

STATUS AND FUTURE OF HEALTH SURVEYS IN THE EUROPEAN UNION

**Final report of Phase 2 of the project Health Surveys in the
EU: HIS and HIS/HES Evaluations and Models**

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List of country codes used:

AT = Austria

BE = Belgium

CH = Switzerland

DE = Germany

DK = Denmark

ES = Spain

FI = Finland

FR = France

GR = Greece

IE = Ireland

IS = Iceland

IT = Italy

LU = Luxembourg

NL = the Netherlands

NO = Norway

PT = Portugal

SE = Sweden

UK = the United Kingdom

1. INTRODUCTION

Both Health Interview Survey and Health Examination Survey methods should be used to obtain comprehensive and comparable information on health and health care in the EU and in Member Countries in a reliable and valid manner. Methods should be appropriate and the measurements valid and reliable. Comparability of information is needed to show differences and similarities between countries, and to point out problems and good examples presented by common indicators relevant for the development of health policy.

Health Interview Surveys (HIS) combinations of Health Interview and Health Examination Surveys (HIS/HES) are central components of a comprehensive health monitoring system. HISs deliver valuable information on health status, illnesses, life styles, functional capacity and use of health care services. By definition, interviews and questionnaires are the only way to obtain data on perceived health, symptoms and health related behaviour. HESs are needed to obtain valid information on many chronic conditions, functional limitations and disabilities, and on several key health determinants.

Chronic diseases are often under-reported or over-reported in HISs (Heliövaara et al 1993, Fisher et al 1996, ILSA 1997). Non-symptomatic persons may suffer from some conditions (e.g. hypertension) requiring treatment, the reported symptoms (e.g. visual or auditory acuity) may not be specific enough or there is a considerable recall bias (e.g. infections and immunisations). The results of physical examination and subjective reporting of pain and disability can differ (Michel et al 1997). A well-documented example of differences in self-reports compared to actual measurements is under-reporting weight and over- or under-reporting height (Bolton-Smith et al 2000).

HES is more expensive and logistically more demanding than HIS, as it requires a variety of highly qualified personnel, and careful training and quality control. In practice, an integral part of every HES is a HIS, and sometimes the HES is carried out on a sub-sample of individuals selected for a HIS due to the special demands in the design and procedures (Fisher et al 1996, Armitage 1976). Many measurements and examinations of a typical HES are closer to clinical practice and some have

better validity than HIS methods, which is not to say that physical examinations are not prone to error (Koran 1975). One major advantage of the HIS/HES combination is in measurement of time trends and differences between population groups, since interpretation of the findings is facilitated by the different types of measures.

Data for health monitoring can also be obtained from other sources. Regular statistical sources and registers, e.g. hospital discharge registers and general practice registers, can provide an overview of morbidity and suggest hypotheses for further investigation (Rose et al 1982). Register data is valuable for the evaluation of health care services, but not sufficient for population health monitoring purposes (Aromaa 1998). Comprehensive register data is only available for some specific diseases and there are differences in the coverage and availability of data. Population surveys overcome much of this selection bias of health service users compared to the total population, provided that participation is high in all population groups.

The future European Health Survey System may consist of national surveys, with a progressive inclusion of common modules. Both international and national surveys are needed to meet the national and European needs for health monitoring. Before inclusion of new common modules and as a basis of development of European surveys, more information is needed on the methods and instruments in current national surveys.

The project *Health Surveys in the EU: HIS/HES evaluations and models (HIS/HES project)* aims to support Health Monitoring by producing an up to date overview of methods and contents of existing and planned Health Interview Surveys (HIS), Health Examination Surveys (HES), combinations of HIS/HES, and other population surveys with a significant health component in the MS and EFTA/EEA countries. The computerised database developed during this project aims to provide insight into the coverage of areas and topics relevant for Health Monitoring by national and international surveys.

The project has been carried out under the auspices of the European Commission (in the framework of the Health Monitoring Program/HMP). Several other projects under the HMP and under international organisations (WHO, OECD) have proposed new

instruments for use in health surveys and made recommendations to enhance international comparability. In this report summaries of existing survey instruments and recommendations will be presented. The aim of the HIS/HES project is to assess the usefulness and feasibility of various methods and instruments and their comparability.

This is the final report of the second phase of the HIS/HES project. It gives an overview of instruments, measurement methods and fieldwork procedures, as well as health topics covered in the health interview and health examination surveys. The evaluation will include the assessment of usefulness, feasibility and comparability of methods, instruments and existing recommendations. Where several instruments and recommendations exist, attention is drawn to their differences and to whether they have been tested in fieldwork with good results or not.

2. SUMMARY OF THE FIRST PHASE OF THE HIS/HES PROJECT

Päivikki Koponen

The aims of the first phase of the HIS/HES project were to produce the database of European health surveys, to review the literature, to collect information and to review European experiences on HIS, HIS/HES and HES, and to create a European network for development and testing of proposed HIS/HES and HES methodologies. It was carried out in 1999-2001.

The project consisted of two related parts, one concerning Health Interview Surveys and a second concerning Health Examination Surveys. The institute primarily responsible for the HIS part was Statistics Netherlands and KTL Finland was primary responsible for the HES part. In addition to CBS and KTL, a Core Group was established to guide the project. The Core Group consisted of experts in the field of health survey research originating from nine different institutes. A European network for development and testing of proposed methodologies was also created with representation of experts on HIS and on HES methods from almost all EU/Efta Member States.

The inventory of national HISs in the EU, Norway, Iceland and Switzerland showed that HISs were executed regularly in most countries (Hupkens & Swinkels 2001). Periodic HISs were recorded in 16 of the 18 countries examined. Especially in Finland, France and UK many health surveys were executed. In most countries one or two national HISs were recorded. Only Greece and Luxembourg did not report any HIS. Information on the methods and contents of these HISs and HIS/HESs were included into the health survey database.

Analyses of the HIS questionnaires included in the database showed topics frequently included in HISs. Questions on the health status of respondents were most often included in the surveys. Questions on disease specific morbidity, perceived health, activities of daily living, and chronic conditions were included in most surveys. Questions on life style factors, such as smoking behaviour, were included in almost all surveys. The comparability of the questions in different national HISs was studied for two frequently included topics: smoking prevalence and heavy drinking. The comparability of both topics appeared to be limited.

Relevant literature on HES was retrieved by using several sources (Koponen & Aromaa 2001). Collection of information about ongoing and planned activities as well as on methods used also relied on personal communication and on a systematic postal survey covering all EU/EFTA Member States. It was found that national population based HESs with a comprehensive focus were conducted at regular or irregular intervals in five countries (Finland, Germany, Ireland, the Netherlands and UK) and in a large region in one country (Catalonia, Spain). In these countries several local, regional and/or focused surveys had been carried out previously or in parallel to the national HESs.

All national HESs included a HIS component preceding or parallel to the HES. National HESs in the planning or pilot stage were identified in four countries (France, Italy, Norway, and Sweden) and there were some preliminary plans for a national survey in one more country (Portugal). More focused and geographically limited HESs had been carried out in almost all EU/EFTA countries. The major reason given for not carrying out national HESs until now was the high cost or the difficulties in implementing fieldwork. However, all respondents from countries without national

HESs considered that such national surveys are necessary. Most respondents also felt that there is a need to develop core modules for HES in Europe.

The HIS/HESs included an interview with a few measurements and/or blood samples, or a comprehensive health examination taking several hours to complete. It was concluded that methodological differences limit comparability of results of the surveys. There was a clear emphasis on cardiovascular diseases in both national and regional/local surveys, but other health status components had also been covered, most often respiratory diseases and diabetes. Mental and dental health issues were often the subject of separate surveys and therefore rarely included in national general health surveys.

3. AIMS AND EXECUTION OF THE SECOND PHASE OF THE HIS/HES PROJECT

Päivikki Koponen

3.1. Aims

The specific aims of this second phase of the HIS/HES project were

- 1) to evaluate and recommend methods for use in HES and HIS/HES surveys and for future field testing and development during phase 3.
- 2) to maintain and develop the health survey (HIS, HES and HIS/HES) database, to update it with new surveys and information on existing recommendations and standards and to develop a system for dissemination of the database.

3.2. Work plan

The second phase was launched in January 2001 and run for two years. (Grant agreement number 2000CVG3-511). The tasks were divided between the contractor, the subcontractor and the HIS/HES core group members.

