	*F*	*M*	*F*	*M*		
0 to 4	494	707	700	987	1201	1687
5 to 9	664	951	900	1271	1615	2171
10 to 14	626	870	828	1188	1496	2016
15 to 19	641	510	844	656	1151	1500
20 to 24	653	412	964	587	1065	1551
25 to 29	643	494	900	658	1137	1558
30 to 34	662	585	936	831	1247	1767
35 to 39	666	493	895	673	1159	1568
40 to 44	501	376	648	524	877	1172
45 to 49	451	284	640	376	735	1016
50 to 54	458	355	652	480	813	1132
55 to 59	479	302	665	437	781	1102
60 to 64	387	255	521	378	642	899
65 to 69	386	298	542	403	684	945
70 to 74	417	251	578	336	668	914
75 to 79	289	193	391	269	482	660
80 to 84	194	145	256	221	339	477
85 to 89	103	53	154	70	156	224
90 plus	47	28	66	46	75	112
Total	8761	7562	12080	10391	16323	22471

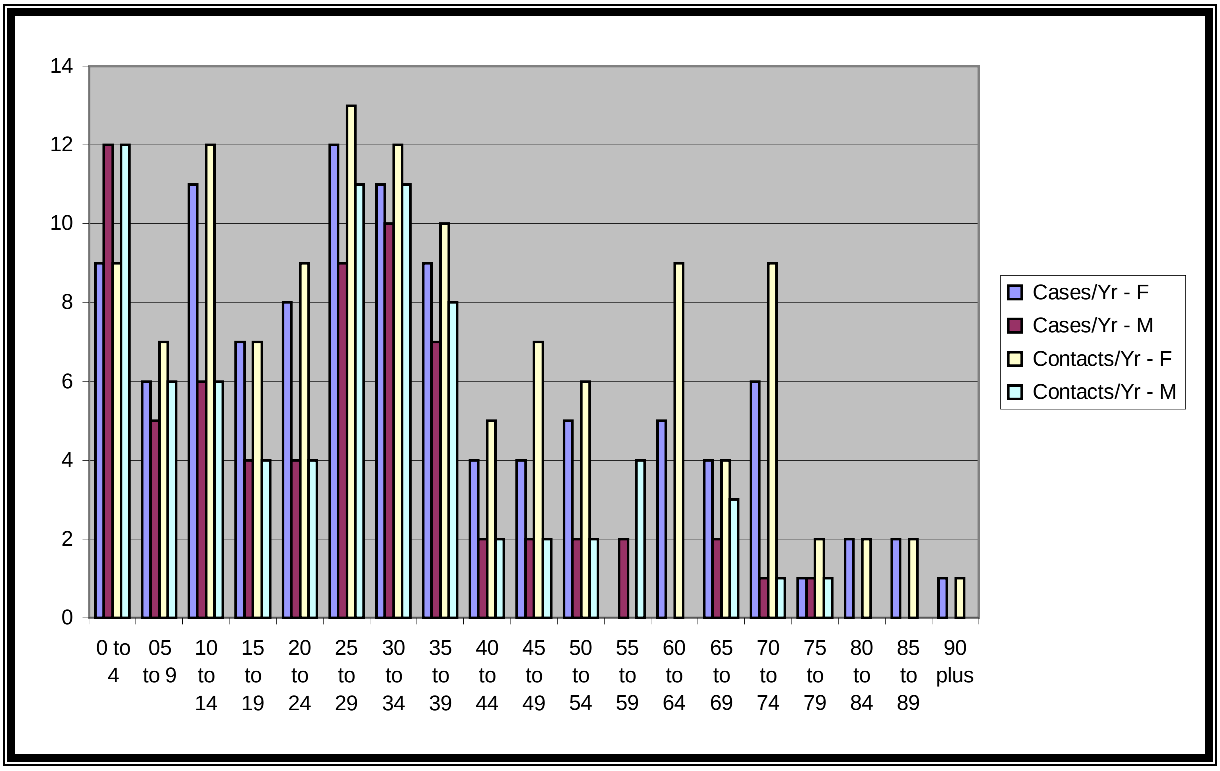

Figure 3.14. Asthma contacts by age groups

Data extracted from dynamic Excell presentation. Here the data from the practice n°138 in the year 2000

3.6.7.4 Iceland : Health sector data base

Although previous agreement of the Iceland General Surgeon, data from Iceland would be not available. “The reason is that there is a considerable paranoia in sharing data and it takes few more weeks to fullfill all the formalities”

Comment extracted from the first meeting (http://www.ulb.ac.be/esp/emd/is_njalsonn.htm):

"In my country we have over 20 years of primary health care records collected in a unified way, the SOAP-way (Subjective, Objective, Assessment, Plan). Overall the quality is in order and the variation in the record not a major problem, however except for my own one year data bank, nobody has connected or collected those records. Surgeon General asks for certain data and uses certain data for his annual public health records from Directorate of Health. The strange thing is that general practitioners do not consider their work and health record keeping important enough to be used for research. Needless to say, I do not agree with them, I think these data is important and useful, not perfect but very useful for health research, health care system research and to monitor population health.

Hospitals in Iceland have registered patient’s demographics and discharge diagnosis for 40 years. This data is all assessable. Currently we are implementing a new medical record for the country and its health system as a whole. The driving force for this computerisation in Iceland is a contract between the company Decode Genetics and Icelandic Health Authorities. A centralised data-bank or intranet is going to be the main method of data-transfer between health professionals. The general concept is to combine information from medical records, family trees (genealogy) and genome research to further scientific research into the role of the humane genes and location of disease causing genes. This we consider to be most important and will make a major contribution to medical science. There is in place a special law in Iceland about this particular arrangement between the government and this company. The personal identifier, which is unique, is going to be scrambled, only coded data is going to be transferred and the data protection agency in Iceland will control the data transfer to the company. The debate in the country has been heated but seems to have reached an agreement. The public opinion has been very much in favour of the project, however many doctors have been sceptical.

Ethically is research in primary health care no different from research in secondary or tertiary care. However the data is enormous and reaches almost every person in the country. It touches us all. This is quite different from hospital environment where only few of us visit throughout our lifetime. The data itself has in my opinion no ethical dilemmas until you connect it to personal identification numbers. However modern computer technology and extensive complicated way of coding these identification numbers makes it almost impossible to identify a person unless you have a strong criminal intent along with extensive computer knowledge and technology.

In primary health you have in most cases a complete medical history of a person. This raises the opportunity to make this promising connection of genes and the health record. However in Iceland we have one more record which is genology, family trees. These three records connected through extensive computer coding and under the control of the data protection committee of Iceland, makes it possible for us to locate disease genes in Iceland. We are looking into how we could combine information on phenotypes and lifestyles with these three data banks. If that is possible then we hopefully will be able to understand why some people get a disease and others not, even when they have the same disease gene on their chromosome.

There has been some uneasiness among the medical profession but I think that is being settled through continuous interchange and debate. The computer part of the data collection and central data bank is financed by the company Decode Genetics however each health institute has to have its own contract with the company, not collectively. This is all in process and as a result the system will be in place within certain timeframe.

Extensive historic data is stored in health institutes in Iceland. Collection of these into one data bank is expected to start within few months. The sources of data used in the future are going to be multiple and therefore important to have the data patient centred and my opinion patient owned. Systems of data-collection are increasingly run by technology people and less by health educated people including doctors. Part of this is normal development but also caused by internal struggle among doctors which has resulted in exclusion of them and direct communication between technology people and administration. We as health professionals need to step in and show some co-operation and take our place again to secure useful data for all of us.

It is my opinion that event and episode based data collection are both useable, however what health care workers are willing to do is the main issue here, not what we want them to do in our fantasies. Our own co-operation with the technology people could possibly tell us what is doable. Health Care professionals do not like to spend time recording information unless they find these useful and that the computer program benefits them in majority of the tasks performed. It is useless to have all our wishes as researchers included in a computer program if the user does not understand, does not like to use, and does not benefit from the data he/she collects. The main issue here is what can we benefit and gain from data which the health care professional feels he/she needs to collect. Health care professionals are just like everybody else, if they see no benefit from the task they perform they find a way around the task and the data is thus useless.

Internal and external validation is needed to confirm the data collected and adjust the computer program to reality. Extensive co-operation of health care professionals is essential for any data collection. What are their needs, how can we adjust our requests to their or do we just have to take what they are ready to leave for us to take?

It is my opinion that the patient is the owner of his/her data, we should have patients agreement and privacy and confidentiality clause as part of every health record. Electronic interchange is a must today and has the potential to save the patient inconvenience and the patient and the payer considerable amount of money"

Thornstein Njalssonn will not assist to the meeting

3.6.7.5 France: The Thales database

3.6.7.5.1 Contribution of Raphael Spira

- ✓ Period of extraction : year 2000
- ✓ Number of GPs in the database in 2000 : 1010
- ✓ Representativeness : the panel of GPs is representative of the GPs population in France according to the age, sex and region criteria.
- ✓ Number of patients with at least one consultation during the year : 1 207 616
- ✓ Number of consultations : 4 707 067
- ✓ Classification : the diagnostic nomenclature is specific to the THALES database

Geographical area : France

Herpes Zoster :

- ✓ Diagnostics selected
    - Herpes Zoster
    - Genicualte Herpes Zoster
    - Herpes Zoster with complications
    - Late effects of Herpes Zoster
    - Herpes Zoster ophtalmicus
    - Keratoconjunctivitis due to Herpes Zoster
    - Thoracic Herpes Zoster infection

Table 3.26. Thales database, year 2000, Shingles,
Number of cases by age and sex

	Males	*Females*	*Total*
< 16	144 (9,2 %)	167 (8,7 %)	311 (8,9 %)
16 to 30	202 (12,8 %)	202 (10,5 %)	404 (11,5 %)
31 to 45	222 (14,1 %)	220 (11,4 %)	442 (12,6 %)
46 to 60	403 (25,6 %)	481 (25,0 %)	884 (25,3 %)
> 60	602 (38,3 %)	857 (44,5 %)	1459 (41,7 %)
Total	1573 (100 %)	1927 (100 %)	3500 (100 %)
Average age	51 years	53 years	52 years

- ✓ Number of GPs involved : 917
- ✓ Number of consultations with the Herpes Zoster diagnostic : 5 049
- ✓ Number of consultations per GP : 5,0
- ✓ Number of patients per GP 3,5
- ✓ Number of consultations per patient : 1,4

Asthma :

- ✓ Diagnostics selected
  - Pure Asthma
  - Exercise-induced Asthma
  - Asthmatic crisis
  - Emphysematous asthma
  - intermittent asthma
  - Minor asthma
  - Moderate Asthma
  - Severe Asthma
  - Asthma-like attack
- ✓ Related activities

  Number of GPs involved : 1009
  Number of consultations with the asthma diagnostic : 63 438
  Number of consultations per GP : 62,9
  Number of patients per GP : 25,3
  Number of consultations per patient : 2,5

Table 3.27. Thales database, year 2000,
Asthma, Number of cases by age and sex

	Males	*Females*	*Total*
< 16	3317 (26,4 %)	1918 (14,8 %)	5235 (20,5 %)
16 to 30	2614 (20,8 %)	2840 (21,8 %)	5454 (21,3 %)
31 to 45	2181 (17,4 %)	2695 (20,7 %)	4876 (19,1 %)
46 to 60	2093 (16,7 %)	2519 (19,4 %)	4612 (18,0 %)
> 60	2349 (18,7 %)	3034 (23,3 %)	5383 (21,1 %)
Total	12554 (100 %)	13006 (100 %)	25560 (100 %)
Average age	36 years	41 years	38 years

Census France, 2000

Table 3.28. France, Populations by Gender and Age in 2000

Age	*Male*	*Female*	*Total*	*Age*	*Male*	*Female*	*Total*
0-4	1767906	1681822	3449728	***45-49***	2102722	2129239	4231961
5-9	1870816	1781202	3652018	***50-54***	2064817	2060126	4124943
10-14	1949541	1863723	3813264	***55-59***	1395311	1406116	2801427
15-19	1992882	1904464	3897346	***60-64***	1308320	1400271	2708591
20-24	1930460	1849110	3779570	***65-69***	1262142	1466571	2728713
25-29	2181046	2101613	4282659	***70-74***	1078958	1397177	2476135
30-34	2146912	2125956	4272868	***75-79***	841667	1263669	2105336
35-39	2137722	2167727	4305449	***80 plus***	702584	1536100	2238684
40-44	2107865	2151630	4259495				
				TOTAL:	**28841671**	**30286516**	**59128187**

Source: U.S. Bureau of the Census [68]

3.6.7.6 Italian Society of General Practice (SIMG)

Contribution of Roberto Nardi

Herpes Zoster

Table 3.29. Incidence Hepes Zoster, 2000, Italy

Age	*Total*	*%*	*Man*	*%*	*Women*	*%*	
<20	62	0,12%	33	0,13%	29	0,12%	**Italy**
20-34	183	0,15%	90	0,14%	93	0,15%	
35-44	200	0,21%	95	0,20%	105	0,21%	
45-54	246	0,30%	102	0,25%	144	0,35%	
55-64	347	0,49%	144	0,42%	203	0,55%	
65-74	365	0,60%	165	0,61%	200	0,60%	
>74	295	0,54%	90	0,45%	205	0,59%	
Total	1698	0,31%	719	0,28%	979	0,35%	
<20	29	0,14%	15	0,14%	14	0,15%	**North**
20-34	85	0,15%	47	0,16%	38	0,13%	
35-44	104	0,22%	55	0,24%	49	0,21%	
45-54	126	0,31%	45	0,22%	81	0,40%	
55-64	186	0,50%	72	0,41%	114	0,60%	
65-74	171	0,56%	77	0,57%	94	0,55%	
>74	160	0,54%	46	0,45%	114	0,59%	
Total	861	0,33%	357	0,29%	504	0,37%	
<20	8	0,13%	3	0,09%	5	0,17%	**Centre**
20-34	23	0,17%	6	0,17%	17	0,18%	
35-44	23	0,14%	11	0,12%	12	0,16%	
45-54	29	0,21%	15	0,20%	14	0,21%	
55-64	44	0,35%	20	0,31%	24	0,40%	
65-74	49	0,45%	17	0,30%	32	0,61%	
>74	51	0,50%	16	0,35%	35	0,62%	
Total	227	0,27%	88	0,22%	139	0,32%	
<20	25	0,10%	15	0,12%	10	0,09%	**South & Isle**
20-34	75	0,15%	37	0,15%	38	0,15%	
35-44	73	0,22%	29	0,18%	44	0,25%	
45-54	91	0,32%	42	0,30%	49	0,34%	
55-64	117	0,52%	52	0,48%	65	0,56%	
65-74	145	0,73%	71	0,81%	74	0,66%	
>74	84	0,51%	28	0,44%	56	0,56%	
Total	610	0,31%	274	0,30%	336	0,33%	

Table 3.30. Prevalence Hepes Zoster, 2000, Italy.

Age	Total	%	Man	%	Women	%	
<20	199	0,30%	99	0,29%	100	0,32%	Italy
20-34	633	0,41%	310	0,40%	323	0,41%	
35-44	717	0,62%	367	0,64%	350	0,59%	
45-54	985	1,00%	404	0,83%	581	1,17%	
55-64	1412	1,64%	565	1,37%	847	1,90%	
65-74	1554	2,12%	646	1,98%	908	2,23%	
>74	1355	2,03%	472	1,94%	883	2,08%	
Total	6855	1,04%	2863	0,91%	3992	1,15%	
<20	91	0,35%	49	0,36%	42	0,34%	North
20-34	317	0,46%	167	0,48%	150	0,43%	
35-44	351	0,62%	179	0,64%	172	0,61%	
45-54	455	0,95%	170	0,71%	285	1,18%	
55-64	706	1,60%	270	1,27%	436	1,90%	
65-74	734	1,98%	303	1,85%	431	2,08%	
>74	691	1,95%	223	1,82%	468	2,02%	
Total	3345	1,06%	1361	0,90%	1984	1,19%	
<20	21	0,25%	6	0,13%	15	0,38%	Centre
20-34	86	0,36%	41	0,34%	45	0,37%	
35-44	90	0,49%	53	0,59%	37	0,40%	
45-54	131	0,83%	63	0,81%	68	0,85%	
55-64	230	1,61%	96	1,39%	134	1,81%	
65-74	240	2,02%	93	1,70%	147	2,29%	
>74	240	2,13%	97	2,25%	143	2,05%	
Total	1038	1,00%	449	0,90%	589	1,09%	
<20	87	0,28%	44	0,27%	43	0,28%	South & Isle
20-34	230	0,38%	102	0,34%	128	0,41%	
35-44	276	0,66%	135	0,68%	141	0,65%	
45-54	399	1,15%	171	1,00%	228	1,30%	
55-64	476	1,73%	199	1,51%	277	1,94%	
65-74	580	2,38%	250	2,34%	330	2,42%	
>74	424	2,11%	152	1,96%	272	2,21%	
Total	2472	1,03%	1053	0,92%	1419	1,13%	

Asthme

Table 3.31. Asthma Incidence, 2000, Italy

Age	*Total*	*%*	*Man*	*%*	*Women*	*%*	
<20	654	1,29%	420	1,59%	234	0,97%	**Italy**
20-34	986	0,79%	500	0,80%	486	0,77%	
35-44	664	0,69%	273	0,58%	391	0,80%	
45-54	546	0,67%	215	0,53%	331	0,80%	
55-64	466	0,66%	179	0,52%	287	0,78%	
65-74	400	0,66%	129	0,48%	271	0,81%	
>74	315	0,57%	108	0,54%	207	0,59%	
Total	4031	0,75%	1824	0,71%	2207	0,78%	
<20	197	0,98%	67	0,63%	9569,5	6,95%	**North**
20-34	335	0,59%	159	0,56%	28426	20,64%	
35-44	255	0,54%	151	0,65%	23828,5	17,30%	
45-54	194	0,48%	121	0,60%	20429	14,83%	
55-64	185	0,50%	109	0,61%	19152	13,91%	
65-74	158	0,52%	109	0,80%	17086,5	12,41%	
>74	144	0,49%	97	0,95%	19222,5	13,96%	
Total	1468	0,56%	813	0,66%	137714	100,00%	
<20	6278,5	7,50%	3368	8,38%	2910,5	6,69%	**Centre**
20-34	13172	15,74%	3496	8,69%	9676	22,25%	
35-44	16917	20,21%	9469	23,55%	7448	17,13%	
45-54	13852	16,55%	7333,5	18,24%	6518,5	14,99%	
55-64	12401,5	14,82%	6367,5	15,83%	6034	13,88%	
65-74	10877,5	13,00%	5663	14,08%	5214,5	11,99%	
>74	10196,5	12,18%	4515,5	11,23%	5681	13,07%	
Total	83695	100,00%	40212,5	100,00%	43482,5	100,00%	
<20	24125,5	12,38%	12445,5	13,40%	11680	11,45%	**South & Isle**
20-34	49480	25,39%	24200,5	26,06%	25279,5	24,78%	
35-44	33796,5	17,34%	16081	17,32%	17715,5	17,37%	
45-54	28606	14,68%	14150,5	15,24%	14455,5	14,17%	
55-64	22484	11,54%	10836,5	11,67%	11647,5	11,42%	
65-74	19986,5	10,26%	8808,5	9,48%	11178	10,96%	
>74	16394,5	8,41%	6347,5	6,83%	10047	9,85%	
Total	194873	100,00%	92870	100,00%	102003	100,00%	

Table 3.32. Asthma Prevalence, 2000, Italy

Age	*Total*	*%*	*Man*	*%*	*Women*	*%*	
<20	2838	4,31%	1834	5,36%	1004	3,18%	**Italy**
20-34	4448	2,87%	2368	3,09%	2080	2,66%	
35-44	2933	2,52%	1264	2,22%	1669	2,82%	
45-54	2245	2,28%	867	1,78%	1378	2,77%	
55-64	2064	2,40%	770	1,87%	1294	2,90%	
65-74	1672	2,28%	606	1,86%	1066	2,62%	
>74	1182	1,77%	412	1,69%	770	1,81%	
Total	17382	2,63%	8121	2,58%	9261	2,67%	
<20	1171	4,49%	769	5,64%	402	3,23%	**North**
20-34	1984	2,85%	1111	3,18%	873	2,52%	
35-44	1295	2,29%	580	2,06%	715	2,52%	
45-54	1007	2,09%	406	1,69%	601	2,49%	
55-64	962	2,18%	353	1,67%	609	2,66%	
65-74	781	2,11%	282	1,72%	499	2,41%	
>74	559	1,58%	169	1,38%	390	1,68%	
Total	7759	2,45%	3670	2,44%	4089	2,46%	
<20	300	3,51%	187	4,10%	113	2,84%	**Centre**
20-34	582	2,42%	308	2,59%	274	2,26%	
35-44	346	1,90%	177	1,96%	169	1,83%	
45-54	283	1,80%	112	1,44%	171	2,15%	
55-64	301	2,10%	126	1,82%	175	2,37%	
65-74	231	1,94%	101	1,84%	130	2,03%	
>74	181	1,60%	73	1,69%	108	1,55%	
Total	2224	2,14%	1084	2,17%	1140	2,11%	
<20	1367	4,39%	878	5,47%	489	3,24%	**South & Isle**
20-34	1882	3,07%	949	3,18%	933	2,98%	
35-44	1292	3,11%	507	2,56%	785	3,61%	
45-54	955	2,75%	349	2,04%	606	3,44%	
55-64	801	2,92%	291	2,21%	510	3,56%	
65-74	660	2,71%	223	2,08%	437	3,21%	
>74	442	2,20%	170	2,20%	272	2,21%	
Total	7399	3,08%	3367	2,94%	4032	3,20%	

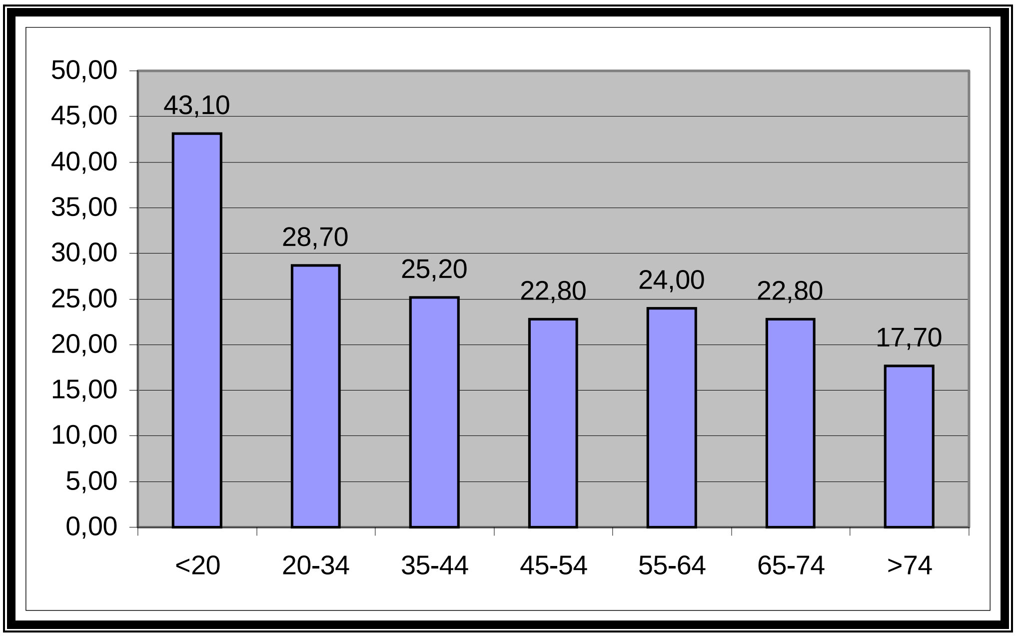

Figure 3.15. Asthma Prevalence, 2000, Italy

Soggetti e Distribuzione

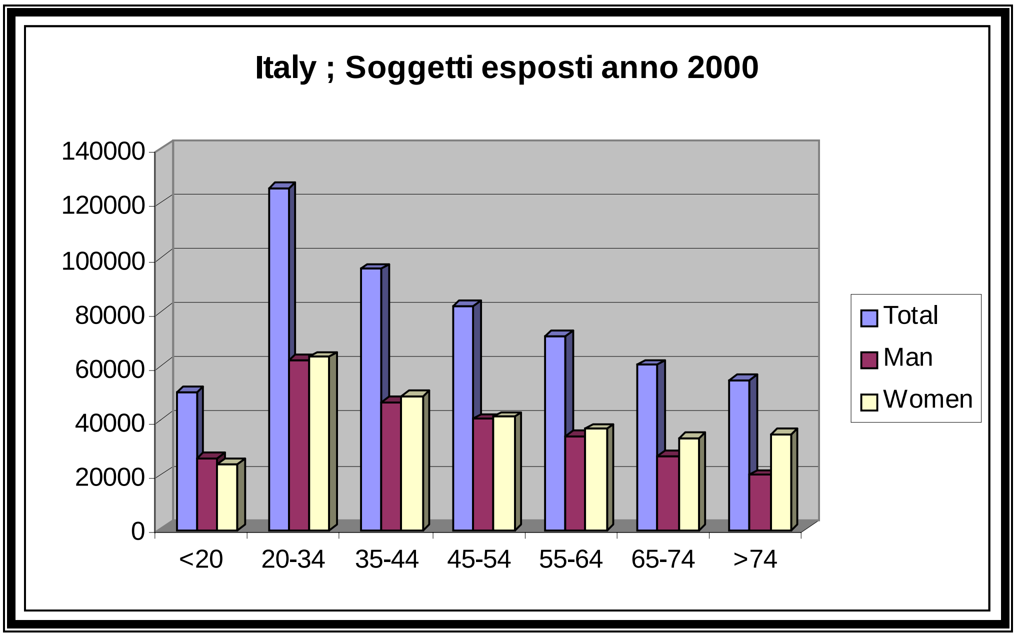

Figure 3.16. Population of Italy, 2000

Total population: 540362; Man: 257162; Women: 283199

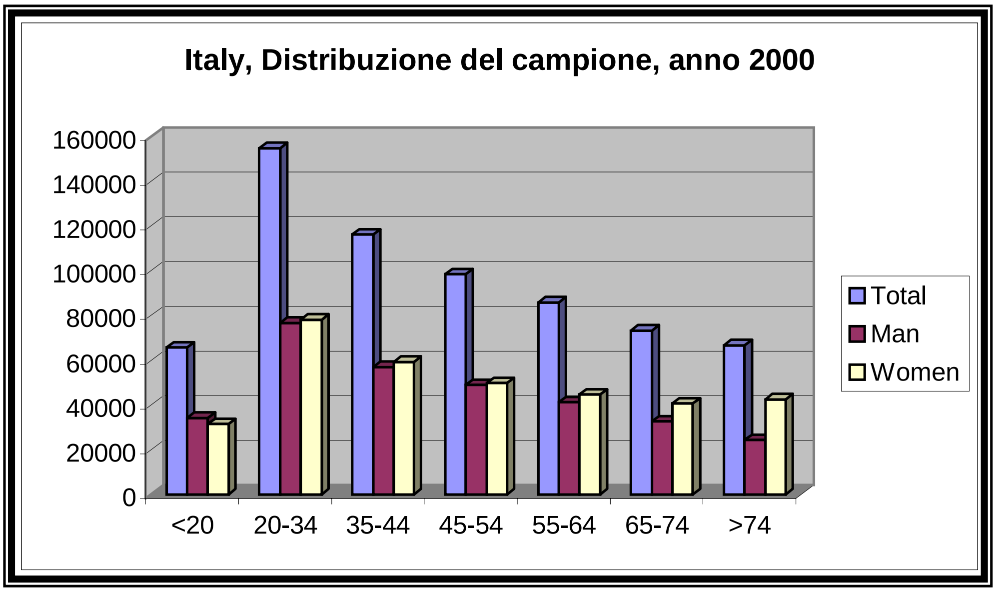

Figure 3.17. Population of Italy, 2000

Total population : 661459 Man : 314903 Women : 346556

Census Italy, 2000

Table 3.33. Italy, Populations by Gender and Age in 2000

Age	*Male*	*Female*	*Total*	*Age*	*Male*	*Female*	*Total*
0-4	1318386	1240354	2558740	***45-49***	1850123	1879207	3729330
5-9	1406747	1325125	2731872	***50-54***	1890999	1948177	3839176
10-14	1415744	1337745	2753489	***55-59***	1593507	1689516	3283023
15-19	1526079	1448914	2974993	***60-64***	1608146	1777414	3385560
20-24	1831447	1762978	3594425	***65-69***	1405844	1658910	3064754
25-29	2248921	2173255	4422176	***70-74***	1192556	1547289	2739845
30-34	2318316	2273675	4591991	***75-79***	888400	1348134	2236534
35-39	2270860	2246127	4516987	***80 plus***	752541	1519714	2272255
40-44	1996794	1994624	3991418				
				TOTAL	**27515410**	**29171158**	**56686568**

Source: U.S. Bureau of the Census [68]

3.6.7.7 Nl : General practice registration network (RNH), Maastricht university

3.6.7.7.1 Contribution of Job Metsemakers,

Maastricht University, Department of general Practice

Herpes Zoster

Table 3.34. Incidence of Herpes Zoster
RNH Network Maastricht, 53 GPs, patients on list.

	1996	*1997*	*1998*	*1999*	*2000*
N° cases	34	45	49	32	18
Total pop.	65909	73232	78024	81787	80749
‰	0,52	0,61	0,63	0,39	0,22

Asthma

Table 3.35. Incidence of Asthma
RNH Network Maastricht, 53 GPs, patients on list.

	1996	*1997*	*1998*	*1999*	*2000*
N° cases	196	237	259	187	150
Total pop.	62989	69896	74295	77841	76751
‰	3,11	3,39	3,49	2,40	1,95

Table 3.36. Prevalence of Asthma
RNH Network Maastricht, 53 GPs, patients on list.

	1996	*1997*	*1998*	*1999*	*2000*
N° cases	3692	4212	4678	4868	4863
Total pop.	66485	73871	78714	82522	81464
‰	55,53	57,02	59,43	58,99	59,70

Census The Netherlands, 2000

Table 3.37. The Netherlands, Populations by Gender and Age in 2000

Age	Male	Female	Total	Age	Male	Female	Total
0-4	470463	448781	919244	***45-49***	582567	563810	1146377
5-9	510357	487300	997657	***50-54***	596782	573948	1170730
10-14	494182	473209	967391	***55-59***	442115	428657	870772
15-19	468405	448677	917082	***60-64***	365169	370936	736105
20-24	482073	461822	943895	***65-69***	307728	339902	647630
25-29	579130	562054	1141184	***70-74***	245544	310756	556300
30-34	680107	645259	1325366	***75-79***	180884	276394	457278
35-39	683592	649783	1333375	***80 plus***	155560	359144	514704
40-44	627475	605739	1233214				
				TOTAL	**7872133**	**8006171**	**15878304**

Source: U.S. Bureau of the Census [68]

3.6.7.7.2 Comments from Job Metsemakers

Some additional information about our data:

1. We have provided you some very basic information about the prevalence and incidence of herpes zoster and asthma. Using our database, we can also quite easy provide stratified numbers (stratified to age, and sex for example).
2. Possibly, the numbers regarding the occurrence of herpes zoster will vary a lot, due to different criteria used by the different registration networks. In our registration we expect it to be relatively low, because health problems are only registered when they are chronic (6 months or longer) or when they are recurrent (with 3 or more recurrences in 6 months). This means that mild short-term cases will not be included in our registration.

3.6.7.8 Barcelona Regional registration

3.6.7.8.1 Contribution of Sebastia Juncosa

1. Annual prevalence

Table 3.38. Annual Prevalence rates per 10.000 attended patients (not repeated episodes).
Total, by sex and age groups. (ICPC Codes)

	Total		Sex		Age group						
	Crude rates	Standardized rates.	Men	Women	0-4	5-14	15-24	25-44	45-64	65-74	75-99
S70 Herpes zòster	46,2	44,1	51,2	38,8	10,3	25,2	25,3	23,8	48,1	118,1	110,9
R96 Asthma	183,4	181,1	196,5	169,6	133,9	462,8	202,5	137,3	139,5	152,5	110,9

Incidence

Table 3.39. Annual Incidence rates per 10.000 attended patients (not repeated episodes).
Total, by sex and age groups. (ICPC Codes)

	Total		*Sex*		*Age group*						
	Crude rates	*Standar-dized rates.*	*Men*	*Women*	*0-4*	*5-14*	*15-24*	*25-44*	*45-64*	*65-74*	*75-99*
S70 Herpes zòster	39,4	38,1	45,3	31,7	10,3	25,2	25,3	22,0	40,9	83,6	103,6
R96 Asthma	94,1	90,2	102,4	80,7	133,9	372,2	68,7	56,7	43,3	49,2	51,8

Census Spain, 2000

Table 3.40. Spain Populations by Gender and Age in 2000

Age	*Male*	*Female*	*Total*	*Age*	*Male*	*Female*	*Total*
0-4	963815	903286	1867101	***45-49***	1211003	1233528	2444531
5-9	958208	899230	1857438	***50-54***	1160259	1201778	2362037
10-14	1060043	1001714	2061757	***55-59***	1020371	1069629	2090000
15-19	1293927	1230112	2524039	***60-64***	870405	976185	1846590
20-24	1634809	1550717	3185526	***65-69***	937337	1090244	2027581
25-29	1684302	1631022	3315324	***70-74***	769331	988186	1757517
30-34	1621017	1587545	3208562	***75-79***	555691	804042	1359733
35-39	1533454	1521562	3055016	***80 plus***	482469	977610	1460079
40-44	1384607	1400798	2785405				
				TOTAL	**19141048**	**20067188**	**39208236**

Source: U.S. Bureau of the Census [68]

3.6.7.9 Finland : Hospital based data only

3.6.7.9.1 Contribution of Mikko Nennonen

Herpes Zoster : ICD-10 codes 'B02' or like 'B02'

Table 3.41. Finland Shingles In-patient episodes, 5 years

	1996	*1997*	*1998*	*1999*	*2000*
Male	360	354	310	315	349
Female	652	589	625	624	597
Total	1012	943	935	939	946

Table 3.42. Finland Number of patient presenting Shingles
In-patient data, 5 years

	1996	1997	1998	1999	2000
Male	302	290	274	276	289
Female	563	520	538	518	500
Total	865	810	812	794	789

Table 3.43. Finland Patient presenting Shingles
Number of In-patient days

	1996	1997	1998	1999	2000
Male	2791	3124	2431	2958	2609
Female	7111	5953	6427	5298	6014
Total	9902	9077	8858	8256	8623

Asthma: ICD-10 codes 'J45','J450','J451','J458','J459','J46'

Table 3.44. Finland Asthma In-patient episodes, 5 years

	1996	1997	1998	1999	2000
Male	10809	10286	9574	9536	9362
Female	12408	12037	11752	11161	11726
Total	23217	22323	21326	20697	21088

Table 3.45. Finland Number of patient presenting Asthma
In-patient data, 5 years

	1996	1997	1998	1999	2000
Male	6939	6701	6208	6321	6299
Female	7831	7636	7427	7349	7734
Total	14770	14337	13635	13670	14033

Table 3.46. Finland Patient presenting Asthma
Number of In-patient days

	1996	1997	1998	1999	2000
Male	58071	58582	53447	54798	57083
Female	101647	97991	100925	95933	100742
Total	159718	156573	154372	150731	157825

Census Finland, 2000

Table 3.47. Finland, Populations by Gender and Age in 2000

Age	*Male*	*Female*	*Total*	*Age*	*Male*	*Female*	*Total*
0-4	149981	144285	294266	***45-49***	202941	198436	401377
5-9	166849	160514	327363	***50-54***	214687	210394	425081
10-14	161557	154556	316113	***55-59***	147010	149698	296708
15-19	169179	161733	330912	***60-64***	122964	133894	256858
20-24	167213	160545	327758	***65-69***	102697	121877	224574
25-29	155777	149019	304796	***70-74***	86885	120983	207868
30-34	179170	172580	351750	***75-79***	56525	103296	159821
35-39	193622	186081	379703	***80 plus***	48576	127353	175929
40-44	195062	188886	383948				
				TOTAL	**2520695**	**2644130**	**5164825**

Source: U.S. Bureau of the Census [68]

3.6.7.9.2 Mikko Nennonen comments

Here are the Finnish in-patient figures for those two diagnoses. At present we do not have anything about out-patients. The population of Finland during those years was about 5 million.

For us episode is only one stay in hospital. This is what we report on routine basis. As a development project we report also episode of disease/treatment concept including in- and out-patient-visits, but in this table the figures are only for one stay.

We do not have any data of that kind from GPs. We are performing a test in Kotka region this month and at the beginning of next year we should have at least that material, but it is not going to be continuous data collection.

3.6.8 DISCUSSION DURING THE 5 DECEMBER 2001 MEETING IN BRUSSELS

The afternoon of the meeting has been consacred to discuss the present exercise about "Data availability about Herpes Zoster (Shingles) and Asthma in some continuous data collections systems in GP/FM in Europe.". (do refer to the CDRom or to the Internet site http://www.ulb.ac.be/esp/emd/program-dec_5.htm)

Each participant has presented his data collection process. The communications are published on the Cdrom. The rough notes by Dr Vania Siderova reproduced below are complementary to the comments exchanged by email before the meeting. The meeting ended by the presentaion by Mike Bainbridge of the project "Quality data in primary care" supported by PRIMIS (UK), Stakes ((Fi) and Health search (It). Roger Weeks(DIN, UK) has announced his organisation is willing to share the project.

Rough notes by Dr Vania Siderova.

- Marc Jamoulle (Be): There are difficulties to share information from different countries due to several reasons: lack of continuity and comprehensiveness of data, no common structure of information, different classifications of data, troubles in ethical point of view, confusion between classification and terminology, data quality issues, economic issues.

- Dimitris Kounoulakis (Gr): Is it COPD (chronic Obstructive Pulmonary Disaese) included in codification of Asthma or not? Less data are available in older people. COPD codification could interfere with results.
- MJ (Be): There is also a problem with standardisation of the concepts. Many coding systems are used (read codes, Snomed, ICD-9, ICPC2) but definitions of health issues are available only in ICHPPC-2 and ICPC-2.
- Mike Bainbridge (UK): There is a difference between symptomatic diagnosis and morbidity prevalence, we need correction by the process. So they can correct that in table 4.
- Roger Weeks(UK): They are many definitions of asthma but we should accept one of them.
- MJ (Be): We can accept the definition of WONCA.
- Eric Falkoe (Dk) : We have a problem coding, you do not have 2 windows, we do not need to put process code, we can not mixt diagnosis and process code.
- X: For the use of the data we should have the morbidity spectrum terms list, cross links, headlines.
- Mikko Nennonen (Fi): In clinical point of view, if we are dealing with public health, then the individual patient is not so important, we can make the difference between these both things and then use concepts, we can not mix both.
- MB (UK): Even when I treat individual patient, labelling is lower priority than to give good treatment.
- Roberto Nardi (It): Coding is a priority one, if you do not give code you do not can prescribe anything. In our experience, we are not using acceptable suitable terminology, but we have to train people with clinical guidelines.
- RW (UK): When a child with cough at night, occasionally come alone with wheezing, we will not diagnose it as asthma, this is very important to make the difference.
- Treating individual patient is the main purpose, if we use data for other thing government should give money.
- Sebastia Juncosa (Sp): Prevalence definition of asthma can be very difficult, prevalence is asthma already diagnosed, incidence is asthma which has not been diagnosed before.
- It is important to define which patients are concerned, patient on the list, active patients or with at least one encounter during the period? If this is not clear we always will have difference in prevalence without knowing if this is due to the way of calculation or to really different prevalence.
- DK (Gr): The culture of the patients is also an important factor, if he does not feel pain he does not go to the doctor, then you can have different prevalence. Episode of disease and episode of care influence the determination of prevalence.
- Sheila Teasadele (UK): We identified 51 531 patients, 1 021 with asthma in 7 GP practices.
- Monitoring code, prescription code, diagnosis code prevalence were used.
- SJ (Sp): The denominator is also important. Incidence denominator exclude those patients with already diagnosed asthma.
- MJ (Be): We can summarise 3 main points until now:
    - approach oriented to the patient,
    - need for definition,
    - epidemiology oriented approach.
- MJ (Be): It is important to make the difference between terminology and classification. Field of taxinomists, field of free text, there is fight between these two disciplines, the progression from free text towards coding, allows you only concept description, terminology allows you to retrieve information. With classification, you have categorisation of concept. That’s why it is so important to have quantitative approach.