The tasks of phase 2 were:

- a) updating, maintaining and further development of the database created during phase 1.
- b) carrying out an inventory of existing recommendations and standards for health survey methods and providing the information to the database.
- c) identification, definition and evaluation of survey indicators and measurement methods for the main health status components required for a system of Community Health Indicators.
- d) selection of HIS/HES topics and methods (based on the work under item c) for detailed analysis under subprojects.
- e) evaluation of the validity, comparability and feasibility of the methods used in current national HISs and HIS/HESs identified during phase 1. This task was carried out in more detail for the topics of the subprojects' and it also comprised an exploratory comparison of some key health data already collected in national surveys.

3.3. Participants and organisation

Phase 2 of the HIS/HES project was co-ordinated by Professor Arpo Aromaa at The National Public Health Institute (KTL) in Finland. In addition to overall co-ordination the contractor in Finland (KTL) was responsible for information concerning HESs. There was a main collaborator (subcontractor), the Scientific Institute of Public Health (IPH) in Brussels (Dr. Jean Tafforeau), mainly responsible for HISs and for updating and improving the database. The core group for HIS and HIS/HES included members from seven MSs, and the HIS and HIS/HES networks comprised all EU Member States.

The core group members and HIS centres were:

Jean Tafforeau and Claudine Vermeire at IPH, Belgium

Jaap van den Berg and Christianne Hupkens at Statistics Netherlands (CBS)

Emmanuelle Cambois at Equipe INSERM Démographie et Santé REVES Network on Health Expectancy, France

Lidia Gargiulo and Luciana Quattrocioni at Istituto Nazionale di Statistica (ISTAT), Italy

Carlos Matias Dias at Observatorio Nacional de Saude Dr. Ricardo Jorge, Portugal

The core group members and HIS/HES centres were:

Arpo Aromaa, Päivikki Koponen and Ulla-Sisko Lehto-Järnstedt at KTL, Finland

Lucie Viet at RIVM, The Netherlands

Bärbel-Maria Kurth at Robert Koch Institut, Germany

Michael Marmot and Paola Primatesta at University College of London, United Kingdom

Gino Farchi and Susanna Conti at Istituto Superiore di Sanita, Italy

In addition several other persons have contributed to the project: Sanna Räty and Virpi Killström at KTL. Also several other members of the HIS/HES network and other persons at the collaborating centres have provided information.

3.4. Subprojects

There were four subprojects. The aims of these subprojects are presented below.

- 1) **The comparison of HIS/HES data: Health-related quality of life and cardiovascular risk**, led by Paola Primatesta at the University College of London, UK.

The aims of this subproject were to compare the self-assessed health status of people with some selected risk factors for cardiovascular disease measured by questionnaire and by biological correlates in different countries. Data from the Health Survey for England 1996 (HIS/HES), from the German National Health Interview and Examination Survey 1998 (HIS/HES) the Italian HIS 1999-2000 (Health Conditions and the Use of Health Services. (see chapter 5.6., and an additional report Primatesta et al 2003)

- 2) **Mental health and quality of life measurement** in national health surveys carried out by Ulla-Sisko Lehto-Järnstedt at KTL, Finland.

The aim of this subproject was to describe the use of and to evaluate the quality and comparability of the measurement on mental health issues in national comprehensive HIS and HES surveys in EU and EFTA countries. The specific aims were 1) Description of the use of mental health and quality of life measurement in the

surveys, 2) Evaluation of characteristics of the measurement and instruments. 3) Presentation of recommendations and principles of proper measurement of mental health and quality of life issues in national health surveys, with the aim to enhance their international comparability. (see chapter 5.4.5., and an additional report Lehto-Järnstedt & Aromaa 2003)

- 3) **Survey design and methodology** in national health surveys carried out by Päivikki Koponen at KTL, Finland and Carlos Matias Dias at INSA (National Institute of Health, Portugal)

The aims of this subproject were to compare 1) sampling frames and samples, recruitment methods, participation rates and implementation, and 2) methods of data collection and adaptations made to the survey protocols for people in institutions. Finally the aim was to suggest recommendations on methods feasible for use in national surveys to increase representativeness and to be taken in consideration when collecting data in institutions (see chapter 5.2. and an additional report Koponen & Aromaa 2003).

- 4) **Measurement of physical functioning** in national health surveys carried out by Sanna Rätty at KTL, Finland.

The aim of this subproject was to describe the current situation of measurement of physical functioning in national HIS and HIS/HES, and to evaluate these from the viewpoint of international comparability and further development. The final aim was to develop rules for linking the questions in the database to the ICF codes by using physical functioning as an example (see chapter 5.4.4. and an additional report Rätty et al 2003).

3.5. Time schedule and events

Four core group meetings were held:

- First meeting: 14th-15th May 2001 in Brussels Belgium, with the aims to discuss the detailed action plan for phase 2, to discuss the update and modification of the database and to agree on the topics for the subprojects.

- Second meeting: 11th-12th October 2001 in Berlin Germany, with the aims to discuss the development and maintaining of the database, the subprojects and the structure of the final report of phase 2.
- Third meeting: 3rd-5th March 2002 in Saariselkä Finland, with the aims to discuss the action plans for the subprojects, the improvement of the database and the structure of the final report of phase 2.
- Fourth meeting: 28th-29th October 2002 in Fiesole Italy, with the aims to introduce the new version of the database to the core group members, and to work on the contents of the final report of phase 2.

The HIS/HES project and the European Health Risk Monitoring (EHRM) project and the European Commission (EC) jointly organised a workshop "Health Surveys in Europe - Role of Surveys in Monitoring" in Luxembourg, 13th-14th May 2002. The purpose of this Workshop was to bring together expertise from several projects all over Europe, and to discuss how their proposals should be integrated into national health monitoring systems (see <http://www.ktl.fi/publications/ehrm/product4/report.htm>).

The HIS/HES project was presented at several international conferences and meetings:

- Health Monitoring Programme, co-ordinators meeting, Luxembourg, 2001
- EUPHA Conference, Brussels, 2001
- Inventory of survey data on disability in EU member states, Brussels, 2002
- WHO planning meeting on Survey methods for environmental health assessments, Bonn, 2002
- Eurostat meeting on Public health statistics in candidate countries, Luxembourg, 2002.
- London congress on collection of morbidity statistics, January 2003.

4. INVENTORY AND DATABASE OF HIS AND HES SURVEYS

Jean Tafforeau

4.1. Development of the HIS/HES database

1997 inventory

Eurostat initiated and supported an inventory of the methods and contents of national health interview surveys in 18 European countries (the 15 EU Member States plus Norway, Iceland and Switzerland) in 1996-1997 (1998). The inventory provided information on how health and health related topics were measured in these countries by means of population surveys.

In order to meet Community priorities, the inventory focused on health topics that were included in the 'Framework for action in the field of Public Health' (COM (93) 1559 final). It also covered the list of WHO Health for All (HFA) indicators for which health interview surveys are relevant, the survey indicators that were proposed by the 'Working Party on Community Health Data and Indicators' and adopted by the High Level Committee (Ministry of Health, Denmark, 1994), and information needs extracted from the Third Community action programme to assist disabled people (HELIOS II).

The inventory started with the development of a list of health topics reflecting the information needs of these health programmes. Next, information on the contents and methods of national HIS in each country was collected. It was checked whether the questionnaires included questions on these topics, and if so, which questions covered these topics.

The inventory presented overviews of 52 HIS questionnaires:

- the national HIS executed in these countries between 1994 and 1997,
- the national HIS planned from 1997 onwards,
- the health topics included in these surveys, and
- the questions used to measure these topics.

For a selection of health topics (e.g. chronic conditions), the questions in different surveys were compared with each other. For some health topics, recommended

instruments have been developed by WHO and Statistics Netherlands (de Bruin et al 1996). These recommendations were used as a reference for evaluating the national questions.

HIS/HES database, phase I

As new health surveys are regularly initiated and as the methods and contents of surveys are frequently adapted, the information collected in 1996-1997 was quickly outdated. The first phase of the HIS/HES project was launched in order to update the results of the 1996-1997 inventory and to extend it to new surveys. The aim was also to classify the surveys and the questions and to store this information in an electronic database in order to improve its accessibility and dissemination as a reference tool for further development of health surveys.

The types of surveys to be included in the inventory were defined:

- Health surveys, i.e. surveys aiming to give a complete picture of health, medical consumption, lifestyle and preventive behaviour
- Surveys with a significant health or health related component, like surveys on impairment, disability and handicaps
- Multi-purpose surveys
- Living condition surveys
- Health related questions of the European Community Household Panel (ECHP) and of the Eurobarometer.