MN (Fi): We have a lot of experience with codes, but we have troubles if we try to use that in practice. Different codes have different values, you should think why you need classification. When you have many coronary diseases, when you need more deepness in your coding you proceed in different way. Deeper codes need when scientific analysis, but if you want just every day work, no need from too many coding. Important not to mix coding and analysis of quality of treatment.

- RW (UK): Coding does not tell you many things about patient, about severity of patient condition.
- MJ (Be): There is no formal agreement with WONCA, ICPC to be included into WHO classification. 28 rubrics will be added in ICPC2 (ICF handicap), now we have better relation with WHO.

(UK): What is the need for the doctor for classification, of taxinomists for classification, these are different things.

- MJ (Be): There are some difficulties in data collection in Europe: problem with nominator/denominator, hidden problem (immigration), no consulting patients, only chronic problem gathered, denominator not known in some data base (Thales).
- MB (UK): Another point is the availability of quality of the used system.

- MJ (Be): There is a problem with age groups: Age groups are all different, these groups can be standardised by using WONCA age groups. By five or by ten , the age groups differ and often begin with different numeric units. A harmonisation is indispensable in order to properly collect data.
- SJ (Sp): In Spain there are primary care paediatrician, then patients often go to them.
- MJ (Be): In Belgium we have a free system, specialists or GP, patient can go to specialist directly. GP see 95 % from his patients within 3years. For example: glucometer is free if prescribed by specialist, as a GP, I do not see any more insulin dependent diabetes patients. Patient can go to the hospital and tell that he is my patient but does not come to me.
- MJ (Be): Quality of data means that data should be complete, accurate, consistent, accessible, updated.
- MJ (Be): We have to pay attention to the ethical problem raised by data collection. A very important question is who is the owner of the data, the patient, the doctor, the State, the social security organisation, the specific data industry, or the pharmaceutical companies? This question must be clarified before developing data collection system. Another point is to merge the vertical and circular information flow systems in order to obtain continuous data management systems in the field of general medicine.
- MN (Fi): We have different kind of questions, we need higher quality, more details, more experience, what simple size is needed to providing. This is dynamic model, we are learning something.
- RW (UK): Active feed back is very important.
- MJ (Be): In Belgiun and France we have the name of referent doctor. We have no list of patients but list of doctors. One information should go to the particular doctor.
- AM (UK): Data provider is a mirror of health care system, you can not take GP practice, this is not common in Europe. In case of disease specific treatment, step by step we can compare data but if we do not do that, things will be different.
- MN (Fi): We are describing what kind of health care functions is provided to patients. Also model standards of figures, sources of services. We need some kind of information system, especially for GP. We have not this in Finland.
- RW (UK): For us, it is time for grandiose ideas.
- X; Novelty ideas are extremely difficult to introduce, we need a lot of work to convince politics.
- MB (UK): The aim of the project “Data quality in primary care” is to establish a platform for assessing and improving PHC data quality, to create a European network of national entities working in the data quality area. In addition, to establish a network of providers of data deriving from routine data collection from PCH environment. The outcome is to obtain a data quality platform as well as good quality health indicators at both national and international level.

3.6.9 CONCLUSION

There are different experiences in data collection in European countries with great variation between systems and with several difficulties in sharing of data between the different databases. Before beginning data collection, it is indispensable to elaborate clear and standard concepts concerning main points such as coding system, structure of collected data, classification, terminology, epidemiological, ethical issues, data quality.

Further research projects are necessary in order to develop a European health information system and good health indicators based on data collection. The project Data Quality in Primary Care should continue the EMD-PHC project.

3.7 LIMITATIONS AND DIFFICULTIES IN DATA ACQUISITION WHEN GATHERING DATA ON MORBIDITY IN GENERAL MEDICINE IN EUROPE.

How can continuous data collection in general medicine data respond to the need for identifiable health indicators and for definable European health-determining factors? That is the question that must be addressed.

As emphasized by Aromaa Arpo, "Information gathering requires knowledge of the current organisation of data collection, storage and distribution in Members States, and expertise in data collection and information technology.

It also requires an understanding of the core subject matter i.e. health,its determinants and consequences, and health system"[70]

Even if general medicine treats 92% of the population’s problems, it is not necessarily easy to retrieve that unique and personal experience and conceive new health indicators.

In fact, this research project, which examines the continuous recording goes hand in hand with other research projects sponsored by the European Communities, notably the study on morbidity in different states conducted by Dr. Azeem Majeed, as well as study on European sentinel networks, conducted by Dr. Fleming. This is therefore not virgin territory. Most of the participants in the meetings already know each other and share a long history in the difficulties related to trading data.

All of these items were examined during the two meetings held in Brussels, and the conclusions at which the group arrived are featured in the following sections.

3.7.1 GENERAL APPROACH OF EUROPEAN DATA BANKS

Naturally, the inventory that was drawn is incomplete and many countries are missing. It must be said that we tried in vain to contact the representatives for Germany, as well as for Portugal, and the Italian database was handed to us at the last minute. The information and communication systems are still very difficult and complex.

Furthermore, there are a variety of different systems: this proves a considerable interest for general practitioners (GP) in morbidity data for primary health care.

Nevertheless, one must note that, in many countries, the primary care services are mixed with the front line actors. Indeed, countries such a Germany, Belgium, France, or Greece, do not have a pyramid-shaped health system, and the patients do not need to consult a GP in order to access the other health levels.

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[70] Aromaa Arpo, Health Surveillance, in: Priorities for Public Health Action in the European Union, Weil O, McKee M, Brodin M, Oberlé D (eds), march 1999

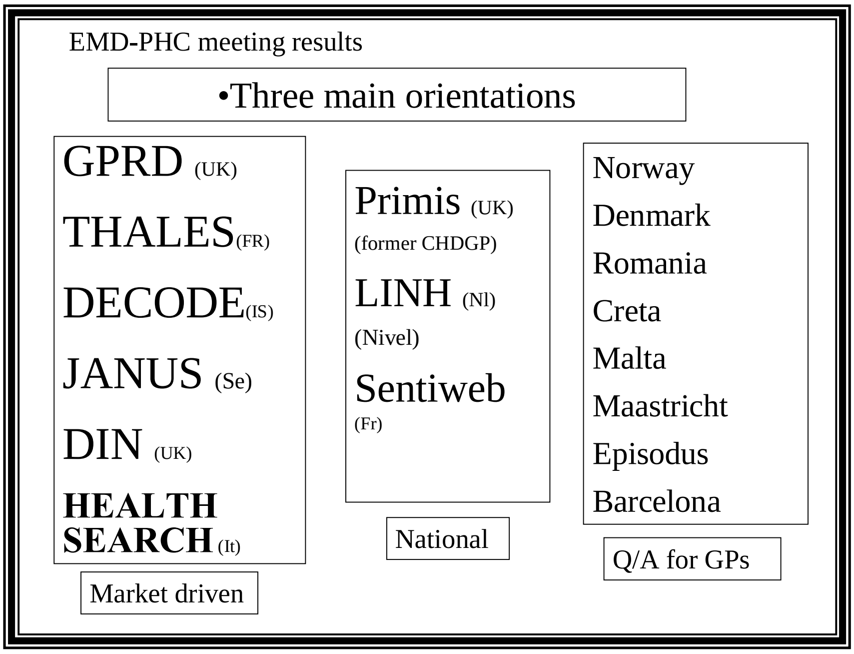

Figure 3.18. Main orientations in data collecting for general medicine in Europe

In the European databases that continuously record registration data, one observes three major groups that differ considerably in both their interests and their means. When referring to the diagram above, one observes a series of large databases with important economic means, which are often supported by industrial companies. The GP's are the foundation of the development of data gathering oriented towards seeking and ensuring quality. The States occasionally subsidise collection tools on the national level.

3.7.1.1 Pharmaceutical-epidemiological approach

First, there is a pharmaceutical-epidemiological approach, with a great deal of commercial support and multiple objectives, although always aimed at researching the market for medication market studies. These databases form a remarkable support for pharmaco-vigilance.

3.7.1.1.1 GPRD

The General Practice Research Database already has a long history. Founded in 1987 by a software company (VAMP), this database that was once dependant on the UK Health Ministry is now controlled by the British medication agency (MCA). Nearly 500 group practices transfer data under a particularly strict quality control. This database has been the source of many pharmaco-epidemiological, pharmaco-vigilance studies, as well as analysis on prescription habit and public health[71] (http://www.gprd.com/).

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[71] Key Health Statistics from General practice 1996. Analysis of morbidity and treatment data, including time trends, England and Wales. Series MB6 n°1. London. Office of national statistics. 1998

3.7.1.1.2 THALES

Another example is the Thales database, which collects data from the computers of over one thousand front line doctors in France.

This database belongs to the industrial group CEGEDIM (http://www.cegedim.fr/) and uses a proprietary terminology transcoded in ICD. The utilisation results for this database[72] were essentially related to m-the use of medication.

3.7.1.1.3 DECODE GENETICS

The system developed in Iceland particularly attracted our attention. The Decode Genetics Company (http://www.decode.com/) has certainly been the talk of the town in recent years, with a triple system database, which unveils a very important ethical question. Indeed, Decode Genetics is attempting to update the genetic defaults within a population. The Icelandic population, reputed for its homogeneity, is the subject of many studies and investigations. The company actually merges three Icelandic databases, made up of a genealogical database, a general medicine database[73], and a genetic database.

Despite the considerable opposition by Icelandic GP's, the health information contained in the Health sector database was made available to the Decode Genetics Company.

Despite the assurances given by Decode Genetics, whose commercial links to the Hoffman Laroche Company are still memorable, many Icelandic GP's opposed the use of this personal health data by a company with genetic research goals.

Many doctors and scientists came together within an association called Association of Icelanders for Ethics in Science and Medicine (http://www.mannvernd.is/english/home.html). The debates on the ethical aspects of personal data are well developed on the association's website.

One must note that in 1999, the State of Iceland voted a law fundamentally modifying the patients' rights over their medical information. In fact, they went from informed consent to presumed consent and, consequently, patients no longer need to be asked for their will to transmit the content of their medical record, even anonymous, for systematic use in the Decode genetics databases.

This example is important for all of Europe. One must underline that the Icelandic representative that participated in the meeting was unable to transfer data from the Health sector database. Indeed, despite the agreement of the Icelandic surgeon general, and for reasons yet unexplained, he was not authorised to transfer data for the exercise described in chapter IV.

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[72] Vallancien G. How are Lower Urinary Tract Urinary Tract Symptoms Managed in Real Life Practice? The French Experience. Eur Urol. 2000 Nov; 38 Suppl S1:54-59

[73] Njalsson T, Sigurdsson JA, McAuley RG. Health problems in family practice. An Icelandic multicentre study. Scand J Prim Health Care. 1996 Mar;14(1): 4-12.

3.7.1.1.4 JANUS

Janus is the result of collaboration between the Karolinska Institute and Stockholm County. This database is mainly oriented towards therapeutics and medication. A brief description is available on the site: http://www.ulb.ac.be/esp/emd/se_henriksson.htm.

3.7.1.1.5 DIN

The Doctor's Independent Network is documented in depth in chapter II and on the CDRom. The data from this network of GP's is split 50-50 between the DIN and the Compudata Company (http://www.compudata.co.uk), specialised in management software for general medicine in England. The pharmaceutical companies are among the DIN's clients.

3.7.1.1.6 Health Search

This company (http://www.healthsearch.it) based in Lombardy is sponsored by SIMG, one of the Italian general medicine scientific societies. Health search markets the Millewin software. Health search is part of the Datamat network (http://www.datamart.it/), an Italian informatics company also specialised in computer banking. Pharmaceutical companies such as Bayer and Astrazeneca support SIMG and Health Search. The GP network uses the Millewin software.

3.7.1.2 Quality-Assurance" approach

In addition, there is also an approach that one could qualify as quality assurance, carried out by GP's for GP's. This approach is the outcome of health specialists who are not especially computer specialists and who lack funds and support. Its objectives include a better understanding of the profession, the patients, and of their demand for care. The drug market occupies a secondary position and the implementation of quality criteria constitutes their priority. In quality assurance, data collection is central to the process[74].

3.7.1.2.1 Nordic countries

The availability of health statistics has a long tradition in Nordic countries[75], but the investment in database networks is recent. General practitioner networks emerged in Finland, Norway, and Denmark.

Particularly in Denmark, the electronic health system network is remarkably well developed[76], but it has not yet truly invested in the field of morbidity databases. The network introduced

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[74] Makela M, Booth B, Roberts R, (Eds). Family Doctor's journey to Quality. The WONCA working party on Quality in Family medicine. Stakes, Helsinki. 2001

[75] Grimsmo A, Hagman E, Faiko E, Matthiesen L, Njalsson T. Patients, diagnoses and processes in general practice in the Nordic countries. An attempt to make data from computerised medical records available for comparable statistics. Scand J Prim Health Care. 2001 Jun; 19(2): 76-82.

around the general medicine department of the University of Odense is still in its beginning stages. (see chapter II)

In Norway, the system developed by the University of Trondheim has proven to be efficient, as can be seen in the exercise featured in chapter IV. This year, the system developed in Trondheim was adopted for all of Norway, and the country will soon develop an electronic network between GP's that will allow for the continuous collection of data based on the ICPC classification.

3.7.1.2.2 Spain

In Spain, there are very few available means. The pilot study carried out in Madrid in 1998 and commented during the meeting on the 8th of December 2000 in Brussels was not continued, while the one carried out in Barcelona in 1999-2000 was extremely localised although it did provide usable figures.

One should note that both experiences were also developed around the use of the ICPC. However, the investment authorised by the public authorities and the place of the basic doctor is not yet specific enough to obtain quality databases.

3.7.1.2.3 France

In France, the health system is based on direct funding with independent doctors wherein primary care is mixed with front line services.

There is no national initiative to process health information from GP/FM. Certain groups are nevertheless active in that domain. Confronted with a lack of resources and a difficulty in convincing professional structures, certain groups have developed database systems based on Open Source and the availability of the ICPC classification. The systems intend to use the Internet's infrastructures and banking security systems in order to protect the personal data and give insight into its work to the medical profession.

The first experiences such as Prometheus and Episodus are scheduled to begin in 2002. There is currently no database available within the GP network.

3.7.1.2.4 Holland

The Netherlands has a great deal of experience in this field and many publications have been centred on the data collection that takes place throughout the country.

Nonetheless, the tendency is slowly being reversed, and some of the large databases have had to end their activities due to lack of funds.

Among the non-specialised databases Dutch databases, only two participated in the Euro-Med-Data (EMD) project. The University of Maastricht and its Department of General

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[76] Medcom, see http://www.medcom2.dk/

Medicine[77] are leaders in the field and have undoubtedly contributed to the improvement of quality and reliability in collected data.

3.7.1.2.5 Malta

The development of general medicine in Malta is relatively recent and the International Community of General Practitioners carries considerable influence.

A data collection was initiated with the support of the University of Amsterdam, using a software program called Transhis. We do not have any information on the resulting data collections.

3.7.1.2.6 Romania

In Romania, a network of approximately one hundred GP's equipped with computers was set up thanks to the SOROS foundation and with the help of the Dutch University of Nijmegen. The network is based on a "pen and paper" experience carried out in 1989-1999.

The network uses the same software program and should be able provide standardised data according to ICPC in the years 2002-2003. (see http://www.geocities.com/mmarginean).

3.7.1.2.7 Crete (Greece)

In Crete, an electronic network for primary health care is being created[78]. Its objective is to evaluate the population's health problems as well as health indicators.

Nine rural health centres record the primary care consultations, for which a software program was specifically designed. The data is collected in ICD-9 and ICPC. However, there is no truly available database.

Nevertheless, such a system is met with great resistance from basic doctors; there is a lack of funding from hospital authorities.

Furthermore, in Greece, GP's have no "gate keeping" role for health systems that, like in France, are freely accessible.

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[77] Metsemakers JF, Knotterus JA, Van Schendel GJ, Kocken RJ, Limonard CB. Unlocking patient's records in general practices for research, medical education and quality assurance: the Registration Network Family Practices. Int J Biomed Comput. 1996 Jul;42(1-2):43-50.

[78] Lionis Ch, Trell E. Health needs assessment in general practice: the Cretan approach. European journal of general practice, vol 5, 75-77, June 1999

3.7.1.3 “National” systems

In between the two systems, one finds “national systems”, which are obviously aimed at GP’s and are sponsored by the State.

3.7.1.3.1 PRIMIS (UK)

Primis is a system developed by the National Health Service and distributed by the University of Nottingham. Its goals the education, practice, and training in managing and returning information on the quality of the data provided by the GP’s.

On top of its support to the GP’s profession, Primis can provide standardised data according to the READ classification. Primis gathers information on 3.000 general medicine practices throughout England. (see http://www.primis.nottingham.ac.uk)

3.7.1.3.2 LINH

The LINH network is run by the NIVELL (Dutch Institute of Primary Health Care) and funded by the State. This networks continuously gathers information from all over Holland, from 200 GP’s, and processes the data according to the ICPC. (htttp://www.linh.nl/)

3.7.1.3.3 SENTIWEB (FR)

The Sentiweb network, developed around the Sentinel network allows GP’s to accurately and continuously encode any data pertaining to the hospitalisation of a patient. This is thus a limited experiment.

One therefore notes that the various databases are extremely variable and that their objectives, funding, structures, as well as their tools are considerably different, so much so that these differences do not allow for an exchange of standardised data.

3.7.2 THE DIFFICULTIES

3.7.2.1 Lack of continuity and consistency in the collected data

Among data collections, one finds collections that have been active for decades and now include several millions of years of patients; these collections are obviously continuous, but not consistent (global) in that they do not record all of the reasons for consulting, the procedures carried out, or even all of the referrals. These databases are very often aimed at pharmaco-epidemiology. (GPRD, DIN, LINH, JANUS)

Upon further examination of the databases described in the previous chapter, one realises that certain databases only relate to certain activities developed in general medicine or to special types of problems, or to specific age groups.

Thus, the system developed in Maastricht, for example, only takes chronic problems into account. The system developed in Italy or Spain, the GP does not see children younger than 14, which implies a complete lack of data for that age group.

In terms of continuity, certain data collections are partial, such as Sentiweb; other are very limited in time such as the experiment led in Madrid and Barcelona.

Furthermore, a number of data collections such as some of the Dutch or Spanish compilations stop after a few years, due to lack of funds. This also produces a lack of continuity.

Several data banks such as LINH in Utrecht nonetheless adopt a policy of continuity; they are sponsored by the state, and manage to assemble an impressive amount of standardised information, based on a common classification.

However, as we will later explain, the comparability problem, even in a continuous system, is significant. There are indeed few potential links between the classification systems used throughout the Anglo-Saxon world and the terminological tools used elsewhere.

3.7.2.2 No common structures for the collected data

The actual objectives of the various databases indicate a difference in the structure of the collected data. Indeed, some of them focus on questions of health, others on therapeutic or diagnostic questions. The gathered data is therefore also diverse.

The way in which the health problems are conceived often differs as well, and the databases do not always have the same notion of active or passive problem, others do not differentiate the reasons for consultation and the diagnoses or appreciations expressed by the doctors. There are databases that revolve around the patient and others around the care provider. Furthermore, some databases integrate the notion of episode in the collection process, while others are strictly based on this very contact. Dr. Grisnmo's comments on the subject are particularly interesting (see chapter VI). One observes that the points concerning the structure of the data must first be discussed before any data exchange can take place.

In the field of data structure, one expects great things from workshop 251 of the European Standardisation Centre (http://centc251.org). Led by Dr. Mennerat, a team from this technical committee elaborated a European pre-norm on the continuity of care, which is currently subjected to the expertise of several actors. Hopefully, this will become an applicable for all of the health computer systems. This pre-norm ENV13940 meticulously describes the structure of medical data, the packaging and contents of the various items required to transfer data from one service centre to another.

Regarding its continuity, some databases are partially continuous, such as Sentiweb; others are very limited in time, such as the experiment led in Madrid and Barcelona.

3.7.2.3 Confusion between classification and terminology

This is also a very diverse field. If the British systems are dominated by the use of the RCC (Read Clinical Code) and standards are ever evolving, the same is not true for other European countries where all of the international classifications are used.

Although we are now witnessing a move towards establishing standards, there is still much room for improvement. The position of the WHO family of classifications such as ICD-9 and ICD-10 is constantly overcome by SNOMED, which, through its recent alliance with the

British-made terminology RCC, will soon equip all British data collection systems under the name SNOMED-CT. (Systematized Nomenclature of Medicine-Clinical Terms).

However, the international classifications of diseases are found in several databases and most States require that, in the end, the collected data by coded in ICD-9 or ICD-10.

For the specific field of general medicine, one still sees the use of ICHPPC-2-d (International Classification of Health Problems in Primary Care 2nd Edition Defined) but in general medicine data collections, ICPC 2nd edition (ICPC2) is used more and more frequently. (see chapter IV)

There is naturally an effort to make these classifications compatible. As a result, a group of researchers from the University of Newcastle and the University of Amsterdam, respectively led by Dr. Booth and Dr. Lamberts, have founded a centre in collaboration with WONCA in the hope of studying the possible concordances between ICPC and ICD-10 on one hand, and between ICPC/ICD-10 and SNOMED-CT on the other hand.

This group's work is essential for the future compatibility of gathered data in general medicine collection systems. In chapter IV (devoted to the exercises) one notes, however, that the main conceptual differences between the READ nomenclature and that of ICPC on one hand, and the nomenclature of ICD-10 on the other. A number of data collections use proprietary terminologies that are sometimes coded into ICD-10.

It is equally important to observe that research in this field progresses in two directions that might seem opposite. While the progression of the free text towards coding allows for a decrease in redundancy and an increased reliability, one notes that the advocates of textual analysis are often opposed to the advocates of taxonomical analysis. (do refer to 3.4.2 Fig 5) Reduction of redundancy, from free text to codes. Linguistic engineering occupies the right of the diagram and taxonomists occupy the left

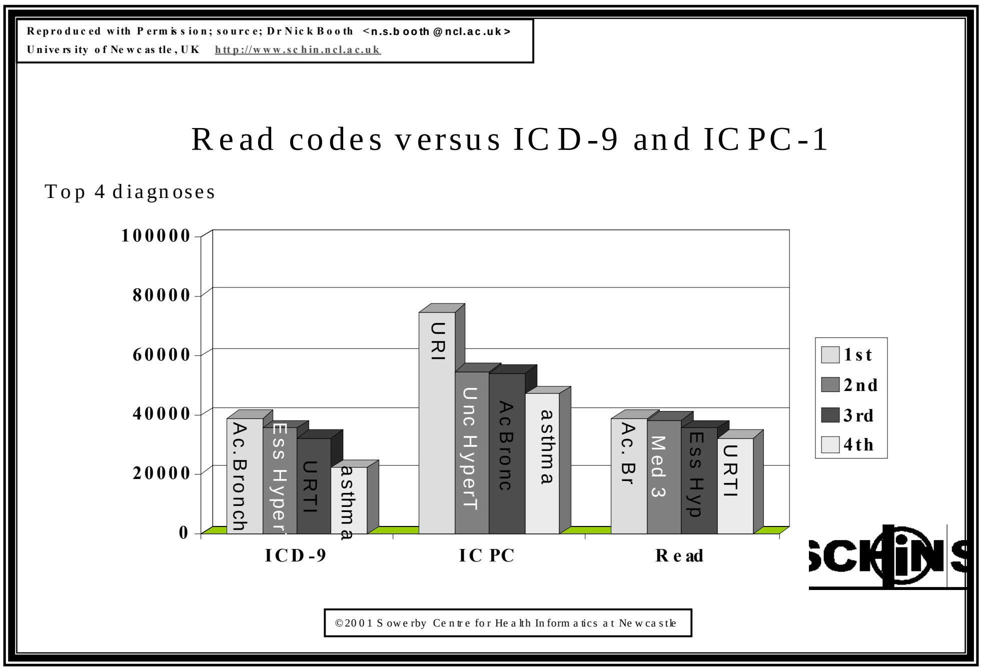
In the free text field, research into the *Natural Language Processing* (NLP) and communication engineering is intense, which uses the latest linguistic computer technologies.

Taxonomists, concerned with identifying the concepts in their discipline and the different diseases and health problems that they face, have developed some very extensive classifications, although still insufficient.

There is a congruence of interests between these two poles. A rapprochement between the ardent NLP researchers and the taxonomists would probably improve the quality of data collection.

The question of transcoding is central; in order to illustrate its importance, we will feature the work of Dr. Booth between the Read, ICD, and ICPC classifications. Using the morbidity data gathered during the fourth national morbidity study in 1992 by the British National Statistics Office (a study by Mc Cornic, Fleming, and Charlton), Dr. Nick Booth recoded the data of 50.000 patients/year, 1.8 million problems collected by three different medical software programs. Initially, the data were gathered in the Read classification, versions 4 and 5. The original analysis of the data was carried out in comparison with ICD-9. Dr. Booth transcoded the data to ICPC using a self made table. He was thus able to reanalyse the data according to ICPC (version1).

The resulting table impressive (see below). One distinguishes considerable differences, according to whether the data for the same patients was expressed using ICD-9, Read, or ICPC.


Reproduced with Permission; source; Dr Nick Booth <n.s.booth@ncl.ac.uk>
University of Newcastle, UK http://www.schin.ncl.ac.uk

Read codes versus ICD-9 and ICPC-1

©2001 Sowerby Centre for Health Informatics at Newcastle

Figure 3.19. Study by Dr. Nick Booth on the recoding of data into ICPC.
The same data seen in three different interpretative frameworks.

ICPC is differential and causes a non-negligible proportion of asthmatics (almost twice as much as in for ICD-9), while this same component, asthma, is not listed if one uses Read. Such a study obviously leads to serious questions and highlights the importance of using truly structured classifications such as ICPC.

3.7.2.4 Ethical problems raised by data collections

The aim is not to draw an exhaustive list of exhaustive questions, whether they concern confidentiality, respect for intimacy, or data preservation.

Nonetheless, the exercise featured in chapter 3.6 highlighted the actual barriers in the collection or transfer of data as well as some of the truly ethical questions that may arise.

We have already mentioned the difficulties in Iceland due to the fact that personal health information can be used for commercial purposes, and be merged with genetic information. We also noted the ease with which Iceland went from informed consent to presumed patient consent.

One should also recall that the Icelandic policy was not approved by all of the GP’s, who maintain an Internet site exclusively devoted to these questions (cf. supra). This case should undoubtedly be taken into account when defining European management norms for personal data.

It is equally important to note that, in the end, Iceland was not allowed to participate in the exercise on asthma and herpes zoster in Chapter IV despite the fact that we were requesting partial and anonymous data that would only be used for the exercise in question.

Another interesting case is that of the PRIMIS system in England (described above). We were unable to obtain data for the exercise because we could not contact the doctors that were to supply the data in time for them to approve the data transfer.

It is notable that in the PRIMIS system, the doctors that supply the data must be consulted, for whatever use, including a partial study. The doctor's rights are fully respected. It is obvious that, had time not been a factor, the doctors would surely have given their consent.

Furthermore, several questions were raised during the meeting held on December 5th 2001. A fundamental question is who is the owner of the data, is it the patient, the doctor, the State, the social security organisation, the specific data industry, or the pharmaceutical companies?

This is a vital question, which must be answered before any European data collection systems can be developed.

Finally, during that same meeting, we approached the question of data confidentiality. Dr. Mikko Nenonen applies the "red line" concept (see the horizontal line in figure 4) in his conception of a Finnish health information system.

The information coming from patients, if it leaves the field of primary care, can in no way return to that field, and an impassable "red line" creates a strict confidentiality. No information can ever be used to identify a patient. One consequently no longer speaks of the anonymous data but rather of "un-identifying" data.

Indeed, simple postcode could identify a patient, a physical person, if that postcode were associated with a rare disease, for example.

One must emphasize that the notion of circular information such as it is described below (see figure 5) the GP is the only person able to identify a patient. This identification can sometimes be necessary, or even vital for some patients.

However, Dr. Metsemakers demonstrated that the GPs constitute the limit for the reuse of the data. Indeed, the databases accumulated in Maastricht help a great deal of researchers. In order to gain access to the patients and their personal data, these scientists must go through the GP. The workload is so demanding for the GP that some have simply stopped giving researchers access to their data.

One therefore observes that the GP plays a considerable role in the processing and the protection of patients.

3.7.2.5 Epidemiological problems

During the meeting on December 5th, we noticed that problems in the database structure appear when one uses epidemiological concepts that seem obvious to everybody. In reality, this is far from being the case. Actually, the concept of prevalence is not used in a standardised manner; some use prevalence by points, others by period.

Similarly, one must determine what happens to "hidden" patients such as immigrants and patients with a very low income who experience high morbidity rates. There is also the problem of non-consulting patients and more general problems of unknown denominators.

In cases involving a listed system, one must ensure that the responsible authorities adequately update the list. There is also the question of age groups. When examining the data from the exercise, one observes that the age groups are all different. These groups can be standardised by using the WONCA age groups. We realise, however, that, by five or by ten the age groups differ and often begin with different numeric units. A harmonisation is definitely indispensable in order to properly collect data.

3.7.2.6 Problems of data quality

In order to be useful for clinical care, clinical audit, research, as well as for epidemiology or health care planning, the data must be of quality. This implies that they must be complete. Patients with a specific morbidity, who might not yet be registered, must be kept in mind.

Data must be consistent, in other words, the terms and definitions or diagnoses must be applied in a coherent manner.

The data must be accessible and published in a truly operational format, in order to be able to extract the data for each individual GP.

Finally, the data must be up to date, which means that the systems must be updateable, as well as the data, which must also be updated in the recordings and the list of problems.

These points are truly fundamental and a detailed study should categorically be undertaken before the creation of a European database.

3.7.2.7 Vertical information vs. circular information

Traditionally, and since the invention of the death certificate, information followed a vertical path from the supplier (i.e. the GP), to the receiver (i.e. the State). This was the case for mortality statistics as well as for communicable diseases that had to be declared.

The vertical information system is well developed in the work of Miko Nennonen, seen in Figure . One notes that the information stemming from the clinical registers and form the work with the patient is moved upwards for statistical use, then towards the State structures responsible for health organisation. There is no feedback to the data suppliers.

In addition, in the system developed by GP's and illustrated in Figure 5, one notes a circular flow of information. The information in a local loop (step 5) in the data supplier's production system allows for him to have an overview of his own production. The local-regional loop (step 7) allows for groups of GP's to develop quality assurance processes.

This outlook was elaborated by the WICC (WONCA International Classification Committee). This was an international consensus established between the members of the working party during the meeting held in Slovenia in 2000.

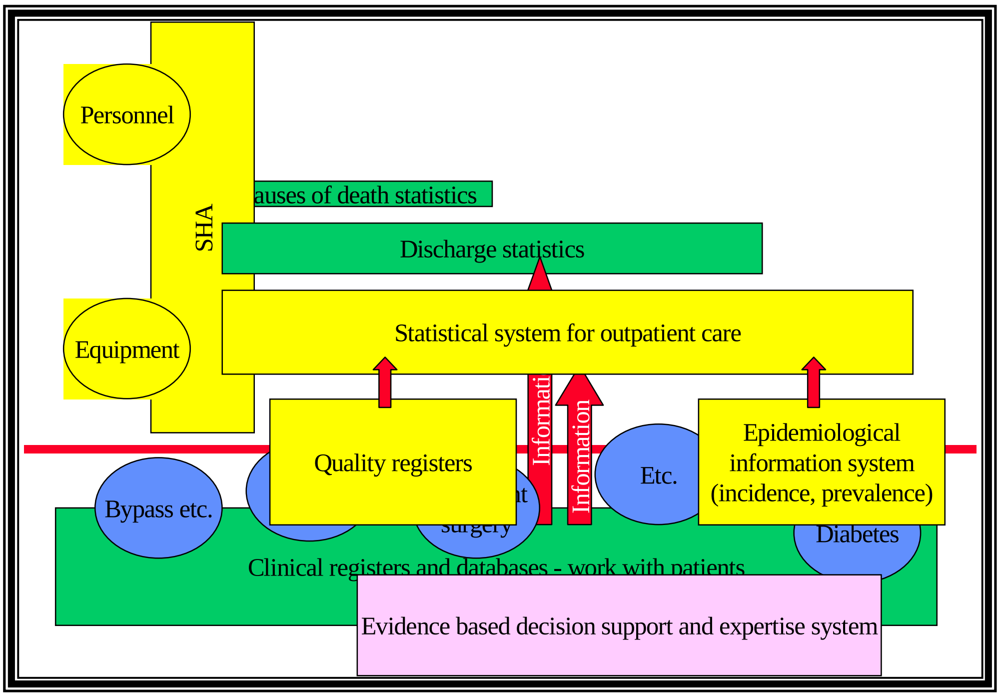


Diagram taken from Miko Nennonen [79].

Figure 3.20. Vertical flow of health information and the "red line" concept (horizontal line).

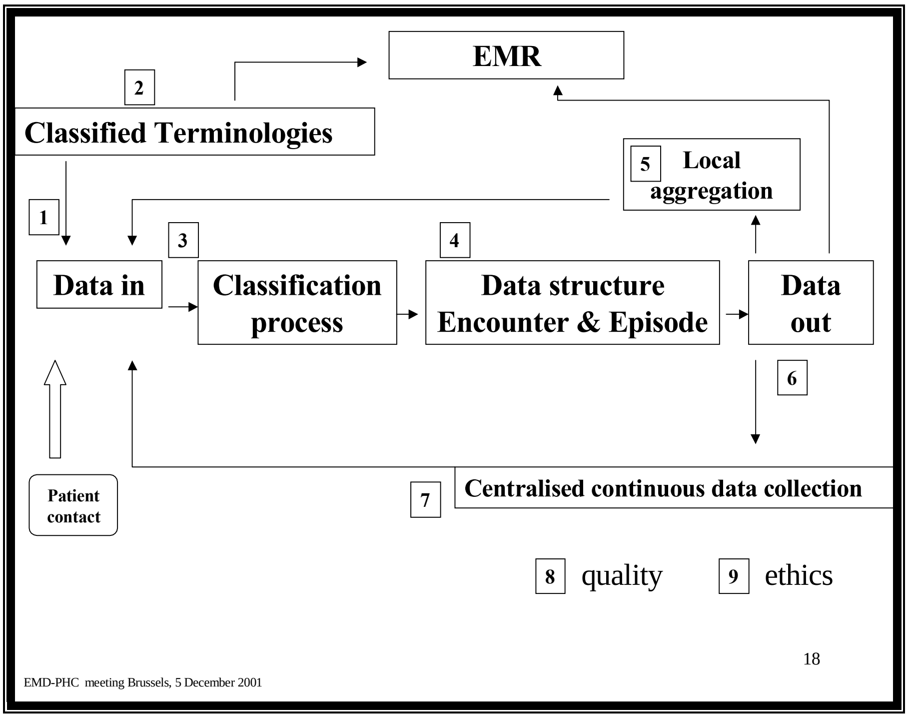


Figure 3.21. Circular flow of information in the WICC model[80]

Steps 5 and 7 are crucial to developing the data. (EMR=Electronic Medical Record)

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[79] The theoretical framework of the New Finnish Health Information System Mikko T. Nennonen, Stakes, May 2001.

[80] WONCA International Classification Committee statement on Health information flow in GP/FM (Strunjan, Slovenia, 2000)

The GP therefore supplies the data and is simultaneously the generator and addressee of the processed information. Naturally, the information can also be extracted and made anonymous for macro-epidemiological purposes. The information are however not completely “unidentified”. The GP “guards the key” that allows to retrace the patient.

One should aim for a system that combines both approaches and that constitutes both a support for clinical data management for the GP, and a vertical flow of data towards the institutions (or persons) in charge of health. **The merging of these two information flow systems, that is to say vertical and circular, probably represents the future of continuous data management systems in the field of general medicine**.

3.8 CONCLUSIONS AND RECOMMENDATIONS

Though the numerous contacts established for this study on general medicine data gathering in Europe, it became clear that the experiences in this domain vary greatly. The general consensus during the meetings was that no data collection system can serve as a common gathering base, nor can it be used to elaborate European health indicators. There is undeniably a consensus on the importance of the information that could be available from and for general practice throughout Europe. No one doubts that the general practitioner’s future lies in the management of health data, nor that he/she will one day be able to provide gathered data.

This data can have an impact on health planning if it is correctly processed. However, for most of the GP’s providing data, this data must first and foremost be useful to them, and the local loop is the fundamental loop that will subsequently ensure the coherence of the data integrated on a higher level.

One has observed the numerous difficulties in merging these data between the different European databases. New research programs and new objectives must be explored if one truly wants to obtain a European health information system and health indicators based on data collection.

With these goals in mind, we have five recommendations:

- ✓ First, taking the recent European Parliament recommendation (Sept. 2001)[81], on the need to develop “Open Source” programs into account, we recommend that the utmost attention be paid to the development of computer programs according an “Open Source” approach.

The aim of developing such programs is first and foremost to obtain a standardised information structure and a successive accumulation of experiences from the groups that use the current programs.

Indeed, the “Open Source” spirit is based not only on a reduction of economic cost, but also on a reduction of the required effort and energy. The “Open source” technique means sharing knowledge and gathering all of the existing systems in order to develop one that is both more efficient and competitive.

Some systems are already operational in this field and can be found on the OSHCA site, the Open Source Health Care Alliance, www.oshca.org, one will find the correspondences necessary to appreciate the importance of the domain.

- ✓ The second recommendation is to favour the management of individual data in computerised medical files as community health data. This implies the development of a

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[81] Resolution of the 5th of September 2001, see http://www3.europarl.eu.int/

multi-professional network centred on the patient and whose data must be gathered on a community level. The PRIMIS example, for example, only highlights general practitioners. Other primary health care actors are also involved, such as social workers, nurses, movement therapists, or workers in the filed mental health.

The possibility of having health information available through databases that would regroup the knowledge and experiences from the various levels would naturally provide a higher quality of data.

Furthermore, the GP being the main data collector, it is necessary on the European Community level, to reach a consensus on the definition of the profession and responsibilities of general practitioners, on their importance in matters of daily health data management, as well as their significant role in the protection of patient’s personal medical information.

✓ Thirdly, we recommend promoting European development in the realm of terminologies and classifications. Particular attention should be turned to the work of the Amsterdam/Newcastle WONCA collaborative centre on transcoding and classifications.

A multilingual European transcoded terminology would constitute a very valuable tool and be indispensable in the development of databases with transferable data.

In addition, we know the significant data acquisition possibilities of new information technologies when applied to texts, and that the extensive experience, for example, of the GALEN group in this domain should not be ignored (http://www.galen.org/). Promoting the development of Natural Language Processing and ontologies such as GALEN is crucial, as is closing the gap between the designers of this type of approach and classification and taxonomists that endeavour to describe their reality.

✓ Fourthly, we recommend to follow with attention the works of CENTC251. This European normalisation organism has recently published a book of primary importance for data quality in general practice. The development of a European pre-standard related to continuity of care (ENV 13940) constitutes a significant step towards the harmonisation in Europe of the concepts which allow the structuring of electronic medical files. (http://www.centc251.org/)

✓ Finally, the fifth recommendation is the result of the meeting of December 5th. We are extremely pleased that Euro-Med-Data’s initiative relating to primary health care was perceived by many of the participants a channelling programme.

Data Quality in Primary Care
Prospective partners

- Finland: Stakes
- Italy: Health Search, Health Care Ministry & Regional Conference of Health Care
- UK: PRIMIS (University of Nottingham), NHSIA
- UK : DIN (Doctor's Independent Network)
- .....→ contact : Lindsay Groom
  Lindsay.Groom@nottingham.ac.uk

Figure 3.22. A new group to take over from Euro-Med-Data

A new group came into being during the meeting. This group will take over the primary health care project that was initiated by EMD-PHC. The "Quality of Primary Health Care Data", proposed by Dr. Mike Bainbridge, Roberto Nardi, and Mikko Nennonen received unanimous support from the meeting's participants.

We can only urge the European authorities to firmly support this group's studies and to provide them with the means to ensure quality research in this field. This new group shall obviously draw on the works that were already presented and achieved throughout the "Primary Health Care" study, as well as on the present report.

4 SECONDARY HEALTH CARE

4.1 INTRODUCTION

Secondary health care is characterised by the presence, in most member countries, of morbidity data recorded during the patient's stay in an institution. These data are coded according to the International Classification of Diseases – 9th or 10th revision (ICD-9 or 10).

The ICD code was the basis for the works of Robert Fetter and his collaborators (Yale University, USA) in the early eighties[82]: the grouping of diagnoses and interventions into pathology groups (DRG: Diagnosis Related Groups) called "iso-resources" (globally consuming the same resources (clinical exams, radiology, infirmary care, pharmaceutical products, …)). These DRG's are themselves regrouped into MDC (Major Diagnostic Category), mainly regrouping pathologies by system

This coding system was adapted in most countries during the eighties and nineties, according to the following steps[83]:

- ✓ "evaluation of the technical feasibility of attaching any standardised "discharge medical summary" to a single DRG,
- ✓ evaluation of the model's capacity to explain a significant part of the variation observed concerning the length of stay, the price, or the cost,
- ✓ development of an analytical accounting model based on the activity measured in DRG and the national accounting and budgetary framework,
- ✓ development of the information systems and the software necessary for the data gathering and analysis to be done on micro-computers in every care institution."

Since the majority of countries have developed or are in the process of developing classification systems based on DRG's, one notes a certain homogeneity in the data collected.

One also finds other types of data in the secondary care sector, but they will not be featured in this study because they do not relate to routinely collected data and/or they have already been the subjects of other international projects. Furthermore, given the initial results for the secondary care sector, it would seem sensible to limit oneself to data gathered on a national basis for only they are directly related to this study.

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[82] Fetter R.B. et al : "Case Mix definition by Diagnosis Related Groups" – Medical Care, Vol XVIII, n°2, supplement: 1-51; February 1980

[83] Official PMSI site : http://www.le-pmsi.fr/mco/presentationgenerale/vii.html

4.2 METHODOLOGY

The project progressed through three consecutive steps:

- ✓ Identify the routinely recorded medical data
- ✓ Test the feasibility of creating a European medical database
- ✓ Analyse the results and proposals

4.2.1 IDENTIFY THE ROUTINELY RECORDED DATA

Although the different patient classification systems used are mostly based on the DRG system, it is necessary to clearly identify the different recorded variables in order to pursue the research (phase 2 and 3). Indeed, it is important to verify that the different variables, although similar, are compatible with each other and allow for an international use.

In order to identify routinely recorded data, we have developed and distributed a survey among our partners (see annex 2). It is made up of 3 parts:

- ✓ Identification of the person who filled out the survey
- ✓ Characteristics of the file (regions concerned, objectives of the collection, ethical aspects, funding for the collection, head organisation, …)
- ✓ Content of the file (variables recorded, description of the variables and possible comments)

On top of the distribution via mail, fax, e-mail to our partners, the survey was also available on the project website (in French and English) as well as relevant explanations.

This first step of the research ended with the organisation of a workshop on December 8th and 9th 2000 in Brussels.

4.2.2 TEST THE FEASIBILITY OF CREATING A EUROPEAN MEDICAL DATABASE

The test's objective is to underline:

- ✓ The difficulties linked to the pooling of data coming from different countries
- ✓ The modes of data transmission
- ✓ The procedures to be put in place for the conversion of certain data in order to obtain homogeneous and utilisable data
- ✓ The possible epidemiological uses for the database
- ✓ The health indicators will bed able to provide

In order to attain these objectives, we have asked our partners to provide us with a sample of 500 recordings of hospital data, such as they are entered by hospitals, that is to say before the data is manipulated by the institution that collects them. Indeed, each country has its own procedure for data processing, which makes any common exploitation of the data very difficult or even impossible.

4.2.3 ANALYSE THE RESULTS AND PROPOSALS

The series of the results obtained was analysed and led to the forming of proposals for the further research.

The analysis as well as the proposals were discusses during the second workshop, organised in Brussels on December 5th 2001.

The entire series of results was submitted to each partner for authentication before the distribution of the report.

4.3 RESULTS

4.3.1 IDENTIFYING THE ROUTINELY RECORDED DATA

Despite the contacts, reminders and the online accessibility of the project, we received very few completed surveys:

✓ Germany (Juergen Stausberg & Rolf Engelbrecht)
✓ Belgium (joined as example in the questionnaire sent to the partners[84])
✓ Spain (Ander Arrazola)
✓ France (Pierre Metral)
✓ Greece (Asterios Terpos)
✓ Italy (Davide Minniti)
✓ The Netherlands (Jacob Hofdijk)

The research proceeded mainly through Internet sites or through visits to other countries. From that moment on, we were able to gather information for all of the participating countries except for Liechtenstein, which allowed us to produce the following forms:

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[84] Desmet M. Utilisation des données médico-administratives au sein de l'institution hospitalière. Ecole de Santé Publique de l'ULB. Bruxelles: 2000

Table 4.1. Germany

The data are collected within each hospital and transmitted to the various insurance funds with the sole purpose of financing the hospitals. The data is therefore not centralised within an institution or a Health Ministry and they do not serve any purpose of epidemiological analysis.

Register name	Datenübermittlung nach § 301 SGB V [similar Datenübermittlung nach § 302 SGB V]
Abbreviation	§ 301-Vereinbarung
Regions	All
Cities	All
Purposes of the registration system	To support the billing process
Period	01.01.1996, event based (admission, discharge, ..)
Financing source of the registration system	The hospital is reimbursed on the basis of the registration.
Ethical aspects	Der Bundesbeauftragte für den Datenschutz: Number, titel and date of the law?
Institution in charge of the registration system	Every health insurance company concerning their insured
Main investigator	?
Detailled description	http://www.dktig.de/
Classification used	ICD-10-SGB-V 2.0 for diagnoses OPS-301 2.0 for procedures
Register type	Unknown, electronic transmission complies to EDIFACT-standard
Storage	Every health insurance company concerning their insured
Accessibility	No access available
Quality of the data	No legislative obliged quality control
Feed-back	Bi-directional communication

Table 4.2. Austria

Register name	
Abbreviation	
Regions	All
Cities	All
Purposes of the registration system	
Period	From ? for diagnoses From 1997 for procedures
Financing source of the registration system	
Ethical aspects	
Institution in charge of the registration system	Federal ministry of social security and generations
Main investigator	
Detailled description	
Classification used	ICD-10 from 2001 pour les diagnoses Catalogue of the procedures
Register type	
Storage	
Accessibility	
Quality of the data	
Feed-back	

Table 4.3. Belgium

Register name	Résumé Clinique Minimum
Abbreviation	RCM
Regions	All
Cities	All
Purposes of the registration system	To support the health policy, concerning: (1) definition of the needs in hospital equipments, (2) définition of qualitative and quantitative rules of approval for hospitals, (3) organization of hospital financing, (4) définition of the policy of medecine practice (5) organization of an epidemiological policy
Period	Since January 1st 1993, continuous
Financing source of the registration system	Part B4 of the day fee paid to hospitals by the Institut National d'Assurance Maladie Invalidité whose funds come mainly from taxes and contributions of workers and employers (A.M. of 02.08.86 published in M.B. the 21.08.86)
Ethical aspects	Law of december 8 1992 concerning the protection of private life and judgment of the protection of private life commission.
Institution in charge of the registration system	Ministère des Affaires sociales, de la Santé Publique et de l'Environnement - Administration des Soins de Santé - Cité administrative de l'Etat - Quartier Vésale - 1010 Bruxelles
Main investigator	Ms Olewicki: 32-2-210.47.85
Detailled description	Yes, the leaflet: "Directives pour l'enregistrement du Résumé Clinique Minimum"
Classification used	ICD-9-CM for diagnoses and procedures
Register type	Files *.txt
Storage	At the Ministère de la Santé Publique
Accessibility	Decision of the RCM Commission based on a written and motivated request
Quality of the data	Yes, the law imposes a commission to supervise and evaluate the statistical data.
Feed-back	Yes, each hospital receives a yearly document with the data concerning it.

Table 4.4. Denmark

Register name	
Abbreviation	
Regions	
Cities	
Purposes of the registration system	
Period	
Financing source of the registration system	
Ethical aspects	The Act on Processing of Personal Data (Act No. 429 of 31 May 2000)
Institution in charge of the registration system	
Main investigator	
Detailled description	
Classification used	ICD-10 from 1994 for diagnoses Nordic Classification for Surgical Procedures (CNPC)
Register type	
Storage	
Accessibility	
Quality of the data	
Feed-back	

[85]

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[85] Koordinationsgruppen for individbaseret patientregistrering. Faellesindhold for basisregistrering af sygehuspatienter. Sundhedsstyrelsen. 2000. Denmark

Table 4.5. Spain

In 1987 the organ of sanitary planning and coordination of the regions of Spain at the Health Ministry decided the variables that compose the collection of medical data in each hospital discharge. Most of the 17 regions of Spain has processed legislation to apply in its territory the agreement. The developments in the regions respect the initial basic agreement. Information presented below provided with one * applies only to Navarre.

Register name	Conjunto Mínimo Básico de Datos
Abbreviation	CMBD
Regions	All
Cities	All
Purposes of the registration system	1 To help the management of the hospitals. 2 Development of new systems of financing. 3 Making of the indicators of output and use. 4 To improve the control of the quality of the care. 5 To have a database for clinical and epidemiologic search.
Period	Progressive since 1987 (January 1, 1995*)
Financing source of the registration system	Include in the public budget. Since January 1, 1999, the medical financing comes from the taxes (before a small part came from the social security contributions).
Ethical aspects	Organic Law of Decembre 13, 1999 (15/1999) on the Protection of Personal Data
Institution in charge of the registration system	Ministerio de Sanidad y Consumo and each Region
Main investigator	Agustin Rivero Cuadrado
Detailled description	http://www.msc.es/cmbd/informacion/
Classification used	ICD-9-CM
Register type	File *.txt
Storage	Ministerio de Sanidad y Consumo (MSC)
Accessibility	It does not have a specific rule: administrative decision after request.
Quality of the data	The technical commission of the CMBD for the totality of the National System of Health has in load the quality of the data. Locally (in Navarre), there is a specific administrative unit which takes care of the quality of the data and the system of coding *.
Feed-back	* Yes, every month. Annual publication by MSC

[86]

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[86] Ministerio de Sanidad y Consumo. Explotacion de bases del CMBD. Estadisticos de referencia estatal de los sistemas de agrupacion de registros de pacientes. Ministerio de Sanidad y Consumo, 1998. Spain

Table 4.6. Finland

Register name	Care register
Abbreviation	HILMO
Regions	All
Cities	All
Purposes of the registration system	
Period	1967
Financing source of the registration system	
Ethical aspects	Tietosuojavaltuutetun toimisto:
Institution in charge of the registration system	
Main investigator	
Detailled description	
Classification used	ICD-10 from 1994 for diagnoses Nordic Classification for Surgical Procedures (CNPC)
Register type	
Storage	
Accessibility	
Quality of the data	
Feed-back	

[87], [88], [89], [90]

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[87] HILMO. 1996. Helsinki: 1996

[88] Registers of Health Care in Finland. 2001. STAKES

[89] Annual report 2000: Joint authority for the Hospital district of Helsinki and Uusimaa. Communications Group. 2001. Helsinki

[90] Nenonen M. The Theoretical Framework of the New Finnish Health Information System. STAKES, 14-5-2001. Helsinki

Table 4.7. France

Register name	Résumé Standardisé de Sortie (anonymised for the transfer)
Abbreviation	RSS / RSA (PMSI-short stay)
Regions	All
Cities	All
Purposes of the registration system	1/ To know the hospital activity in the sector of the care of short duration (characteristics of the patients and assumptions of responsibility). 2 / To contribute to the budgetary allocation of resources (and to propose new tools of tariffing related to the characteristics of the patients and of their assumption of responsibility) 3 / To have the elements of activity and an approach of the needs for planning hospital;
Period	Since 1990 uninterrupted, collection by stay, semi-annual transmission with the area since 1994, bases national annual
Financing source of the registration system	Financing of the medical service of information integrated into the annual equipment of financing of the establishment or price increase of day (private lucrative)
Ethical aspects	Law of January 6, 1978 relating to data processing, the files and freedoms and European Directive of October 25, 1995
Institution in charge of the registration system	Ministère de l'emploi et de la solidarité - Direction de l'Hospitalisation et de l'organisation ds soins - Bureau E3 - Mission PMSI
Main investigator	Ms Burette (chef de bureau) 33-1-40-56-53-35
Detailled description	Yes: the "guide méthodologique de production des résumés de sortie standardisés (PMSI)" - Published in the Bulletin Officiel
Classification used	CIM-10, medical acts - classification in homogeneous groups of patients (close to the DRG)
Register type	File *.txt
Storage	For the Ministry, by the CTIP, centre de traitement des informations du PMSI (from 2001 Agence Technique de l'Information Hospitalière)
Accessibility	Agreement of the CNIL, (commission nationale de l'informatique et des libertés) and writting request to the Ministry
Quality of the data	Obligatory internal audit has minimum on a sample of 100 drawn RSS to the sort/semestre, controls external of 40 dossiers/year. Objectif/valorisation of the activity (revision in progress)
Feed-back	Yes, each hospital receives a semi-annual document and an annual document on the processing of its data and its position in its area. Internet access to the national statistical results (not at the bases): www.le-pmsi.fr

[91], [92]

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[91] Collectif. Guide méthodologique de production des résumés hebdomadaires standardisés. Ministère de l'Emploi et de la Solidarité, editor. 97/5 bis, 1-111. 1998. Paris. Bulletin Officiel

[92] Logiciel d'anonymisation des RHS. Ministère de l'Emploi et de la Solidarité, 1999

Table 4.8. Greece

Register name	Hospital & Patient Discharge Statistics
Abbreviation	
Regions	All
Cities	All
Purposes of the registration system	To support the health policy research and planning
Period	Since 1962, continuous
Financing source of the registration system	The Ministry of National Economy via the National Budget's accounts
Ethical aspects	Law 2472 of 1997 (according to EU guidelines of 1992) concerning the protection of private life and judgment of the protection of private life commission.
Institution in charge of the registration system	At the National Statistical Service of Greece (which belongs to the Ministry of National Economy)
Main investigator	?
Detailled description	?
Classification used	ICD-9-CM
Register type	?
Storage	At the National Statistical Service of Greece (which belongs to the Ministry of National Economy)
Accessibility	Permission by the National Statistical Service of Greece required
Quality of the data	?
Feed-back	?

Table 4.9. Ireland

Register name	
Abbreviation	
Regions	
Cities	
Purposes of the registration system	
Period	
Financing source of the registration system	
Ethical aspects	Data Protection Act, 13th July 1988
Institution in charge of the registration system	
Main investigator	
Detailled description	
Classification used	ICD-9-CM for diagnoses and procedures
Register type	
Storage	
Accessibility	
Quality of the data	
Feed-back	

Table 4.10. Iceland

Register name	
Abbreviation	
Regions	
Cities	
Purposes of the registration system	
Period	
Financing source of the registration system	
Ethical aspects	
Institution in charge of the registration system	
Main investigator	
Detailled description	
Classification used	ICD-10 from 1997 for diagnoses Nordic Classification for Surgical Procedures (CNPC)
Register type	
Storage	
Accessibility	
Quality of the data	
Feed-back	

Table 4.11. Italy

Register name	Scheda di dimissione ospedaliera
Abbreviation	SDO
Regions	Piemonte (to short other regions)
Cities	all
Purposes of the registration system	1. epidemiological search 2. support to the funding system 3. support to the EBM 4. support to the evaluation and control system 5. support to the sanitary planning
Period	Since 1997
Financing source of the registration system	Include in the public budget
Ethical aspects	Protection of individuals and other subjects with regard to the processing of personal data Act no. 675 of 31.12.1996
Institution in charge of the registration system	Department of public health – University of Torino
Main investigator	Roberta Siliquini
Detailled description	-
Classification used	ICD-9-CM
Register type	File*.txt
Storage	Agenzia regionale per i Servizi Sanitari (Aress)
Accessibility	Centro Informatico regionale (CIR): Sdo coded for some variables (es: name)
Quality of the data	a. completeness of data b. optimum for the funding system c. Shortage for a few of variables
Feed-back	-

Table 4.12. Liechtenstein

Register name	
Abbreviation	
Regions	
Cities	
Purposes of the registration system	
Period	
Financing source of the registration system	
Ethical aspects	
Institution in charge of the registration system	
Main investigator	
Detailled description	
Classification used	
Register type	
Storage	
Accessibility	
Quality of the data	
Feed-back	

Table 4.13. Luxemburg

Register name	
Abbreviation	
Regions	
Cities	
Purposes of the registration system	
Period	1998
Financing source of the registration system	
Ethical aspects	Amended law of 31 March 1979 regulating the use of the personal data in the data-processing processing; Large-ducal payment of 2 October 1992 regulating the use of the medical personal data in the data-processing processing; Code of ethics of the doctor-dentist and medical professions
Institution in charge of the registration system	
Main investigator	
Detailled description	
Classification used	
Register type	
Storage	
Accessibility	
Quality of the data	
Feed-back	

Table 4.14. Norway

Register name	Norsk Pasientregister
Abbreviation	NPR
Regions	All
Cities	All
Purposes of the registration system	1) To answer to the need for statistical data on the hospitals following the change of the system of financing of those; 2) To deliver an opinion to the Minister for Health concerning the economic incentives, to evaluate effect of these incentives and to detect the irregularities in the recording of the data; 3) To calculate the " economic point " (DRG-poeng) which is used as a basis for the payment of the hospitals; 4) To provide the scientists, students and other agencies of scientific search statistics of health for Norway; 5) To provide to the public by Internet information on the waiting time for a selection of minor operations to ambulatory some
Period	1997 (actual version)
Financing source of the registration system	By the state, via the hospital budget
Ethical aspects	Data anonymized not allowing " to go up " to the patient – Data protection agency
Institution in charge of the registration system	Ministry for Social and Health, treated by Sintef Unimed
Main investigator	Sintef Unimed
Detailled description	Yes
Classification used	ICD-10 for diagnoses Nordic Classification for Surgical Procedures (CNPC)
Register type	SPSS
Storage	Sintef Unimed
Accessibility	On reasoned request with Sintef Unimed
Quality of the data	It's made via the financing car it depends of the quality of the data
Feed-back	Not directly to the hsopital, but via Folkelsa (aggregate data)

[93], [94], [95]

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[93] Innsatsstyrt finansiering. Social- og Helsedepartementet. 2000. Norway

[94] Spesialisthelsetjenesten 1990-1998 . Norges Offisielle Statistikk. 2000. Norway

[95] Rognerut M, Stensvold I, Strand BH, Hesselberg O , Lyshol H. The National health Indicator System and the data base. Folkehelsa, 2000. Norway

Table 4.15. The Netherlands

Register name	Landelijke Medische Registratie
Abbreviation	LMR
Regions	All
Cities	All
Purposes of the registration system	Discharge abstracting
Period	Since 1963
Financing source of the registration system	Hospitals Pay, allowance in budget
Ethical aspects	Wet bescherming persoonsgegevens (WBP, Staatsblad 2000 302)
Institution in charge of the registration system	Prismant, Utrecht
Main investigator	
Detailled description	http://www.prismant.nl
Classification used	ICD-9-CM for the diagnosis CVV for the procedures (ICPM based)
Register type	Relational database
Storage	Hospital database, nationaly
Accessibility	Only on request
Quality of the data	Quite good
Feed-back	Yes, via reports

Table 4.16. Portugal

Register name	
Abbreviation	
Regions	
Cities	
Purposes of the registration system	
Period	
Financing source of the registration system	
Ethical aspects	LEI n.º 67/98 de 26 de Outubro 98: Lei da protecçao de dados pessoais
Institution in charge of the registration system	
Main investigator	
Detailled description	
Classification used	ICD-9-CM for diagnoses and procedures
Register type	
Storage	
Accessibility	
Quality of the data	
Feed-back	

Table 4.17. United Kingdom

Register name	
Abbreviation	
Regions	
Cities	
Purposes of the registration system	
Period	
Financing source of the registration system	
Ethical aspects	The Data Protection Act 1998 (Commencement) Order 2000 Statutory Instrument 2000 No. 183 (C.4)
Institution in charge of the registration system	
Main investigator	
Detailled description	
Classification used	ICD-10 depuis 1995 for diagnoses Classification of procedures OPCS, 4th revision
Register type	
Storage	
Accessibility	
Quality of the data	
Feed-back	

Table 4.18. Sweden

Register name	Hospital Discharge Register
Abbreviation	HDR
Regions	All
Cities	All
Purposes of the registration system	
Period	1960 for certain hospitals, 1984 for all the hospitals
Financing source of the registration system	
Ethical aspects	Datainspektionen
Institution in charge of the registration system	National Board of Health and Welfare
Main investigator	
Detailled description	Yes
Classification used	ICD-10 since 1998 for diagnoses Nordic Classification for Surgical Procedures (CNPC)
Register type	
Storage	
Accessibility	
Quality of the data	Control of the data by the National Board of Health and Welfare
Feed-back	

[96]

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[96] The Swedish Hospital Discharge Register 1987-1996 Quality and Contents. Center for Epidemiology. 1998. Sweden

The following table reiterates the most important points for the rest of the project.

Table 4.19. Summary Table

	Germany	***Austria***	***Belgium***	***Denmark***	***Spain***	***Finland***	***France***	***Greece***	***Ireland***	***Iceland***	***Italy***	***Liechtenstein***	***Luxemburg***	***Norway***	***Country-Bas***	***Portugal***	***United Kingdom***	***Sweden***
Coverage	A	A	A	A	A	A	A	A	A	A	A			A	A	A	A	T
Pathology coding	ICD-10-SGB-V 2.0	ICD-10	ICD-9-CM	ICD-10	ICD-9-CM	ICD-10	CIM-10	ICD-9-CM	ICD-9-CM	ICD-10	ICD-9-CM			ICD-10	ICD-9-CM	ICD-9-CM	ICD-10	ICD-10
Coding procedures	OPS-301 2.0	Procedure Catalogue	ICD-9-CM	CNPC	ICD-9-CM	CNPC	CIM-10	N	ICD-9-CM	CNPC	ICD-9-CM			CNPC	CVV	ICD-9-CM	OPCS-4	CNPC

One can thus quickly notice from studying this table:

- ✓ That all of the hospitals in every country is concerned with recording minimum medical data,
- ✓ That all of the countries, except for France, use ICD codification for diagnoses,
- ✓ That there is no consensus concerning codification procedures, except for in Scandinavia, where 5 countries use the Nordic Classification of Surgical Procedures.

4.3.2 TEST THE FEASIBILITY OF THE CREATING A EUROPEAN MEDICAL DATABASE

4.3.2.1 Definition and methodology

This test's objective was to underline:

- ✓ The data transmission procedures
- ✓ The codifications used for each recorded variable featured in the test
- ✓ The necessary procedures for the database to become functional

In order to respond to this objective, during the December 2000 workshop, we asked our partners to give us, as a first step, a sample consisting of data registered within a hospital of their choice for a given year, for the year 2000 if possible. We already had use of the sample for Belgium.

In March of 2001, we had not yet received any sample, we reiterated our request by mail and reduced the sample to 500 anonymous registrations and specifying that an official request could be forwarded upon simple request. We then received 2 samples. (France and Spain).

In July 2001, during a trip to Scandinavia, we received a sample from Norway.

Finally, following a reminder sent in October and November 2001, to which the official request was attached, Austria and Sweden sent the requested sample. Nonetheless, we were able to further include the following countries in this test (Germany, Denmark, Finland, Greece and Italy) because they had supplied us with a complete description of the variables recorded during the first stage of the study or during the trip to Scandinavia.

4.3.2.2 Lists of variables retained a priori

Given that there are a certain number of variables that are recorded in each country exclusively for internal management reasons, we only selected the variables that respond to the exploitation objectives for the European database:

- ✓ Hospital identification number: the interest of this variable is the ability to geographically locate the place where the certain pathologies are treated,
- ✓ Patient identification number: although this has no bearing on the data processing because they are anonymous, this does allow one to assign a number to each recording,
- ✓ Type of stay: this allows one to know which pathologies are generally treated in an ambulatory manner, and to have a geographic distribution by coupling this variable with the hospital number
- ✓ Length of stay,
- ✓ Length of stay in intensive care: the stay in intensive are is a good indicator of the severity of the pathology treated or can also an indicator to help compare medical practice and thus quality or safety of the care offered,
- ✓ Discharge date: this allows one to date each registration, and possibly to emphasise re-hospitalisations,
- ✓ Sex,
- ✓ Age,

- ✓ Residence post code: this allows one to construct geographical maps for different variables such as: the diagnoses, the type of admission,…and to include the results of these analyses in environmental characteristics such as the presence of polluting industries, …,
- ✓ Type of admission: certain pathologies lead to a specific admission in emergency care, while others are very rarely taken in outside of an explicit hospital program,
- ✓ Addressed by: allows to underline the types of professional practices such as: collaboration with other institutions, …,
- ✓ Type of discharge: besides the number of deaths, discharges against doctors' orders are also a very interesting indicator,
- ✓ Destination: the patient's place of destination after his/her discharge from the hospital constitutes an important indicator of the type of extra-hospital care needed by the population,
- ✓ Main diagnosis,
- ✓ Degree of certainty for the main diagnosis: certain diagnoses are simply presumptions, others are confirmed by an anatomical or pathological exam, which is also an interesting indicator,
- ✓ Secondary diagnoses and complications,
- ✓ Procedures: provided during the hospitalisation, they allow one to highlight the different professional practices for a given pathology,
- ✓ Length of stay calculated at admission for each procedure: this gives an idea of the chronological development of the hospital stay,
- ✓ Degree of urgency of the procedure: this information can, for some pathologies, give an indication on the health of the population, as well as on the accessibility of care,
- ✓ Anaesthetic code for the procedure,
- ✓ Speciality where the patient stayed,
- ✓ Length of stay in each speciality.

4.3.2.3 Primary and secondary diagnoses

When collecting the data from different countries, we came to realise that the definition of primary and secondary diagnoses varies greatly from country to country, as shown in the following spreadsheet:

Table 4.20. Definition of Main diagnoses, and Secondary diagnoses and complications

	Main diagnosis	*Secondary diagnosis and complications*
Germany	Discharge diagnosis	For each departmental stay (maximum of 30 departmental in 1 hospital stay): 1main diagnosis and 20 secondary diagnoses are possible, each diagnosis could be a combination of asterisk and cross diagnoses of ICD
Austria		
Belgium	Since January 1 2000: diagnosis which, after examination, justified the admission	Diagnoses which modify the hospital care according to one of the following criteria: evaluation clinical, therapeutic, diagnostic procedures, lengthening of the lenght of stay, increase in the care male nurses. Thus among the secondary diagnoses, one finds the complications of the principal diagnosis, pathologies associated, the complications of care, the antecedents heavy and the problems to be followed. Maximum 25 per stay
Denmark	?	?
Spain	Diagnosis which, after examination at the exit of the patient, justified the admission	Those diagnoses that coexist with the main or are developed throughout the hospital stay, and influence the duration of the stay or the administered treatment.
Finland	?	?
France	Diagnosis considered by the doctor responsible for the patient at the end of his stay in a medical unit having mobilized the essence of the medical effort and looking after	If it is necessary: affected associated with the principal diagnosis, complications of this one or its processing Maximum 98 per stay
Greece		No data recorded
Italy	Disease which absorbed the greatest amount of resources during the hospitalization in terms of diagnosis, treatment and care	Diseases associated with the principal diagnosis
Norway	List by order descending of importance	Maximum 7 per stay
Sweden	Diagnosis which, at the exit of the patient, is the principal person in charge of the stay of the patient	Maximum 7 per stay

4.3.2.4 Availibility of the variables in the various countries

The following table shows the accessibility of the data in each country.

Table 4.21. Availibility of the variables in each country

	Germany	*Austria*	*Belgium*	*Denmark*	*Spain*	*Finland*	*France*	*Greece*	*ItalY*	*Norway*	*Sweden*
Identification number of the hospital	X	X	X	X	X	X	X	X	X	X	X
Identification number of the patient	X	X	X		X	X	X	X	X	X	X
Type of stay			X						X	X	
Lenght of stay	X	X	X	X	X	X	X	X	X	X	X
Lenght of stay in intensive care unit			X		X				X		
Date of discharge	X	X	X		X	X	X	X	X	X	X
Sex		X	X	X	X	X	X	X	X	X	X
Age	X	X	X	X	X	X	X	X	X	X	X
Postal code of residence	X	X	X	X	X	X	X	X	X	X	X
Type of admission	X	X	X	X	X	X		X	X	X	X
Send by			X	X		X	X		X	X	X
Type of discharge	X	X	X						X		
Destination	X	X	X	X	X	X	X		X	X	X
Main diagnosis	X	X	X	X	X	X	X	X	X	X	X
Degre of certainty of the main diagnosis			X						X		
Secondary diagnosis and complications	X	X	X	X	X	X	X		X	X	X
Procedures	X	X	X	X	X	X	X		X	X	X
Lenght of stay calculated from the admission	X	X	X						X	X	
Emergency degre			X								
Type of anesthesia			X							X	
Speciality where remained the patient	X	X	X	X	X			X	X	X	X
Lenght of stay in each speciality	X		X		X				X		X
Result								X	X		

This table clearly demonstrates that there is a disparity between countries in terms of the variables recorded. Indeed, Belgium and Italy show a very comprehensive registration while other countries such as France show a more limited number of variables.

4.3.2.5 *Variables selected with hindsight (a posteriori)*

In the first stage, it seemed important to take interest exclusively in the variables that were common to most countries featured above. For the next step in the project, we will only take into account the following variables:

- ✓ Hospital identification number
- ✓ Patient identification number
- ✓ Length of stay
- ✓ Date of discharge
- ✓ Sex
- ✓ Age
- ✓ Residence post code
- ✓ Type of admission
- ✓ Sent by
- ✓ Destination
- ✓ Main diagnosis
- ✓ Secondary diagnoses and complications
- ✓ Services
- ✓ Speciality where the patient stayed
- ✓ Length of stay in each speciality

For each of these variables, we will now analyse their recording characteristics (content and codification) as well as the procedures required to incorporate these variables in the European database.

4.3.2.5.1 Hospital identification number

Table 4.22. Hospital identification number

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	Number IK of the hospital	Alphanumeric	9
Austria	Hospital number	Alphanumeric	6
Belgium	Number allotted to the hospital by the Processing center of the Information of the Ministry for the Public health	Alphanumeric	3
Denmark	?	?	?
Spain	Identification number of the hospital	Text	12
Finland	Identification number of the hospital	?	5
France	Number FINESS which locates the hospital in a department or an area.	Text	9
Greece	Identification number of the hospital	?	?
Italy	Identification number of the hospital	Numeric	9
Norway	Identification number of the hospital	Numeric	9
Sweden	Identification number of the hospital	Numeric	5

Procedure: Define a numeric field de 12 positions

4.3.2.5.2 Patient identification number

Table 4.23. Patient identification number

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	Number of the inssurance company (optional)	Alphanumeric	12
Austria	Admission number	Alphanumeric	10
Belgium	Single number of the patient allotted by each hospital for at least a year	Alphanumeric	13
Denmark	?	?	?
Spain	Medical record number or Health system personal number	Text	20
Finland	Identification number of the patient	?	11
France	Hospitalization number	?	?
Greece	Sociel security number	?	?
Italy	Hospitalization number	Numeric	9
Norway	Number allotted by the hospital for one one year period	Numeric	11
Sweden	Personal number of identification containing the date of birth	?	12

Procedure: To define an alphanumeric field, 20 digits, and ask to Germany to collect it always

4.3.2.5.3 Length of stay

Table 4.24. Length of stay

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	To be calculated from the variables "Date of admission" and "Date of discharge"		
Austria	To be calculated from the variables "Admission date" and "Date of discharge"		
Belgium	Date of discharge – Date of admission One-day: 0	Numeric	5
Denmark	Date of discharge – Date of admission	?	?
Spain	To be calculated from the variables "Date of admission" and "Date of discharge"	Numeric	
Finland	To be calculated from the variables "Date of admission" and "Date of discharge"		
France	Number of days between the Date of admission and the Date of discharge.	?	?
Greece	Date of discharge – Date of admission	?	?
Italy	To be calculated from the variables "Date of admission" and "Date of discharge"		
Norway	Date of discharge – Date of admission	Numeric	4
Sweden	To be calculated from the variables: "Hôpital", "Date of admission" and "Date of discharge"		

Procedure: Define a numerical field containing 5 positions: For Sweden, one has to calculate according to the formula: Σ (Exit date – admission date) for each hospital for each patient number.

4.3.2.5.4 Date of discharge

Table 4.25. Date of discharge

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	Date of discharge (yyyymmdd)	Alphanumeric	8
Austria	Date of discharge (yyyymmdd)	Numeric	8
Belgium	Year and month of discharge (2 variables)	Numeric	
Denmark	?	?	?
Spain	Date of discharge (dd/mm/yy)	Date	8
Finland	Date of discharge (ddmmyyyy)	?	8
France	Date of discharge	?	?
Greece	Date of discharge	?	?
Italy	Date of discharge (ddmmyyyy)	Numeric	8
Norway	Date of discharge (yyyymmdd)	Numeric	8
Sweden	Date of discharge (yyyymmdd)	Numeric	8

Procedure: Define a numerical field with 6 positions (yyyymm)

4.3.2.5.5 Sex

Table 4.26. Sex

Country	Content	Format	N^{ber} of digits
Germany	No, because it's known by the insurrance company		
Austria	M: male W: female	Alphanumeric	1
Belgium	0: unknow (new-born whose sex is not given) 1: male 2: female	Numeric	1
Denmark	1: male 2: female	?	1
Spain	1: male 2: female	Text	1
Finland	1: male 2: female	?	1
France	1: male 2: female	Numeric	1
Greece	1: male 2: female	?	1
Italy	1: male 2: female	Numeric	1
Norway	1: male 2: female	Numeric	1
Sweden	1: male 2: female	?	1

Procedure: Define a numeric field with 1 position containing only men and women, i.e. to convert Austrian alphanumeric coding into 1 and 2 and to remove the Belgian “0” category which very rarely appears. To ask to Germany to add this variable in the records.

4.3.2.5.6 Age

Table 4.27. Age

Country	Content	Format	N^{ber} of digits
Germany	Date of birth (yyyymmdd) (optional)	Alphanumeric	8
Austria	Date of birth (yyyymmdd)	Numeric	8
Belgium	Year of birth	Numeric	4
Denmark	?	?	?
Spain	Age in years	Numeric	3
Finland	Date of birth	?	?
France	Age in years	Numeric	3
Greece	Age et Date of birth (2 variables)	?	
Italy	Date of birth (ddmmyyyy)	Date	8
Norway	Year of birth	Numeric	4
Sweden	Age at the discharge	?	?

Procedure: Define a numeric field with 3 positions that only include the patient's age, which means using the following formula for Germany, Austria, Belgium, Finland, Italy and Norway: "Date of discharge – date of birth".

4.3.2.5.7 Residence post code

Table 4.28. Residence post code

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	Postal code (optional)	Alphanumeric	7
Austria	Country of stay: state or postal code of Austria	Alphanumeric	
	Postal code: Belgian residents: postal code of the official domicile - SDF for professional reason: postal code of the commune of reference - Other SDF: 9999 - Residents abroad: 0+code of Country of residence	Numeric	4
Belgium	Code INS (National Institute of Statistics): geographics zones Belgian residents: postal code of the official domicile - SDF for professional reason: postal code of the commune of reference - Other SDF: 99999 - Residents abroad: 00000	Numeric	5
Denmark	?	?	?
Spain	Postal code	Text	5
Finland	Postal code	?	?
France	Postal code automatically gathered in geographical areas of at least 1000 inhabitants	Numeric	4
Greece	Residence	?	?
	Region	?	?
Italy	Code INS (National Institute of Statistics)	Numeric	5
	Community of residence	Numeric	4
Norway	Region	Numeric	2
	Country of origin	Alphabétique	3
Sweden	Region, City	Numeric	6

Procedure: Define a numeric field with 7 positions regrouping the patient's region of origin based on Nuts codification, which implies a conversion of the codes in use for each country.

4.3.2.5.8 Type of admission

Table 4.29. Type of admission

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	Reason of admission: 3 and 4 digit: 1: normal – 2: industrial accident or occupational disease – 3: Road accident, sport or other – 4: ? – 6: ? – 7: urgency	Alphanumeric	4
Austria	A: normal – H: half-stationary area (only psychiatry) – K: admission in a day-clinic – L: flag of data sets for stay of in-patients after asylum – P: admission in the area of care – R: admission in the area of rehabilitation – T: transfer from another hospital – W: readmission	Alphanumeric	1
Belgium	0: unknown - 1: urgency via 100 - 2: other urgency – 3: childbirth - 4: new-born baby hospitalized since his birth and remaining after the output of his/her mother or hospitalized in service N - 5: admission envisaged - 6: internal transfer - 7: administrative admission - 9: other	Numeric	1
Denmark	Urgent - Nonurgent	?	?
Spain	1: urgency – 2: programmed	Numeric	1
Finland	Type of admission	?	?
France	Internal transfert– Transfer of another legal entity - Residence	?	?
Greece	Urgent – Normal	?	?
Italy	1: programmed – 2: emergency – 3:TSO – 4:programmed with pre-hospitalisation – 5: new born	Numeric	1
Norway	1: programmed - 2: urgency - 3: born in the hospital - 5: deceased before arriving at the hospital - 6: deceased during the admission to the urgencies - 8: admission after a refusal of admission	Numeric	2
Sweden	1: programmed – 2: urgency	Numeric	1

Procedure: Define a numeric field with 1 position that would only include 2 items: "1: in emergency" and "2: programmed", which implies that certain countries (Germany, Austria, Belgium, Italy and Norway) must pool variables together, and that others (Denmark, Greece and Sweden) must modify their codification if necessary.