The surveys to be included in the database had also to meet the following conditions:

- Use national population-based samples
- Recur at certain regular intervals (thus not once-only/one single wave)
- Not restricted to a part of the population only such as children, adolescents or patient groups
- Not restricted to a certain health component such as nutrition or AIDS.

The collection of information was limited to the 15 MS of the European Union plus Iceland, Norway and Switzerland (EFTA countries).

The collection of the information started in September 1999; a letter was sent to the institutes responsible for national health surveys development and implementation explaining the aim and the background of the new inventory, together with a questionnaire on the methodological aspects of each administered survey. If no new survey was executed since the former inventory, the institutes were asked to check the information already collected. If a new wave or a new survey was conducted, the institutes were asked to update the methodological information.

In addition, the institutes were requested to provide recent questionnaires, preferably in the original language(s) and in English. If no English translation was available, a German or French version was requested. In addition, in order to facilitate the development of the database, computer files of the questionnaires were requested (in the original language(s), and in English, German and/or French).

Finally, the institutes were asked to check whether the overview of surveys in their country was complete. If they were aware of health or health related surveys not listed, they were asked to send information on that survey, or provide the name and address of the responsible institute.

In order to facilitate the overview of contents of HIS questionnaires, a list of health topics was developed (see annex 1). This list serves as a reference tool for identifying health related topics included in each survey. This list is also used as a tool in the HIS/HES database to search for a particular set of questions: each question included in the database is labelled with at least one topic code according to the health topic code list. Questions on a particular subject included in the database can be selected with help of the health topic code list. The main reason for using this list is that the search for questions with help of only the verbal text of the question can cause difficulties.

In developing the health topic code list, the following criteria were considered:

1. Clarity: clear and easy to understand.
2. Complete and concise: cover a broad range of health aspects, including health status, health determinants, medical consumption, health prevention and background variables associated with health, but include only topics that can be measured in HIS.

3. Reliability: Two persons searching for the same information should obtain the same results using the health topic list.
4. Limited number of levels: a hierarchical system was selected with seven areas and 102 topics.
5. Mutually exclusive topics: the topics do not overlap.
6. Questions may refer to more than one topic: one question may refer to one, two or a maximum of three topics.

In order to meet these conditions, the topic list has been built on 1) the list of health areas and health topics developed for the former inventory of HIS in 1996/1997 and 2) a draft set of European Community Health Indicators (Kramers 2001).

At the beginning of phase 1 of the HIS/HES project there were no previous systematic inventories of national HES. Information was gathered by literature reviews and a systematic postal survey covering all EU/EFTA Member States (Koponen & Aromaa 2001). Methodological questionnaires were sent to contact persons for each initially identified national HES and for further surveys identified during the inventory. These contact persons were also asked to provide documents describing the examination methods and protocols. Due to the small number of surveys, no topic list for HES was developed at this stage.

At the end of the phase I of the project (end of year 2000) eight Health Examination Surveys, 41 national HIS and two international surveys were included in the database with a total of 5000 questions.

4.2. Current version of the HIS/HES database: contents and technical notes

With the start of the second phase of the HIS/HES project, a consolidation period was initiated: all the content of the database was verified and missing parts were added. This work included for example, ensuring the English translation of a national survey, comparing the number of questions in the database with the original printed questionnaire and filling in the missing questions.

Second, all the contact persons for each survey were contacted by regular mail (see a copy of the letter in annex 2) and they received a paper copy of the information

included in the database on the survey they were in charge of. The aim was to verify the quality of the information included in the database both at the level of the survey in the national language(s) and for the English translation. Repeated contacts by email and by phone were necessary to get these verified and sent back to the database managers. In addition, a questionnaire was used to collect methodological information about each HIS: e.g. design, sample, mode of interview, and participation rate (see questionnaire in annex 3).

The inventory of HES was also updated by contacting all the persons responsible for the national surveys. Methodological questionnaires for HES (see annex 4) were used to verify and supplement previous information. Examination protocols were collected in more detail than during phase 1 and a list of HES topics was developed for the database (see annex 5).

The same persons were also asked to check whether new surveys had been implemented in their country and to provide information about those surveys. The aim was to have the inventory and the database continuously updated with information on both the contents and methods of new HIS and HES.

The information on the HESs was collected by KTL, Finland, while the information concerning the HISs was collected by IPH, Belgium. Annex 6 shows for each survey which version of the questionnaires or examination protocols (paper copy and computer files) are available at IPH and KTL. Annex 7 shows for each survey part of the information that is included in the database: survey name, year, country, name of the contact person, type of survey, frequency, years in which the survey was conducted, survey design, data collection mode and language.

Including the HIS questionnaires into the database, is a long process. In order to facilitate this, contact persons were asked to provide electronic formats of the questionnaires when available. These computer files were in various formats and needed to be adapted before entering the electronic information into the database.

Some countries provided their questionnaire in the national language and in English. Other questionnaires were only available in the original language. These were translated into English either in Belgium or in the country of origin by translators

identified through the contact person. Translation costs were covered by the project. The English versions of the questionnaires cannot be considered as a validated translation as no budget line was available at the time to support back translations. They can only be used to facilitate the comparison of the questions between the different countries and surveys.

Each question in the resulting 'electronic' files had to be reviewed one by one in order to have the health topic codes assigned. The next step was the manual 'copy-paste' of each question in the database. After entering all questions of a given survey (national language and English version) and methodological aspects into the HIS/HES database a printed copy was sent to the institute in charge of the questionnaire for review. It was not unusual to have three review cycles before the institute declared the HIS/HES database content was representative for their survey. This process highly increased the quality and preciseness of the database content.

Despite this quality control process, some problems may still exist; e.g. it was recently discovered that some self-completed questionnaires are missing. For example the self-completed questionnaire of the Italian HIS has not been included in the database. Another example is combinations of HIS and HES: the interview component has been included in the inventory but not all questionnaires used during the examination. This is currently the situation of the most recent HIS/HES survey in Finland where the module on mental health and quality of life has not yet been included.

The whole process of identification of a HIS, gathering the information, translation, formatting and inclusion in the database takes approximately three weeks of work for a team of one university level person and one secretarial person. Since only a few HES survey protocols are as extensive as the HIS questionnaires, the corresponding process of collecting information and inclusion of a new HES in the database takes about 1-2 weeks.

4.3. Overview of the current content of the database

With respect to HES the database contains information on 15 surveys (see Annex 8 for a detailed list of HES included in the HIS/HES database by the end of year 2002). The database covers an overview of health status components and measurements, such as whether blood samples are collected, and if so, how these samples were collected and analysed, and what kind of laboratory determinations were carried out. The methodological information on HESs includes information on sample, response, mode of data collection, quality control of the measurements etc.

With respect to HISs, the database includes information on 92 surveys (see Annex 9 for a detailed list of HIS included in the HIS/HES database as of end 2002). Among these are a few other surveys in addition to the national HIS and HES from EU and EFTA Countries:

- National surveys: it was decided to extend the inventory to several countries outside the European Union in order to be able to assess the comparability of the questionnaires administered in countries with similar profile (Australia HIS 2001, Canada HIS 2000, USA HIS 2000).
- The health modules of population censuses: these have been included in order to improve the comprehensiveness of the inventory (Belgium General Socio-Economic Survey 2001, Greece Population Census 1991 ¹, UK Census 2001)
- Recommendations: inclusion of recommendations when available, in order to be able to assess the comparability of the questionnaires/examinations with the recommended instruments (WHO 1996, EuroHIS 2002, EHRM)
- International surveys:
 - Inclusion of questions on disability in the Labour Force Survey 2002 (Eurostat will prepare a report on the results by the end of 2003).
 - WHO- Multicountry 2001, WHO-World Health Survey 2002: it was decided to include these international surveys because several European countries were included in the sample

¹ Greece 1991 census had been incorporated by OECD and CBS during the phase I of the project because at that time Greece didn't have any health survey performed. The health related questions of the 1991 census have thus been incorporated. The most recent census in Greece did not contain any health questions. The National Greek Survey on Psychosocial factors and Health of 1998 is mainly related to (il)licit drugs use and related behaviours but Greece is now working at the development of a "general national health survey".

- Eurobarometer: inclusion of selected health topics administered in all the Member States
- ECHP (European Community Household Panel): initially started as a living condition survey in the Member States it has been quickly extended to include specific health topics. ECHP will become SILC (Survey on Living Conditions) from 2003 onwards. Health modules of this survey are included in the database. Longitudinal ECHP data analysis will take some time and a report should be delivered by end 2004.