4.3.2.5.9 Sent by

Table 4.30. Sent by

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	?	?	?
Austria	Data no collected		
Belgium	0: unknown - 1: initiative of the patient - 2: general practitioner - 3: specialist in the hospital - 4: specialist except hospital - 5: other hospital - 6: convalescent home approved - 7: other convalescent home - 8: organization insurer - 9: other	Numeric	1
Denmark	Patient initiative – general practitioner – other hospital – ambulatory	?	?
Spain	Data no collected		
Finland	Who referred the patient	?	?
France	?		
Greece	Data no collected		
Italy	1: initiative of the patient - 2: general practitioner - 3: specialist - 4: public hospital - 5: accredited private hospital - 6: private hospital - 7: other regions - 8: 118 - 9: other	Numeric	1
Norway	1: residence - 2: place of accident - 3: other institution - 4: polyclinic of the hospital - 6: other - 9: other department - 10: program of search - 11 to 14: transfer of an urgency of another hospital for lack of place - 15: Convalescence after processing abroad - 16: other urgency - 19: choice according to the waiting list - 20: paying project to circumvent the waiting list - 21 to 26: subsidized national - 30: private private clinic - 40: kosovars	Numeric	2
Sweden	1: other department of or except hospital - 2: home or residence for old people - 3: residence	Numeric	1

Procedure: Define a numeric field with 1 position that would only contain 2 items: "1: residence" and "2: other institution or department", which that all countries pool their variables.

4.3.2.5.10 Destination

Table 4.31. Destination

Country	*Content*	*Format*	*N^ber^ of digits*
Germany	Reason of discharge: 1 and 2 digits: 01-04: home – 06: transfert to an other hospital – 07: death – 08: transfert to an other hospital within the framework of a co-operation – 09: back to an institution of rehabilitation – 10: back to an institution of care – 11: back to an old people's home – 12: internal transfert	Alphanumeric	3
Austria	A: hospital-internal transfer from half-stationary area (only psychiatry), from area of rehabilitation and from the exclusive area of care in the general stationary area (incl. intensive area) – E: discharge from the hospital – H: hospital-internal transfer in the half-stationary area (only psychiatry) – L: flags of data sets, documentary completed in the time of asylum – P: hospital-internal transfer in the exclusive area of care – R: hospital-internal transfer in the area of rehabilitation – S: case of death – T: tranfer to another hospital	Alphanumeric	1
Belgium	0: unknown - 1: residence - 2: internal transfer - 3: other nonuniversity hospital - 4: other university hospital - 5: psychiatric hospital - 6: convalescent home approved - 7: other convalescent home - 8: death - 9: other	Numeric	1
Denmark	General practitioner - specialist - other department of the hospital or ambulatory - death - unknown	?	?
Spain	1: residence - 2: transfer to another center - 5: voluntary output - 6: death - 9: unknown	Text	10
Finland	Destination of the patient	?	?
France	Internal transfer - transfer to another establishment - residence - death	?	?
Greece	Data no collected Item "death"	?	?
Italy	1: death - 2: ordinary - 3: RSA - 4: protected residence - 5: voluntary - 6: external transfer - 7: internal transfer - 8: convalescent home - 9: ADI	Numeric	1
Norway	1: residence - 2: death - 3: other institution - 4: transfer in a hospital of Country of origin of the patient - 6: other - 9: other department in the same hospital	Numeric	2
Sweden	1: other department of or except hospital - 2: home or residence for old people - 3: residence - 4: death	Numeric	1

Procedure: Define a numeric field with 1 position that would only include 3 items: "1: residence", "2: other institution or department" and "3: death", which implies that all countries must pool their variables.

4.3.2.5.11 Main diagnosis

Table 4.32. Main diagnosis

Country	***Content***	***Format***	***N^{ber} of digits***
Germany	Code in ICD-10-SGB-V 2.0	Alphanumeric	9
Austria	Code in ICD-10	Alphanumeric	7
Belgium	Code in ICD-9-CM	Alphanumeric	6
Denmark	Code in ICD-10	?	?
Spain	Code in ICD-9-CM	Text	6
Finland	Code in ICD-10	?	5
France	Code in CIM-10	Alphanumeric	5
Greece	Code in ICD-9-CM	?	?
Italy	Code in ICD-9-CM	Alphanumeric	5
Norway	Code in ICD-10	Alphanumeric	5
Sweden	Code in ICD-10	Alphanumeric	5

Procedure: Define an alphanumeric field with 9 positions in which the codes will be introduced after their conversion (see below, the section entitled Proposals).

4.3.2.5.12 Secondary diagnoses and complications

Table 4.33. Secondary diagnosis and complications

Country	***Content***	***Format***	***Nber of digits***
Germany	Code in ICD-10-SGB-V 2.0	Alphanumeric	9 (x 20)
Austria	Code in ICD-10	Alphanumeric	7
Belgium	Code in ICD-9-CM	Alphanumeric	6 (x 25)
Denmark	Code in ICD-10	?	?
Spain	Code in ICD-9-CM	Text	6 (x 13)
Finland	Code in ICD-10	?	5 (x 2)
France	Code in CIM-10	Alphanumeric	5 (x 5)
Greece	Data no collected		
Italy	Code in ICD-9-CM	Alphanumeric	5
Norway	Code in ICD-10	Alphanumeric	5 (x7)
Sweden	Code in ICD-10	Alphanumeric	5 (x 7)

Procedure: Define an alphanumeric field with 9 positions in which the codes will be introduced after their conversion (see below, the section entitled Proposals).

4.3.2.5.13 Procedures

Table 4.34. Procedures

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	Code OPS-301 2.0	Alphanumeric	30 (x 3)
Austria	Code of the national procedure catalogue	Alphanumeric	10
Belgium	Code in ICD-9-CM	Alphanumeric	5 (x 3)
Denmark	Code in CNPC	Alphanumeric	5
Spain	Code in ICD-9-CM	Text	5 (x 13)
Finland	Code in CNPC: only surgical procedures	?	? (x 3)
France	Code in CIM-10	Alphanumeric	4 (x 10)
Greece	Data no collected		
Italy	Code in ICD-9-CM	Alphanumeric	5
Norway	Code in CNPC	Alphanumeric	5 (x 4)
Sweden	Code in CNPC	Alphanumeric	5

Procedure: Define an alphanumeric field with 11 positions in which the codes will be introduced after their conversion (see below, the section entitled Proposals).

4.3.2.5.14 Speciality where the patient stayed

Table 4.35. Speciality where the patient stayed

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	Speciality	Alphanumeric	4
Austria	?		
Belgium	Index of the unit (give the speciality)	Alphanumeric	2 (x 6)
Denmark	?	?	?
Spain	Department where remained the patient*	Text	10
Finland	?	?	?
France	Number of the medical unit (code determined by each establishment) recorded in the RUM (summarized per unit) but not included in the PMSI	?	?
Greece	Only reference unit	?	?
Italy	Unit where remained the patient	Numeric	4
Norway	Department where remained the patient	Numeric	5
Sweden	Department where remained the patient	Numeric	3

Procedure: Define a numeric field with 2 positions that would include the various medical specialties, which would require that certain countries pool their variables.

4.3.2.5.15 Length of stay in each speciality

Table 4.36. Lenght of stay in each speciality

Country	*Content*	*Format*	*N^{ber} of digits*
Germany	To be calculated from the variables "Date of discharge" – "Date of admission"		
Austria	?		
Belgium	Lenght of stay in the unit	Numeric	4
Denmark	?	?	?
Spain	Lenght of stay in the unit*	Numeric	8
Finland	?	?	?
France	Cfr previous table		
Greece	Data no collected		
Italy	To be calculated from the variables "Date of discharge" – "Date of admission"		
Norway	?	?	?
Sweden	To be calculated from the variables "Date of discharge" – "Date of admission"		

Procedure: Define a numeric field with 8 positions

4.4 PROPOSALS

Creating a European database is only feasible if certain procedures are undertaken that include data with an identical format.

The table below reiterates the various procedures noted in the previous section for each variable that was considered.

Table 4.37. Procedures noted for each variable

Variable	*Procédure*
Hospital identification number	Define a numeric field de 12 positions
Patient identification number	To define an alphanumeric field, 20 digits, and ask to Germany to collect it always
Lenght of stay	Define a numerical field containing 5 positions: For Sweden, one has to calculate according to the formula: Σ (Exit date – admission date) for each hospital for each patient number
Date of discharge	Define a numerical field with 6 positions (yyyymm)
Sex	Define a numeric field with 1 position containing only men and women, i.e. to convert Austrian alphanumeric coding into 1 and 2 and to remove the Belgian "0" category which very rarely appears. To ask to Germay to add this variable in the records.
Age	Define a numeric field with 3 positions that only include the patient's age, which means using the following formula for Germany, Austria, Belgium, Finland, Italy and Norway: "Date of discharge – date of birth"
Residence post code	Define a numeric field with 7 positions regrouping the patient's region of origin based on Nuts codification, which implies a conversion of the codes in use for each country.
Type of admission	Define a numeric field with 1 position that would only include 2 items: "1: in emergency" and "2: programmed", which implies that certain countries (Germany, Austria, Belgium, Italy and Norway) must pool variables together, and that others (Denmark, Greece and Sweden) must modify their codification if necessary.
Send by	Define a numeric field with 1 position that would only contain 2 items: "1: residence" and "2: other institution or department", which that all countries pool their variables.
Destination	Define a numeric field with 1 position that would only include 3 items: "1: residence", "2: other institution or department" and "3: death", which implies that all countries must pool their variables.
Main diagnosis	Define an alphanumeric field with 9 positions in which the codes will be introduced after their conversion (see below, the section entitled Proposals).
Secondary diagnosis and complications	Define an alphanumeric field with 9 positions in which the codes will be introduced after their conversion (see below, the section entitled Proposals).
Procedures	Define an alphanumeric field with 11 positions in which the codes will be introduced after their conversion (see below, the section entitled Proposals).
Speciality where the patient stayed	Define a numeric field with 2 positions that would include the various medical specialties, which would require that certain countries pool their variables
Lenght of stay in each speciality	Define a numeric field with 8 positions

In view of improving the database through time, the proposals are expressed as short-, medium-, and long-term proposals.

The last part of this chapter is devoted to proposals related to feedback from or to the accessibility of the database.

4.4.1 SHORT-TERM PROPOSALS

- ✓ Coordinate the various projects, whether financed by the European Commission or not, which relate to the same subject, with the intention of optimising the various resources and increase the projects' efficiency.
- ✓ Establish a convention with each country, which organises the yearly transmission of data and specifies the format in which the data will be transferred. The transmission can only be done once a year because some of the countries do not have a monthly or quarterly internal data transfer system. Furthermore, given the fact that certain countries (such as Belgium) receive data from hospitals 6 months after the period in question, there is reason to foresee a transfer at "n + 1".
- ✓ Define the database and the fields that will be included according to the list (above).
- ✓ Request that the countries complete the missing data.
- ✓ Establish automatic variable conversion programs for each country in order to obtain a single data format.
- ✓ Request that certain countries record the currently missing data and specify the desired registration format (corresponding to that defined in the database for each variable:

    Austria: Send by, Units where remained the patient, Lenght of stay in each unit

    Spain: Send by and in the most of the regions Units where remained the patient, Lenght of stay in each unit.

  Greece: Send by, Destination, Secondary diagnosis and complications, Procedures, Units where remained the patient, Lenght of stay in each unit

  France: Units where remained the patient, Lenght of stay in each unit

  Norway: Units where remained the patient, Lenght of stay in each unit

  Sweden: Units where remained the patient, Lenght of stay in each unit
- ✓ Specify the type of procedures that must be included in the database:

  Only the surgical procedures?

  Only the procedures directly linked to primary diagnoses.

  All of the procedures.

  Only the procedures that influence the length of stay or reflect morbidity?
- ✓ Define the notions of "main diagnosis" and "secondary diagnoses and complication " in order to obtain homogeneous and comparable data.
- ✓ Establish a conversion table for diagnoses, pathology groups, and procedures. Indeed, each country uses its own version of the ICD (International Classification of Diseases). Although the differences are not always significant, it is difficult, or even impossible to use this type of data. This explains our proposal to pursue this study through the development of a concordance table for all of the national classifications in use. This comparability table would then be updated with every modification brought by a member state to its classification system.
- ✓ Carry out a "full-scale" test in collaboration with the HIEMS services.

4.4.2 MEDIUM-TERM PROPOSALS

- ✓ Include in the database the variables that are not currently part of the data collected in most countries, which implies defining these variables beforehand and asking all of the countries to collect them and transfer them at a given point in time. The variables in question are:

  Type of stay

  Readmission rate

  Length of stay in intensive care unit

  Type of exit

  Degree of certainty of each diagnosis

  Degree of urgency of the service

  Length of stay calculated from time of admission for each procedure performed

  Anaesthetic code for each procedure performed

  Result
- ✓ For the variables already collected on a short-term basis: evaluate their content in terms of codification possibilities and thus of precision and, if necessary, modify the content in order to obtain more detailed information.

4.4.3 LONG-TERM PROPOSALS

Define the possible links between the European database for primary care and that for secondary care, which would allow for interesting uses in terms of health indicators, population follow-up, and evolution of certain pathologies.

4.4.4 FEEDBACK OR ACCESSIBILITY PROPOSALS

Throughout the fulfilment of this project, the entire team was struck by the importance given to the feedback and accessibility of the European database by the various people who participated in the study. This observation is reinforced by the experiences of each and every one of us.

It appears to be essential to organise a regular feedback (in the form of activity reports and/or publishing of statistics) and to define the terms of accessibility for the European database.

The project's objective is not to deliver a detailed study on the ethical and legal aspects of the database, we will therefore merely voice some of the propositions that should be the subject of further studies:

- ✓ Define access keys for the different types of users:
- ✓ Public
- ✓ Care providers
- ✓ Private research teams
- ✓ Universities
- ✓ Regional authorities

- ✓ Health ministries
- ✓ Define the accessibility terms and conditions

4.5 LINKS WITH OTHER PROJECTS

4.5.1 ECHI

The ECHI project[97], coordinated by Pieter Kramers (National Institute of Public Health and the Environment – Bilthoven – The Netherlands), is aimed at drawing up a list of health indicators in view of contributing to the implementation of a European health monitoring system.

Among the list of indicators featured in the ECHI project, one notes the general indicators such as:

- ✓ Morbidity,
- ✓ Use of health care
- ✓ Surgical operations and procedures
- ✓ Quality and performance of health care:
- ✓ Indicators of the health process
- ✓ Health results

The results of the feasibility test regarding the creation of a medical database for hospital care (secondary care) show that the exploitation of this database will provide the indicators mentioned above. Some of the indicators are not yet part of the list proposed by ECHI.

4.5.1.1 Morbidity indicators

- ✓ The incidence and prevalence of all pathologies: indeed, through the codification of patient pathologies in the form of primary and secondary diagnoses and/or complications and related co-morbidities, one can approximate, by region or by country, the incidence and prevalence rate for each pathology. In order to obtain comparable data, it is essential that all countries have the same definition for primary and secondary diagnoses, and/or related complications and co-morbidities; this is not yet the case. Furthermore, it is vital to establish a concordance table for all of the codifications used by the European countries (see "Short-term proposals ")
- ✓ The evolution of any given pathology through time and space.
- ✓ The degree of certainty for the primary diagnosis by pathology

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[97] ECHI project. Design for a set of European Community Health Indicators. National Institute of Public health and the Environment. 2001. The Netherlands

4.5.1.2 Use of health care

- ✓ Average length of stay per pathology
- ✓ Average length of stay per DRG: for this indicator, one will also need to create a concordance table for the different classifications used in European countries (see “Short-term proposals ")
- ✓ Average length of stay in intensive care per pathology
- ✓ Average length of stay in intensive care per DRG
- ✓ Average length of stay per speciality
- ✓ Number of discharges per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Number of discharges per DRG: can be associated with other variables such as sex, age, place of residence, (region, country), type of admission, specialty
- ✓ Type of discharge per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Type of discharge per DRG: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Type of admission per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of exit, specialty
- ✓ Type of admission per DRG: can be associated with other variables such as sex, age, place of residence (region, country), type of exit, specialty
- ✓ Sent by, per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, type of exit, specialty
- ✓ Sent by, per DRG: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, type of exit, specialty

4.5.1.3 Surgical operations and procedures

- ✓ Number and type of surgical interventions
- ✓ Number and type of surgical interventions per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Number and type of surgical interventions per DRG: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Degree of urgency per surgical intervention: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, Primary diagnoses, specialty
- ✓ Type of anaesthesia per surgical intervention: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, Primary diagnoses, and specialty

4.5.1.4 Health process indicators

- ✓ Variations in the number of specific surgical interventions (based on a list to be established)
- ✓ Readmission rate per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, and type of exit
- ✓ Readmission rate per DRG: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, and type of exit
- ✓ Destination, per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, type of exit, specialty
- ✓ Destination, per DRG: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, type of exit, specialty

4.5.1.5 Health results

- ✓ Number of intra-hospital death: this indicator does not make sense that if it is put in relation to the health care system in force in each country, because of the variations of accessibility to the care and mode of assumption of responsibility can explain variations of certain come results the number of deaths
- ✓ Number of intra-hospital death per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Number of deaths per DRG: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Incidence of renal insufficiencies in terminal phase
- ✓ Incidence of diabetes in terminal phase
- ✓ Number of nosocomial infections
- ✓ Number of nosocomial infections per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Number of nosocomial infections per DRG: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Number of resistances to antibiotics
- ✓ Number of resistances to antibiotics per pathology: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty
- ✓ Number of resistances to antibiotics per DRG: can be associated with other variables such as sex, age, place of residence (region, country), type of admission, specialty

4.5.2 HOSPITAL DATA

The "Hospital Data" project[98] (launched in 2001), coordinated by Hugh Magee (Health and Children Department – Dublin – Ireland) and Richard Willmer (Health Department – London – United Kingdom), is aimed at preparing a detailed and practical methodology for the production of comparable hospital data. The chosen methodology is very similar to that adopted by Euro-med-Data, that is to say:

- ✓ Inventory of existing data
- ✓ Evaluation of comparability
- ✓ Definition of certification levels
- ✓ Creation of a set of European hospital data

The fact that there are two projects devoted to the same problems and relying on the same methodology is harmful to both projects, even if Euro-Med-Data clearly predates Hospital Data. Indeed, both projects mostly contact the same people, which in turn discredits both projects. This explains why, in the short-term proposals (see above), we mentioned first the coordination of all projects dealing with similar issues.

- ✓ Most points are thus approached by both projects. Nonetheless, we have noted two very original points developed by Hospital Data that justify further studies.
- ✓ Definition of the population concerned by the different files
- ✓ Identification of the type of hospital (public and/or private) concerned by the different files

4.5.3 OTHER PROJECTS

The creation of a European hospital database will allow for the gathering of a number of interesting data for a range of projects, such as:

- ✓ Indicators for monitoring and evaluating perinatal health in Europe (France).
- ✓ Child health indicators of life and development (CHILD) (United Kingdom).

4.6 CONCLUSION

The results obtained in this study are particularly positive because they demonstrate the true possibility of creating a European database and the variety of potential uses for his information.

The studies should be pursued according to the outline suggested in the chapter dedicated to Proposals.

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[98] Magee H, Willmer R. Hospital Data Project: Interim Technical Report. Magee H, 2001. Dublin, Department of Health and Children

5 HEALTH AT WORK

5.1 INTRODUCTION

Health and safety at work are essential elements in maintaining an active, flexible, and productive population. The protection of workers at the European level seeks to ensure that the creation of a single market and the free movement of workers do not lead to the degradation of workers' conditions, or to a distorted competition.

Given this context, it is clear that the creation of a comparable European database in the field of health at work is an important venture for the European Community, notably in order to plan for a reliable evaluation of the impact of relevant European legislations.

Health in the workplace focuses on improving working conditions, improving the understanding of occupational illnesses and accidents, and improving human behaviour. This is therefore as much a will stemming from the employers as from the employees to: a) obtain a more secure environment at work; b) identify; c) evaluate the risks and diseases caused by work; d) to implement more efficient control and prevention methods; and e) to develop and promote health and security ideals.

Within the framework of our analysis, routinely collected data concerning health at work should lead to statistical studies and consequently, the epidemiological exploitation of this data. This research presents some particularities linked to the actual context of health at work.

These distinctive features are listed below:

1. Unlike the two other sectors studied by EURO-MED-DATA (EMD), health at work has its **own legislation**. Because of its many socio-economic implications, the issue of health at work should be clearly defined in order to protect both workers and employers in a harmonised European context where competition would not be detrimental to the protection of workers.
2. One important feature of the job market is the **division** of labour and consequently the division of health risks. Regulations exist to cover these specific risks.
3. Medical practice with respect to health at work can be **preventive**; it also has the **therapeutic** power to treat health problems related to a specific exposure and occupational illnesses; and finally it has a **rehabilitative** role in dealing with people who were either injured at the workplace or who suffered an occupational disease.
4. At both the European and national levels, the bodies that handle health at work have a tripartite structure of government, employers' representatives, and workers' representatives.

During the first phase of the EMD study, the aforementioned characteristics were identified and their impact on the feasibility of a routine database was stressed. The second phase dealt with: a) the review of European Directives regarding workers' health and safety; b) their implementation in various sectors in the member States; and c) the feasibility of their implementation at the European level.

European legislation and the transcription of such legislation in the Member States should provide a source of comparable data that could feed the European data files. Already legislative texts reflect the divisions in the job market. This is highly important if we consider data related to specific exposures. The feasibility of the data collection depends on the specifics of the sector and the influence of the European context thereupon.

5.2 LEGISLATION

In Europe several measures were adopted over the course of the last century regarding health and safety at work. Since the foundation of the European Community the Member States have tried to harmonise their policies in various areas. Adaptation to social changes is one area where progress has been important albeit uneven because of the different standings of Member States.

In 1978 the first action programme in the field of health and safety at work indicated that the Community might play a central role in the future. The same year specific legislation targeted a substance, which doctors knew was hazardous: vinyl chloride monomer. Throughout the decade 1978-1988, directives related to defined exposure risks were adopted by the Council.

The drafting of the Single European Act gave the Community more leverage to harmonise the policies of Member States. With the prospect of the single market in 1992, a series of legislative measures were elaborated in 1989 to prevent the degradation of workers' conditions and distorted competition. Legislation is a key issue in the search for higher competitiveness. Progress in this area can be shown as follows:

5.2.1 FRAMEWORK DIRECTIVE

In 1989, following recommendations by the Commission based on Article 118A (presently Article 138) of the EEC Treaty[99], the Council adopted minimum requirements by way of the Framework Directive 89/391/EEC[100] with a view to promote certain measures to ensure a better level of health and safety for workers at work. This Framework Directive provides a solid foundation for the adoption of specific measures in various fields.

5.2.2 INDIVIDUAL DIRECTIVES

Individual Directives within the meaning of Article 16 of the Framework Directive are adopted regarding among other things: the workplace, work equipment, equipment designed for individual protection, work with VDU screen equipment, handling heavy loads involving a lumbar risk, temporary and mobile construction sites, fishing and agriculture.

To this day legislation contains a number of Directives that can be classified as follows:

1. <u>Protection of specific groups of workers:</u> specific Directives concerning temporary workers[101], pregnant women[102], and young people at work[103] were adopted.
2. <u>Manual handling[104]</u>: concerning loads that involve dorsal-lumbar risks for workers.

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[99] Recommendation drawn up upon consultation with the Consultative Committee for security, hygiene and the protection of health at work, in co-operation with the European Parliament, and having regard for the opinion of the social and economic Committee.

[100] OJ L 183 from 29.06.1989, p.1

[101] Council Directive 91/383/EEC of 25 June 1991

[102] Council Directive 92/85/EEC of 19 October 1992 (tenth individual directive of directive 89/391/EEC)

[103] Council Directive 94/33/EC of 22 June 1994

[104] Council Directive 90/269/EEC of 29 May 1990 (fourth individual directive of directive 89/391/EEC)

3. Medical treatment on board vessels[105]: with a view to promote medical assistance on board boats.
4. Work Equipment: in 1982, a directive on the approximation of the laws of the Member States related to electrical equipment allowed for use in the explosive atmosphere of firedamp mines[106] was adopted. This Directive was amended several times[107] and will be repealed as of 01.07.2003. In 1989 two Directives were adopted, one concerning minimum health and safety requirements for the handling of work equipment by workers [108], and another concerning the use of equipment for individual protection by workers[109]. Finally in 1990, regarding work equipment, a Directive concerning work with VDU screen equipment[110] was adopted.
5. Safety and/or health signalisation at work[111]: signalisation Directive regarding a given object, activity, or situation, which offers an indication or a prescription with respect to health and safety at work.
6. Workplace[112]: first Separate Directive of Framework Directive 89/391/EEC (in broader terms), followed by Directives concerning specific workplaces: temporary or mobile construction sites[113], extractive industries by way of drilling[114], open-air and underground extractive industries[115], and work aboard fishing vessels[116].
7. Exposure to chemical agents: in 1978 the Directive on sanitary protection for workers exposed to the vinyl chloride monomer.[117] Then in 1980 the Directive concerning the protection of workers from risks of exposure to chemical, physical, and biological agents at work[118], allows for Separate Directives to define limit values as well as other specific requirements and their adaptation to progress.

   Specific Directives adopted lists of limit values as a rough guide for exposure to agents such as: asbestos, arsenic and compounds, benzene, cadmium and compounds, mercury and compounds, nickel and compounds, lead and compounds, chlorinated hydrocarbons: (chloroform, paradichlorobenzene, carbon tetrachloride), the first[119] in 1991 and the second[120] in 1996.

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[105] Council Directive 92/29/EEC of 31 March 1992

[106] Council Directive 82/130/EEC of 15 February 1982, will be repealed as of 01.07.2003

[107] Commission Directive 88/35/EEC of 2 December 1982, Commission Directive 91/269/EEC on 30 April 1991, Commission Directive 94/44/EC of 19 September 1994, Commission Directive 98/65/EC on 3 September1998, will be repealed as of 01.07.2003

[108] Council Directive 89/655/EEC of November 30th 1989 (second individual directive of directive 89/391/EEC), amended by Council Directive 95/63/CE on December 30th 1995

[109] Council Directive 89/656/EEC of November 30th 1989 (third individual directive of directive 89/391/EEC)

[110] Council Directive 90/270/EEC of May 29th 1990 (fifth individual directive of directive 89/391/EEC)

[111] Council Directive 92/58/EEC of June 24th 1992 (ninth individual directive of directive 89/391/EEC)

[112] Council Directive 89/654/EEC of November 30th 1989(first individual directive of directive 89/391/EEC)

[113] Council Directive 92/57/EEC of June 24th 1992 (eighth individual directive of directive 89/391/EEC)

[114] Council Directive 92/91/EEC of November 3rd 1992 (eleventh individual directive of directive 89/391/EEC)

[115] Council Directive 92/104/EEC (twelfth individual directive of directive 89/391/EEC)

[116] Council Directive 93/103/EC of November 23rd 1993 (thirteenth individual directive of directive 89/391/EEC)

[117] Council Directive 78/610/EEC of June 29th 1978, will be repealed as of 04.29.2003, see directive 98/38/EC

[118] Council Directive 80/1107/EEC of November 27th 1980, amended by Council Directive 88/642/EEC on December 16th 1988, and repealed as of 05.05.2001 – See Directive 98/24/EEC

[119] Council Directive 91/322/EEC of March 29th 1991

[120] Council Directive 96/94/EC of December 18th 1996, repealed as of 12.31.2001 – See Dir. 00/39/EEC

Separate Directives were adopted in the field of chemical agents regarding: risks of exposure to metallic lead and its ionic compounds at work[121], risks of exposure to asbestos at work[122], the protection of workers by banning specific agents and/or certain activities[123], the risks of exposure to carcinogens at work[124] (extended in a second amendment to include mutagenic agents[125]).

In 1998 a new Directive concerning the protection of health and safety of workers from risks related to chemical agents[126] at work replaced a large amount of previous Directives. Recently a new Directive established a preliminary list of limit values for occupational exposure[127] as a rough guide.

8. <u>Exposure to physical agents</u>: also covered by the 1980 Directive, which dealt with exposure to chemical, physical, and biological agents at work. In 1986 an individual Directive focused on exposure to noise [128] at work, and currently there are several proposals of Directives that relate to noise, mechanical vibrations, optical radiations, electromagnetic fields and electromagnetic waves, and ionising radiations.
9. <u>Exposure to biological agents</u>: this was part of the1980 Directive on exposure to chemical, physical, and biological agents at work. Individual Directives[129] were adopted and amendments and adaptations were introduced in the event of technical progress. They have been repealed not so long ago and replaced by a new Directive.[130]

The Aforementioned legislation, further legislation (recommendations, reports, action programmes…) and other precise actions (setting up monitoring committees, creating the European Foundation for the Improvement of Living and Work Conditions, creating the Agency for Safety and Health at Work…) testify to the commitment towards workers' health in Europe.

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[121] Council Directive 82/605/EEC on July 28th 1982, repealed as of 05.05.2001 – See Dir 98/24/EEC

[122] Council Directive 93/477/EEC of 19 September1983 (second individual directive within the meaning of article 8 of directive 80/1107/EEC), amended by Council Directive 01/382/EEC of 25 June1991

[123] Council Directive 88/364/EEC of 9 June1988 (fourth individual directive within the meaning of article 8 of directive 80/1107/EEC) repealed as of 05.05.2001, see Directive 98/24/EC

[124] Council Directive 90/394/EC of 27 June 1997 (sixth individual directive of directive 89/391/EEC) amended by Council Directive 97/42/EC of 27 June 1997

[125] Council Directive 1999/38/EC of 29 April 1999

[126] Council Directive 98/24/EC of 7 April 1998 (fourteenth individual directive of directive 89/391/EEC)

[127] Council Directive 2000/39/EC of 8 June 2000

[128] Council Directive 86/188/EEC of 12 May 1986

[129] Council Directive 90/679/EEC of 2 November 1990 (seventh individual directive of directive89/391/EEC) amended by Council Directive 93/88/EEC of 12 October 1993; Commission Directive 95/30/EC of 30 June 1995; Commission Directive 97/59/EC of 7 October 1997, and Commission Directive 97/65/EC of 2 November 1997, repealed as of 05.11.2000. – See Directive 00/54/EEC

[130] European Parliament and Council Directive 2000/54/EC of 18 September 2000 (seventh individual directive of directive 89/391/EEC

5.2.3 LEGISLATIVE FRAMEWORK

The legislative tools of the EC Treaty are: Regulations, Directives, Decisions, Recommendations and Notes. They enable Community institutions to influence national legal systems to various degrees.

In the case of health at work, as the amended legislation shows, Directives are the legislative tools of interest.

"Directives seek to reconcile the search for a necessary unity of Community Law and the preservation of the diversity of special national features. Their main goal is not legal harmonisation but the approximation of different legislations. They attempt to eradicate differences and contradictions in national legislations until basic requirements are as similar as possible in all Member States".

Directives are binding for Member States insofar as they must meet the stated goals. However decisions regarding the means by which Community goals are to be met is left entirely up to national legislation. Hence the scope of Community intervention in national legal and administrative systems is limited.

5.2.4 LEGISLATIVE HARMONISATION OF HEALTH AT WORK

The Framework Directive 89/391/EEC is based on article 138 (ex 118A) of the Treaty of the Union, which states that: "the Council is to adopt, by means of directives, minimum requirements for encouraging improvements, especially in the working environment, to ensure a better level of protection of the safety and health of workers; These requirements will be implemented gradually, given that special conditions must be taken into account, and that the Member States must lay down technical regulations. Each State can contribute requirements of its own for a "special protection", either by maintaining existing provisions, or by introducing new ones.

Directives lay down various obligations for both employers and workers, but they don't introduce specific rules regarding the collection and communication of data. In article 9 of the Framework Directive, one of the employer's obligations reads as follows: "The employer must:… (d) draw up, for the responsible authorities and in accordance with national laws and/or practices, reports on accidents at work suffered by his workers." In other specific directives one can read for instance that: "health surveillance should be undertaken in accordance with the practice of company medical services…[131]" or " … Member States shall introduce arrangements for carrying out appropriate health surveillance of workers in accordance with national laws and/or practice[132]

The comparability of data collected by different means and through different channels is obviously problematic.

The creation of the Community action programme for health surveillance in the field of public health[133] opened new doors as far as collecting quality and comparable data is concerned. This "framework programme" seeks to improve the quality of collected data, to analyse and diffuse data on the basis of standard health indicators, to set up a network for sharing data, and to draft reports. (see above, introduction)

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[131] Decision 86/188/ EEC, Article 9.d

[132] Decision 2000/54/EC, Article 14.1

[133] Decision 1400/97/EC of the European Parliament at the Council of 30 June 1997

5.3 THE ACTORS OF HEALTH AT WORK

5.3.1 WORKERS

Although the Framework Directive provides a clear and simple definition of the term ‘worker’: “any person employed by an employer, including trainees and apprentices but excluding domestic servants”, one is confronted with the problem of defining a common denominator at the European level because the scope of legislation varies across Member States with regards to the working population (see Appendix **X)**. Furthermore all workers are not declared: according to the prevailing hypothesis, undeclared workers represent between 7 and 19% of total declared jobs (COM (98)-219).

For instance, regarding accidents at work – the only piece of data that is explicitly mentioned in legislative texts – the scope of current legislation (in terms of population and risks covered) differs from one country to the next (see Appendix **X**). The manipulation of this data[134] is subject to a standardisation procedure that seeks to solve the denominator problem in order to allow regular data analysis.

Regarding data collection and analysis, and policymaking, the aforementioned factors should not be overlooked. The characterisation of workers is a necessary step in the structuring of a database.

5.3.2 EMPLOYERS

The employer is defined as: “any natural or legal person who has an employment relationship with the worker and has responsibility for the undertaking and/or establishment”

In the field of health at work the employer has the duty to ensure the safety and health of workers in every work-related aspect, on the basis of the general principles of prevention[135]. Moreover in the light of the nature of the activities that take place in the undertaking and/or establishment, the employer also has to evaluate the risks for the safety and health of workers, including the risks that pertain to the choice of equipment, chemical substances and preparations, and the layout of the workplace.

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[134] Eurostat, European statistics on accidents at work. http://europa.eu.int/comm/eurostat

[135] (a) avoiding risks; (b) evaluating the risks which cannot be avoided: (c)combating the risks at source; (d) adapting the work to the individual, especially as regards the design of work places, the choice of work equipment and the choice of working and production methods, with a view, in particular, to alleviating monotonous work and work at a predetermined work-rate and to reducing their effect on health. (e) adapting to technical progress; (f) replacing the dangerous by the non-dangerous or the less dangerous; (g) developing a coherent overall prevention policy which covers technology, organisation of work, working conditions, social relationships and the influence of factors related to the working environment; (h) giving collective protective measures priority over individual protective measures; (i) giving appropriate instructions to the workers.

5.3.3 COMPANY MEDICAL SERVICES

Workers and the appropriate health services interact in accordance with national legislation and practice. These rules often describe how routine contacts occur, and they allow data to be collected routinely in registers of entrance and periodic examinations.

The industrial medical officer plays a big part in the collection of morbidity data and in monitoring risk exposure.

In the field of occupational health services a precise diagnosis – particularly a complex one – is referred to the therapeutic sector. Hence all data on occupational pathologies is gathered, either in the sector for primary healthcare or in the sector for specialised healthcare.

A few examples that illustrate the disparities in company medical service from country to country:

a) Great-Britain: specialisation in company medical service exists but is not required. Health surveillance is not compulsory be it in practice or upon hiring a worker. Socio-economic considerations guide the medical practice of specialised nurses and general practitioners and specialised doctors.

b) Spain: industrial medical officers are always wage-earning specialists who practice preventive medicine essentially. The company service is multidisciplinary and preventive, and it can be supported by an external service. The policy for company medical insurance varies according to the risks the worker faces. Risks are defined by regulations.

c) Germany: Various systems co-exist. The industrial medical officer is specialised both in preventive and curative medicine. He or she can work as an independent or as a salaried employee. Some companies even receive the service of independent doctors who don’t belong to any organisation. Hence medical service is highly competitive. Traditionally however doctors join an inter-company service or the company itself (if it is large enough). Medical insurance is negotiated within the company (board of administration) and tends to vary a lot. Germany features special provisions for small and medium enterprises in which the employer is trained and informed. In this case the worker does not undergo examinations (this system is called the “employer system”).

d) Belgium: industrial medical officers are specialised. They can be independent or work as salaried employees. They take preventive action. Inter-company and company health services are common; they are multidisciplinary. Company medical insurance is settled by way of law and decree on the basis of work risks.

e) France: the French system features salaried medical officers working in company or inter-company services. They receive a normal wage, however when there is a shortage of doctors, specialisation is no longer compulsory. In practice medical treatments are essentially preventive. French workers enjoy total medical insurance if they take medical examinations on a regular basis.

Each system offers diversified services. The system in Luxembourg is similar to the Belgian and Spanish models. In Scandinavia company health services always include one or several medical officers, whose role depends on the analysis of post activity.

The feasibility of a European database for health at work is tied – regarding morbidity and exposure data – to preventive medical action in each of the Member States. Disparities between States are a genuine obstacle in the elaboration of a feasible database that would feature morbidity figures in the context of health at work.

5.3.4 THE ACTORS INVOLVED IN RISK MANAGEMENT

The call for multidisciplinary company healthcare services can be traced back to the 1985 Convention of the ILO on health services at work[136] and the resulting Recommendation[137]. However the multidisciplinary clause is only optional in the Convention. The Recommendation draws up a specialisation list including company medical services, occupational hygiene, ergonomics, occupational nurses, safety engineers, and other related fields. European Directives offer piecemeal solutions to the problem of a multidisciplinary service. This implies an important diversity both in the structure and the practice of health at work in different Member States, and in the relations between the company medical officer and other specialists, where these exist.

In the field of health at work risk management is aimed at the protection of workers' physical and mental well-being. The presence of risk (likelihood of damage) at the workplace follows from a presence of danger combined with risk factors. It follows that effective risk management in the field of health at work hinges on preventive control of dangers and risk factors. Given that the economy is shifting toward the service sector, multidisciplinary teams are required to take this sort of preventive action.

The goal is to make sure that no body lesion and/or material damage ensues from a potential risk. Prevention will be most effective if the four steps of the scientific approach are strictly applied: a) danger identification; b) risk and/or risk factor identification; c) analysis; and d) evaluation.

Analysis and evaluation can be problematic because of individual sensitivities and the interference of general risk factors and environmental factors. Furthermore the lack of knowledge about the short-term effects of certain working conditions also complicates the evaluation process. The role and importance of clinical, biological, and functional examinations and the level of prevention measures should be decided on the basis of all these factors. With the number of actors engaged in occupational medicine always on the rise, data collection related to the dangers (potential exposure) and risks (real worker exposure: individual monitoring) at the workplace must be structured comprehensively. This adds to the difficulty of compiling a database that focuses on exposure.