The list of the surveys already performed in 2002 or planned to be performed from 2003 to 2007 is represented in annex 10. In the EU and EFTA countries, and in USA, Australia and Canada 22 surveys have been performed in 2002; among these, nine have already been introduced in the database. 13 surveys still have to be entered in the database for the year 2002.

List of the health surveys performed in EU and EFTA countries in 2002 included in the HIS/HES database:

Country	Survey name	Type
FINLAND	National Finrisk Study	HIS/HES
FRANCE	Health and Social Protection Survey	HIS
FRANCE	Health and Care Interview Survey	HIS
IRELAND	Survey of Lifestyle, attitudes and nutrition (SLAN)	HIS/HES
European MS/EFTA	LFS module employment of disabled people	HIS
European MS/EFTA	Eurobarometer	HIS
NORWAY	Living conditions, health, care and social relations	HIS
World wide	World Health Surveys-Consolidated multi-country questionnaire	HIS
SWITZERLAND	Swiss Health Survey	HIS
UNITED KINGDOM	General Household Survey	HIS
UNITED KINGDOM	Health Survey for England	HIS/HES

The HIS part of the database covers all the questions raised during the interview (in national language and a translation in English). The methodological information on the HIS refers to information on the sampling frame, numbers of persons or households participating, response rates, mode of data collection, standard instruments used, contact person, inclusion of institutionalised persons, availability of data for analysis, etc.

The HIS part the database contains 12.725 questions. In some cases a translation into English still has to be entered in the database (e.g. for the Health and Care Interview Survey, France, 2002 for which the translation just arrived at IPH). For most of HISs the entire questionnaire is included in the database. However for multi-purpose surveys, such as the living condition surveys, only the health related modules have been included in the database.

The HIS questions included in the database were divided into seven health-related areas according to the health topic code list (see annex 1). The number of questions per area is presented in table 4.3.1. The number of questions gives only a general overview of the focus of the surveys. Also, it does not distinguish between single items and instruments comprising many questions.

Table 4.3.1 Number of questions per area in the HIS/HES database.

Area	Number of Questions	Percentage
1 Demographic and socio-economic factors	1552	12.1%
2 Health status	3672	28.8 %
3 Personal factors	278	2.1 %
4 Life style factors	2723	21.4 %
5 Living and working conditions	1035	8.1 %
6 Prevention, health protection and promotion	420	3.3 %
7 Use of health and social services	2859	22.4 %
9 Other factors: not classified	186	1.4 %
Total	12725	100 %

The majority of questions in the database (almost 30%) referred to the measurement of the health status of respondents, like perceived health, chronic conditions and physical disability. The second most frequently occurring area referred to questions on the use of health services and other social services (22%). This area includes questions like visits to the general practitioner (GP), hospitalisation and the use of medicines. 2723 questions (21%) dealt with life style factors such as smoking, the use of alcoholic beverages and physical exercise.

Questions on demographic and socio-economic background made up 12% of all questions in the database. The number of these questions is relatively low because corresponding questions from the multi-purpose surveys were not included. Questions on living and working conditions (8%) and prevention, health protection and promotion (3%) are quite infrequent. About 1% of the questions of the HIS questionnaires could not be classified according to the HIS health topic code list.

Concerning HESs the database contains over 224 physical or biological examinations. Just as for the HIS, the examinations included have been classified on the basis of a list of health status components and health topics. The complete list of health status components (HES) is available in annex 5 and Table 4.3.2 shows the coverage of HES topics in the surveys included in the database. All surveys included some measurements of risk factors and of cardiovascular function and diseases. Concerning the laboratory analyses from the blood samples the coverage of topics is not fully comprehensive, since some tests are typically made later and not at the time of the examination.

It must be emphasised that the surveys not following the inclusion criteria defined a priori, were not included in the database; these are for example regional and topic-specific surveys (e.g. cardiovascular risk factor surveys), and surveys restricted to a specific part of the population such as children or the elderly. Pilot surveys (such as the pilot HES survey in the Florence region in Italy) have also been excluded.

Table 4.3.2 Health areas (health status components) covered in clinical examinations in national HIS/HES in Europe with the number of surveys covering each area (total number of surveys = 14).

Topic	Number of surveys
Risk factors	14
Cardiovascular function and diseases	14
Respiratory function and diseases	7
Diabetes mellitus and other metabolic function	6
Kidney, urinary tract and thyroid function	4
Liver, gallbladder, stomach and pancreas function and diseases	5
Haematological system function and diseases	7
Infections and inflammations	5
Allergy	5
Cancer	0
Reproductive functions	1
Musculoskeletal function and diseases	2
Sensory function, physical function and fitness	4
Mental disorders, mental and cognitive function	4
Dental health	1
Nutritional status	6
Other health components	4

4.4. Dissemination and migration to the Internet

The first inventory made in 1997 by the CBS in the Netherlands was distributed on paper only (Hupkens 1998). The limited possibilities of such a paper version lead to the creation of the HIS/HES database and storing the data in an electronic format. The objective was to improve the accessibility of the information and make comparison of survey instruments between member states easier.

The database was constructed with Access® during Phase I of the HIS/HES project and distributed on a CD-rom to potential users at the end of the year 2000. An additional advantage of this electronic database was that it allows quick and regular updating; a second version of the database was thus distributed on CD-rom to 120 users by the end of the year 2001 after the consolidation phase of the project. During

the same period, the database was converted from the Access® 1997 to the Access® 2000 version. This caused some problems to several users still working with an older version of Access®. They did not have easy and full access to the information included in the new CD-rom version of the HIS/HES database.

KTL and IPH also received frequent additional requests to obtain the HIS/HES database by persons or institutions not receiving the CD-rom. Requests also came from outside Europe, for example from the Department of Public Health of the University of Cape Town in South Africa. An ad-hoc solution was developed for those persons by sending the database as an attachment to the email (the Access® file was first compressed in a ZIP file). This solution gave good results, at least for those having Access® 2000 on their computer.

The limitations in the dissemination procedures of the database were an obstacle for easy access and in the utilisation of this instrument in the design of new surveys. In addition, the co-ordinators of the Health Monitoring Programme frequently emphasised the need to feed in the HIEMS system (Health Information and Exchange Monitoring System) of the European Commission.

It was thus decided by the core group of the HIS/HES project to try to give direct access to the database via Internet. The first intention was to keep the Access® database and develop an interface for Internet. However, the technical recommendations of the European Commission for the development of Internet sites was quite different: Oracle® as relational database and Coldfusion® as the interface for Internet.