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[136] Convention 161 concerning health services at work of 7 June 1985

[137] Recommendation 171 concerning health services at work of 7 June 1985

5.4 DIVISION / CHARACTERISATION

5.4.1 DIVISION

In the job market workers must be classified before they can be characterised. The characteristics and the context of work define the workers' environment, and might therefore indicate risk exposure related to a specific job.

This aspect is very important. Indeed data analysis in the context of health at work requires knowledge of working conditions for three reasons:

a) to compare the risks in different jobs;

b) to elaborate specific prevention policies for one or several sectors;

c) to monitor occupational illnesses on the basis of sector risks.

In the HIEMS project (Health Information Exchange Monitoring System), which enables the aggregation and the exchange data at the European level, data is classified on a regional basis (NUTS).

The aggregation of data on a regional basis can be difficult in terms of the division of risk. The European word list is called NUTS (Nomenclature of Territorial Units for Statistics). Nonetheless for a large number of indicators the New-Cronos database (see hereafter) also features a NUTS regional basis of level 3, for instance for socio-economic data. The pilot study SEMP (occupational illnesses, see hereafter) also uses a NUTS key to describe the country at hand. One should also note that in Italy for example databases for occupational illnesses are sometimes compiled on a territorial basis[138].

However our study focuses on the feasibility of a comparative European database in order to gauge the status of health in general. Therefore industrial division is only recommended insofar as it can be a useful indicator of the status of health.

5.4.2 CHARACTERISATION OF WORKERS

5.4.2.1 The anthropometrics characteristics that are generally used are:

Age

Gender

Weight, Height, the BMI

Invalidity (or depending on State nomenclature: disability)

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[138] Instituto superiore per la prevenzione e la sicurezza del lavoro. Sistema informativo prevenzionale. Rapporto

5.4.2.2 Classifications by sector, work post, and job type

In Europe several classifications are used to characterise job sectors. The following are among the most common (according to surveys performed by EuroStat, the Foundation for the Improvement of Living and Work Conditions, and the Agency for Safety and Health at Work):

a) by work activity

NACE/CLIO: general word list regrouping all economic activity that takes place in the European Community (4 digits).

CITAE/ISIC: ILO international classification: Classification, by industry, of all branches of economic activity. (CITAE classification is a simplified version of the NACE classification, in 2 digits).

b) by occupation

CITP/ISCO 88 (ILO): international classification according to types of occupation (3 digits).

For example:

Group 3: Intermediate occupations: (large group)

Intermediate occupations in the fields of technical science and physics

3.1.1. Technicians in the fields of technical science and physics

3.1.2. System operators

c) by occupational status

CISP[139]/ICSE: ILO International classification according to the occupational situation. Occupational status: classification used by the Foundation for the Improvement of Living and Work Conditions and the Agency for Safety and Health at Work in their respective surveys.

For example:

Group 1: salaried employees
Group 2: employers
Group 3: self-employed workers
Group 4: members of producer cooperatives
Group 5: family workers collaborating within a family business
Group 6: workers unclassifiable according to their occupational situation

Both these classifications were designed to sort workers according to their occupational situation.

d) by geographical region

NUTS: Nomenclature of Territorial Units for Statistics, launched by Eurostat and widely used in Community legislation since 1988, NUTS is a hierarchical classification system, which contains a total of 5 levels. NUTS brings together comparable units (territories) according to various distributions.

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[139] Caution: not to be confused with CISP: Classification Inrernationale en Soins Primaires (ICPC)

5.4.3 OTHER CHARACTERISATIONS USED IN THE FIELD OF WORK

5.4.3.1 Lesions

The international classification of professional lesions (ILO), the methodology of which features several stages: company (size, economic activity); organisation (work post, process, type of exposure); worker characterisation (occupation, age, sew, nationality); events sequence (activity associated with the exposure, departure from this activity, action leading to the lesion); lesion (type, body area, days without work).

This classification is very broad in the case of accidents, and it is also found in the SEAT system (EUROSTAT: database for accidents at work, within the limits of data aggregation between Member States).

Morbid exposure was targeted by a Eurostat classification for the SEMP pilot study (occupational illnesses; Eurostat pilot study)[140].

5.4.3.2 Classification of occupational illnesses

In 1990 the European Commission made a Recommendation regarding the adoption of a European list of occupational illnesses[141]. This Recommendation applies to the occupational illnesses, which are targeted by preventive measures, and for which workers may receive compensation. However each Member State has devised its own compensation scheme and its own list of occupational illnesses. These lists are far from compatible (see Eurogip study[142]).

5.4.3.3 International classification of diseases

CIM/ICD-10: the international classification of diseases and related health problems.

This is the most widespread and widely used international classification throughout the world in statistical databases. It is used for instance in the SEMP project (mentioned earlier).

5.4.3.4 International classification of functioning, disability, and health (ICIDH)

Functioning and disabilities associated with health problems are classified in the ICIDH classification (a WHO classification). This classification is based on concepts that were borrowed from occupational medicine, namely individual performance and capacity. It contains four main parts: the “organism” part and the “activities and participation” part (on the the functioning and disabilities axis), as well as the “environmental factors” part and the

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[140] Eurostat work document, Population and social conditions 3/2000/E/n°18 – Classification of agents that cause occupational illnesses – SEMP. http://www.unece.org/stats/documents/ces/sem.41/18.s.f.pdf

[141] Commission Recommendation n° 90/326/EEC of 22 May 1990 concerning the adoption of a European list of occupational illnesses. (Official Journal of the European Community, n° L 160, 26 June 1990, pp. 39-48)

[142] Eurogip report. Occupational illnesses in Europe. Comparative Study in 13 countries. September 2000. http://www.eurogip.fr

"personal factors" (on the contextual factors axis). This classification is very recent (2001), and its application should be monitored closely. However this interactive classification clearly aims to pinpoint the health status of a given individual along several axes and in relation to several parts. The qualitative aspect of indicators like performance and capacity further helps to evaluate the possible deficit in the classification. This procedure could be useful in the field of health at work but also in the ECHI study.

5.4.3.5 Financial classification

The OECD developed a considerable amount of indicators and classifications[143]: the new ICHA (International Classification for Health Account) classifications, which complete the SHA (System of Health Accounts) classifications. Three classifications appear to be important: the functional classification of the type of healthcare (ICHA-HC). Here level HC.6 is interesting to us: prevention and public health services. It contains six subcategories (3-digit system), including HC.3 to 5, which are particularly interesting: HC.6.3: Prevention of communicable diseases; HC.6.4: Prevention of non-communicable diseases; HC.6.5: Occupational healthcare (prevention, first aid…). The health function HC.R.4: Food, hygiene and drinking water control as well as HC.R.6: Environmental health, might also be of interest in the area of work. Then comes the classification for providers of healthcare goods and services (ICHA-HP) and the classification for sources of healthcare funding (ICHA-HF). These last two classifications don't really intervene in health at work. Indeed they deal with the financial aspects of healthcare rather than with the issues of prevention and insurance against accidents and occupational illnesses.

5.5 INDICATORS

Since indicators are only synthesized pieces of information, they are only valuable[144] when applied to a given situation or used for comparison across lines of time and space.

An indicator offers mainly a quantitative description of a given phenomenon (disease frequency, risk exposure…), although in some cases the description may be qualitative. Its goal is to measure the level or the variation in the health of individuals and groups. Indicators usually represent only one category of data, and they are based on: i) concepts that deal plainly with the existence of the individual: mortality, life expectancy, potential amount of years lost…; ii) concepts that refer to a single pathology or a number of pathologies: morbidity, impact, frequency…; iii) notions of temporary and permanent disability: scales of motor and sensitive capacities, aptitude scales, scales related to individual daily activities or social activities… iv) notions of psychological well-being; v) notions of social well-being and integration; vi) notions of quality of life; vii) measures of pain; viii) combinations of these elements.

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[143] System of health accounts for international data collection. OECD Health Policy Unit. ICHA classifications

[144] A valid indicator must be simple (in terms of the user's understanding, handling…) and relevant (aptitude to describe the expected phenomenon or objective).

5.5.1 ECHI PROJECT (EUROPEAN COMMUNITY HEALTH INDICATORS)

ECHI offers a classification of useful indicators for the present study of health at work. These classifications should be checked against the more useful databases that exist in the field of health at work.

In their study “Definition of a series of health indicators in the European Community” Kramers et al. defined indicators with three objectives in mind: the monitoring of trends in every country of the European Union, the evaluation of European policy, and the possibility of establishing international comparisons.

The indicators defined according to these criterion should: i) be intelligible and coherent; ii) take into account the work already accomplished in this area by the WHO Europe, the OECD, and the services of Eurostat and the Commission to prevent overlap and to promote international co-operation; and iii) cover the sectors of public health that Member States would like to control and satisfy the needs of the Community.

Four broad classes were defined : demographic and socio-economic situation (population, socio-economic factors); health status, health determining factors, and health systems.

The following indicators make up the “health determining factors” axis: physical exposure at the workplace, mental exposure at the workplace (complaints), accidents and occupational illnesses. These indicators should be marked up against the databases that appear hereafter. We will then discuss which indicators are coherent in the area of health at work.

5.6 DATA / DATABASES

5.6.1 ROUTINE DATA

Routine data in the field of health at work includes data that is gathered from an ordinary contact between a worker and the competent healthcare services. These contacts, as was mentioned above, are subject to regulations. The Commission finds that data collected during an investigation also qualifies as routine data. However in this report, routine data should be read as exposure and morbidity data that is systematically collected through preventive medicine (occupational medicine) and through insurance for accidents at work and occupational disease as well as mortality data. Investigation data is not included in this report.

Bearing this in mind, one encounters in the context of health at work two types of routine data: those gathered routinely (anthropological, related to a particular exposure, and regulated) and those related to isolated events (morbidity, traumas, occupational illnesses, and mortality).

A large amount of routine data is available locally but cannot be used at the regional, national, and of course international levels because of harmonization problems. The attempts to approximate data at the European level cast light on some of the important difficulties encountered in the aggregation of data nationally. Under present legislation and current practice it’s even hard to compile relevant data locally (at the level of company healthcare services).

The European Foundation for the Improvement of Living and Work Conditions (Dublin) performed a survey of databases in different member countries called the HASTE[145] survey. 159 Member State databases are listed, and their description shows how ill-assorted they are. For instance 9 databases are listed for Portugal: (information regarding accidents at work, information regarding occupational illnesses, information regarding the structure of the labour force, quarterly survey of employment, social evaluation, surveys by sector, safety and health at work in the food and soft drink industries, survey on the management of work hours, survey on the social conditions of work, anthropometrics of workers in Lisbon). For Germany 6 databases were listed: (micro-census, integrated information system regarding dangerous products (GESTIS), the database of the Technical Control Committee for the Rheinland, the database for fatal occupational accidents, qualification and work control, statistics on occupational illnesses and accidents at work). As this review shows, the data on accidents at work and occupational illnesses notwithstanding, <u>none of these systems can provide a benchmark at the international level</u>. A routine morbidity database cannot be compiled with the data that's already out there. The databases are too different and their focus is often incompatible with the goals of this study.

Fragmented routine data on pathological observations is sometimes published for individual sectors, but the methods used tend to vary. Thus the data is ill-sorted for comparison beyond a given industrial sector.

Presently the creation of a database for routine data is only possible through the collection of partial data in a survey-type format. The European Foundation for the Improvement of Living and Work Conditions (Dublin) and the Agency for Safety and Health at Work (Bilbao) have used this method successfully.

In the field of health at work, some European databases compile European data regarding precise events. These databases are usually encountered in the insurance sector (both public and private at large) and in social security at large. Mortality is a good example. Accidents at work are compiled at the European level (SEAT-Eurostat, see hereafter) despite obvious disparities between countries. Occupational illnesses are targeted by a Eurostat pilot study (see SEMP hereafter). In this area national regulations vary even more than in the area of accidents at work.

5.6.2 EXISTING DATABASES

5.6.2.1 *The European Commission*

<u>SEAT/ESAW</u>: European statistics regarding accidents at work: Eurostat database for all accidents at work resulting in more than 3 days off work for the worker. Its objective is to supply data regarding groups and sectors that present a high risk and ultimately, indicators on causes and costs of accidents at work.

<u>SEMP/EODS</u>: European statistics on occupational illnesses: database for all occupational illnesses that entail compensation in the countries of the European Union. Eurostat collects data on occupational illnesses that entail compensation with the help of the national

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[145] European Health and Safety Database (HASTE) – Summaries of descriptions of systems for monitoring health and safety at work. European Foundation for the Improvement of Living and Working Conditions. Dublin. SBN 92-826-8856-9. 1995

institutions[146] that handle compensation procedures. The data is analysed on the basis of several variables and indicators: country of appearance, age, gender, activity at the time of exposure, economic activity of the employer at the time of exposure, number of reference on the European list of occupational illnesses, diagnosis (CIM 10, 4 digits), seriousness of disease (temporary or permanent disability), exposure (on the basis of a European word list), the year a disease was first recognised, the seriousness of disease when first recognised. Upon collecting the data case by case (case by case pilot study), problems began to creep up. For instance in Sweden the concept of occupational disease receives no wording because compensation exists for all diseases leading to worker disability.

NEW CRONOS: New Cronos is a macroeconomic and social database designed by Eurostat containing over 160 million data inputs. It's probably the database that comes closest to fulfilling the needs of the present study. However data is gathered with surveys. The labour force survey focuses on all Member countries with the exception of Belgium, France, and Austria.

With regards to health at work, we should focus on the indicators that interest us in this method, namely the identification of the sector of employment, job characteristics (normal, abnormal), duration, data for different age groups, gender and marital status, anthropometric data, and morbidity data (general health, occupational health), as well as mortality.

Two modules should retain our attention: "The labour force" and "The health domain[147]". The following issues are related to the field of health at work (see complete list in Appendix X):

Working population; unemployment; education; employment; inactivity; foreign population; atypical work; work duration; safety and health at work; accidents at work; occupational illnesses; (number of occupational illnesses diagnosed per group according to age; number of occupational illnesses diagnosed per group according to gender; number of occupational illnesses per disease and according to sector of economic activity); public health; (cause of death;…); state of health; ((anthropometric features): height and weight according to gender and age; disability); morbidity; (AIDS – cancer – a few communicable diseases)).

5.6.2.2 ILO: International Labour Organisation

LABORSTA (ILO) : database for labour statistics, particularly regarding the working population since 1945, employment, unemployment, duration of work, wages, labour costs, consumer prices, labour conflicts, strikes and lockout (since 1969). This database can be consulted online courtesy of the International Computing Centre in Geneva.

LABSSM: database that compiles methodological descriptions and data sources collected by the BIT: for example, volume 4 (Employment, unemployment, wages, and work duration (archive documents and assimilated sources). 1989.) and volume 6 (Surveys on household revenue and expenses. 1994).

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[146] in the 15 Member States

[147] Commission Regulation(EC) n° 1571/98 of 20.07.98 on the terms of Council Regulation (EC) n° 577/98 related to the organisation of a sample survey of the labour force in the Community. OJ L 205 (22.07.98), pp. 40-65

LABPROJ: numerical database containing estimations and forecasts regarding the working population according to gender and age category for large sectors of activity. Data is collected in surveys that cover a period of 60 years between 1950 and 2010.

LABCOMP: contains data that can be compared across borders since 1981 regarding total working population and total civilian population, total employment by age category and industry as well as employment and unemployment by age category in approximately 30 countries. Data is gathered from annual mean estimations.

LABISCO: database for the description and denomination of coded occupations following 1968 publications of the "International Standard Classification of Occupations" (ISCO-88) published by the BIT (1988 edition). The ISCO-88 classification is also available on disk.

SEGERGAT: numerical database for employment in terms of detailed occupational groups and gender. Data is obtained from population census labour surveys for the years around 1970, 1980, and 1990. The database was created to measure and analyse labour market segmentation across gender lines everywhere in the world; it covers approximately 40 countries.

5.6.2.3 The European Foundation for the Improvement of Living and Work Conditions

HASTE (the European health and safety database): this project was put together by the Foundation's work group and provides an overview of the database situation in various European countries. A total of 152 databases were listed and the differences from one to another were emphasized.

European survey on working conditions: the Foundation conducted three surveys on working conditions in Europe. In 1991 they covered the 12 Member States of the Community, and in 1996 and 2000 they covered the 15 Member States of today.

5.6.2.4 The European Agency for Safety and Health at Work

Survey of safety and health at work in the Member States: the Agency conducted a pilot study on safety and health at work (SST) in all Member States of the EU. It provided the present overview of safety and health at work in the European Union.

The methodological framework used by the national focal points for health at work was surmised from the instruction manual for collecting data. This manual was put together by the Agency in collaboration with the Foundation for the Improvement of Living and Working Conditions and Eurostat.

Data was gathered from existing data at European and national levels. Furthermore Member States received personalised appendixes including relevant European data from the Foundation for the Improvement of Living and Working Conditions (second survey on working conditions) and Eurostat (European statistics on accidents at work).

The selected classifications are: gender, age, sector (level 2 digits), size of the company, occupation type (level 2 digits), occupational status, duration of exposure. The selected indicators are: physical exposure (noise, vibrations, high and low temperatures); posture (carrying and dragging heavy loads, repetitive movements, inadequate posture); chemical exposure (handling, carcinogens, neurotoxins, human reproductions); biological factors (infectious micro-organisms and non-infectious micro-organisms in the case of repeated exposure), psychosocial (work speed, social requirements, work rhythm, violence at work, harassment, monotony).

This study shows the lack of available data and the difficulty of comparing data from various sources in Europe.

5.7 RELATIONS WITH THE FIELDS OF PRIMARY AND SECONDARY HEALTH

The field of health at work falls under the ‘preventive health’ label. At the moment there has been no attempt to standardise the various indicators and classifications used locally by company healthcare services. Hence under present circumstances, the aggregation of prevention and exposure data is a perilous task. Local services in the field of health at work lag behind other fields such as primary and secondary health. Only Finland has some experience of preliminary research with respect to finding common indicators and classifications. One might already ask why medical data from the field of occupational medicine should be relevant when data is available in the primary health sector (for example on indicators such as weight, blood pressure, tobacco addiction…). Regarding compensation, one can be more optimistic. For instance the two main surveys that were conducted are global cohort studies regarding compensation (accidents at work and occupational illnesses) for which insurance data (both private and public) exists in a more or less complete form. However difficulties still arise due to the disparities in compensation between Member States. Broadly speaking, it’s clear that this field covers social security. In this respect, the fields of primary and secondary health are also concerned. Hence the therapeutic sector in the field of health at work should be searched for morbidity data. Such data can also be found in the field of occupational medicine when workers take part in certain activities and in the work insurance sector (accidents at work and occupational illnesses). However this data can only be generated by the therapeutic sector can when the worker ceases to be active (after retirement for instance), or by occupational health insurance (when the disease breaks out late).

5.8 FEASIBILITY OF THE DATA COLLECTION

5.8.1 EXAMPLES OF EXISTING RISK FACTORS

5.8.1.1 Vinyl Chloride: toxic exposure, effects on health

Introduction

Plastic industries and in particular PVC industries have to manage situations of dangerous exposure (danger), which have always been part of their history. Important measures have already been decided in the European headquarters of multinational companies to improve the safety of workers (limitation of risk). Approximately 95% of vinyl chloride production is used in PVC, ¼ of which is made in Europe. This sector employs 500.000 European workers in 21.000 companies, including 8 important multinationals. These companies are the primary consumers of chlorine (many PVC producers actually run the entire production chain in which PVC is the final link). Vinyl Chloride is one of the most toxic substances used in the sector. The toxicity of this substance was recognised in 1965, and in the beginning of the 1970s, the risk of cancer was established (liver hemangiosarcomas). Since those years important measures were implemented regarding worker exposure in order to reduce the risks of a morbid effect. These measures were effective judging by the sharp fall in hemangiosarcomas rates.

Today we must ask whether or not other carcinogen or non-carcinogen pathologies can result from the exposure to dust from chloride vinyl, to the PVC polymer, or to other substances used in the process of production. For instance the CIRC survey for Europe, (Simonato, 1991, survey of the effects of historic exposures to vinyl chloride before 1974) shows an SMR rate of 286 for liver cancers including hemangiosarcomas, and an SMR rate of 107 for brain tumours. Yet what are health risks like under present circumstances of low exposure? Epidemiologists want to sample large groups since the risk is considerably reduced. This group will feature active workers and retired workers if the study focuses on morbidity. This kind of database should encompass all concerned industries globally so that the presence or absence of a risk can be highlighted in a given sector. The method should include data collected from witnesses in order for example to avoid the “healthy worker effect” in which small effects result in major problems of analysis. Only a large sample of data will allow us to answer these questions. Many will shy away from the sheer complexity of this type of study and opt instead for a mortality survey.

European Regulation

The specific Directive concerning vinyl chloride dates back to 1978. It was the first of its kind. It was adopted by the entirety of European countries belonging to the Community. The occupational exposure limit (OEL) was set at 7 ppm in the air.

The fact that the Directive is fairly old makes the chosen example all the more valuable since it is hoped that the surveys and observations carried out over time (for instance the large CIRC survey encompassed practically all concerned producers and workers) would to a certain extent allow the standardisation of data collection.

Indicators

Regarding the problem of exposure to chloride vinyl and its by-products or to products used in production, several possibilities co-exist:

First of all systematic and automatic monitoring of the surrounding atmosphere is usually undertaken and the head of a production unit is aware of levels of exposure on the premises. Workers' health is up-dated frequently, usually by means of x-rays and spirometry. The point of these examinations is to identify and track any signs premature lung damage caused by the inhalation of dust. Finally the mortality register should account for the appearance of rare and specific cancers such as hemangiosarcomas or the possible increase in other less specific and more common forms of cancer.

Reliability of the morbidity compendium

A comparable compendium should include not only all the factory data from a single group (multinational) but also a cross-examination of data between factories of different groups (intra-regional and international comparative). Finally we will need the routine compendium including a large proportion of exposed workers in order to generate statistical power in the findings so that rare effects or effects that have only a slight impact on certain groups can be marked up against the general population.

Generic anthropometrics data within a company is available locally. These are called semi-professional data: gender, age, age upon hiring, type of industry – examine the precision digit of the information-, the type of occupation – examine the precision of the digit used-, the type of work. Social data are also available locally, for example socio-economic status and family status.

Collecting data that concerns individual exposure specifically seems more difficult: age of first exposure, scale of the exposure in semi-quantitative terms, duration of exposure. The collection of such data seems unfeasible at this stage.

The data gathered by way of monitoring the atmosphere in a factory can be compiled. In actuality this type of monitoring obeys strict government norms that stem from European Recommendations and/or national regulations. It would be extremely complicated to process this data in an anonymous compendium on individual exposure levels.

However toxicological examinations exist for individual exposure (urine or blood samples) in many cases of exposure to chemical agents. Results are not easily usable (for lack of consistent measures) or comparable (several examination types exist for one toxic agent, let alone the problem of validating the results). Vinyl chloride cannot be detected this way. However related exposures can be tracked such as for instance, exposure to mercury used in the electrolysis process involved in making chlorine.

Radiological data could be collected routinely on the basis of the IHO classification for pneumoconiosis. However the variability in the appreciation of different examiners requires a complex validation of each reading by three experimented judges in order for the data to be comparable on the international level. This is not feasible in a routine operation.

Regarding the data from the functional respiratory examination (spirometry), variability in the results is such that one cannot hope to edit a reliable compendium in this case. For example, the mean decrease in FVC (forced vital capacity) is roughly equal to 30 ml/year for non-smokers and up to 45ml/year for smokers. The loss resulting from average dust inhalation would reach the same order of magnitude. Given the order of magnitude of these values and the great variability in the measured results (the measuring technician should also be validated), it would be unrealistic to collect data routinely on this basis.

This catalogue sheds some light on the problem of conducting international surveys in this field (PVC) on the basis of anything but databases for mortality: these alone are directly available.

Recommendations

Regarding the collection of routine data on workers in the PVC plastic industry, it appears quite clearly that only the compendium of the causes of mortality coupled with the data from the compendium of occupational anthropometrics would allow us to distinguish useful pathological trends.

However it seems unreasonable at present to use routinely collected morbidity data in the context of manufacturing industries. This does not mean that it can’t be used in the long run, but it might be more appropriate and more effective as of now to collect such data through surveys and not through a routine collection process.

Finally the more precise the digits used in the classification of labour and industry, the more relevant the database. In geographical terms, regarding industrial health, a compendium drawn up on a regional basis is less relevant than one drawn up within a given sector.

5.8.2 NOISE

Introduction

According to the IHO, noise can cause hearing impairment, hinder communication, disrupt sleep, lead to cardiovascular and psycho-physiological problems, undermine performance at work, and trigger hostile reactions and mood swings.

It was discovered just recently that noise was not only a nuisance but also a health hazard, and currently exposure to noise is acknowledged as an important problem of public health.

Noise at work can have a negative impact on worker performance, for example on reading, concentration, problem solving and memory. Shortcomings in these areas can cause accidents, not to mention irreversible and disabling hearing impairment.

Noise sources are primarily located in machinery and industrial processes. They include rotors, valves, liquid flows, percussive work, electric machines, internal combustion engines, inflatable equipment, drilling and crushing equipment, explosives, pumps, and compressors… Noise is an occupational hazard that can be found in many workplaces.

Regulation / Ratification

On May 12th 1986 and on the basis of article 100, the Council adopted the Directive 86/188EEC, which aims to improve the protection of workers from the risks related to exposure to noise at work.

All Member States ratified the Directive (see Appendix X), and the limitations that were established were incorporated into the national legislation of each Member State.

A new Directive proposal seeks to modify exposure limits and values. It should trigger some preventive measures to various degrees.

Indicators

Individual daily exposure level (dosi-sonometry)

Audiometry

Reliability

Integrative sonometers are used to measure continuous acoustic pressure (equivalent to impulse noise), which determine personal exposure levels according to precise European norms. If they have been tuned recently and meticulously in a laboratory, and if the microphone is well adjusted, the results show – short of a few exceptions – if a given exposure level has been reached. If these instruments are used well, they are reliable, and the data they provide is comparable.

The reliability of audiometric measures is guaranteed in part by present norms regarding these instruments and the disposition of microphones. However one must bear in mind that the capabilities of system operators, the proper handling of these devices, and fine-tuning all come into play as well. Furthermore the conditions under which the measures are taken matter (in a soundproof booth or simply with ear phones and no other protection).

Feasibility of a comparable compendium

Exposure data is available locally. The data from initial and routine examinations appears in workers' individual medical records. It would be useful only if one could compare it over time to see how it changes according to the duration and intensity of exposure or in the case of a grouped study of occupational posts in a firm.

Which indicators would be useful? If one considers only lesions caused by noise, the hearing loss caused by noise occurs specifically at and around a frequency of 4000 Hz. If one refers to the ensuing disability, the social frequencies (speech intelligibility) are located between 500 and 3500 Hz. The method for assessing disabilities varies from one country to another. But only this data is useful in terms of evaluating health standards.

Furthermore comparing data can be complicated since initial and routine examinations are regulated at the national level, so they occur periodically at different times in different countries. Also – and this was already mentioned – company healthcare services function differently in different Member States.

A final problem concerns privacy rights and the confidentiality of private records. Inevitably those who try to collect and transfer data will be confronted with this problem.

Recommendations

Concerning noise, data that is routinely collected in the medical files of workers can be reliable if:

a) It can be proved that noise is the cause of hearing disorders, and that it plays a role in other health ailments both physical and psychological.

b) Data collection can contribute to the verification and application of norms. Data aggregation of this kind should make it possible to compare and transfer quality data without violating privacy and confidentiality laws.

Noise reduction at the source is the optimal preventive measure. Monitoring and limiting sound emissions must also be encouraged, perhaps by adapting to new technologies. If controlling the source is difficult, then efforts should focus on training, information, and awareness programmes for employers, workers, and their representatives. Technicians in training centres can share their knowledge.

5.9 DISCUSSION: SURVEY OF ECHI INDICATORS AND THEIR FEASIBILITY IN HEALTH AT WORK: RECOMMENDATIONS

The ICIDH (International Classification of Functioning Disability and Health) indicators of the WHO should merge with the various classes of ECHI indicators so that the human dimension of work can be fully taken into account in ECHI determining factors.

Here we have selected only the ECHI indicators that are relevant in the field of health at work.

Class 1: Demographic and socio-economic situation

This ECHI class seems irrelevant with regards to routine indicators in occupational medicine.

Certain items in other ECHI classes could be relevant in the area of health at work in terms of defining features of health.

Class 2: Health status in terms of causes of mortality. One must add the industrial sector (NACE), the type of work (ISCO) and the type of status (ICSE) to the indicators that allow the epidemiological analysis of causes of mortality.

Class 3: Health determining factors

The Body Mass Index (BMI) and blood pressure can be usefully collected in occupational medicine. However one might ask why this would be more effective than collecting data in a survey. Indeed the routine collection of data requires more effort than a survey.

Furthermore what advantage is there in collecting data in the context of health at work rather than in the primary health sector?

Exposure to ionising radiation

An individual dosimetry is performed on the basis of Euratom Directives for all workers who suffer occupational exposure throughout the countries of the Community. All the data on this is available at the national level. However this data is partial on two counts. First of all it does not cover the entire population (only those who suffer occupational exposure). Secondly this data does not cover natural exposure including the important domestic exposure to radon and medical exposures.

Physical Exposure

We recommend that at the national level databases be created on the basis of an ISCO-type international classification regarding the types of exposure that workers suffer from. Member States should be able to supply important determining factors regarding ECHI indicators and health status.

Furthermore the interpretation of ECHI indicators with respect to “physical exposure” is ambiguous. Therefore we recommend subdividing this category into “physical exposure”, “biological exposure”, and “chemical exposure”.

Regarding the violence indicator: we recommend defining indicators concerning the different kinds of “violence” at work: sexual harassment, moral harassment, physical violence.

Class 4: Health system

The “company medical officer” indicator should be maintained. Perhaps one should distinguish between qualified medical officers according to Community standards and other medical officers.

However the disparity between countries regarding company healthcare service is such that data aggregation in a European compendium on “healthcare services at work” will have little comparative value.

5.10 CONCLUSION AND PROPOSALS:

Many problems remain unsolved in the area of data aggregation with a view to collecting reliable data in the field of health at work (preventive medicine) and even partially validating the ECHI project.

Data collections regarding both exposure and health/morbidity must be standardised within a country.

Anthropometrics data is easy enough to find, but it should be defined in legislative terms for this is the only way to gather data routinely and massively on an international scale.

Data on individual exposure is widespread, and some of it is used to fulfil the objectives of many European Directives. However in the absence of truly binding legal force, aggregation

is hopeless with the exception of data on exposure to ionising radiations, a field in which precise Community instruments (dosimetry) have existed for a long time. The next stage involves using this model for carcinogen agents.

Regarding health, national healthcare services across Europe are ill-sorted and show few signs of complying with data aggregation efforts. Nevertheless it’s technically possible to obtain valid and objective screening data, for instance in screening for noise-related impairments using audiometric techniques.

On the hand morbidity data from insurance systems (public or private) can be aggregated regarding accidents at work (achieved by Eurostat) and occupational illnesses (Eurostat pilot study underway).

General company data by sector should undergo a particular ECHI classification on the basis of international and European classifications (NACE, ISCO, ISIC). This data should be precise (digit level) so that it can be analysed effectively. This data and mortality data are available at the national level. The aggregation of both these dimensions should produce epidemiological data of the highest order. This is our most pressing recommendation.

Some databases on morbidity and exposure use specific codes for the field of health at work (New Cronos for example), but data here is based on surveys rather than on routine examinations or on the entirety of events considered (accidents at work and occupational illnesses). However, in terms of methodology, they are partially applicable in the case of routine examinations. In any event, the projects of the Commission regarding survey data on health (projects n°2 and n°21 (see above)) should also include health at work.

Finally it should be assessed whether or not there is any advantage in having routinely collected data on health at work, seeing as data is available in surveys and more importantly, data can be retrieved in the primary and secondary health sectors.

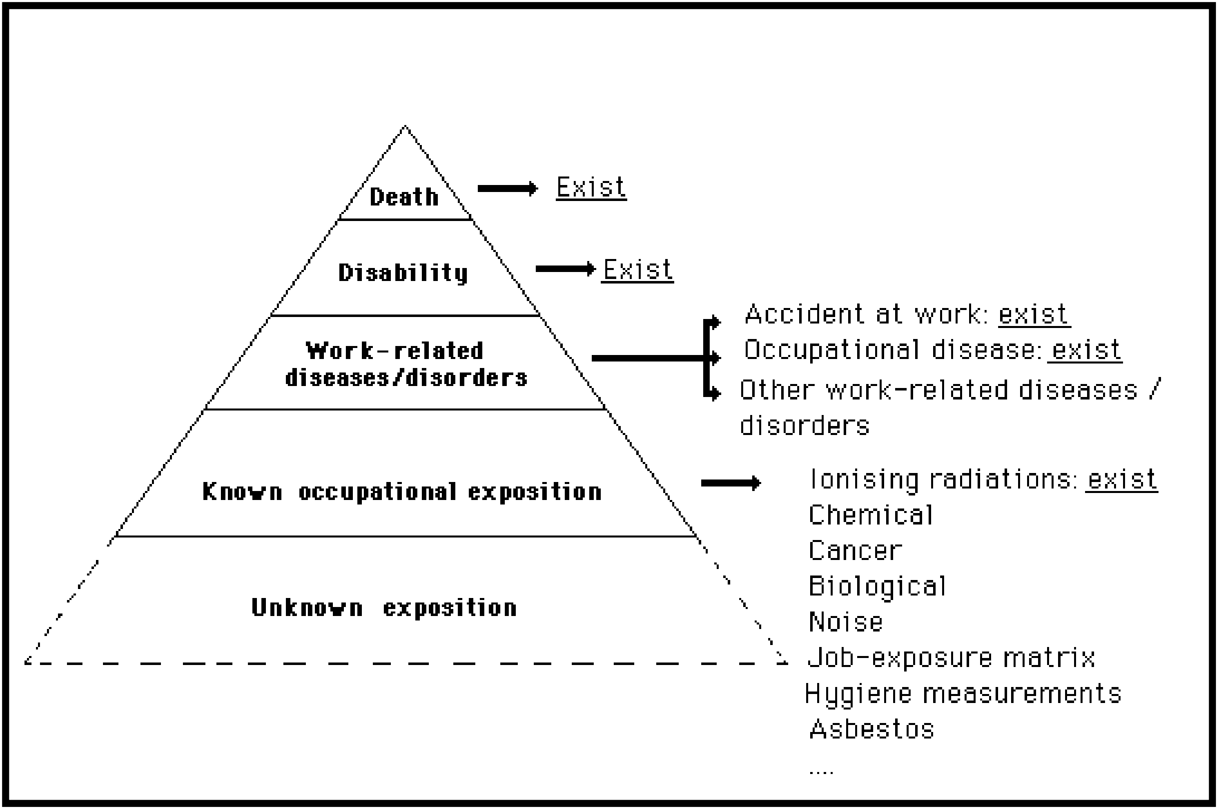

Figure 5.1. Medical data in the sector of health at work

In short the European institutions must adopt legislative measures that will enable compatible data to be collected routinely in the field of health at work at local, national, and European levels.

here is available data on exposure at work. Some areas are targeted by regulations that are often embodied in European Directives. Insofar as this data is technical and objective, it can be aggregated at the national and international levels. Legislative measures should focus on technical aspects of data.

Useful indicators were suggested by the European Commission and classified (for example the type of work). A number of exposures – both physical and mental – are dealt with in minimum-type directives, which are nevertheless converging pieces of legislation. Hence possibilities do exist.

Finally our most important recommendation calls for the aggregation of data on worker characterisation in the firm (available at the national level) and data on causes of mortality (also available). This should be feasible at the ECHI level.

6 CONCLUSIONS AND RECOMMENDATIONS

6.1 PRIMARY HEALTH CARE

Though the numerous contacts established for this study on general medicine data gathering in Europe, it became clear that the experiences in this domain vary greatly. The general consensus during the meetings was that no data collection system can serve yet as a common gathering base, nor can it be used to elaborate European health indicators. There is undeniably a consensus on the importance of the information that could be available from and for general practice throughout Europe. No one doubts that the general practitioner's future lies in the management of health data, nor that he/she will one day be able to provide gathered data.

This data can have an impact on health planning if it is correctly processed. However, for most of the GP's providing data, this data must first and foremost be useful to them, and the local loop is the fundamental loop that will subsequently ensure the coherence of the data integrated on a higher level.

One has observed the numerous difficulties in merging these data between the different European databases. New research programs and new objectives must be explored if one truly wants to obtain a European health information system and health indicators based on routine data collection.

With these goals in mind, we have five recommendations:

✓ First, taking the recent European Parliament recommendation (Sept. 2001)[148], on the need to develop "Open Source" programs into account, we recommend that the utmost attention be paid to the development of computer programs according an "Open Source" approach.

The aim of developing such programs is first and foremost to obtain a standardised information structure and a successive accumulation of experiences from the groups that use the current programs.

Indeed, the "Open Source" spirit is based not only on a reduction of economic cost, but also on a reduction of the required effort and energy. The "Open source" technique means sharing knowledge and gathering all of the existing systems in order to develop one that is both more efficient and competitive.

Some systems are already operational in this field and can be found on the OSHCA site, the Open Source Health Care Alliance, www.oshca.org, one will find the correspondences necessary to appreciate the importance of the domain.

✓ The second recommendation is to favour the management of individual data in computerised medical files as community health data. This implies the development of a multi-professional network centred on the patient and whose data must be gathered on a community level. The PRIMIS example, for example, only highlights general practitioners. Other primary health care actors are also involved, such as social workers, nurses, movement therapists, or workers in the filed mental health.

The possibility of having health information available through databases that would regroup the knowledge and experiences from the various levels would naturally provide a higher quality of data.

Furthermore, the GP being the main data collector, it is necessary on the European Community level, to reach a consensus on the definition of the profession and responsibilities of general practitioners, on their importance in matters of daily health data

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[148] Resolution of the 5th of September 2001, see http://www3.europarl.eu.int/

management, as well as their significant role in the protection of patient's personal medical information.

- ✓ Thirdly, we recommend promoting European development in the realm of terminologies and classifications. Particular attention should be turned to the work of the Amsterdam/Newcastle WONCA collaborative centre on transcoding and classifications.

  A multilingual European transcoded terminology would constitute a very valuable tool and be indispensable in the development of databases with transferable data.

  In addition, we know the significant data acquisition possibilities of new information technologies when applied to texts, and that the extensive experience, for example, of the GALEN group in this domain should not be ignored (http://www.galen.org/). Promoting the development of Natural Language Processing and ontologies such as GALEN is crucial, as is closing the gap between the designers of this type of approach and classification and taxonomists that endeavour to describe their reality.

- ✓ Fourthly, we recommend to follow with attention the works of CENTC251. This European normalisation organism has recently published a book of primary importance for data quality in general practice.. The development of a European pre-standard related to continuity of care (ENV 13940) constitutes a significant step towards the harmonisation in Europe of the concepts which allow the structuring of electronic medical files. (http://www.centc251.org/)

- ✓ Finally, the fifth recommendation is the result of the meeting of December 5th. We are extremely pleased that Euro-Med-Data's initiative relating to primary health care was perceived by many of the participants a channelling programme.

Data Quality in Primary Care
Prospective partners

- ♦ Finland: Stakes
- ♦ Italy: Health Search, Health Care Ministry & Regional Conference of Health Care
- ♦ UK: PRIMIS (University of Nottingham), NHSIA
- ♦ UK : DIN (Doctor's Independent Network)
- ♦ .....→ contact : Lindsay Groom Lindsay.Groom@nottingham.ac.uk

Figure 6.1. A new group to take over from Euro-Med-Data.

A new group came into being during the meeting. This group will take over the primary health care project that was initiated by EMD-PHC. The "Quality of Primary Health Care Data", proposed by Dr. Mike Bainbridge, Roberto Nardi, and Mikko Nennonen received unanimous support from the meeting's participants.

We can only urge the European authorities to firmly support this group's studies and to provide them with the means to ensure quality research in this field. This new group shall obviously draw on the works that were already presented and achieved throughout the "Primary Health Care" study, as well as on the present report.

6.2 SECONDARY HEALTH CARE

For this section of the project, we have attained most of the objectives.

Indeed, for most of the participating countries (with the exception of Liechtenstein), we were able to collect information on routinely collected hospital data. These data were compiled into recapitulative tables.

The second part of the project was focused on carrying out a feasibility test for the creation and exploitation of a European database. This test, carried out for 11 participating countries, brought very encouraging results that convey the possibility of a European database contingent on the implementation of certain procedures and the definition of certain terms or variables.

We drew the list of health indicators that will be able to be directly established from this database. Moreover, we formulated several proposals concerning the accessibility of this database.

Finally, the test's conclusions naturally lead to short-term, medium-term, and long-term proposals that should form the basis for further studies in the field secondary or hospital care, with the aim of determining health indicators destined for the community surveillance system.

6.2.1 SHORT TERM

✓ Coordinate the various projects relating to the same subject;

✓ Establish, for each Member State, a proposed convention for the transfer of data;

✓ Define the database and its fields;

✓ Ask the countries to complete the missing information;

✓ Establish automatic conversion programs for variable and for each country in order to obtain data in a single format;

✓ Ask certain countries to record the data that is currently missing and indicate the desired format;

✓ Specify the type of procedures that must be included in the database;

✓ Define the notions of "primary diagnosis" and "secondary diagnosis and complications";

✓ Establish a conversion table for diagnoses, pathology groups, and procedures;

✓ Carry out a "full scale" test in collaboration with the HIEMS services.

6.2.2 MEDIUM TERM

✓ include in the database variables which are not presently collected by most countries ; this implies a clear definition of these variables, and to ask to all countries to collect and transmit them from a certain point in time

✓ evaluate the content of the variables which are collected already, in terms of possibilities of coding and precision, and, if necessary, to modify this content in order to get more detailed information

✓ evaluate the procedures aiming at including data from new Member States (candidate countries)

6.2.3 LONG-TERM

In the long-term, the question of data relative to patients that are cared for both on the primary and secondary level. In that case the difficulty is the link to be established between the two levels, as well as the incompatibilities between the classifications used at thos two levels.

6.3 HEALTH AT WORK

The routine collection of data at work presents certain special features related to the actual context of health in the workplace, namely:

1. The existence of **a proper legislation**
2. The **division** of labour and, consequently, of health risks.
3. Medical practice at work has a **preventive** mission, sometimes a **therapeutic** power in the case of health disorders related to the specific exposure and to occupational diseases. It also plays a **rehabilitative** role in cases of accidents at work and occupational diseases;
4. On the European and national level, the organisations centred on the field of health at work are mainly **tripartite structures**: government representatives, employers, and workers.

During the first phase of the EMD study, the characteristics cited above were identified and their influence on the feasibility of a continuous collection of data was underlined.

The second phase focused on: a) the study of European directives relating to the health and security of workers; b) their sectoral application in Member States; and c) the feasibility of their application on the European level.

One could classify the routine data on health at work into two categories: those collected on a regular basis (anthropological, linked to specific exposure, and regulated)) and those linked to isolated events (morbidity, trauma, occupational diseases, or even mortality).

A great number of routine data are available at the local level, but it is currently impossible to use them on a regional, national, and a fortiori an international level given the harmonisation problems.

Except for data on accidents at work and occupational diseases, the examination of these routine databases demonstrates the impossibility of using these databases as comparable international reference databases in the elaboration of a European morbidity data bank. They are too different from each other and their objectives are usually incompatible with the aims of this study.

There are databases in the field of health at work whose aims are to gather European data concerning specific events. These databases stem from the insurance sector (public or private, in general terms), and more generally from social security. This is the case for mortality. The data on accidents at work are gathered at the European level (SEAT-Eurostat), despite certain disparities between countries. Occupational diseases are subject to a pilot study within the Eurostat framework (SEMP). This is a domain where the national regulations are even more divergent than for accidents at work.

Two examples emphasise the concrete difficulties related to the collection and use of routine data in the field of health at work: exposure to vinyl chloride monomer and exposure to noise. The quality and comparability of such data in an international comparison was analysed, leading to a number of specific recommendations. Such an exercise should be carried out, one problem at a time, before proposing relevant and valid indicators for a European health information system.

Finally, a careful analysis was performed on the various indicators for the sector proposed by the ECHI project (Kramers et al., 2001). They were extensively reviewed during the second meeting, on December 5th 2001. This did allow us to formulate recommendations in order to pursue the reflections on indicators of health at work.

6.3.1 SHORT TERM

- ✓ Complete the proposed list of ECHI indicators by extending the group of indicators related to determining factors in health while adding some indicators related to the "work" dimension; gather these indicators according to the activity sector or the employment status (NACE, ISCO, ICSE).
- ✓ Break up the "physical exposure" indicator into "physical exposure", "biological exposure", and "chemical exposure".
- ✓ Introduce indicators concerning violence at or around the workplace: sexual harassment, moral harassment, and physical violence.

6.3.2 MEDIUM TERM

Obviously, since we have demonstrated that the indicators proposed by the ECHI project are only partially workable within the field of health at work (preventive medicine), important and difficult steps must be taken before being able to gather relevant routine data.

Within the country, one will have to standardise data collection (concerning exposure, health/morbidity). The anthropometric data are simple to obtain and should be the subject of a more detailed instrumentation through legislative measures, which is the only way to obtain these" data in a routine, systematic, and international manner.

One will need to verify the real advantage of a routine data collection for health at work, first compared to the same data on health at work collected through surveys, and more importantly, to routinely collected data or survey data obtained in other sectors.

It is vital that a certain number of legislative tools that contribute to uniting European countries be implemented in order to render the routine data collected for occupational medicine compatible and comparable on the local, national, and European level. There are already data available relating to exposure at work. Among these data, some are subjected to regulations that often stem from "minimum" type European directives (article 138 of the EU Treaty), which are insufficiently restrictive to allow for a real convergence. The standardisation of data collections will greatly depend on these efforts of convergence.

6.3.3 EVEN LONGER TERM

Our most important recommendation concurs with the general objectives of the European health surveillance programme and is integrated in the framework proposed by the ECHI project. We strongly recommend the establishment of a statistical apparatus allowing one to compare data on the worker’s characterisation within the firm, on the one hand, (this is a tool that must be implemented in the short and medium-term, cf. supra), and the data on mortality (cause by cause) along with the data related to accidents at work and occupational diseases (already available) on the other hand.

Reference List

Please, find the list of the web sites visited during the project on the following address: http://www.ulb.ac.be/esp/emd/emd_links.html

1. Agence européenne pour la sécurité et la santé au travail. L'étude de la santé et de la sécurité au travail dans l'Union Européenne. Luxembourg: Office des Publications Officielles, Communautés européennes, 2001.
2. Angaran D-M. Measuring and monitoring health care. Top Hosp Pharm Manage 1990; 10(2):1-11.
3. Annual report 2000: Joint authority for the Hospital district of Helsinki and Uusimaa. Communications Group. 2001. Helsinki.
4. Aromaa A., Health Surveillance, Priorities for Public Health Action in the European Union, Weil O, McKee M, Brodin M, Oberlé D (eds), march 1999
5. Battail G. Théorie de l'information, application aux techniques de la communication. Masson, Paris, 1997
6. Baumann RP. Données médicales en Anatomie Pathologique - Évaluation d'un grand collectif. Revue médicale de la Suisse romande 1999; 119:805-824.
7. Boerma W, de Jong F, Mulder P. Health Care and General Practice across Europe. Utrecht: NIVEL, 1993.
8. Building up an administrative data base for population-based studies in a statutory health insurance environment: The case of KORA. Cooperative Health Research in the Region of Augsburg.: 2000.
9. Chen M-K. Aggregated physiological measures of individual and group health status. Int J Epidemiol 1975; 4(2):87-92.
10. Chen M-K, Bryant B-E. The measurement of health. A critical and selective overview. Int J Epidemiol 1975; 4(4):257-264.
11. Chen M-K. Classification of consequences of disease and health care planning and evaluation. Int J Epidemiol 1981; 10(1):5-7.
12. Cochrane A-L. The history of the measurement of ill health. Int J Epidemiol 1972; 1(2):89-92.
13. Collectif. Guide méthodologique de production des résumés hebdomadaires standardisés. Ministère de l'Emploi et de la Solidarité. 97/5 bis, 1-111. 1998. Paris. Bulletin Officiel.
14. Commission européenne. La réglementation des conditions de travail dans les Etats membres de l'Union européenné. Luxembourg: Office des Publications Officielles, Communautés européennes, 1999.
15. Commission européenne. Méthodologie de fixation des valeurs limites d'exposition professionnelle. Luxembourg: Office des Publications Officielles, Communautés européennes, 1999.
16. Commission européenne. Santé et sécurité au travail, Textes de référence. Luxembourg: Office des Publications Officielles, Communautés européennes, 1999.

17. Commission européenne. L'emploi en Europe 2000. Luxembourg: Office des Publications Officielles, Communautés européennes, 2000.
18. Commission européenne. La réglementation des conditions de travail dans les Etats membres de l'Union européenne. 2001.
19. Commission européenne. Missoc-info, Evolution de la protection sociale dans les Etats membres de l'UE et de l'Espace économique européen. Luxembourg: Office des Publications Officielles, Communautés européennes, 2001.
20. Côté RA, Rothwell DJ, Palotay JL, Beckett RS, and Brochu L, eds. The Systematised Nomenclature of Human and Veterinary Medicine: SNOMED International. College of American Pathologists, Northfield, 1993.
21. Culyer AJ. Health Indicators. An international study for the European Science Foundation. Oxford: Martin Robertson, 1983.
22. Data Security for Health Care I. Amsterdam: IOS Press, 1996.
23. Data Security for Health Care II. Amsterdam: IOS Press, 1996.
24. Data Security for Health Care III. Amsterdam: IOS Press, 1996.
25. De Brouwer Ch. La médecine dans l'entreprise. De Boeck Université, 1997.
26. Design and Implementation of Health Information Systems. Geneva: WHO, 2000.
27. Desmet M., Jamoulle M., Dujardin M., Roland M., de brouwer C. et Lagasse R. Situation européenne du recueil des données médicales de routine et de leur utilisation pour le monitorage de la santé: Euro-Med-Data: présentation des premiers résultats. Porto: 2000.
28. Desmet M., Dujardin M., Jamoulle M., Roland M., de brouwer C. et Lagasse R. European situation of routine medical date collection and its use in health monitoring. First results of the Euro-Med-Data study at the level of secondary health care. Paris: 2000.
29. Desmet M. Utilisation des données médico-administratives au sein de l'institution hospitalière. Ecole de Santé Publique de l'ULB. Bruxelles: 2000
30. Desmet M., Jamoulle M., Dujardin M., Roland M., de brouwer C. et Lagasse R. European situation of the medical data routinely collected and their using for the health monitoring. Melbourne: 2000.
31. Desmet M., Jamoulle M., Roland M., Hoyois P., de brouwer C. et Lagasse R. Situation européenne des données médicales de routine et de leur exploitation pour le monitorage de la santé: Euro-Med-Data: présentation des premiers résultats. Lyon: 2001.
32. Desmet M., Jamoulle M., Correa G., Hoyois P., de brouwer C., Roland M., et Lagasse R. European situation of the collection of routine medical data and their exploitation in health monitoring: Euro-Med-Data: presentation of preliminary results. Bruges: 2001.
33. Desmet M. European situation of routine medical data collectio and its use in health monitoring. Results of the Euro-Med-Data (EMD) study at the level of secondary health care. Brussels: 2001.
34. A Dictionary of Epidemiology. 4ème ed. Oxford: Oxford University Press, 2001.
35. ECHI project. Design for a set of European Community Health Indicators. National Institute of Public health and the Environment, editor. 4-93. 2001. The Netherlands.
36. Eurogip report. Occupational illnesses in Europe. Comparative Study in 13 countries. September 2000. http://www.eurogip.fr

37. European Commission. European statistiscs on accidents at work, methodology. Luxembourg: Office for Official Publications, European Communities, 2001.
38. European Foundation for the Improvement of Living Conditions. The European Health and Safety Database (HASTE). Dublin: Office for Official Publications, European Communities, 1995.
39. European Health and Safety Database (HASTE) – Summaries of descriptions of systems for monitoring health and safety at work. European Foundation for the Improvement of Living and Working Conditions. Dublin. SBN 92-826-8856-9. 1995
40. Eurostat. Regions: nomenclature of territorial units for statistics - NUTS. 1999. European Commission.
41. Evans J, Rogers C, Kaul S. The General Practice Morbidity Database Project Wales - a methodology for primary care data extraction. Med Inform (Lond) 1997; 22(2):191-202.
42. Feinleib M. Setting and monitoring health objectives for the nation. 23 ed. 1995.
43. Fetter R.B. et al. Case Mix definition by Diagnosis Related Groups. Medical Care, Vol XVIII, n°2, supplement: 1-51; February 1980
44. FynCom 1991-1999 Expectations, Results, Outlook. FynCom, Rugaardsvej 15,2 5000 Odense C, Denmark
45. Galletly D, Le Goff B. IDA EUPHIN Project: HIEMS User Manual. European Commission, editor. 1.0, 2-139. 1999.
46. Gissler M, Jarvelin M-R, Hemminki E. Comparison between research data and routinely collected register data for studying childhood health. Eur J Epidemiol 2000; 16(1):59-66.
47. Goldberg M, Dab W, Chaperon J, Fuhrer R, Gremy F. Indicateurs de santé et "sanométrie": les aspects conceptuels des recherches récentes sur la mesure de l’état de santé d'une population. Rev Epidémiol Santé Publique 1979; 27(1):51-68.
48. Goldberg M, Dab W, Chaperon J, Fuhrer R, Gremy F. Indicateurs de santé et "sanométrie": les aspects conceptuels des recherches récentes sur la mesure de l’état de santé d'une population. Seconde partie. Rev Epidémiol Santé Publique 1979; 27(2):133-152.
49. Les grandes bases de données épidémiologiques et financières des soins de santé en Belgique. Briefing 29, Annex. 2000. IBES.
50. Grimsmo A, Hagman E, Falkoe E, Matthiessen L, Njalsson T. Patients, diagnoses and processes in general practice in the Nordic countries. An attempt to make data from computerised medical records available for comparable statistics. Scand J Prim Health Care. 2001 Jun;19(2):76-82.
51. Harrington JM, Gill FS, Aw TC, Gardiner K. Occupational Health. Fourth Edition ed. 1998.
52. Hill A-M. Trends in paediatric medical admissions. BMJ 1989; 298(6686):1479-1483.
53. HILMO. 1996. Helsinki: 1996.
54. ICD-10. International Statistical Classification of Diseases and Related Health Problems. Geneva (Switzerland): World Health Organisation; 1992.

55. ICPC-2 International Classification of Primary Care, second edition. Prepare by the International Classification Committee of WONCA. Oxford: Oxford University Press, 1998.

56. Innsatsstyrt finansiering. Social- og Helsedepartementet. 2000. Norway.

57. ISO/TC 215/WG3. Health Informatics - Vocabulary on terminological systems. Working document: 2000-10-21 Reference number : ISO/WD nnn-n

58. Jamoulle M. Information et informatisation en médecine générale: Les informa-g-iciens.: Presses Universitaires de Namur; 1986:193-209.

59. Jamoulle M, Booth NW, Bernstein R. Standardisation, structure and exchange of information in primary care: the aim of clinical coding Tutorial presented at Medinfo 2001, London.

60. Key Health Statistics from General practice 1996. Analysis of morbidity and treatment data, including time trends, England and Wales. Series MB6 n°1. London. Office of national statistics. 1998

61. Koordinationsgruppen for individbaseret patientregistrering. Faellesindhold for basisregistrering af sygehuspatienter. Sundhedsstyrelsen. 6, 7-175. 2000. Denmark.

62. Korkeila J. Measuring aspects of Mental Health. STAKES. 6, 4-131. 2000. Finland.

63. LaDou J. Occupational & Environmental Medicine. Second ed. Appleton & Lange, 1997.

64. Lamberts H, Wood M, Hofman-Okkes IM, (eds.) The International Classification of Primary Care in the European Community: With a Multi-Language Layer. Oxford University Press, Oxford, 1993.

65. Lamberts H, Oskam SK. Zoekalgoritme ICD and ICPC. Amsterdam: UVA, Department of General practice, 2001.

66. Lanata C-F, Stroh G, Black R-E. Lot quality assurance sampling in health monitoring. Lancet 1988; 1(8577):122-123.

67. Landolt-Theus P, Danninger H, Braun RN. Kasugraphie. Benennung der regelmäßig häufigen Fälle in der Allgemeinpraxis. Mainz: Kirchheim Verlag, 1994.

68. Lefebvre F. Mémento Pratique: Communauté Européenne: juridique, fiscal, social, comptable, financier. Francis Lefebvre ed. Levallois: 1996.

69. Lehmann P, Watson E, Majeed A. Compiling a European-Union wide inventiry of morbidity data - development of an electronic inventory of data sources. Office of National Statistics. 2001. United Kingdom.

70. Levy BS, Wegman DH. Occupational Health, recognizing and preventing work-related disease. Third ed. Little, Brown, 1998.

71. Lévy E, Bungener M, Duménil G, Fagnani F. Economie du système de santé. Paris: Dunod, 1975.

72. Lionis Ch, Trell E. Health needs assessment in general practice: the Cretan approach. European journal of general practice, vol 5, 75-77, June 1999

73. Logiciel d'anonymisation des RHS. Ministère de l'Emploi et de la Solidarité, 1999.

74. Lorentzen EF. International Classification of Primary Care converted to ICD-10: Extended Danish ICPC. Proceedings of Medical Informatics 1996;188-192.

75. Magee H, Willmer R. Hospital Data Project: Interim Technical Report. Magee H, 2001. Dublin, Department of Health and Children.

76. Makela M, Booth B, Roberts R, (Eds). Family Doctor’s journey to Quality. The WONCA working party on Quality in Family medicine. Stakes, Helsinki. 2001

77. Markowe H. Monitoring health in Sweden: on the rationale for working environment regulations. Health Econ 1993; 2(4):323-332.

78. Markowe H. The work of the Central Health Monitoring Unit in the Department of Health (England). J Epidemiol Community Health 1993; 47(1):6-9.

79. Medinfo 2001 workshop. Co-ordination between clinical coding systems developers and researchers using open reference terminology approach. Is there a need for an international network organisation? Londres: 2001.

80. Metsemakers JF, Knotterus JA, Van Schendel GJ, Kocken RJ, Limonard CB. Unlocking patient’s records in general practices for research, medical education and quality assurance: the Registration Network Family Practices. Int J Biomed Comput. 1996 Jul;42(1-2):43-50.

81. Minimum data set of European mental health indicators. STAKES, European Commission. 2000.

82. Ministerio de Sanidad y Consumo. Explotacion de bases del CMBD - Estadisticos de referencia estatal de los sistemas de agrupacion de registros de pacientes. Ministerio de Sanidad y Consumo, 1998. Spain.

83. Nenonen M. The Theoretical Framework of the New Finnish Health Information System. STAKES, 14-5-2001. Helsinki .

84. Njalsson T, Sigurdsson JA, McAuley RG. Health problems in family practice. An Icelandic multicentre study. Scand J Prim Health Care. 1996 Mar;14(1): 4-12.

85. O'Brien J, Bowie C. A methodology for collecting outcome measures for common hospital conditions. J Public Health Med 1992; 14(4):380-384.

86. Okkes I, Booth N, Lamberts H. The international classification of primary care in its relation with other classification systems and nomenclatures relevant for general practice/family medicine. WONCA classification committee meeting, 2001.

87. Okkes IM, Jamoulle M, Lamberts H, Bentzen N. ICPC-2-e. The electronic version of ICPC-2. Differences with the printed version and the consequences. Family Practice 2000; 17:101-106.

88. Perry J, OXMIS problem codes for primary medical care. Oxford: OXMIS Publications, 1978.

89. Registers of Health Care in Finland. 2001. STAKES.

90. Rodrigues, JM, Rogers R. Co-ordination between clinical coding systems developers and researchers using open reference terminology approach. Is there a need for an international network organisation? Medinfo 2001 workshop, London, 2001

91. Roger-France FH, De Moor G, Hofdijk J, Jenkins L. Diagnosis Related Groups in Europe. 2nd ed. Gent: UZ Gent, 1989.

92. Rognerut M, Stensvold I, Strand BH, Hesselberg O , Lyshol H. The National health Indicator System and the data base. Folkehelsa, 2000. Norway.

93. Roos N-P. Establishing a population data-based policy unit. Med Care 1999; 37(6 Suppl):JS15-26.

94. Roos N-P, Black C, Roos L-L, Frohlich N, DeCoster C, Mustard C et al. Managing health services: how the Population Health Information System (POPULIS) works for policymakers. Med Care 1999; 37(6 Suppl):JS27-41.

95. Rusch E, Kaba-Schoenstein L, Rodgers J, Deccache A. Glossary of Public Health Terms, Glossaire de termes techniques en Santé Publique. Luxembourg: European Commission, Health & Consumer Protection, 2001.

96. Social welfare and health care statistics ans registers in STAKES. STAKES, 29, 1-22. 1995. Helsinki. Statistical report.

97. Spesialisthelsetjenesten 1990-1998. Norges Offisielle Statistikk. 2000. Norway.

98. Statens helsetilsyn. Den Internasjonale statistiske klassifikasjonene av sykdommer og beslektede helseproblemer. 1998. Norway.

99. Stroup NE, Zack MN, Wharton M. Sources of routinely collected data for surveillance. In: Teutsch SM, Churchill RE, editors. Principles and practice of public health surveillance. New York, Oxford: Oxford University Press, 1994: 31-85.

100. The Swedish Hospital Discharge Register 1987-1996 Quality and Contents. Center for Epidemiology. 1998. Sweden.

101. System of health accounts for international data collection. OECD Health Policy Unit. ICHA classifications

102. The Systematised Nomenclature of Human and Veterinary Medicine: SNOMED International. Northfield: College of American Pathologists, 1993.

103. Taskinen H. Good occupational health practice. 2001.

104. Teutsch S-M, Thacker S-B. Planning a public health surveillance system. Epidemiol Bull 1995; 16(1):1-6.

105. Vallancien G. How are Lower Urinary Tract Urinary Tract Symptoms Managed in Real Life Practice? The French Experience. Eur Urol. 2000 Nov; 38 Suppl S1:54-59

106. Westerhof H, ICPC demonstration and search program, version 2, October 1997, revision 2, Netherlands Huisarts Genootschap, 1998

107. Wonca classification committee. International Classification of Health Problems in Primary Care. 2nd ed. Oxford University Press, 1979.

108. Wonca classification committee. Funtional status measurement in primary care. Springer-Verlag, 1990.

109. WONCA International Classification. Committee statement on Health information flow in GP/FM Strunjan, Slovenia, 2000

110. Young J-C, Macioce D-P, Young W-W. Identifying injuries and trauma severity in large databases. J Trauma 1990; 30(10):1220-1230.

111. Zweigenbaum P. Encoder l'information médicale : des terminologies aux systèmes de représentation des connaissances. Innovation Stratégique en Information de Santé 1999; 2-3:27-47.

Annex

Annex 1:

Mental Health, psychiatry, administrative and routinely data, indicators for health systems

Santé mentale, psychiatrie, données administratives et de routine, indicateurs pour les systèmes de santé.

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1. Problématique générale

1.1. Les études épidémiologiques récentes ont montré que le taux de prévalence, pour la vie entière, des troubles psychiatriques (agrégation des troubles anxieux, troubles de l'humeur et troubles liés à l'abus de substance) variait de 37,5 % à 48,6 % chez les adultes dans quatre pays développés. La prévalence à 12 mois est estimée se situer entre 19,9 % et 29,1 % selon le pays étudié (Satcher, 1999 ; WHO, 2000). En soins primaires, la prévalence instantanée de l'ensemble des troubles dépressifs, anxieux et de la dépendance alcoolique varie entre 18 et 26 % dans 6 grandes villes européennes (Goldberg et Lecrubier, 1995) . La prévalence à quatre semaines des troubles dépressifs, anxieux et somatoformes a été estimée à 16,3 % en Autriche (Katschnig et al., 1993) et est de même ordre en Allemagne (Wittchen et al., 1999). En France, la prévalence annuelle des dépressions est d'environ 15% et reste stable (CREDES, 1999). La prévalence des troubles mentaux de l'enfance et de l'adolescence est plus difficile à estimer puisque la frontière entre développement normal et anormal peut être difficile à définir. Quelques études réalisées dans des pays industrialisés estimeraient cette prévalence autour de 20 % (Weyerer et al., 1988 ; Gomez-Beneyto et al., 1994 ; Shaffer D. et al., 1996 ; Steinhausen H. et al., 1998). L'OMS, dans son rapport sur la santé dans le monde de 2001, met aussi l'accent sur la maladie d'Alzheimer, le retard mental et sur un trouble neurologique, l'épilepsie, toutes pathologies dont le poids social peut être important (OMS, 2001)

1.2. Ces maladies sont souvent associées à des difficultés d'emploi, à une réduction de la productivité et des revenus (Bartel et Taubman, 1986 ; Mullahy et Sindelar, 1993 ; Ettner et al., 1997 ; Lecrubier et al ., 2000), à un appauvrissement des relations sociales (Lecrubier et al., 2000), au divorce (Bartel et Traubman, 1986), aux maltraitances à l'égard des enfants et aux négligences en matière de soins et d'éducation (Kelleher, 1994), à la violence et la dangerosité dans certains sous-groupes de patients (Torrey, 1994 ; Steadman et al., 1998), aux tentatives de suicide (Kessler et al., 1999) , au suicide (Moscicki, 1997) et à une augmentation de la consommation de soins de médecine générale (Hannson et al., 1997 ; Cuffel et al., 1999).

1.3. La maladie mentale génère des processus d'étiquettage social et de stigmatisation. Ces concepts sont liés aux différences observables entre être humains. La différence va être associée à une croyance en défaveur de la personne désignée ou à une façon de la considérer qui lui est défavorable (Witztum et al., 1992). La stigmatisation a un effet important sur le bien-être et peut persister même lorsque le traitement a amélioré les symptômes et le fonctionnement (Link et al., 1997).

1.4. L’impact des problèmes de santé mentale dans une population a été mise en évidence en 1996 par l’étude de l’OMS et de la Banque Mondiale. Dans le monde, les dépressions majeures unipolaires représentaient la première cause d’incapacité, l’usage d’alcool la cinquième, la schizophrénie la septième, les troubles bipolaires la neuvième, la maladie d’Alzheimer et les autres démences la treizième. Le caractère chronique de ces maladies représente une part importante de la charge qu’elles représentent (Murray et Lopez, 1996 ; Bowie et al., 1997 ; Melse et al., 2000).

1.5. Le nombre de personnes suivies paraît en augmentation constante. En France, depuis 1992, le nombre de consultations a augmenté 17 % dans le secteur privé et de 46 % dans le secteur public (CREDES, 1999). Au Royaume-Uni, le nombre de personnes recevant des soins dans les services de psychologie clinique a augmenté de 49 % entre 1988-89 et 2000-2001(DoH, 2001c). Le nombre de celles qui ont bénéficié de soins infirmiers psychiatriques ambulatoires a augmenté de 65 % dans la même période (DoH, 2001d). En Ecosse, le nombre total de patients suivis en consultation psychiatrique ambulatoire a augmenté de 32 % entre 1991 et 1999 ; le nombre de nouveaux cas a augmenté de 55 % pendant cette même période ISD Scotland, 2001).

1.6. La croissance de la consommation de médicaments psychotropes ces dernières années est un autre indice de la reconnaissance des troubles mentaux et de santé mentale par le public et le personnel médical et de la nécessité d’y apporter un traitement (Nomesco, 2001 ; DoH, 2001e ; Agence du Médicament, 1998), sans signifier nécessairement une augmentation de l’incidence des troubles (van Dijk, 2001).

1.7. L’impact socio-économique des troubles mentaux n’est pas négligeable. En Allemagne, entre 1985 et 1995, les retraites anticipées pour raison de santé liées à un trouble mental sont en croissance. En 1995, le trouble mental représente la 3ème cause de retraite anticipée pour raison de santé chez les hommes (15 %) et la 2ème cause chez les femmes (23 %) (Federal health monitoring system, 2001). En Autriche, les troubles psychiatriques sont la deuxième cause d’octroi d’une pension d’invalidité (Wörister, 2000). En France, les maladies mentales sont au premier rang des causes médicales à l'origine de l’attribution d’une pension d'invalidité (CNAM, 2001). Aux Pays-Bas, où la législation leur est favorable, les troubles mentaux sont à l'origine de 40 % des coûts des congés de maladie et des incapacités de travail et plus de 300.000 personnes reçoivent une allocation de handicapé à cause d'un problème psychique (Trimbos, 2000).

1.8. Le coût économique total des troubles mentaux est important. Des estimations récentes montrent qu’en 1990, aux USA, le total des coûts directs et indirects associés aux troubles mentaux (abus de substances exclus) se montait à 147,8 milliards de dollars (Rice et Miller, 1998 ; Rice, 1999). En 1995, le coût économique des abus de substance étaient estimés à 428,1 milliards de dollars (alcool : 175,9 ; drogues : 114,2 ; tabac : 138) (Rice, 1999). En 1996, les Etats-Unis ont dépensé 99 milliards de dollars pour le traitement direct des troubles mentaux, des abus de substance, de la maladie d’Alzheimer et d’autres troubles démentiels (Satcher, 1999). Les dépenses de santé pour les troubles mentaux ont représenté 8,3 % du total des dépenses de santé aux U.S.A. en 1995 ; 16,6 % au Royaume-Uni en 1992/1993 ;

11,4 % au Canada en 1993 et 8,4 % en Australie en 1993-1994 (Triplett, 1999). En Angleterre, en 1999-2000, les épisodes d'hospitalisations sous la responsabilité de psychiatres représentent 2.04 % des épisodes hospitaliers mais 11.14 % de leurs coûts (DoH, 2001). Aux Pays-Bas, en 1995, le budget des hôpitaux psychiatriques représentait 16.5 % du budget hospitalier total et en 2000 les dépenses de santé pour les troubles mentaux ont représenté 7,8 % de l'ensemble des dépenses de santé (Statistics Nederland, 2001).

2. Santé mentale, bien-être psychologique, détresse psychologique, maladie mentale

2.1. Le terme “ santé mentale ” est maintenant largement usité, souvent sans que soit explicité ce qu'il recouvre. En 1988, le Ministère canadien de la Santé définit la “ santé mentale ” comme “ la capacité de l'individu, du groupe et de l'environnement d'avoir des interactions qui contribuent au bien-être subjectif, au développement et à l'emploi optimaux des capacités mentales (cognitives, affectives et relationnelles), à la réalisation de buts individuels et collectifs justes et à la création de conditions d'égalité fondamentale ”. La proposition d'indicateurs de santé mentale de STAKES-ENMHPO (2000) introduit aussi une définition de la santé mentale qui “ comme part indivisible de la santé générale, reflète l'équilibre entre l'individu et l'environnement. Elle est influencée par : 1) des factors biologiques et psychologiques individuels ; 2) une interaction sociale ; 3) des structures et des ressources sociétales et 4) des valeurs culturelles. Dans ce contexte, [elle] … peut être vue comme un processus qui comprend des facteurs prédisposant, précipitant et de soutien aux conséquences et devenirs variés ”.

2.2. Pour STAKES-ENMHPO (2000) il existe deux dimensions de la santé mentale : la santé mentale positive …. que l'on résumera comme la capacité à faire face à l'adversité et la santé mentale négative qui concerne habituellement les troubles, symptômes et problèmes mentaux. Un état mental sera qualifié de “ trouble lorsque les symptômes sont de longue durée, hors du contrôle de l'individu, sans proportion avec des causes externes possibles et réduisent les capacités fonctionnelles. Les symptômes et les problèmes mentaux peuvent exister sans que les critères du trouble mental soient atteints. Ces états sub-cliniques sont souvent la conséquence d'une détresse persistente ou temporaire ”. De même, les canadiens avaient en 1988 distingué le “ problème mental ” qui est “ perturbation des rapports entre la personne, le groupe et l'environnement ”, du “ trouble mental ” qui est une “ maladie caractérisée, qui peut être diagnostiquée et qui entraîne une détérioration marquée des capacités cognitives, affectives ou relationnelles de l'individu ” .

2.3. Ces distinctions entre santé mentale, bien-être psychologique, détresse psychologique et trouble mental sont importantes dans la mesure où selon les facteurs de soutien dont un patient bénéficie et la perception qu'il a de ses difficultés, les ressources utilisées dans le système de santé vont varier. On sait que maladie mentale et utilisation des ressources de santé ne se recouvrent pas nécessairement (Kessler et al., 1997 ; Trimbos, 2000) et que les patients présentant les états les plus graves ou les plus déficitaires vont consommer des ressources beaucoup plus importantes que ceux présentant des états de détresse de mal-être de plus ou moins longue durée (Frank et al., 1994 ; Trimbos, 2000). Ces derniers peuvent cependant représenter une part relativement importante de la consommation des ressources médicales et non médicales affectées au traitement des maladies mentales et des assuétudes (Kessler et al., 1997).

2.4. Le recours aux soins ambulatoires est plus sensible au coût quand il s’agit de santé mentale que lorsqu’il s’agit de santé physique : à diminution ou augmentation de coût égale, la demande de soins psychiatriques ou de santé mentale va croître ou diminuer dans des proportions supérieures à la demande de soins somatiques (Frank et McGuire, 1999). Les modalités de remboursement des soins psychiatriques et de santé mentale vont donc avoir une incidence manifeste sur la consommation des soins.

2.5. La demande croissante de soins spécialisés pour des troubles modérés ou légers a pu conduire à des processus d’exclusion des soins de patients souffrant de troubles mentaux sévères, moins à même d’exprimer leurs besoins d’aide et de soins (Civeira, 1996). Cet état de fait pourrait rendre utile, comme le propose Thornicroft et Tansella (1999), d’arrêter une définition de la maladie mentale sévère qui facilite les comparaisons entre les différentes modalités d’offre de soins spécialisés des systèmes de santé et les modes de prise en charge en arrêtant les contours d’une population nécessitant des traitements importants et souvent continus.

3. Organisation du système de soins psychiatriques et de santé mentale

3.1. Les problèmes de santé pris en charge par la psychiatrie sont souvent caractérisés par la récurrence, la chronicité, la relation directe des professionnels de santé aux patients dans laquelle la place des actes techniques est faible et celle des réseaux de proximité importante. Au cours des dernières décennies, leurs formes de prise en charge ont connu une évolution considérable. Les développements en matière de thérapeutique et d’organisation des soins ont permis d’envisager le traitement ambulatoire de la plupart des pathologies mentales graves. Les transformations en matière de soins spécialisés, la croissance d’une demande de soins pour des troubles ou problèmes mentaux de sévérité moyenne et des difficultés psychologiques liées à la détresse psychique ont achevé cette transformation du champ des soins psychiatriques et de santé mentale.

3.2. Dans ce contexte, un système de soins de santé mentale devrait pouvoir assurer les tâches suivantes, organisées ici selon la sévérité des affections à traiter :

- interventions précoces pour les patients en phase initiale d’un trouble mental de façon à prévenir ou à le développement d’un trouble complet ou à en réduire la sévérité,
- aide d’urgence et de crise pour les personnes présentant des troubles mentaux aigus,
- interventions visant à la restauration complète de la santé mentale dès que possible,
- interventions visant à prévenir la rechute des patients qui ont connu une amélioration complète ou partielle de leur état,
- interventions visant à améliorer la santé mentale si la guérison ne peut être complètement réalisée,
- interventions visant à éviter la détérioration de l’état des patients dont la guérison complète ou partielle n’est pas possible. (Lavikainen et al., 2000)

3.3. Ces tâches sont moins qu’avant directement associées à un équipement particulier. Ainsi, par exemple, Wasylenki et al. (2000) relèvent que certains patients présentent des troubles mentaux sévères complexes dont le traitement ne peut être assuré dans les services primaires et secondaires. Ces patients caractérisés par l'agressivité, la non-compliance aux médications et la dangerosité requièrent des soins “ tertiaires ”. Il s'agit, pour ces patients référés par les services de soins secondaires, d'évaluations et de traitements très détaillés et spécialisés fournies par des équipes spécialement formées. Or contrairement aux approches anciennes qui associaient soins tertiaires et cadre hospitalier, les auteurs rendent compte du fait qu'*il n'y a plus maintenant de nécessité de lier ces soins à des lieux ou à des cadres temporels particuliers grâce aux progrès des thérapeutiques* (souligné par nous).

3.4. Les interventions préconisées se traduisent par un changement dans l'organisation des soins : les gens ne seront plus traités seulement par un médecin et par un service. Au cours d'un épisode important de maladie, les patients sont pris en charge, en fonction de leur situation et de leurs besoins, successivement ou simultanément, par des équipes différentes regroupant des infirmières, des médecins consultants, des personnels de soins spécialisés, du personnel administratif et éventuellement des techniciens de laboratoire. Une des conséquences de cette situation est que les psychiatres ne représentent qu'une petite proportion des soignants employés dans le secteur psychiatrique et de santé mentale (6 % aux Pays-Bas – Trimbos, 2000 ; au maximum 11 % en France – Roelandt et Piel, 2001) dont les compétences professionnelles se sont largement diversifiées. En Suède, entre 1975 et 1996, le profil des professions en santé mentale a évolué de façon caractérisée. En 1974, les psychiatres voyaient 100 % des cas ambulatoires. En 1994, suite à une baisse de leur recrutement, ils ne voyaient plus que 15 % des consultations ; 30 % étaient assurées par des psychologues et des travailleurs sociaux et plus de 40 % par des infirmières (Munk-Jorgensen et al., 1995).