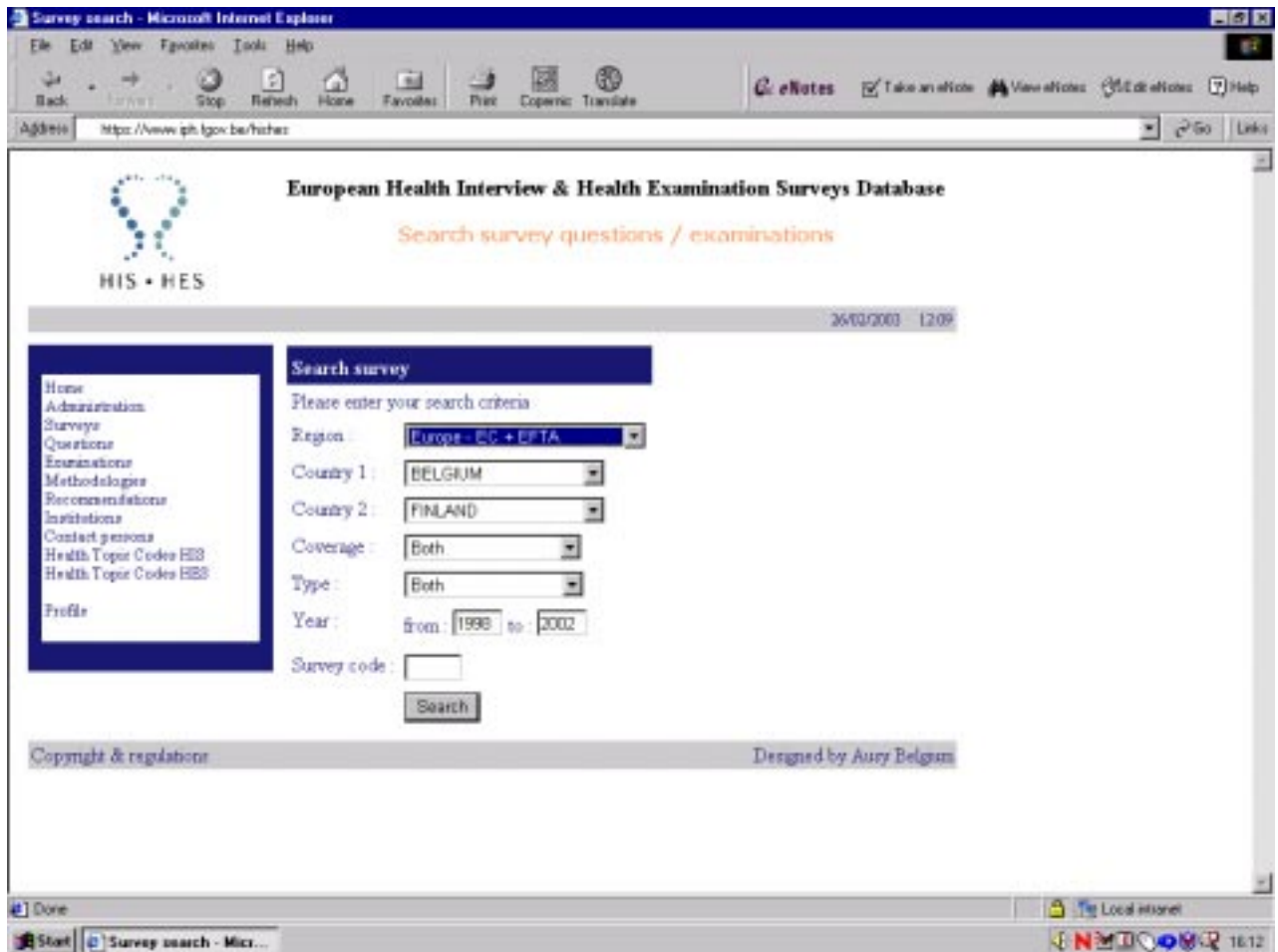
It was clear that the plans as far as the development of the HIS/HES website had to be reconsidered. It was not possible to keep the Access® format for a future hosting of the database on the Internet site of the Commission. Oracle® however was a heavy system requiring highly qualified technicians; in addition the cost of the licence of Oracle® was prohibitive. It was thus decided to migrate to an SQL® server database, which is also a relational database system. SQL® is technically more accessible than Oracle® and also less expensive. In addition, it will not be too difficult to make a second migration if necessary from SQL® to Oracle®. Coldfusion® was selected for the interface for Internet as recommended by the Commission.

The migration process and the creation of the HIS/HES Internet site started in August 2002. A private firm (Ausy®) in Brussels was selected after an open call for proposals in Belgium to do the technical work. This migration process was in addition a good occasion to revise the content, the design and the functionalities of the database.

The HIS/HES Internet site will be hosted by IPH for the time being. It has been designed in such a way that the persons with administration rights can make changes (updates, corrections, additions, subtractions) with a remote access to the web site. The HIS/HES Internet site is accessible on the website of the IPH: <https://www.iph.fgov.be/hishes/>.

The information about the opening of the Internet site will be widely diffused via E-mail by KTL, IPH and the members of the HIS/HES core group.

Here is an example of the screens allowing to perform searching procedures in the HIS/HES database via Internet:



5. METHODOLOGICAL CONSIDERATIONS AND RECOMMENDATIONS

5.1. Requirements for national and European health monitoring

Arpo Aromaa

Health monitoring must be public health relevant and serve health policy. Findings must provide a broad picture of the current situation of health and health care, and on time trends and thus be a starting point for assessing future developments. To be useful the surveyed topics must be up-to-date. The monitored health threats and diseases need to be currently important or emerging, the health promotion, prevention and care items should focus on those, which are common or with growing importance. Many established monitoring systems and surveys tend to look too much into the past instead of the present and the future.

Health surveys, both interviews and examinations, are the single most important source of information on the population's health and functional capacity and their determinants and also on primary health care including dental care and prevention. In comparison with other data sources their advantages also include easy access to background data such as socio-economic information making it simple to investigate differences between population groups.

1) Overall methodology

Health and illnesses, behaviour and other health determinants and also use of health care and medicines are related to socio-economic and other living conditions. It has been repeatedly shown that non-participation in health surveys is related to all of these and is therefore selective. In young and middle-aged adults a low participation rate may lead to underestimation of smoking and heavy alcohol use as well as of mental disorders, and to overestimation of physical activity. In older age groups non-participants suffer from more chronic illnesses, they have more severe functional limitations and a higher proportion of them needs assistance in everyday chores. This means that participation rates must be high. Some 70-80 % may be acceptable but requires a thorough examination of non-respondents in order to estimate biases. The Finnish HIS/HES with a participation rate of 85-90% still was biased in respect of e.g. mental disorders and severe functional limitations. Excluding institutionalised persons also leads to severe underestimation of functional limitations. Thus, samples and participation should be improved in many surveys in European countries.

2) Quality assurance

Both interview and examination surveys must incorporate a sensible quality assurance scheme beginning from the choice of good methods through a detailed protocol to good manuals followed by intensive training, observation and feed back during field work. Quality assurance is also needed for data entry, management and analysis. External reference methods should be used particularly in examination surveys.

3) Methods

It is obvious that all health survey methods should be valid and in the international context they should yield comparable results. It is equally obvious that many present

methods do not fulfil this criterion but several do. Both to improve validity and comparability many current methods and their application should be modified.

Preoccupation with the choice, development and standardisation of measurement methods is characteristic of the preparatory phases of many surveys, international collaborations and development efforts. The same preoccupation has continued in the EU health monitoring programme and is continuing in the public health programme. The message is that current activities are insufficient.

First, newly developed methods have rarely been tested in practice before being put into use and/or approaching the status of recommendations. Particularly in the context of interview surveys there seems to be a widespread belief that validity and comparability can be guaranteed by conceptual work and formulation of questions in working groups and at the desktop. There are many excellent examples of how testing and quality assessment should be done in order to be sure that the methods meet reasonable standards. Unless sufficient experience has already been gained all proposed methods should be exposed to practical survey use, to comparison with current methods and to validity tests when indicated and feasible. Only when this information is available or has been obtained should methods be put into practical use and then the proven ones may evolve into recommendations.

Second, implementation and associated quality assurance are integral parts of survey methods. As much concern should be devoted to them as to the choice of measurement methods. Implementation should begin with pilot phases and the experiences from them should also be taken into account in the final choice of the methods, replacing poor questions even at this stage. Many national surveys share the experience of implementing prematurely recommended methods, which have proven to be too difficult for the subjects. A recent example are the IPAQ physical activity questions, which turned out to create many problems in recent national surveys in Belgium, Denmark and Finland. Furthermore, it is extremely important to invest in proper repeated training of field personnel and observation of performance.

Third, international application of methods calls for meticulous preparatory work. Health examination methods are quite robust in this regard. For these it is often sufficient to ensure equal measurement methods and adequate quality assurance. Many biological and physiological phenomena, symptoms and diagnoses surveyed

by measurements, interviews or physical examinations in health examinations are rather robust. These phenomena are relatively universal and the same sets of questions and examinations can be used successfully in numerous countries. However, interviews on other topics are affected by differences between countries, regions, environments, cultures and ways of life. Comparable methods should be chosen and developed by taking such differences into account.

Whereas it is important to make sure that translations are linguistically valid and equivalent it is much more important to make sure that conceptually the questions are equivalent and that they are understood in the intended way by the populations to be studied. A method intended for international use should measure the same concept in all the countries. It is preferable to phrase the question alike, if only feasible. Sometimes the basic idea must be replicated by a different question to be understood. Obviously, this may lead to problems in prevalence estimates but is much preferable to entirely unsuitable questions. Therefore, the final aim must be development and use of culturally adapted questions suitable for the circumstances in each of the countries.

4) The national situation

In most countries many national surveys have been performed previously. It is important to retain key items so that time series remain intact. This consideration is so important that changes of the contents will only be made if considerable improvements can be expected. Among experienced national survey teams many known examples cause the concern that the recommended items are poorer than the current national ones. Improved international comparability is but one of the arguments. Improvements and agreements can only be achieved by high quality development work carried out together.

5) The need for international comparability

For international comparability it is best to use a step by step approach based on collaboration. Only the most important items should be developed to become comparable and at the same time acceptable to national surveys. The approach of choice may be for national surveys to add new items and modules to their existing survey. New items recommended for international (and national) use should undergo professional development and testing in all or most countries. Such work should be

contracted by EU to national survey organisations (Public Health Institutes and Statistics Offices) on a negotiation basis. The current project and tender based methods are not suitable frames.

The final consideration concerns the choice between gathering internationally comparable data by national surveys or international surveys. The latter approach has some strengths if carried out by experienced national survey organisations. However, its greatest weakness is that it adds yet another survey in each country. Also, recent experiences from surveys organised by international organisations without collaboration with national survey organisations have been unsatisfactory due to poor participation and inadequate content. For the time being the best choice seems to be to gather internationally comparable information by national health surveys, e.g. by adding common modules to these surveys. Regardless of the choice survey methodology must be meticulous in all the countries involved.

5.2. Implementation and fieldwork procedures

This section includes results based on information from the HIS/HES database (total 60 HIS and 12 HES carried out 1998-2002, out of which 48 national HIS and 12 national HIS/HES in Europe). In addition detailed information on sampling and participation (questionnaires and documents) was collected from five recent national HIS/HES surveys (from Finland, Germany, the Netherlands, and from UK/England and Scotland) and two national HIS (from Italy and from Belgium). Detailed results will be presented in a separate report (Koponen & Aromaa 2003).

5.2.1. Population samples

Päivikki Koponen

A sampling frame, the list or register of the population from which the sample is drawn, often includes additional information on the structure of the population (Lehtonen & Pahkinen 1995). However, the availability of an adequate sampling frame differs between European countries and the use of different types of registers,

which are up-dated at different intervals may lead to differences in study populations (Riedel-Heller et al 2000).

Different sampling techniques can be applied in national health surveys, either using a particular method or a combination of methods (Lehtonen & Pahkinen 1995). To ensure representation it would be preferable to take a systematic or random sample of the total population. Practical reasons, however, lead to multistage samples. The EHRM project recommends the use of probability sampling and a single-stage sampling scheme (Tolonen et al 2002). If analyses for specific population subgroups or geographical areas are anticipated, stratification is recommended to guarantee sufficient representation of the subgroups in the survey.

Information from the HIS/HES database shows that both household samples and individual samples were used in the national surveys (table 5.2.1.1). Household samples were used for 20 HISs in seven EU/EFTA countries and individual samples for 20 HISs in six countries. For HIS/HES individual samples were used in six surveys in all countries, except UK (6 surveys). Several HISs with both individual and household samples were carried out in three countries. If household samples were used, all persons in the household were included in the survey (16 surveys), or a limited number of persons (10 surveys, selecting 1-4 persons). In case of individual samples also other members in the household were included in two surveys.

Multistage probability sampling was used in most surveys (table 5.2.1.1) and in all European countries except in Iceland, Luxembourg and Sweden. Simple probability sampling was not used as often. Other sampling procedures were rare and included one-stage cluster sampling, a sample based on former health surveys or based on screening in one disability survey.

In multistage probability samples stratification by geographic area was most common (table 5.2.1.1). Stratification by degree of urbanisation, by age and by sex was less often used. Other stratification variables used in single surveys were household size, size of building, size of the municipalities, city blocks, severity of impairment/disability or responses to the screening survey (in disability surveys), occupation and other socio-economic indicators.

Table 5.2.1.1 Sampling in national HIS and HIS/HES surveys in EU/EFTA countries (number of HIS and HIS/HES carried out 1998-2002).

	HIS (Total 43)	HIS/HES (Total 12)
Sample type:		
Households	20	6
Individuals	20	6
Unknown/missing	3	0
Sampling procedure:		
Multistage probability	29	11
Simple probability	10	1
Other	3	0
Unknown/missing	1	0
Stratification by:		
Geographic area	27	10
Degree of urbanisation	12	2
Age	6	2
Sex	4	3
Other variables	7	1

Over-sampling for certain groups of persons was applied in eight HISs and in five HIS/HESs in seven European countries. This meant over-sampling of certain geographic areas (e.g. certain provinces or sparsely populated areas), of certain age groups (children, adolescents or the elderly), of severely disabled persons (disability survey) or of specific ethnic groups.

No age-restriction/age limits were applied in 20 HISs and in two HIS/HESs in ten European countries. If age limits were applied, the lower limit ranged from 2 years (UK) to 20 years (IS) for HIS and from 2 years (UK) to 30 years (FI) for HES. Children under the age of 15 were included in 24 HISs and in 6 HIS/HESs. The upper age limit ranged from 64 to 84 years.

The household sample size (the net/crude sample) for HIS in EU/EFTA countries ranged from 2431 (LU) to 79 000 (E). The mean household sample size for HIS was 16 375. The household sample size for HES ranged from 6343 (UK/E) to 15332 (UK/S). The sample size for individuals in HIS ranged from 1010 (IS) to 400 000 (DE). In proportion to the population size, the differences in sample sizes were minor (e.g. the sample equals 0.7% of the population in Iceland and 0.5% in Germany). The

individual sample size for HES ranged from 1035 (IE) to 13 500 (FI). In proportion to the population size the sample sizes for HES vary between 0.002% in Ireland and 0.2% in Finland.

5.2.2. Inclusion of institutionalised persons

Carlos Matias Dias

In the first inventory of HIS in Europe 26 surveys (conducted in 12 out of 18 European countries) were identified to include data collection on persons living in institutions (out of 78 surveys). This report suggests that there is considerable variation in the type of surveys used to collect this data and also in the type of institutions included in each survey, in the mode of data collection and in the data collected (Hupkens 1998).

Although in most developed countries the current trend is to reduce the number of persons living in institutions, a fraction of the population will continue to live in institutions for various time lengths of their lives for diverse reasons. Older people and people suffering from chronic psychiatric or physical morbidity have special care needs that face great difficulties to be met outside institutions. Other specific subgroups of the population may have legal, religious or life cycle characteristics that impose life in prisons, monasteries, military barracks or schools, for example. The expected different demographic and health characteristics presented by these subgroups of the population will result in methodological problems to be taken into account when planning HIS or HES data collection in institutions (Matias Dias 1999).

Special instruments have been developed and tested in cross-national comparisons of residents in institutions. These instruments have been mainly developed to evaluate health care needs and they have been shown to be an important factor for the improvement of the quality of health care provided (e.g. Hawes et al 1997a). However, some instruments may also be used to assess health status and health determinants of residents in institutions. E.g. the Minimum Data Set Resident Assessment Instrument, MDS/RAI, can be used to present a comprehensive evaluation of a resident's functional ability, cognitive status, health conditions and psycho-social well-being (Hawes et al 1997b). The MDS/RAI instrument has been

used in several countries. However, in the EC countries, collection of health data in institutionalised populations during HIS or HES uses different approaches and different instruments (Hupkens 1998).

The simple definition of what is an “institution” for purposes of health data collection through HIS/HES is unclear. During a Medline search using the English Language terms “Homes for the elderly”, “nursing homes”, “psychiatric institutions”, “institutions for the mentally handicapped”, “boarding schools”, “prisons”, “convents” and “monasteries”, no study could be found on the meaning these terms have in languages other than English.

Comparison of health data stratified by type of institution could thus be hampered. A specific study on the feasibility of different sampling frames of communal establishments, to be used in the Family Expenditure Survey in the United Kingdom (Bruce 1993), lists 14 types of “communal establishments”, among which are the above mentioned “Institutions” that are more often mentioned in the HIS/HES database.

For national surveys in EU/EFTA countries in 1998-2002, health data was collected from people in institutions in 13 HIS and three HIS/HES, out of which three are disability surveys, two are surveys on living conditions, one is a general socio-economic survey, and two are surveys on lifestyles.

Homes for the elderly and nursing homes were included in all but one survey. Twelve surveys included psychiatric institutions, ten institutions for the mentally handicapped, ten boarding schools, 11 prisons, and nine convents or monasteries. According to the HIS/HES database special permission to conduct the interviews in institutions was necessary in four surveys, either from the institutions or from an ethical committee.

Two surveys reported different wording for interview questions or different examination resources. However information on this subject was not available in 13 surveys. Only four surveys reported separate data analysis for institutionalised persons. Ten surveys reported data analysis together for institutionalised and non-institutionalised persons. Information on this subject was not available for 12 surveys.

Imputation methods were applied for children (10 surveys), adults not at home (6 surveys), adults not able to reply (12 surveys). Only in five surveys were proxy answers not allowed. Information on this aspect was not available in three surveys.

Additional information on adaptations made to the survey protocols in order to meet demands originated from data collection in institutions was not available from all surveys. Examples of these adaptations were specific training to field personnel, and adaptations to data collection instruments and to examination protocols. Definition of an adequate minimum dataset and higher non-response rates than for non-institutionalised populations were the most frequently reported difficulties.