3.5. L'organisation des soins se diversifie. Les systèmes les plus complets vont chercher à répondre à la diversité des besoins des patients en développant des équipements nombreux et complémentaires, qui devront collaborer pour assurer la continuité des soins. Le Département anglais de la Santé (1996) a, par exemple, défini de la façon suivante les services susceptibles d'être requis pour répondre à la majorité des besoins des patients :

	Soins urgents/aigus	*Soins continus/à long terme*
Services à domicile	* Intervention de crise pour évaluation et traitement * Soutien intensif à domicile	* Gestion de cas * Services de soutien à domicile
Services de soins ambulatoires et de jour	* Hôpital de jour aigu * Département hospitalier d'urgence * Service de consultation - liaison * Service ambulatoire de consultations de crise et sans rendez-vous.	* Service de consultations sur rendez-vous * Services d'accueil * Groupes de soutien * Services de réhabilitation sociale et professionnelle * Centres de jour

	Soins urgents/aigus	*Soins continus/à long terme*
Services résidentiels		
a) hospitaliers	* Unités hospitalières de soins aigus	* Unités d'hospitalisation à long-terme * Unités d'hospitalisation de sécurité *Hôpitaux spécialisés de haute sécurité
b) non-hospitaliers	* Service d'hébergement de crise	* Appartements/habitations encadrés et non encadrés * Services de placement spécialisé * Services de soins résidentiels * Soins infirmiers résidentiels à temps complet

D'autres catégorisations existent qui détaillent plus ou moins l'un ou l'autre aspects des réponses à apporter aux besoins des patients (Thornicroft et Tansella, 1999) ou définissent les équipements légaux minimum à développer dans une région donnée (Ministero della Sanita, 1998 ; Roelandt et Piel, 2001).

3.6. Les interventions à développer et les équipements à mettre en place, peuvent aussi être déclinés en fonction de groupes d'âges (le plus souvent : enfants et adolescents, adultes, personnes âgées), de pathologies particulières (malades mentaux sévères, alcoolisme et toxicomanie) ou de situations spécifiques (psychiatrie médico-légale). Avec le développement progressif de la “ gestion de la maladie ”, on commence à voir se développer des programmes particuliers centrés par exemple sur la dépression ou les troubles de personnalité mais ce phénomène est loin d'être général. L'importance relative de ces groupes aura une incidence sur l'organisation possible de services qui leur soient plus ou moins spécifiques.

3.7. Les descriptions des différentes modalités possibles de soins en fonction des besoins des patients ne doivent pas faire oublier que l'ensemble des patients qui pourraient en bénéficier sont loin d'y avoir recours et le rôle que joue la médecine de premier recours dans la prise en charge des problèmes et des troubles de santé mentale. Aux Pays-Bas, on considère que seulement 1/3 des personnes souffrant d'un trouble mental cherche une aide professionnelle et que dans 80 % des cas elles entre en contact avec leur médecin généraliste (Trimbos, 2000). En France des constats du même ordre ont été fait en matière de traitement des patients déprimés (Parquet et al., 2001) et 68 % des traitements antidépresseurs y sont prescrits par des omnipraticiens (Zarifian, 1996). Aux USA, en 1996, 60 % des patients recevant des soins de santé mentale étaient traités dans des services médicaux non spécialisés ou dans des services non médicaux (Kessler et al., 1996).

3.8. Pour les patients qui accèdent aux soins spécialisés, les traitements ambulatoires sont largement la règle. En France, en 1999, 86 % des adultes et 97 % des enfants suivis par le secteur public (qui représente 80 % des lits d'hospitalisation complète et 89 % des places d'hospitalisation partielle) le sont en ambulatoire et les consultations représentent le mode de prise en charge le plus fréquent (73 % des adultes et 92 % des enfants) (Roelandt et Piel, 2001). Aux Pays-Bas, 83 % des patients sont traités en ambulatoire et seuls 17 % sont traités en hospitalisation complète, dans une structure protégée ou en traitement de jour. (Trimbos, 2000).

3.9. Selon la définition donnée à l'adolescence, les enfants et les adolescents représentent de 18 à 30 % du total des prises en charge dans différents systèmes de soins (DoH, 2001c ; Trimbos, 2000, Roelandt et Piel, 2001).

4. Données administratives et de routine

4.1. Des indicateurs basés sur des données administratives et de routine doivent pouvoir rendre compte de ces évolutions dans l'organisation des systèmes de santé et de leur incidence sur la consommation de soins.

4.2. Les indicateurs disponibles ou à envisager sont élaborés au départ de données issues du système de soins. En ce sens, ils reflètent les ressources disponibles, leurs activités et, lorsqu'existent des indicateurs appropriés, leurs performances. Ils ne permettent pas de rendre compte de l'état de santé mentale dans la population générale ni de la prévalence des pathologies mentales. Compte tenu des réticences à consulter déjà signalées, l'accroissement de la demande de soins pour des problèmes psychiques ou des troubles mentaux qui paraît un phénomène général en Europe ne doit pas être confondu avec un accroissement de l'incidence de ces états morbides. Au mieux et pour autant que cela puisse être démontré avec suffisamment de robustesse et de façon répétée à travers le temps, la fréquentation des services spécialisés ne sera qu'un indicateur de tendance.

4.3. L'étendue du domaine sur lequel portent ces indicateurs devrait être définie. En effet et à juste titre, il est de plus en plus souvent fait état de la nécessité de collaborations entre le secteur psychiatrique et de santé mentale et d'autres secteurs économiques et sociaux : travail et emploi, éducation, logement, aide sociale, justice …. Ces secteurs tendent à solliciter de façon croissante le secteur psychiatrique et de santé mentale pour lui adresser des personnes considérées comme présentant des troubles et dont elles ne peuvent s'occuper. Inversement, le secteur psychiatrique et de santé mentale est de façon croissante amené à entrer en contact avec ces services pour assurer à leurs patients des possibilités d'inclusion sociale qui leur font totalement ou partiellement défaut. Dans un pays comme la Suède, il y a d'ailleurs eu substitution : les soins aux malades mentaux chroniques sont passé de la responsabilité des services psychiatriques à celle des services sociaux des municipalités (Munk-Jorgensen, 1995). En France, des patients malades mentaux chroniques peuvent bénéficier d'allocations de handicapés qui, dans un certain nombre de cas, les font entrer dans un autre circuit de prise en charge que celui des soins psychiatriques. Il est possible alors qu'ils ne soient plus repris dans les bases de données recensant l'activité des services psychiatriques (Roelandt et Piel, 2001). Par ailleurs, si nombre de patients souffrant de problèmes ou de troubles mentaux sont soignés par leur médecin généraliste, il est notable aussi que nombre d'autres patients dont la pathologie n'est pas susceptible de créer de désordres, sont traités dans des services de médecine d'hôpitaux généraux (Katschnig et al., 2001) **Dans la perspective d'indicateurs de santé mentale envisagés sur le long terme, la question de l'étendue du domaine exploré devrait être très sérieusement envisagée.**

4.4. Ce dernier point pose plus largement la question de l'information sur chaque système de soins de santé, son organisation, ses modes de financements, les dispositifs de traitement qu'il met en place et idéalement, les résultats qu'il en obtient. Les grandes orientations des systèmes de soins en Europe (modèle beveridgien de financement des soins par l'impôt et modèle bismarckien de financement des soins par les revenus du travail) semblent être à l'origine de différences parfois notables entre les dispositifs nationaux de psychiatrie et de santé mentale. Dans les pays d'orientation beveridgienne le nombre de lits psychiatriques hospitaliers a diminué de façon plus importante que dans les pays d'orientation bismarckienne). Les pays disposant d'un service national de santé ou d'un système de santé publique (orientation beveridgienne : Grande-Bretagne, Italie, Portugal, Espagne, Pays scandinaves) ont vu leurs réformes imposées plus facilement par le haut. Dans les pays où les systèmes d'assurances sociales prédominent (orientation bismarckienne : France, Allemagne, Belgique, Pays-Bas), les négociations ont été difficiles entre hôpitaux privés, professionnels libéraux et assurances, même lorsqu'elles se sont déroulées sous l'égide des autorités. Dans ces pays aux systèmes de financement compliqués, l'Etat ne peut agir que par décret et ordonnances, en espérant que celles-ci seront suivies. (Van Os et Neeleman, 1994)

4.5. D'autres facteurs peuvent avoir une incidence sur les modes de recours aux soins comme la densité de médecins généralistes et de spécialistes (OCDE, 1998 ; Peers, n.d.) ; la structure de production des soins et la place relative qu'y occupent les soins primaires, secondaires et tertiaires (OCDE, 1997 ; OCDE, 1998) ; l'existence d'un système de régulation des entrées dans le dispositif de soins (Gerdtham, 1994) ; le mode de rémunération des soins (Mahieu, 2000) ; le coût des soins pour les patients (Peers, n.d.). L'organisation des soins psychiatriques et de santé mentale est donc insérée dans un dispositif législatif et réglementaire général, spécifique à chaque pays, dans le cadre duquel s'inscrivent les dispositions juridiques et administratives qui la concerne plus directement. **Les définitions, normes, critères et valeurs qui structurent dans chaque pays ces soins spécialisés devraient faire l'objet d'une comparaison systématique de façon à distinguer les similitudes et les différences qui existent et permettre une interprétation informée des indicateurs retenus.**

4.6. A titre indicatif, il a été relevé que le système de soins public paraît plus adapté au suivi des patients souffrant de troubles sévères chroniques alors que celui des assurances sociales correspond mieux aux besoins des patients plus légèrement perturbés psychologiquement (Van Os et Neeleman, 1994).

4.7. Tous les pays européens disposent de systèmes de recueil d'informations sur le système de soins psychiatriques et de santé mentale. Le type de données recueillies peut cependant varier grandement selon les pays en fonction des critères légaux qui encadrent le secteur et des objectifs poursuivis en matière de politique de santé mentale. Les systèmes de soins publics permettent en général de disposer d'une information plus détaillée.

4.8. Trois pays européens se sont dotés ou sont en train de se doter d'un système national de recueil de données en matière de soins psychiatriques. Le Résumé Psychiatrique Minimum belge (Delesie et al., 1997) et le Programme de Médicalisation des Systèmes d'Information pour la psychiatrie en France (Site officiel du PMSI, 2001) comporte un recueil de données relatives à l'hospitalisation complète, aux prises en charge à temps partiel, aux activités externes et aux actions pour la communauté mais reste essentiellement centré sur les soins hospitaliers. Le Mental Health Minimum Data Set anglais porte lui sur tous les épisodes de soins hospitaliers ou ambulatoires pris en charge dans le cadre du service national de santé (DoH, 2001a). Le RPM belge lancé en 1996 a étendu le recueil des données aux maisons de soins psychiatriques et aux habitations protégées, financées par le gouvernement fédéral, en 1998. Pour des raisons de confidentialité des données transmises, son utilisation est pour l'instant suspendue. Le PMSI-Psychiatrie français doit être mis en application à titre expérimental dans 4 régions pilotes à partir du 1er janvier 2002. Sa généralisation est prévue en septembre 2004 et son utilisation à des fins budgétaires à partir de septembre 2006. L'objectif est de constituer des groupes homogènes de journées (GHJ) à partir de catégories diagnostic principalement sur base desquels des financements pourraient être établis. Les premières expérimentations des GHJ psychiatriques n'expliqueraient actuellement que 9 % de la variance des durées de séjour hospitalier. Un boycott du PMSI en psychiatrie aurait été préconisé par de nombreux psychiatres. A côté du PMSI actuel, centré sur les épisodes d'hospitalisation et de consultation, un second PMSI serait envisagé qui se centrerait sur les trajectoires de soin des patients, intégrant l'ensemble des soins hospitaliers, ambulatoires, de jour …. assurés par les secteurs psychiatriques (Site officiel du PMSI, 2001).

Le Mental Health Minimum Data Set anglais s'inscrit dans le cadre de l'important programme de révision de l'organisation des soins de santé mentale du NHS - le “ National Mental Health Framework ” - qui a été entamée depuis 2 ans (DoH, 2000). Ce programme comporte un volet spécifique consacré à la stratégie d'information en santé mentale. L'objectif de cette stratégie est d'intégrer l'information issue de sources différentes (services de santé mentale ambulatoires, hospitaliers, de soins primaires et de soins communautaires, sociaux) de façon à disposer de données de santé mentale complètes intégrées au dossier électronique de chaque bénéficiaire du NHS. Deux outils d'information sont en cours d'implantation :

- le "Mental Health Minimum Data Set" (MHMDS)
- l' "Integrated mental Health Electronic Record" (IMHER).

Le “ Mental Health Minimum Data Set ” (MHMDS) est centré sur les épisodes de soins d'un patient. Il a pour objectif premier de fournir une information de meilleure qualité pour les audits cliniques, la planification et la gestion des services. Sa mise en œuvre du MHMDS devrait avoir commencé en mars 2001, date à laquelle il était prévu que toutes les autorités locales de santé (trusts) aient informatisé leur “ Care Programme Approach ”. Son application obligatoire dans tous les services est prévue en avril 2003. Le MHMDS concerne tout patient adulte (âgés inclus) recevant des soins de santé mentale dans le cadre du NHS. Il porte sur l'ensemble des interventions possibles, qu'elles soient brèves pour répondre à un problème spécifique, ou qu'il s'agisse de soins de longue durée à un patient chronique qui peut nécessiter une hospitalisation suivie de soins de jours et de consultations hebdomadaires par exemple.

L' "Integrated Mental Health Electronic Record" (IMHER), s'intègre dans la stratégie nationale de constitution d'un dossier électronique pour chaque patient. Il est directement centré sur le patient et vise à intégrer les données issues de l'utilisation de l'ensemble des ressources de santé au cours du temps, plus détaillées que dans le MHMDS et les organisant, comme l'"Electronic Patient Record" en plusieurs niveaux d'information. L'IMHER est actuellement en cours de développement. Le début de sa mise en œuvre est envisagé à la date du 31 mars 2003. Sa généralisation à l'ensemble du territoire anglais devrait être terminée en mars 2007.

4.9. Dans les autres pays européens, le recueil des données n'est pas aussi systématisé et les informations sont rarement recueillies au niveau du patient sauf dans les pays scandinaves qui ont une tradition de registres psychiatriques bien établies et dans quelques régions, à l'initiative des responsables locaux des services de psychiatrie. Depuis 1994, la Suède recueille, pour chaque patient psychiatrique hospitalisé ou suivi en ambulatoire, le diagnostic DSM IV et le degré global de fonctionnement. Au Danemark, où existe un registre national, la définition de futurs " Ambulatory Patient Groups " est envisagée ainsi que l'évaluation du devenir des interventions.

4.10. Compte tenu de la place des soins de première ligne dans le traitement et le suivi des troubles mentaux, une indication des prestations effectuées est indispensable. En dehors des réseaux sentinelles ou assimilés, il n'existe dans aucun pays de relevé systématique et exhaustif de données portant sur les pathologies traitées par les médecins généralistes. Un relevé des pathologies traitées en médecine de ville est envisagé en France. Les réseaux-sentinelle sont cependant considérés comme des instruments valides de recueil de données de santé pour autant qu'ils soient représentatifs (Van Casteren et al., 2001). Se pose cependant la question du diagnostic. En effet, **dans le secteur des soins primaires et dans les services de santé mentale ambulatoire**, **nombre de patients présentent un état pathologique sub-clinique qui ne correspond pas à la totalité du tableau décrit dans les classifications spécialisées. Il semble dans ce cas que l'International Classification of Primary Care deuxième version (ICPC-2) qui définit et catégorise les motifs de consultation soit plus appropriée (Jamoulle, 2001).** En Grande-Bretagne, cependant, les codes Read sont utilisés en médecine générale (Graham , 2000).

4.11. Dans le secteur des soins secondaires, les résumés de sortie permettant la constitution de DRG sont maintenant une règle générale dans la plupart des pays. La **Classification Internationale des Maladies est la référence diagnostique** utilisée partout pour les soins somatiques et dans de nombreux pays pour les soins psychiatriques., Des variations existent selon les pays en fonction des versions utilisées ou des modifications qui ont pu y être apportées. **Le problème majeur est alors la transposition des codes d'une version dans une autre. Il semble que les tables de conversion de la CIM-8 et de la CIM-9 vers la CIM-10 aient été réalisées, pour le chapitre des troubles mentaux, par l'OMS**. Reste que le passage d'une version à la suivante peut poser des problèmes de compatibilité si l'on ne dispose pas d'une information suffisamment détaillée.

4.12. Les politiques de décentralisation et de régionalisation des soins déjà existante dans certains pays et qui se sont développées dans d'autres au cours de la dernière décennie ont au moins deux conséquences assez directement visibles. D'une part, elles se traduisent par la diversité des dispositifs locaux mis en place, source éventuelle d'iniquité d'accès aux soins. D'autre part, elles conduisent à une fragmentation de l'information qui en rend difficile le rassemblement et à une difficulté d'analyse liée à la diversité des systèmes. Ce constat incite à chercher à **obtenir des données suffisamment détaillées au plan géographique pour rendre possible des comparaisons nationales et régionales pertinentes**. A titre d'exemple, une étude a montré qu'en France, quatre modèles différents pouvaient être distingués en fonction du nombre de lits de psychiatrie et de psychiatres dans chaque département (Guilmin et al., 2000). Un constat du même ordre a été fait au Danemark (Munk-Jorgensen, 1999) et en Italie (Ministerio della sanita, 1998).

5. Indicateurs

5.1. Sur base de ce qui vient d’être dit, des indicateurs en matière de santé mentale et de psychiatrie peuvent être constitués sur base de données administratives et d’activité recueillies en routine. Nombre de ces indicateurs sont déjà connus mais devraient être raffinés pour correspondre aux évolutions qui sont constatées.

5.2. Les travaux portant sur la définition de variables descriptives de l’offre de soins psychiatriques et de santé mentale d’une part et sur celle d’indicateurs d’activité et de performance construits sur base de données recueillies en routine se sont multipliés (Thornicroft et Tansella, 1999 ; DoHAC, 1999 ; NASMHPD, 2000 ; CIHI, 2001 ; InterRAI, 2001 ; DoH, 2001a ; ICMHPS, 2001). Cette évolution est liée aux préoccupations croissantes en matière de performance et d’efficience de systèmes de santé de plus en plus coûteux. D’autre part, en lien avec les propositions en matière d’indicateurs de santé pour la communauté européenne (ECHI Project, 2001), des indicateurs spécifiques à la santé mentale ont été envisagés (ENMHPO, 2000) cependant sans développements détaillés sur les informations susceptibles d’être extraites des banques de données basées sur les caractéristiques et les activités des services de santé et des prestataires de soins.

5.3. Sur base des données recueillies dans les différents pays européens, deux types d’indicateurs sont actuellement possibles : des indicateurs de ressources et conjointement des indicateurs d’activité. Les indicateurs de ressources devraient pouvoir rendre compte de la diversité de celles-ci ; les indicateurs d’activités devraient préciser l’utilisation qui est faite de ces ressources.

5.4. Un premier groupe d’indicateurs nous semble devoir porter sur le personnel spécialisé disponible. Les choix de l’OMS (2001) nous servant ici de référence. Il s’agira de disposer des informations suivantes :

- **a) nombre de psychiatres pour 100.000 habitants**
- **b) nombre de neurologues pour 100.000 habitants**
- **c) nombre de neurochirurgiens pour 100.000 habitants**
- **d) nombre d’infirmier(e)s psychiatriques pour 100.000 habitants**
- **e) nombre de psychologues intervenant en santé mentale pour 100.000 habitants**
- **f) nombre de travailleurs sociaux intervenant en santé mentale pour 100.000 habitants**

Ces informations devraient être données **par pays et par région (NUTS 2).**

5.5. Quelques difficultés peuvent être déjà soulignées :

- la définition des spécialités et le type de formations reçues n’est pas toujours harmonisé au niveau européen. Ce problème paraît cependant secondaire, le point principal restant le volume de personnel spécialisé.
- la pénurie de personnel infirmier qui touche de nombreux pays peut conduire les services spécialisés à engager du personnel infirmier non spécialisé en psychiatrie à défaut de compétences suffisantes disponibles sur le marché du travail.

– le nombre de psychologues intervenant en santé mentale ne permet pas de rendre compte de la croissance du nombre de psychologues engagés dans d'autres secteurs que celui de la santé mentale et qui peuvent y jouer un rôle non négligeable en matière de prévention et de suivi des détresses psychiques. On pensera ici plus particulièrement aux secteurs de l'éducation et de l'aide sociale.

5.6. Les indicateurs portant sur les services hospitaliers paraissent les plus aisés à constituer. Actuellement, le nombre de lits psychiatriques pour chaque pays a été retenu. Il semble cependant nécessaire qu'une définition commune soit adoptée. La liste des définitions fournies par l'OCDE rend compte déjà de quelques différences dans la façon de comptabiliser les lits. Ces différences rendent déjà la comparaison difficile. Par exemple, les chiffres pour la Norvège sont de 66 lits psychiatriques, dans les hôpitaux agréés, pour 100.000 habitants en 1999 (69 lits en 1997) (NOMESCO, 2001). En fait, le nombre total de lits dans les institutions hospitalières et résidentielles psychiatriques reconnues est de 134 pour 100.000 habitants à cette même date (SoHd, 2001). Aux Pays-Bas, le nombre de lits psychiatriques hospitaliers inclut les maisons de soins et exclut les lits des services psychiatriques des hôpitaux généraux et universitaires. Si l'on ne considère que les lits hospitaliers pour adultes et les lits des maisons de soins, le nombre de lits est de 153/100.000 habitants en 1999. Il est de 170/100.000 si l'on y inclut les lits pour enfants et adolescents et les lits des services spécialisés pour toxicomanes et de 190/100.000 si l'on y ajoute les lits psychiatriques des hôpitaux généraux et les lits de sécurité des hôpitaux psychiatriques spécialisés (Trimbos, 2000).

5.7. Ces divergences, selon le type de lits considérés, pour un même pays nous conduisent à préconiser une distinction qui s'appuie sur les **classification des fonctions de soins de santé (OCDE, 2000a) et des fournisseurs de soins de santé (OCDE, 2000b) du “ System of Health Accounts (SHA) ” de l'OCDE**. La première distingue les traitements curatifs résidentiels des traitements résidentiels de réhabilitation et des soins infirmiers résidentiels. Cette distinction est pertinente en psychiatrie où, en fonction du caractère et de la chronicité de la maladie les soins curatifs proprement dits sont susceptibles de passer au second plan dans l'organisation du traitement au profit des soins de réhabilitation et de soins infirmiers à long-terme. La distinction entre les différents types de soins est indispensable et permet seule de se faire une idée de la gamme et l'étendue des soins offerts dans une région déterminée.

Pour les **soins curatifs**, on pourrait donc avoir des :

- **lits des services psychiatriques des hôpitaux généraux,**
- **lits des hôpitaux psychiatriques,**
- **lits résidentiels de services spécialisés de santé mentale ou pour toxicomanes**.

Il semble cependant plus pertinent de réunir les deux dernières catégories en une seule : les hôpitaux psychiatriques et les services spécialisés de santé mentale ou pour toxicomanes paraissant souvent accueillir des patients relativement semblables. On notera cependant qu'il peut exister, comme en Belgique, des lits “de traitement aigu ” dans les hôpitaux psychiatriques. Ces lits présentent les mêmes caractéristiques en personnel que les lits des services psychiatriques des hôpitaux généraux mais s'en distinguent par des durées de séjour plus longues.

Pour les **soins de réhabilitation**, on aurait des :

- **lits de réhabilitation des hôpitaux psychiatriques,**
- **lits de réhabilitation des services spécialisés de santé mentale ou pour toxicomanes.**

La distinction semble en fait peu pertinente. Il s'agira probablement de nuances dans les types de soins offerts.

Pour les **soins infirmiers à long-terme**, on aurait des :

- lits de soins infirmiers à long terme des hôpitaux psychiatriques,

- lits de soins infirmiers à long terme des maisons de soins psychiatriques,

- lits de soins infirmiers à long terme des services spécialisés de santé mentale ou pour toxicomanes.

Ici aussi un regroupement des trois catégories paraît pertinent. Seule la gravité des pathologies prise en charge pourrait, peut-être, distinguer les structures.

5.8. Pour les différents types de lits (curatifs, de réhabilitation, de soins infirmiers à long terme), il paraît utile de disposer des indicateurs suivants :

a) **nombre de lits pour 100.000 habitants**
b) **ratio de personnel soignant pour lit**
c) **nombre de sorties par an pour 100.000 habitants**
d) **taux d'occupation des lits (peut être approché par a. et c.)**
e) **nombre de journées d'hospitalisation par an pour 100.000 habitants**
f) **durée moyenne de séjour (peut être approchée par a. et e.)**

Ces indicateurs devraient être fournis par pays et par région NUTS 2. Les sorties et les journées d'hospitalisation devraient être référées à la région de résidence du patient et détaillées par âge, sexe et diagnostic ICD-10. Le choix de la classification ICD se justifie par les facilités de comparaisons au travers des systèmes de santé considérés dans leur entièreté. Les tables de conversion des différentes versions (8, 9, 9-CM) vers la version la plus récente (10) semblent exister et le DSM IV permet le renvoi vers l'ICD-10. L'utilisation de l'ICPC-2 dont le transcodage à l'ICD10 est opérationnel et l'introduction dans la Famille de classification de l'OMS est imminente, pourrait être justifiée par sa plus faible granularité, sa capacité à définir les rubriques et son identification des besoins, peurs, préoccupations et demandes du patient.

5.9. Dans certains plans de santé américain et au Royaume-Uni, la réhospitalisation en service de psychiatrie dans les 30 – 60 jours après la sortie ou la réadmission en urgence ont été retenus comme indices de performance. Un tel indicateur pourrait être utile.

5.10. Un exercice semblable au précédent peut être mené pour les soins curatifs de jour, les soins de réhabilitation de jour, les soins infirmiers à long-terme de jour, les soins de réhabilitation à domicile et les soins infirmiers à long-terme à domicile. Une difficulté peut résider ici dans l'identification des services amenés à fournir ces types de prestation. La distinction entre soins de jour et soins à domicile paraît aisée. La différence de nature entre soins curatifs, soins de réhabilitation et soins infirmiers n'est pas toujours clairement perceptible. Elle peut varier en fonction des définitions qui en sont données et de la réalité des prestations effectuées, qui peuvent fluctuer dans le temps, particulièrement pour les patients chroniques. entre ces soins. D'autre part, certaines équipes offrent les deux types de soins, d'autres sont intégrées dans des équipes qui offrent les deux types de prestations, de jour et à domicile. On peut se demander s'il n'y a pas lieu de regrouper d'une part les soins de jours, théoriquement identifiables par les places offertes, et d'autre part les soins à domicile qui se caractérisent par le nombre de contacts entre les prestataires et les patients.

Les indicateurs suivants nous paraissent les plus pertinents :
Soins de jour :

a) **nombre de places pour 100.000 habitants**
b) **ratio de personnel soignant par place**
c) **nombre de sorties par an pour 100.000 habitants**
d) **taux d'occupation des places (peut être approché par a. et c.)**
e) **nombre de journées de soins par an pour 100.000 habitants**
f) **durée moyenne de suivi en soins de jour (peut être approchée par a. et e.)**

Soins à domicile :

a) **nombre de personnel soignant (en équivalent temps plein) par 100.000 habitants**
b) **nombre de patients traités par an pour 100.000 habitants**
c) **nombre de nouveaux cas par an pour 100.000 habitants**
d) **nombre de contacts/patient par an pour 100.000 habitants**
e) **nombre moyen de contacts par patient (peut être approché par b. et d.)**

Comme pour les services résidentiels, ces indicateurs devraient être fournis par pays et par région NUTS 2. Les sorties et les journées de soins de jour, les patients traités à domicile devraient être référées à la région de résidence du patient et détaillées par âge, sexe et diagnostic ICD-10.

5.11. En matière de soins ambulatoires, une division s'opère entre soins généralistes et spécialisés. Les omnipraticiens apportent à nombre de patients souffrant de problèmes de santé mentale une aide non spécialisée. Dans de nombreux pays cette aide est difficile à estimer sur base des données disponibles. Une manière de contourner la difficulté pourrait être de retenir comme indicateur **les médications psychotropes vendues sur prescription d'un généraliste** qui devraient être distinguées de celles **vendues sur prescription d'un spécialiste**. Il semble qu'une majorité de pays européens disposent des moyens de produire ce type d'information (Agence du médicament, 1998). Dans certains pays cependant, les ventes de médicaments calculées sur base des informations fournies par les grossistes ne rendront compte que du volume total des ventes en pharmacie sans permettre de distinction des prescripteurs (NOMESCO, 2001).

5.12. La classification de référence est pour nous la classification " Anatomique Thérapeutique Chimique/Dose Quotidienne Définie " (ATC/DDD) de l'OMS. Les produits pharmaceutiques qui nous intéressent relèvent du groupe N (système nerveux central) et des sous-groupes 05A (antipsychotiques), 05B (benzodiazépines), 05 C (hypnotiques et sédatifs) et 06A (antidépresseurs). L'expérience, rapportée par des pays familiers de l'emploi de la classification ATC/DDD (Nomesco, 2001), semble montrer que les codes ATC jusqu'aux niveaux 4 ne sont pas sujets à erreur dans des proportions significatives, susceptibles d'influencer les comparaisons. Le nombre de Doses Quotidiennes Définies peut rencontrer des difficultés d'application lorsque l'information sur les dosages, dans les registres de médicaments, présente des incohérences. Cette situation se retrouve par exemple avec une des formes commerciales d'une benzodiazépine. Les erreurs de calcul qui peuvent en découler n'ont cependant qu'une influence mineure sur les résultats lorsque ceux-ci sont agrégés au 3ème ou au 4ème niveau de la classification ATC.

5.13. Selon les pays, la consommation de médicaments peut cependant varier en fonction des systèmes de remboursements. Outre l'impact direct possible sur la consommation, des différences sensibles peuvent apparaître au niveau des montants de dépenses pour certaines médications. (Nomesco, 2001). L'accent mis sur le recours aux médicaments génériques influera aussi le montant total des dépenses. En Angleterre par exemple, les médicaments génériques représentent 92 % des hypnotiques et anxiolytiques achetés, 52 % des antidépresseurs et 34 % des antipsychotiques et antimanies (DoH, 2001e).

5.14. L'obligation de prescription pour le remboursement peut aussi influencer la consommation. A cet égard, la place de certaines médications phytothérapiques sur les listes de médicaments remboursés pourrait avoir une incidence, actuellement difficile à mesurer, sur la consommation totale. On retiendra ici les exemples de la valériane, utilisée en Suède comme sédatif ou du millepertuis largement utilisé en Allemagne pour le traitement des dépressions légères à modérées (15 % des prescriptions d'antidépresseurs par les omnipraticiens, Agence du Médicament, 1998) et remboursé depuis 1988. L'Irlande a suivi récemment la voie allemande en imposant la prescription pour l'achat du millepertuis.

5.15. On retiendra aussi qu'existe, en Grande-Bretagne, un système d'évaluation des prescriptions en médecine générale : les prescriptions d'hypnotiques, d'anxiolytiques et d'antidépresseurs font l'objet d'une évaluation par groupes d'âge par sexe. Compte tenu des risques d'accoutumance lié à leur consommation, les benzodiazepines (y inclus le zopiclone et le zolpidem) mesurées en doses quotidiennes définies (DDD) ont été retenues par les autorités britanniques de santé comme un des 5 indicateurs de qualité des prescriptions (Prescription Pricing Authority, 2001). Envisager les benzodiazépines comme indicateur spécifique implique de tenir compte du fait que qu'elles apparaissent dans la classification ATC/DDD au chapitre des antiépileptiques, à celui des anxiolytiques et à celui des hypnotiques et des sédatifs.

5.16. Le lithium pourrait aussi poser un problème de classification. Classé parmi les antipsychotiques dans la classification ATC/DDD, il figure par exemple parmi les antidépresseurs dans la classification pharmacothérapeutique belge.

5.17. Les **soins ambulatoires spécialisés**, qu'ils soient curatifs, de réhabilitation ou infirmiers à long-terme, sont souvent d'une grande diversité et fournis par une grande variété de prestataires. Cela peut aller du psychiatre ou du psychothérapeute travaillant seul en privé à l'équipe multidisciplinaire assurant le suivi quotidien de patients psychiatriques chroniques et qui selon les besoins, fournit des soins curatifs, infirmiers, de réhabilitation, une aide sociale … en centre ambulatoire mais aussi à domicile si nécessaire. La **consultation remboursée** et/ou le **contact/patient** qui sert souvent de point de référence par rapport au financement de services semblent les indicateurs les plus pertinents pour appréhender le volume des soins ambulatoires. La variété des formes d'organisation des soins ambulatoires risque de rendre la comparaison entre les pays et les régions difficiles. Plusieurs indicateurs sont envisageables. :

a) **le nombre de consultations réalisées par an par les psychiatres pour 100.000 habitants.**
b) **le nombre de cas traités par an par les psychiatres pour 100.000 habitants.**
c) **le nombre de nouveaux cas traités par an par les psychiatres pour 100.000 habitants.**

d) **le nombre de consultations réalisées par an par les psychologues pour 100.000 habitants.**
e) **le nombre de cas traités par an par les psychologues pour 100.000 habitants.**
f) **le nombre de nouveaux cas traités par an par les psychologues pour 100.000 habitants.**
g) **le nombre de contacts/patient réalisés par an par les différents types de services psychiatriques et de santé mentale ambulatoire pour 100.000 habitants.**
h) **le nombre de cas traités par an par les différents types de services psychiatriques et de santé mentale ambulatoire pour 100.000 habitants.**
i) **le nombre de nouveaux cas traités par an par les différents types de services psychiatriques et de santé mentale ambulatoire pour 100.000 habitants.**

Un détail par âge, sexe et diagnostic serait souhaitable mais ne pourra être fourni pour les prestations réalisées en cabinet privé dans plusieurs pays. La question du diagnostic peut se poser aussi ici dans la mesure ou une partie importante des prestations ambulatoires concerne des patients dont la pathologie est sub-clinique. Ces données devraient être disponibles par pays et région NUTS 2.

5.18. Dans certains pays où les consultations de psychologues ne sont pas remboursées, les indicateurs qui les concernent ne seront pas disponibles. D’autre part, la distinction entre soins ambulatoires et à domicile est parfois difficile à réaliser. Il arrive que des équipes offrent ces deux types de prestations successivement ou simultanément à un même patient chronique en fonction de ses besoins du moment. Il serait peut-être alors pertinent de regrouper dans un même indicateur l’ensemble des prestations réalisées en ambulatoire et à domicile. Ce qu’on retiendra ici c’est que ces indicateurs sont un reflet des soins ambulatoires spécialisés qui sont offerts dans le cadre d’organisation d’un système de santé donné. Compte tenu de la diversité d’organisation des systèmes de santé, il pourrait s’avérer pertinent d’agréger ces différentes données de façon à fournir un indice global de production de soins ambulatoires de psychiatrie et de santé mentale.

5.19. Enfin, plusieurs indicateurs de financement pourraient être retenus portant sur :

a) **le montant annuel des dépenses de psychiatrie et de santé mentale attribuables aux services hospitaliers.**
b) **le montant annuel des dépenses de psychiatrie et de santé mentale attribuables aux services résidentiels non hospitaliers.**
c) **le montant annuel des dépenses de psychiatrie et de santé mentale attribuables aux services ambulatoires.**
d) **le montant total annuel des dépenses de psychiatrie et de santé mentale.**

Il pourrait être utile de distinguer ici les amortissements de capital et les dépenses de santé proprement dite.

5.20. L’ensemble des indicateurs envisagés ici devrait permettre une comparaison pertinente des dispositifs psychiatriques et de santé mentale des différents pays européens et apporter un éclairage en matière d’orientations à définir et de décisions à prendre. Il reste que l’interprétation des données doit pouvoir s’appuyer sur une base documentaire détaillée qui permette d’éclairer les différences. La tâche pour aboutir à cet objectif reste considérable. Une équipe de travail permanente, chargée de la récolte de ces données, de leur mise à jour, de leur exploitation devrait être constituée. Sa permanence lui permettrait d’assurer la qualité des données recueillies, des retours d'information et des échanges entre les multiples services nationaux et internationaux impliqués. Un lien devrait être établi avec le département de la santé mentale du bureau régional de l'OMS, probablement plus particulièrement en matière d'évaluation de programmes et de planification.

BIBLIOGRAPHIE

1. Agence du médicament (1998) : Etude de la prescription et de la consommation des antidépresseurs en ambulatoire. Direction des Etudes et de l'information Pharmaco-économiques. Observatoire national des precriptions et consommations de médicaments. Juillet.
2. Caisse Nationale d'Assurance Maladie (CNAM) (2001) : Causes médicales d'attribution de pension d'invalidité. Département statistique. Juin.
3. Canadian Institute for Health Information (CIHI) (2000) : Mental health and addiction services : review of health information standards. July. http://www.cihi.ca/french/roadmap/Health_Ind/indicators2000f/tocf.shtml (mars 2001)
4. Civeira J. (1996) : Psychiatry in Spain. Inequalities in Health. Communication. Xth World Congress of Psychiatry. Madrid, 23-28 août.
5. CREDES (1999) : Prévalence et prise en charge médicale de la dépression en 1996-1997. Bulletin d'information en économie de la santé, 21, septembre.
6. Delesie L., Wuits Y., Nassen E., Haspeslach M. (1997) : Pourquoi un résumé psychiatrique minimum ?. Patient Classification Systems News, 27, septembre. http://www.hospvd.ch/public/ise/livres/pcs27/resu_psy.htm (mars 2001).
7. Department of Health (2001a) : Information and IT for the NHS : Mental health information strategy. March http://193.32.28.83/nhsexipu/strategy/nsf/2.htm (juin)
8. Department of Health (2001b) : National service framework for mental health : modern standards and services models. Glossary. July 11. http://www.doh.gov.uk/nsf/mhnsfannex.htm (août).
9. Department of Health (2001c) : Clinical psychology. Summary information for 2000 - 01. England. August 13. http://www.doh.gov.uk/public/kt240001/index.htm (septembre)
10. Department of Health (2001d) : Patient care in the community. Community psychiatric nursing summary information for 2000-01. september 20. http://www.doh.gov.uk/public/kc570001/index.htm (novembre)
11. Department of Health (2001e) : Prescription dispensed in the community. Statistics for 1999 to 2000 : England. Statistical Bulletin, 19. http://www.doh.gov.uk/stats/pca2000.htm (septembre)
12. Department of Health (2001f) : Hospital in-patient data, based on Hospital Episode Statistics (HES). Table 7 Main specialty, NHS Hospitals, England, 1999. http://www.doh.gov.uk/hes/standard_data/available_tables/index.html (novembre)
13. Department of Health and Aged Care (1999) : Mental health information development : National information priorities and strategies under the second national mental health plan, 1998-2003. Canberra.
14. ECHI Project (2001) : design for a set of European Community health indicators. Final Report, February 15, 2001.