Comparison of methods of health data collection in persons living in institutions should be pursued further. Comparison of key indicators obtained in the general population and in institutional populations with identical demographic characteristics, together with comparison of key indicators obtained from different surveys using different methods could also be important to clarify possible bias when collecting this kind of information.

5.2.3. Recruitment

Päivikki Koponen

Methodological research on recruitment is rare and very little is known about different fieldwork procedures and their effect on willingness to participate in surveys. There is some evidence that the more personal the contact, the more likely is successful recruitment, e.g. face-to-face or other personal contacts result in higher response rates than invitation by letter (Eastwood et al 1996, Riedel-Heller et al 2000). The response is higher if several different contact modes are used (Stang et al 1999). Factors found to be relevant to the recruitment of diverse populations into research studies are awareness, acceptance, and access (Brown et al 2000). Awareness is defined as an understanding of the importance of research, the procedures during the research process, and the value of the individual's participation. Acceptability is defined as social support for participation, reflected in the messages disseminated by community leaders and through media. Promoting access means reducing the

practical barriers to participation, e.g. through transportation, understandable consent forms, translation services in multilingual populations, and financial remuneration.

Several randomised controlled trials of strategies to influence the response to a postal questionnaire have been carried out (Edwards et al 2002). Less is known about strategies to influence the response in surveys with personal interviews and/or examinations. A few studies indicate that relatively simple interventions such as an explanatory letter before the telephone contact (Kessler et al 1995), a reminder postcard or other follow-up contacts (Carter et al 1999, Hartge 1999) can significantly improve participation rates. The more effort is given to recruiting the higher is the response rate (Cottler et al 1987), with relatively low cost per late respondent (Rodes et al 1990). Several studies have shown differences between early respondents and late respondents, and some of them influence population estimates (Locker et al 1981, Cottler et al 1987, Rodes et al 1990).

Requiring written authorisation (signed consent) or seeking consent to access medical records have been found to be associated with lower participation in some surveys (Woolf et al 2000, Pokorny et al 2001), whereas no effect has been seen in other studies (Sugarman et al 1998, Shah et al 2001). Monetary or lottery incentives have increased the response in studies using mailed questionnaires (Edwards et al 2002). The use of direct payments seems to be more effective than lotteries (Roberts et al 2000). Some researchers question the relative importance of financial inducements, especially if the study comprises several data collection phases and methods (Wedeen 2000, Hellard et al 2001). In such studies other factors like the nature of contacts between the survey personnel and the participants may be more important.

Information on the recruitment process was collected from the seven surveys selected for detailed analysis (5 HIS/HES and 2 HIS). Invitation letters and reminders were used in all these surveys, and in addition all surveys, except the Italian one, utilised brochures/leaflets informing about the purpose of the survey and the nature of the interviews/examinations. Telephone contacts were also used in almost all surveys (not UK), but other personal contacts (home visits) were not used in the Netherlands. In all countries the non-respondents were contacted on average 3-5 times.

In all seven surveys the invitation letter was signed by the person(s) responsible for the survey and/or the directors of the institutes responsible for the survey. In Italy another letter of the mayor of the municipality of the sampled household was also mailed to selected households. Telephone numbers, e-mail addresses and/or an Internet address were given for further queries in Belgium, Finland and Italy. Information leaflets/brochures were mailed to the participants together with the invitation/recruitment letter, or they were given to the participants during personal contacts by the interviewers/survey personnel.

To motivate participation national media was used in Belgium, Finland and Germany, and regional media in all other countries except in UK and in Italy, where only personal contacts were used to inform the target population about the survey.

The signed informed consent was obtained during the interview phase before the examination and/or during the clinic/home visit for the examination. In Finland and in UK two consent forms were signed; the first during the interview phase and the second at the examination. No signed informed consent was used in the HISs in Italy and in Belgium.

No financial compensation or lotteries for participants were used in Belgium, UK and Italy. Travel expenses were reimbursed for selected participants in Finland and in Germany. In Germany travel expenses could be covered if requested and the subject could be picked up from home by the survey "travel service" if needed. In Finland compensation for travel expenses (e.g. taxi fares) was offered if this seemed to be necessary to motivate and/or help the subject to participate in the examination. This could be due to illness or difficulties in mobility, or lack of public transport or private car.

Gift-vouchers were used in the Netherlands. A lottery among the young adults (18-29 years of age) was conducted in Finland to motivate participation in the interview. In Belgium a summary of the general survey results was sent to the participants after the survey, and in Finland, Germany and UK a summary of personal survey results (e.g. laboratory examinations). In Finland the summary explained the findings and was accompanied by recommendations for further action, if needed.

Our inventory shows that more attention should be given to the recruitment process. Possible means to minimise non-response are:

- using several publicity and recruitment strategies, and giving potential participants several options for obtaining further information (media, Internet, mail, telephone, personal visit)
- enhancing readability of consent forms and other information on the study
- providing intensive training for fieldwork personnel
- using several persons to contact subjects if needed (e.g. asking the subjects to reconsider if they refuse during the first contact)
- emphasising the importance of the participation of every individual, whether extremely healthy, ill or anything between
- using compensations/incentives for participation (financial or other) and securing easy access to examination sites, and arranging interviews and examinations at home or in institutions if needed
- emphasising the personal benefits to the participants and making sure that they are received quickly, e.g. rapid feedback on examination/test results.

5.2.4. Participation and non-response

Päivikki Koponen

The comparison of response rates is difficult as there is no uniformly applied definition of eligibility (Asch et al 1997). In principle, it should be easy to agree that non-response is calculated from the number of persons sampled after removing those not belonging to the target population, i.e. those who had died and those who do not live in the country/area any more. Due to the differences in sample selection and recruitment and the lack of common eligibility criteria it is very difficult to define a simple figure representing an acceptable response rate. The EHRM project recommends that the response rate should be at least 70% for all population sub-groups of interest (Tolonen et al 2002). Multi-centre studies conducted in several European countries have shown that participation rates differ a lot by country and by local study centre (O'Neil et al 1995, European Community Respiratory Health Survey 1996, Wolf et al 1998). In multi-centre studies differences in response rates have been explained referring to the importance of cultural factors, but there may

also be differences in recruitment and fieldwork procedures, even though the survey protocols are similar in broad outline.

The reported percentage of non-response in the 43 national HIS ranged from 6 (IE) to 38 (BE) for households and from 6 (FR, FI) to 48 (IS) for individuals. For the 12 HIS/HESs the household non-response in UK ranged from 23% to 29% and the individual non-response for examinations in other countries has ranged from 15% (FI) to 75% (NL).

The detailed analysis from seven surveys showed that due to inconsistencies in the calculation the response rates cannot be compared. E.g. in UK the denominator of the individual response rate (the total number of adults in the sampled households) is not known and must be estimated. The exact refusal rate was not available for all surveys, but it ranged from 5 % (FI) to 36% (NL). In Finland only 1.4% of the original (eligible) sample were not contacted, while 20% were not contacted in the Netherlands. For the Italian HIS, the refusal rate was 6 % of the households and only 7 % of the households could not be contacted, while in Belgium the refusal rate was 38 % and 26 % of the households could not be contacted.

In Finland only those who had died before the survey fieldwork began were considered ineligible (0.6% of the original sample). Those having moved were invited to participate, even though they no longer lived in the sampled municipalities (health centre districts). In Germany 12% of the persons in the original sample were considered ineligible (deceased, removed, not known in the address or non-citizens). In Belgium 28% of the households and 5% of individuals were ineligible (moved or deceased). The response rate was reported only at the household level in Belgium and this is calculated from all households invited to participate and contacted (the replaced and the replacement households were taken into account).

In the surveys with an interview phase before the examination, the response rates varied in different phases of data collection, in different measurements and by different population groups. E.g. in the English survey in 1999 the household response rate for the interviews was 76 % while blood samples were obtained from only 24% of the Bangladeshi population. In Germany the subjects were considered participants if they had the blood pressure measurements, weight and height

measurements, and urine samples taken, and at least two of the following: questionnaire, medical interview and/or blood samples. In Finland the response rate for the interviews was 87 % and for the examination 85%, but a complete data set (interview, examination and all self-administered questionnaires) was received from 68% of the eligible persons.

It is recommended to report actual numbers of the original sample, eligible, contacted, refused and those interviewed and examined. Attention should be given to the calculation of response rates in a comparable way, taking into account the use of proxies and selection of new respondents in case of non-contact or refusal. Eligibility needs to be defined in comparable ways, and the number of different groups of ineligible persons (died, moved out) need to be reported, as well as the number of those not contacted and those who refused. It is also useful to record and report in detail all reasons for non-participation and refusal.