15. ENMHPO (2000) : Establishment of indicators for mental health monitoring in , Interim Report (octobre 6)
16. Federal Health Monitoring System (2001) : Health report for Germany, 1998. http://www.gbe-bund.de/gbe/owa (septembre)
17. Federal Health Monitoring System (2001) : Deaths per 100,000 inhabitants (years, region, age, sexe, ICD 9). http://www.gbe-bund.de:80/oowa62a (septembre)
18. Fernandez J., Bonifacj C., Bouthiaux J.-P ., Dujols P. (1997) : Qualité des informations et financement des hôpitaux : critique méthodologique du contrôle officiel de la qualité des données du PMSI. Informatique et Santé, 9, 139 – 47.
19. Frank R., McGuire T., Regier D., Manderscheid R., Woodward A. (1994) : Paying for mental health and substance abuse care. Health Affairs, 13, 1, 337-42.
20. Frank R., McGuire Th. (1999) : Economics and mental health. NBER Working Paper 7052. March. http://www.nber.org/papers/w7052 (septembre 2000).
21. Gerdtham U.-G., Jönsson B., MacFarlan M., Oxley H. (1994) : Factors affecting health spending : a cross-country econometric analysis. Annexe de : Oxley H., MacFarland M. : Health care reform : controlling spending and increasing efficiency. OECD, Economics Department. Working papers n° 149, Paris.
22. Goldberg D., Lecrubier Y. (1995) : Form and frequency of mental disorders across centres. In : Üstün T., Sartorius N. : mental illness in general health care : an international study. Chichester, John Wiley & ons, 323-34.
23. Gomez-Beneyto M., Bonet A., Catala M., Puche E., Vila V. (1994) : Prevalence of mental disorders among children in Valencia, Spain. Acta Psychiat. Scand., 89, 352-7.
24. Graham L., Ward A., Mulvenna G. (2000) : Read Code User Guide. ISD Scotland. http://www.show.scot.nhs.uk/isd/primary_care/intro.htm (avril)
25. Guilmin A., Boisguérin B., Parayre C. : L'offre de soins en psychiatrie : des "modèles" différents selon les départements. DREES, Etudes et résultats, 48, janvier.
26. Häfner H., Maurer K., Löffler W., van der Heiden W., Munk-Jorgensen P., hambrecht M., Riecher-Rössler A. (1998) : The ABC schizophrenia study : a preliminary overview of the results. Soc. Psychiatry Psychiatr. Epidemiol., 33, 380-6.
27. Hurst J., Jee-Hughes M. (2000) : Performance measurement and performance management in OECD health systems. DEELSA/ELSA/WD (2000)8, OCDE, Paris, 66 p.
28. International Consortium for Mental Health Policy and Services (2001) : Country profile. April. http://www.world-mental-health.net (juillet).
29. InterRAI (2001) : Minimum Data Set-Mental Health. http://interrai.providence.on.ca/mds_list.htm (juillet)
30. ISD Scotland (2001) : Key health topics/mental health : outpatients. http://www.show.scot.nhs.uk/isd/mental_health/intro.htm (avril)
31. Jamoulle M. (2001) : ICPC use in the European Community. WONCA International Classification Committee. 16th WONCA World Congress of Family Doctors, Durban, South Africa,13- 17th May.
32. Katschnig H., Ezersdorfer E., Muzik M. (1993) : “ Nicht nur eine minderwertige Gesundheit ”. Eine Untersuchung ûber die Einstellung der österreichischen Bevölkerung zur psychisch Kranken und zur Psychiatrie. Forschungsbericht, Wien.
33. Katschnig H., Ladinser E., Scherer M., Sonneck G., Wancata J. (2001) : Daten zur psychiatrischen und psychosozialen Versorgung der österreichischen Bevölkerung. Ludwig-Boltzmann-Institut für Sozialpsychiatrie. Wien, März.

34. Kessler R., Berglund P., Zhao S. Leaf P., Kouzis A., Bruce M., Friedman R., Grossier R., Kennedy C., Narrow W., Kuehnel T., Laska E., Manderscheid R., Rosenheck R., Santoni T., Schneier M. (1996) : The 12 month prevalence and correlates of serious mental illness. In manderscheid R. et Sonneschein M. (Eds) , Mental Health, United States, 1996, DHHS publication N° (SMA) 96-3098, Washington DC, US Government Printing Office, 59-70.
35. Kessler R., Frank R., Edlund M. et al. (1997) : Differences in the use of psychiatric outpatient services between the United States and Ontario. New England J. Medicine, 336, 8, 551-7.
36. Kovess V., Soyris D. (1994) : DIM et PMSI en psychiatrie. Faisabilité et enjeu. L'Encéphale, XX, 37-45.
37. Lavikainen J., Lathinen E., Lehtinen V. (2000) : Public health approach on mental health in Europe. National Research and Development Centre for Welfare and Health, STAKES. Pp 13X
38. Löffler W., Häfner H., Fätkenheuer B., Maurer K., Riechler-Rössler A., Lützhoft J., Skadhede F., Munk-Jorgensen P., Strömgren E. : validation of Danish case-register for schizophrenia. Acta Psych. Scand., 90, 196-203.
39. Mahieu R. (2000) : Les déterminants des dépenses de santé : une approche macroéconomique
40. Document de travail. INSEE. Direction des Etudes et Synthèses Economiques. Janvier. Pp.40
41. Massé G. (1992) : Rapport de la mission confiée par le ministre délégué à la santé. Juin.
42. Ministère de la Santé (1988) : Définition de la santé mentale. In : La santé mentale des Canadiens : vers un juste équilibre. Ottawa.
43. Ministero della Sanita (1998) : Stato di realizzazione dei dipartimenti di salute mentale. Dipartimento della Prevenzione e Dipartimento della Programmazione. Roma.
44. Munk-Jorgensen P., Lehtinen V., Helgason T., Dalgard O., Westrin C. (1995) : Psychiatry in the five nordic countries. Eur. J. Psychiat., 10, 197 – 206.
45. Munk-Jorgensen P. (1999) : Nordic European countries. In : Thornicroft G., Tansella M. (eds) : The mental health matrix. A manual to improve services. Cambridge University press, Cambridge, 228 – 242.
46. Murray C., Lopez A. (1996) : The global burden of disease. Vol. I : a comprehensive assessment of mortality and disability from diseases, injuries and risks factors in 1990 and projected to 2020. Vol. II : global health statistics. Harvard School of Public Health, World health Organization and World Bank. Cambridge Massachusetts.
47. NASMHPD (2000) : Mental health statistics improvement program. http://www.mhsip.org/projects.html (mars 2001)
48. National Health Service Information Authority (2001) : Mental Health Minimum Data Set. Data manual Version 2.0, July. http://www.nhsia.nhs.uk/mentalhealth (août).
49. Nordic Medico-Statistical Commitee (NOMESCO) (2001) : Health Statistics in the Nordic Countries, 1999. http://www.nom_nos.dk/nomesco.htm (août).
50. OCDE (1997) : Eco-Santé, Paris
51. OCDE (1998) : Health Data, Paris
52. OCDE (2000a) : ICHA-HC functional classification of health care. In : A system of health accounts. Version 1.0. Paris. 111-34.
53. OCDE (2000b) : ICHA-HP classification of health care providers. In : A system of health accounts. Version 1.0. Paris. 135-50.

54. OMS (2001) : Rapport sur la santé dans le monde. La santé mentale : nouvelle conception, nouveaux espoirs. Genève, 182 p. + annexes.
55. Parquet Ph.-J. et le groupe d'experts sur l'itinéraire des déprimés (2001) : Itinéraires des déprimés : réflexions sur leurs trajectoires en France. Janvier. http://psydoc-fr.broca.inserm.fr/bibliothq/sallelec/Itindeprimes (août)
56. Peers J. (n.d.) : Les soins de santé en Belgique : Défis et opportunités. Sans nom d'éditeur. Bruxelles.
57. Prescription Pricing Authority (2001) : Measuring prescribing. http : www.ppa.org.uk/education (avril)
58. Prescription Pricing Authority Newsletter (2000) : PACT centre pages : Mental Health. ImPACT, september, http://www.ppa.org.uk/pdfs/imPACTsept.pdf (avril 2001).
59. Robinson J., Tartaryn D. (1997) : Reliability of the Manitoba Mental Health Management Information System for Research. Can. J. Psychiatry, 42, 744-9.
60. Roelandt J.-L., Piel E. (2001) : De la psychiatrie vers la santé mentale. Rapport de mission au Ministre Délégué à la Santé. Juillet. http://www.sante.gouv.fr/htm/actes/index_rapports.htm (9 juillet 2001).
61. Santé Canada : Bureau de la Santé et de l'Inforoute (1998) : initiatives internationales dans le secteur des dossiers médicaux électroniques : identification formelle et ICP. Ottawa. Pp 25. http://www.hc-sc.gc.ca/ohih-bsi (avril 2001)
62. Shaffer D., Fisher P ., dulcan M., davies M., Piacentini J., Schwab-Stone M., lahey B., Bourdon K., Jensen P., Bird H., Canino C., Regier D. (1996) : The NIMH Diagnostic Interview Schedule for Children version 2.3. (DISC-2.3) : description, acceptability, prevalence rates and performance in the MECA study. J. Am. Acad. Child Adol. Psychiat., 35, 864-77.
63. Site officiel du PMSI (2001) : Trajectoire de soins et glossaire.
64. http://www.le-pmsi.fr/commun/glossaire/gloss.htm (mars et octobre)
65. Social –og Helse departementet (2001) : Mental health 1999-2006. http://odin.dep.no/archive/shdvedlegg/01/05/Psych061.pdf (avril)
66. STAKES-ENMHPO (2000) : Minimum data set of mental health indicators. Proposed set of mental health indicators ; definitions, description and sources. (august 20)
67. Statistics Nederland (2001) : Health and welfare : cost and financing of health care. http://www.cbs.nl/en/figures/keyfigures/kwg0640z.htm (juin)
68. Steinhausen H., Winkler C., Metzke C., Meier M., Kannenberg R. (1998) : Prevalence of child and adolescent psychiatri disorders : the Zurich Epidemiological Study. Acta psychiat. Scand., 98, 262-71.
69. Stuart H. (2000) : Acess to physician treatment for a mental disorder : a regional analysis. Soc. Psychiatry Psychiatr. Epidemiol., 35, 61-70.
70. Thornicroft G., Tansella M. (1999) : The mental health matrix. A manual to improve services. Cambridge University Press.
71. Trimbos-instituut (2000) : Major challenges to Dutch mental health care. Fact sheets mental health care (GGZ), 1, August.
72. Van Casteren V., Fleming D., Schellevis F. (2001) : Information about health from sentinel pratice networks : the example of diabetes mellitus. Communication. EUPHA Meeting, Brussels, 6-8 december.
73. Vander Stichele R. (XXXX) : Strategy for " Mapping Europe ". EURODURG bulletin,

74. van Dijk L. (2001) : Patterns in the prescription of antidepressants drugs in the Netherlands. Communication. EUPHA Meeting, Brussels, 2001.
75. Van Os J., Neeleman J.(1994) : Caring for mentally ill people. BMJ, 309 (6963), 1218-21.
76. Wagenaar G. (1993) : Indicateurs et systèmes d'information en santé mentale. Journal d'Economie Médicale, 11, 4, 201-24.
77. Wasylenki D., Goering P., Cochrane J., Durbin J., Rogers J., Prendergast P. (2000) : Tertiary mental health services : I. Key concepts. Can. J. Psychiatry, 45, 179 – 84.
78. Weyerer S., Castell R., Biener A., Artner K., Dilling H. (1988) : Prevalence and treatment of psychiatric disorders in 3-14 year old children : results of a representative field study in the small rural town region of Traunstein, Upper Bavaria. Acta Psychiat. Scan., 77, 290-6.
79. Wittchen H., Müller N., Pfister H., Winter S., Schmidtkunz B. (1999) : Affektive, somatoforme und Angststörungen in Deutschland – erste Ergebnisse des bundesweiten Zusatzsurveys " Psychische Störungen ". Gesundheitwesen 61, 2, 216-22.
80. Wörister K (2000) : Pensionen wegen verminderter Arbeitsfähigkeit – aktuelle Daten. Manuskript der Abteilung Wirtschaftswissenschaften der Arbeiterkammer, Wien.
81. Zarifian E. (1996) : Le prix du bien-être. Odile Jacob, Paris.

Annex 2:

Questionnary for Secondary Health Care

Identification of the provider

Items	Answer
Name and forename	
Institution	
Address	
Zip code number and City	
Country	
Telephone number	
Fax number	
e-mail	

1. Characteristics of the registration system

Items	Content	Example	Answer
Register name	Official name and/or currently used name	Résumé Clinique Minimum	
Abbreviation	Common abbreviation of the register	RCM	
Country concerned		Belgium	
Regions concerned	222 regions *	BE	

* Please select the concerned region(s) and give the corresponding code (example: IE022 for Mid-East). If it is a national register, give the country code (example: AT for Austria)

Concerned City		All	
Purposes of the registration system	Description of the specific aims of the basis	To support the health policy, concerning: (1) definition of the needs in hospital equipments, (2) définition of qualitative and quantitative rules of approval for hospitals, (3) organization of hospital financing, (4) définition of the policy of medecine practice (5) organization of an epidemiological policy	
Period	Date of the beginning and end of the registration period, periodicity	Since January 1st 1993, continuous	
Financing source of the registration system	Financing sources	Part B4 of the day fee paid to hospitals by the Institut National d'Assurance Maladie Invalidité whose funds come mainly from taxes and contributions of workers and employers (A.M. of 02.08.86 published in M.B. the 21.08.86)	
Ethical aspects	Security and privacy of the registration system (please send us a copy of the law in your country)	Law of december 8 1992 concerning the protection of private life and judgment of the protection of private life commission.	

Items	Content	Example	Answer
Institution in charge of the registration system	Institution in charge of the registration system and address	Ministère des Affaires sociales, de la Santé Publique et de l'Environnement - Administration des Soins de Santé - Cité administrative de l'Etat - Quartier Vésale - 1010 Bruxelles	
Main investigator	Person to contact and address	Mrs Olewicki: 32-2-210.47.85	
Description	Does a detailed description of the registration system exist? If yes, please transmit us a copy.	Yes, the leaflet: "Directives pour l'enregistrement du Résumé Clinique Minimum"	
Registration method	Classification type	ICD-9-CM	
Register type	Data registration format	Records *.txt	
Storage	Where are the data stored?	At the Ministère de la Santé Publique	
Accessibility	What are the access conditions to the data?	Decision of the RCM Commission based on a written and motivated request	
Quality	Is there a process for controlling the data quality? Which one?	Yes, the law imposes a commission to supervise and evaluate the statistical data.	
Feed-back	Is there a feed-back ?	Yes, each hospital receives a yearly document with the data concerning it.	

2. Content of the register

Variables	Content	Remarks

We now ask you to give us the complete list of the register variables, with a description of their content, and eventual remarks. If everything already appears in a document, you can send this document , provided it is in french or in english.

To help you to understand what we wish to receive as informations, you'll find here (click here) an example of completed file

Regions (NUTS codes)

Country	Regions	Code
Austria		AT
	Ostösterreich	AT1
	Burgenland	AT11
	Niederösterreich	AT12
	Wien	AT13
	Südösterreich	AT2
	Kärnten	AT21
	Steiermark	AT22
	Westösterreich	AT3
	Oberösterreich	AT31
	Salzburg	AT32
	Tirol	AT33
	Voralberg	AT34
Belgium		BE
	Bruxelles-Brussel	BE1
	Vlaams-Gewest	BE2
	Antwerpen	BE21
	Limburg (B)	BE22
	Oost-Vlanderen	BE23
	Vlaams Brabant	BE24
	West Vlanderen	BE25
	Région Wallonne	BE3
	Brabant Wallon	BE31
	Hainaut	BE32
	Liège	BE33
	Luxembourg (B)	BE34
	Namur	BE35
Deutschland		DE
	Baden-Württemberg	DE1
	Stuttgart	DE11
	Karlsruhe	DE12
	Freiburg	DE13
	Tübingen	DE14
	Bayern	DE2
	Oberbayern	DE21
	Niederbayern	DE22
	Oberpfalz	DE23
	Oberfranken	DE24
	Mittelfranken	DE25
	Unterfranken	DE26
	Schwaben	DE27

	Berlin	DE3
	Brandenburg	DE4
	Bremen	DE5
	Hamburg	DE6
	Hessen	DE7
	Darmstadt	DE71
	Giessen	DE72
	Kassel	DE73
	Meckelnburg-Vorpommern	DE8
	Niedersachsen	DE9
	Braunschweig	DE91
	Hannover	DE92
	Lüneburg	DE93
	Weser-Ems	DE94
	Nordrhein-Westfalen	DEA
	Düsseldorf	DEA1
	Köln	DEA2
	Münster	DEA3
	Detmold	DEA4
	Amsberg	DEA5
	Rheinland-Pfalz	DEB
	Koblenz	DEB1
	Trier	DEB2
	Rheinhessen-Pfalz	DEB3
	Saarland	DEC
	Sachsen	DED
	Sachsen-Anhalt	DEE
	Dessau	DEE1
	Halle	DEE2
	Magdeburg	DEE3
	Schleswig-Holstein	DEF
	Thüringen	DEG
Denmark		DK
	Koebenhavn og frederiks kom	DK001
	Koebenhavn amt	DK002
	Frederiksborg amt	DK003
	Roskilde amt	DK004
	Vestsjaellands amt	DK005
	Storstroems amt	DK006
	Bornholms amt	DK007
	Fyns amt	DK008
	Soenderjyllands amt	DK009
	Ribe amt	DK00A
	Vejle amt	DK00B
	Ringkoebing amt	DK00C
	Aarhus amt	DK00D
	Viborg amt	DK00E

	Nordjyllands amt	DK00F
Spain		ES
	Noroeste	ES1
	Galicia	ES11
	Asturias	ES12
	Cantabria	ES13
	Noreste	ES2
	Pais Vasco	ES21
	Navarra	ES22
	Rioja	ES23
	Aragon	ES24
	Madrid	ES3
	Centro (E)	ES4
	Castilla-Leon	ES41
	Castilla-La Mancha	ES42
	Extremadura	ES43
	Este	ES5
	Cataluna	ES51
	Comunidad Valenciana	ES52
	Baleares	ES53
	Sur	ES6
	Andalucia	ES61
	Murcia	ES62
	Ceuta y Melilla	ES63
	Canarias	ES7
Finland		FI
	Manner-Suomi	FI1
	Itae-Suomi	FI13
	Vaeli-Suomi	FI14
	Pohjois-Suomi	FI15
	Uusimaa	FI16
	Etelae-Suomi	FI17
	Ahvenmaavaaland	FI2
France		FR
	Ile de France	FR1
	Bassin Parisien	FR2
	Champagne-Ardenne	FR21
	Picardie	FR22
	Haute-Normandie	FR23
	Centre	FR24
	Basse-Normandie	FR25
	Bourgogne	FR26
	Nord-Pas-De-Calais	FR3
	Est	FR4
	Lorraine	FR41

	Alsace	FR42
	Franche-Comté	FR43
	Ouest	FR5
	Pays De La Loire	FR51
	Bretagne	FR52
	Poitou-Charentes	FR53
	Sud-Ouest	FR6
	Aquitaine	FR61
	Midi-Pyrénées	FR62
	Limousin	FR63
	Centre-Est	FR7
	Rhones-Alpes	FR71
	Auvergne	FR72
	Méditerranée	FR8
	Languedoc-Roussillon	FR81
	Provence-Alpes-Côte d'Azur	FR82
	Corse	FR83
	Départements D'Outre Mer	FR9
	Guadeloupe	FR91
	Martinique	FR92
	Guyane	FR93
	Réunion	FR94
Greece		GR
	Voreia Ellada	GR1
	Anatoliki Makedonia	GR11
	Kentriki Makedonia	GR12
	Dytiki Makedonia	GR13
	Thessalia	GR14
	Kentriki Ellada	GR2
	Ipeiros	GR21
	Ionia Nisia	GR22
	Dytiki Ellada	GR23
	Sterea Ellada	GR24
	Peloponnisos	GR25
	Attiki	GR3
	Nisia Aigaiou	GR4
	Voreio Aigaio	GR41
	Notio Aigaio	GR42
	Kriti	GR43
Ireland		IE
	Border, Midland and Western	IE01
	Border	IE011
	Midland	IE012
	West	IE013
	Southern and Eastern	IE02
	Dublin	IE021

	Mid-East	IE022
	Mid-West	IE023
	South-East (IRL)	IE024
	South-West (IRL)	IE025
Italy		IT
	Nord Ovest	IT1
	Piemonte	IT11
	Valle D'Aosta	IT12
	Liguria	IT13
	Lombardia	IT2
	Nord Est	IT3
	Trentino-Alto Adige	IT31
	Veneto	IT32
	Friuli-Venezia Giulia	IT33
	Emilia-Romagna	IT4
	Centro (I)	IT5
	Toscana	IT51
	Umbria	IT52
	Marche	IT53
	Lazio	IT6
	Abruzzi-Molise	IT7
	Abruzzi	IT71
	Molise	IT72
	Campania	IT8
	Sud	IT9
	Puglia	IT91
	Basilicata	IT92
	Calabria	IT93
	Sicilia	ITA
	Sardegna	ITB
Luxembourg		LU
Netherlands		NL
	Noord-Nederland	NL1
	Groningen	NL11
	Friesland	NL12
	Drenthe	NL13
	Oost-Nederland	NL2
	Overijssel	NL21
	Gelderland	NL22
	Flevoland	NL23
	West-Nederland	NL3
	Utrecht	NL31
	Noord-Holland	NL32
	Zuid-Holland	NL33
	Zeeland	NL34

	Zuid-Nederland	NL4
	Noord-Brabant	NL41
	Limburg (NL)	NL42
Portugal		PT
	Continente	PT1
	Norte	PT11
	Centro (P)	PT12
	Lisboa E Vale Do Tejo	PT13
	Alentejo	PT14
	Algarve	PT15
	Accores	PT2
	Madeira	PT3
Sweden		SE
	Sweden Nuts 1	SE0
	Stockholm	SE01
	Oestra Mellansverige	SE02
	Sydsverige	SE04
	Norra Mellansverige	SE06
	Mellersta Norrland	SE07
	Oevre Norrland	SE08
	Smaaland Med Oearna	SE09
	Vaestsverige	SE0A
United Kingdom		UK
	North East	UKC
	Tees Valley and Durham	UKC1
	Nothumberland	UKC2
	Notrth West (including Merseyside)	UKD
	Cumbria	UKD1
	Cheshire	UKD2
	Greater Manchester	UKD3
	Lancashire	UKD4
	Merseyside	UKD5
	Yorkshire and The Humber	UKE
	East Riding and North Lincolnshire	UKE1
	North Yorkshire	UKE2
	South Yorkshire	UKE3
	West Yorkshire	UKE4
	East Midlands	UKF
	Derbyshire and Nottinghamshire	UKF1
	Leicestershire	UKF2
	Lincolnshire	UKF3
	West Midlands	UKG
	Herefordshire	UKG1
	Shropshire and Staffordshire	UKG2

	West Midlands	UKG3
	Eastern	UKH
	East Anglia	UKH1
	Bedfordshire	UKH2
	Essex	UKH3
	London	UKI
	Inner London	UKI1
	Outer London	UKI2
	South East	UKJ
	Berkshire	UKJ1
	Surrey	UKJ2
	Hampshire and Isle of Wight	UKJ3
	Kent	UKJ4
	South West	UKK
	Gloucestershire	UKK1
	Dorset and Somerset	UKK2
	Cornwall and Isles Of Scilly	UKK3
	Devon	UKK4
	Wales	UKL
	West Wales and The Valleys	UKL1
	East Wales	UKL2
	Scotland	UKM
	North Eastern Scotland	UKM1
	Eastern Scotland	UKM2
	South Western Scotland	UKM3
	Highlands and I	UKM4

Example: Résumé Clinique Minimum (RCM)

Variables	Content	Remarks
Hospital		
CTI Number	Single number given to the establishment by the Ministry of Social Affairs, Public Health and Environment .	It isn't the agreement number.
Year	Example: 1999	
Registration semester	1 or 2	
Agreement number	Number given by the appropriate Minister for the agreement of the hospitals.	It is different of the CTI number.
Date of creation of the ASCII	Example: 22071999 (DDMMYYYY)	
Patient		
Anymous patient number in the hospital (patient's key)	Number given to the patient at least for one year, wathever how often he comes.	This number is usefull as well for the hospitalization as for the outpatient treatment, it protects the patient's anonymity and it's the connection between the RCM and the patient medical record (patient's key)
Birth year	Example: 1958	
Hospitalization		
Hospitalization number	One number for each hospitalization	Number valid for the whole during of only one stay , totally protecting the patient's anonymity
Kind of hospitalization	Classical hospitalization (H), day hospitalization (D), long stay (F, M, L), complete psychiatric stay (P)	
Entrance year	Example: 1999	
Entrance month	Example: 08	
Day of the entrance week	Monday (1), Tuesday (2), Wednesday (3), Thursday (4), Friday (5), Saturday (6), Sunday (7) .	
Readmission code	Unkown (0), within year (1), no readmission within year (2), long stay (F, M, L)	To use when the patient has left the same hospital, to the maximum one year before the beginning of the current stay.
Readmission: number of days since last entrance	Current admission date minus date of the last outgoing from the same hospital	
Outgoing month	Example: 09	It must be in the recording period.
Day of the outgoing week	Let's see to "day of the entrance week".	
Total during hospitalization, in number of days.	Outgoing date minus admission date	

Variables	Content	Remarks
Sex	Indefinable (newborn child) (0), male (1), female (2), changed (transsexuals) (3)	
Age indicator	Newborn child or aged of less than 29 days (1), aged from 29 days until 1 year (2), aged of more than 1 year (3)	Age at the moment of the admission
Postal code Belgium		
INS code Belgique		Number given to each commune by the "National Statistic Institute"
Land code		It's the domiciliation land of the patient
Nationality indicator	Unknown (0), belgian (1), citizen of the EU (2), other lands (3)	
Place before the admission	Unknown (0), home (1),administrative admission of a long during stay during a fusion (2), other non-universitary hospital (3), other universitary hospital (4), other psychiatric hospital (5), rest home and old people's home (6), mental home and protected habitations (7), born in the hospital (8), others (9), long during stay (M,L)	Place where was the patient just before his admission.
Kind of admission	Unknown (0), emergency admission by the 100 or the SMUR (1), unexpected admission, in emergency (2), planified admission (3), day hospitalization admission (4), return (5), placement (6), born in the hospital (8), long during stay (M, L)	
Send by	Unknown (0), on his own initiative (1), general practitioner (2), specialist (doctor) of the hospital (3), specialist (doctor) out of hospital (4), insurer organization (5), third party (6), born in the hospital (8), long during stay (M, L)	
Destination	Unknown (0), home (1), administrative outgoing for a long during stay during a fusion (2), other non-universitary hospital (3), other universitary hospital (4),other psychiatric hospital (5), rest home and old people's home (6), mental home and protected habitations (7), dead (8), others (9), long during stay (F, M)	

Variables	Content	Remarks
Kind of outgoing	Unknown (0), on medical advice (1), against medical advice (2), dead with autopsy (3), dead without autopsy (4), transfer to another institution for specialized care (5), transfer or return to another institution for rehabilitation or care (6), return after a one day treatment in the hospital where he's hospitalized (D), long during stay (F, M)	
Total number of days to completely invoice for the hospitalization		
Hospitalization in specialized area		
Chronological order number of the specialized area	Example: 02	If the patient has stayed in different specialized areas during his hospitalization
Specialized area code	Example: 125	Determined by the hospital
During of stay in the specialized area - calculated in days	Date of outgoing from specialized area minus date of the admission in specialized area	
During of stay in the "intensive cares" - in days ***During of stay in the "intensive cares" - in hours***		For the approved or not approved services, and for the coronary units To complete the previous variable if the during of stay is over 24 hours
Stay in bed index		
Chronological order number of the bed index	Example: 05	If the patient has different bed indexes during one hospitalization
Code of the bed index	Code used for the invoicing - Example : chirurgical bed (C), medical bed (D)	
During of stay in bed index calculated in days	The date of outgoing from bed index minus the date of admission in bed index	
Number of days to completely invoice for the current record year		
Number of days to completely invoice for the previous records years	For long during stays	
Number of days to partly invoice for the current record year		
Number of days to partly invoice for the previous records years	For long during stays	

Variables	Content	Remarks
Number of days to don't invoice for the current record year		
Number of days to don't invoice for the previous records years	For long during stays	
Stay in care units		
Chronological order number of the care unit		If the patient has stayed in different care units during his hospitalization
Care unit code	Codes used for the RIM record	
During of stay in care unit calculated in days	Date of outgoing from care unit minus date of the admission in care unit	
Diagnosis		
Diagnosis	Following the ICD-9-CM classification	
Main/Secondary diagnosis' code	Main (P), secondary (S)	The main diagnosis is the diagnosis that, after examination, has been indicated as the main cause for patient admission in the hospital. The secondary diagnoses are defined as diseases that were present at the admission or developped during hospitalization and which have effects on the cares given to the patient during the considered hospitalization.
Certitude degree	Unknown (0), probable (1), certain (2),confirmed by the anatomo-pathology (3)	
ICD-9-CM procedure		
Diagnosis' code	Diagnosis that has given rise to the implementation of the mentioned procedure	
ICD-9-CM procedure code		
Time between the admission in the hospital and the realisation of the ICD-9-CM procedure	Procedure realisation date minus admission date	
Code "realised outside"	Unknown (0), in the hospital for a patient of the hospital (1), in another hospital for a patient of the hospital (2), in the hospital for a patient of another hospital (3)	
Emergency degree	Unknown (0), urgent: < 6 hours after the diagnosis (1), deffered: > 6 hours after the diagnosis (2)	

Variables	Content	Remarks
Anaesthesia code	Unknown (0), no anaesthesia (1), local anaesthesia (2), loco-regional anaesthesia (3), general anaesthesia (4), rachianesthesy (5), epidural anaesthesia (6), sedation (7), general and epidural (8),general and loco-regional (9), hypnosis (H), other (A)	
INAMI procedure		
INAMI procedure code	Mention the services mentioned in the enclosure 8	Only for the services invoiced at 100%
Chronological order number of the same INAMI procedure		For the services invoiced more than once
Time between the admission in the hospital and the realisation of the INAMI procedure	Procedure realisation date minus admission date	
Birth of the newborn		
Year of recording of the newborn		=Birth registration year
Year of recording of the mother's stay		
Semester of recording of the mother's stay recording		
Mother's stay number		
Year of recording of the mother's stay		
Anonymous patient number of the mother in the hospital		
Birth place	In the hospital (0), in another hospital (1), not in an hospital (2)	
ICD-9-CM birth code	Following V30 to V39 codes of the ICD-9-CM classification	For alive birth
Birth chronological order code of the succession.	Only one child (0), 1st of a multiple birth (1), second of a multiple birth (2), third of a multiple birth (3), 4th of a multiple birth(4), 5th of a multiple birth(5), 6th of a multiple birth (6), 7th of a multiple birth (7), since the 8th of a multiple birth (8), not specified (9)	
Birth hour	From 00 until 23	
Weight at birth	In grams	
Apgar score after one minute	From 0 until 10	
Apgar score after 5 minutes	From 0 until 10	

Variables	Content	Remarks
Number of pregnancy weeks		
During of the mother's stay before childbirth	Childbirth date minus mother's admission date	
Year of recording of the birth stay or of the first stay for the children born on another place		
Semester of recording of the birth stay or of the first stay for the children born on another place		
Stay number of the birth stay or of the first stay for the children born on another place		

Annex 3:

Industrial Accidents and Occupational Diseases

I Financement

II Soins de santé

III Maladies - Prestations en espèces

IV Maternité

V Invalidité

VI Vieillesse

VII Survivants

VIII Accidents du travail et maladies professionnelles

IX Prestations familiales

X Chômage

XI Garantie de ressources

Tableau VIII

Accidents du travail et maladies professionnelles

	Belgique	Danemark	Allemagne	Grèce	
Législation en vigueur	*Accidents du travail*: Loi du 10 avril 1971. *Maladies professionnelles*: Lois coordonnées par l'arrêté royal du 3 juin 1970.	Loi du 8 mars 1978, modifiée. Loi du 20 mai 1992 qui s'applique aux accidents survenus après le 1er janvier 1993 et aux maladies professionnelles déclarées après cette date, modifiée par la loi du 30 mai 1998, en vigueur depuis le 1 janvier 1999.	Code social *(Sozialgesetzbuch)* 7ème partie du 7 août 1996, dernièrement amendé par la loi du 16 juin 1998.	Il n'existe pas d'assurance spécifique, le risque est couvert par les assurances maladie, invalidité, survivants, sous réserve de modalités spécifiques.	**Législation en vigueur**
Champ d'application	*Accidents du travail*: travailleurs assujettis à la sécurité sociale, apprentis et personnes auxquelles le roi a étendu le bénéfice de la loi. *Maladies professionnelles*: les mêmes (sauf les personnes auxquelles le roi a étendu le bénéfice de la loi sur les accidents du travail), les stagiaires, même non rémunérés, les élèves et étudiants exposés au risque du fait de leur instruction.	Tous les salariés et certains travailleurs indépendants (secteur de la pêche et de la navigation). Les stagiaires ou autres personnes qui, à l'occasion de leurs études ou de leur formation professionnelle, se trouvent dans un établissement de formation ou sur un lieu de travail. Les enfants qui souffrent d'une maladie ou d'une lésion congénitale due au travail de la mère ou du père.	Salariés, certains indépendants, écoliers, étudiants et enfants au jardin d'enfants, personnes en réadaptation et certaines autres personnes.	Salariés et assimilés.	**Champ d'application**

Accidents du travail et maladies professionnelles

Tableau VIII

Espagne	France	Irlande	Islande	Italie	
Accidents du travail: Texte refondu de la législation des accidents du travail; décret du 22 juin 1956. *Maladies professionnelles*: Décret royal législatif 1/94 du 20 juin, qui approuve le texte refondu de la loi générale sur la sécurité sociale *(Ley General de la Seguridad Social)*. Décret royal n° 2609 du 24 septembre 1982. Décret royal n°1647 du 31 octobre 1997. Loi n°50 du 30 décembre 1998 portant sur les mesures fiscales, administratives et d'ordre social.	Code de la sécurité sociale, livre IV.	Loi unifiée sur la protection sociale *(Social Welfare Consolidation Act)* de 1993, modifiée.	Loi sur la sécurité sociale *(Lög um almannatryggingar)*, n° 117/1993 de décembre 1993 et amendements ultérieurs. Loi sur l'aide sociale *(Lög um félagslega aðstoð)*, n° 118/1997 de décembre 1993 et amendements ultérieurs. Loi sur l'invalidité *(Lög um málefni fatlaðra)*, n° 59/1992 de juin 1992 et amendements ultérieurs.	Décret-loi (DPR) du 30 juin 1965, n° 1124. Loi du 10 mai 1982, n° 251. Décret-loi (DPR) du 13 avril 1994, n° 336.	**Législation en vigueur**
Salariés.	Personnes qui travaillent à quelque titre que ce soit, en quelque lieu que ce soit pour un ou plusieurs employeurs.	Tous les salariés et certains stagiaires.	• Tous les salariés, • les travailleurs indépendants sauf en cas d'exemption volontaire, • les apprentis, • les personnes participant à des opérations de sauvetage, • les athlètes participant des activités sportives organisées, • les patients durant leur traitement dans les établissements médicaux, • les personnes effectuant des travaux ménagers peuvent s'assurer volontairement.	Travailleurs salariés et certaines catégories de travailleurs indépendants.	**Champ d'application**

Tableau VIII

Accidents du travail et maladies professionnelles

	Liechtenstein	Luxembourg	Pays-Bas	Norvège	Autriche
Législation en vigueur	Loi sur l'assurance accidents obligatoire *(Gesetz über die obligatorische Unfallversicherung)*, LGBl. 1990 n° 46, modifiée pour la dernière fois par LGBl. 1998 n° 110.	Livre II du Code des assurances sociales, modifié notamment par la loi du 17 novembre 1997.	Il n'existe pas d'assurance spécifique en matière d'accidents de travail et de maladies professionnelles. Ces risques sont couverts par l'assurance maladie (prestations en nature et en espèce), l'assurance incapacité de travail (invalidité) et l'assurance survivants.	Loi sur l'Assurance nationale *(folketrygdloven)* du 28 février 1997, chapitre 13. Loi sur l'assurance contre les accidents du travail du 16 juin 1989.	Loi générale sur les assurances sociales *(Allgemeines Sozialversicherungsgesetz, ASVG)* du 9 septembre 1955, dernièrement amendée par BGBl. *(Journal Officiel)* I n. 2/2000. Loi fédérale sur les établissements hospitaliers *(Krankenanstaltengesetz, KAG)* du 18 décembre 1956 et lois des *Länder* sur les établissements hospitaliers, modifiées. Indemnité de soins *(Pflegegeld)*: Loi fédérale sur l'indemnité de soins *(Bundespflegegeldgesetz, BPGG)* du 19 janvier 1933, dernièrement amendée par BGBl. I n. 111/1998.
Champ d'application	• Salariés, y compris les travailleurs à domicile, les apprentis et les stagiaires, ainsi que les personnes travaillant dans des entreprises de protection ou des entreprises d'invalides. • Accidents non liés au travail: salariés à temps plein et salariés à temps partiel dont le temps de travail pour un employeur s'élève à 12 heures au moins. • Assurance volontaire: travailleurs indépendants et les membres de leur famille travaillant dans l'entreprise et non assujettis aux assurances sociales.	Les personnes exerçant une activité professionnelle salariée ou indépendante, celles qui suivent une formation professionnelle ou un stage d'insertion ou de réinsertion. Sont par ailleurs couverts entre autres: les élèves, étudiants et chargés de cours, les délégués participant aux séances des chambres professionnelles, des organes des institutions de sécurité sociale, les personnes participant aux actions de secours et de sauvetage...	Pas d'application.	Assurance nationale *(folketrygden)*: Tous les salariés, les pêcheurs (également à leur compte), les conscrits, les étudiants et les personnes en formation sont couverts. Les personnes exerçant une profession libérale et les travailleurs indépendants peuvent s'assurer volontairement. Assurance contre les accidents du travail *(yrkesskadeforsikring)*: Tous les salariés.	• Tous les employés exerçant une activité rémunérée, les apprentis; • les membres de la famille travaillant dans l'entreprise d'un indépendant; • les personnes exerçant une activité commerciale, artisanale ou industrielle; • certains indépendants assimilés comme les enseignants, les musiciens, les artistes; • les personnes qui n'ont pas un contrat de travail, mais travaillent essentiellement dans les mêmes conditions qu'un salarié (ex.: pas de structure professionnelle propre, prestation de travail effectuée personnellement); • les écoliers et les étudiants.

Accidents du travail et maladies professionnelles

Tableau VIII

	Portugal	Finlande	Suède	Royaume-Uni	
Législation en vigueur	Loi n° 100/97, du 13 septembre 1997. Décret-Loi n° 143/99, du 30 avril 1999 (accidents du travail). Décret-Loi n° 159/99, du 11 mai 1999 (accidents de travail des travailleurs indépendants). Décret-Loi n° 247/99, du 2 juillet 1999 (maladies professionnelles).	Loi sur l'assurance accidents du travail *(Tapaturmavakuutuslaki)* du 20 août 1948, modifiée. Loi sur les maladies professionnelles *(Ammattitautilaki)* du 29 décembre 1988.	Loi sur les accidents de travail *(Lag om arbetsskadeförsäkring)* de 1976 valable pour les accidents/maladie du travail survenus après le 1er juillet 1977.	Loi sur les cotisations et les prestations de sécurité sociale *(Social Security Contributions and Benefits Act)* de 1992. Loi sur l'administration de la sécurité sociale *(Social Security Administration Act* de 1992*).*	**Législation en vigueur**
Champ d'application	Tous les salariés et les indépendants.	Tous les salariés et agriculteurs, certains étudiants et apprentis. Les indépendants peuvent s'assurer volontairement.	Toute personne active est assurée.	Salariés.	**Champ d'application**