5.2.5. Proxy interviews and selection of new respondents

Päivikki Koponen

The validity of proxy responses has been questioned in several studies, both for the elderly (Hoeymans et al 1998, Neuman et al 2000), for children (Rajmil et al 1999) and for the general adult population (Clarridge & Massagli 1989, Grootendorst et al 1997, Todorov & Kirchner 2000). It has been shown that proxies consistently under-report morbidity and health care utilisation (Clarridge & Massagli 1989, Grootendorst et al 1997), systematically underestimate the health status of the respondent (Hoeymans et al 1998), and they report poorer function than the older patients themselves (Ball et al 2001). Obviously, these are not an evaluation of the validity of either proxy or subject's own reports. In any case, there may be differences in the validity of proxy reports by the type of proxy and their relationship with the subject (Rajmil et al 1999, Dewey et al 2000), by the age of subjects (Todorov & Kirchner 2000) and by type disease or disability (Neuman et al 2000). Several studies have found that differences between self and proxy responses are larger for subjective psychosocial dimensions than for more observable and chronic physical dimensions (Clarridge & Massagli 1989, Grootendorst et al 1997, Dewey et al 2000, Todorov & Kirchner 2000).

Proxy interviews have been allowed for children in most surveys (table 5.2.5.1) in almost all EU/Efta countries. Proxy interviews for adults not able to reply and for adults not at home have also been commonly used. Proxy interviews have not been allowed at all in a minority of surveys. The share of interviews with proxies varied according to the different situations where proxies were allowed. E.g. in Finland 5% of all interviews were carried out with a proxy, while in Belgium this figure was 23%.

Table 5.2.5.1 Proxy use in national/international HIS in Europe (60 HIS carried out 1998-2002, including HIS part of HIS/HES).

Use of proxies allowed in interviews:	Number of surveys
For children	26/60
For adults not able to respond	28/60
For adults not at home	22/60
No proxies allowed	13/60

In most national health surveys in Europe a non-respondent is not replaced. In case of non-response new respondents were selected if the respondent/household could not be contacted in two HISs, in case of refusal in one survey, and in both cases in five surveys. E.g. in Belgium three replacement households were selected for each sampled household, using geographic area, household size and age as selection criteria.

It is recommended to avoid both proxy use and replacement as far as possible and to use proxies only in well-defined conditions, if needed. The validity of proxy reports should be analysed and a minimum set of basic data should be collected also from the proxy respondent him/herself (e.g. age, sex, relationship to the subject) to evaluate different patterns of response. Allowing replacement is likely to introduce health related bias. If replacements are used, their selection and the replacement process should be carefully documented.

5.2.6. Collection of information on non-respondents

Päivikki Koponen

Register linkages, audition of medical records, questionnaires mailed to non-respondents (abbreviated versions if needed for these non-participant surveys), and brief telephone or face-to-face contacts are typical sources of information about individuals declining to participate or unable to participate. For surveys where data is collected at several phases, information from the subjects attending the first phase, typically a mailed questionnaire or interview, has been compared to the data of subjects attending the next phase, e.g. the examination.

Most studies, both HISs and HESs, have found significant differences between participants and non-participants concerning socio-economic status, education, marital status, participation in social activities and social support (Rodes et al 1990, Carter et al 1991, Pietilä et al 1995, Van't Hof et al 1996, Hoeymans et al 1998, Boeing et al 1999, Riedel-Heller et al 2000, Freudenstein et al 2001, Manjner et al 2001). In these studies differences have also been found in physical health status and disabilities, substance abuse and mental health, cognition, risk factors (e.g. smoking and obesity) and use of health services. Several studies have shown biased estimates of morbidity rates, disabilities and risk factors due to non-response (Hoeymans et al 1998, Riedel-Heller et al 2000), although there are some exceptions where no bias has been reported (Cottler et al 1987, Andersen et al 1998). The direction and magnitude of this bias varies according to type of disease and health outcome and is therefore difficult to predict.

Non-participation seems to be selective: for the younger age-groups people with addictive behaviours or problematic life situations, in the middle-aged those with higher risk and in the elderly those with chronic diseases and/or disabilities are less likely to participate. In general those with several health problems or disabilities are less likely to respond, but the effect of health status on participation may differ by type of disease/disability and also by age group.

Prospective studies have shown that mortality rates among participants have been lower than in the whole sample, or lower than among non-participants (Rosengren et al 1987, Bentsson et al 1997, Andersen et al 1998, Goldberg et al 2001, Manjer et al

2001). Excess mortality among the non-participants has been found to be due to diseases directly related to abundant alcohol use and smoking, life-style related cancers, cardiovascular diseases, accidents, and suicides (Rosengren et al 1987, Goldberg et al 2001, Manjer et al 2001).

Since this information has not been collected in all European surveys, some examples are presented here. Information on non-respondents is available from short mailed questionnaires or telephone interviews **in Finland**. Some register information is also available, if this has not yet been analysed. Abbreviated/adapted examinations and/or interviews were also carried out at home, if needed. Short telephone interview or questionnaire data only is available of 6.6% of the original (eligible) sample.

For all sampled persons in **the Netherlands** information on sex, age and marital status is available from the municipal administration. HIS data for some of the non-respondents in HES is also available. **In UK** some information on the non-respondents of HES was available if at least one subject in the household agreed to take part in the survey (interview) otherwise no information from non-respondents was collected. Register information on household size, nationality, age, sex and residency is available from the National Registry of Population **in Belgium**.

The reasons for non-participation were reported in different ways or not reported/listed at all. No reasons for refusal were asked/listed in UK and in Italy. In other surveys the reported main reasons for refusal were: illness, the subject considers that he/she is too old, has no interest, lack of time or other practical difficulties in participation, and family circumstances.

Based on the experience of the experts carrying out the surveys, people are motivated to participate if they feel there is at least some advantage or feedback for them personally, e.g. they receive personal results of the examination, or get information on the survey results in general. Other motivating factors are that the survey covers a disease meaningful to the participants or their relatives, or people want to help and support science and to participate in order to serve public interest. Good coverage in the national and local media, and media campaigns seem to be helpful.

Several methods have been developed to reduce non-response bias by the use of statistical models. However, statistical adjustments cannot control for the many independent factors affecting non-response. Certainly, the notion that non-respondents would equal the respondents concerning health or health behaviour is wrong. Analysis of personal and health status characteristics of non-respondents is essential. The design of all surveys should include some mechanism to collect data and information on non-respondents to facilitate this analysis. There is an obvious need for further analysis of non-participation in national health surveys in Europe and particularly for its effect on the findings and comparability. International comparisons of non-participation rates and reasons for non-participation are needed in the evaluation of comparability of survey results.

5.2.7. Data collection

Päivikki Koponen

For the HISs the data was collected most often by face to face interviews (in 19 surveys this was the only method, see table 5.2.7.1). Telephone interviews (two surveys using this as the only method), and self-administered questionnaires (nine surveys using this as the only method) were also common. Several methods were applied in most surveys, e.g. both face to face interviews and self administered questionnaires (one or several) were used in 12 surveys. In surveys using household samples the interviews typically consisted of short household questionnaires and longer individual questionnaires. In many surveys the questionnaires were adapted for different age-groups with special questions e.g. to young adults or to the elderly.

The interviews were computer assisted (CAPI) in half of the surveys (HIS or HIS part of HIS/HES) and also the examination part was computer assisted in most surveys (table 5.2.7.1).

For the HIS/HES the average duration of the interview ranged from 35 minutes to 1.5 hours and the average duration of the examination from 30 minutes to 4 hours.

Table 5.2.7.1 Data collection procedures for national/international HIS and HIS/HES in Europe (60 HIS and 12 HES carried out 1998-2002).

Mode of data-collection:	Number of surveys
Face-to-face interview	43/60
Telephone interview	14/60
Self-administered questionnaires	28/60
Computer assisted interview	30/60
Computer assisted examination	9/12

For the HES phase only those first participating in the interview phase were invited in the Netherlands and in UK. In the UK the participants also filled in self-administered questionnaires during and after the interview phase. In Finland even those who had not participated in the interview were invited to examinations and if needed (and if the participant agreed) an abbreviated version of the interview (and self-administered questionnaires) was conducted during the clinic/home visit for examination. In Germany there was no interview phase before the examination. The German participants filled in self-administered questionnaires before/during the examination and there was a medical interview with e.g. questions on diseases and use of medicines, carried out by a physician during the examination.

In most HESs the examinations were carried out at normal health care organisations/facilities. Other rented rooms or stationary clinics were also used in Germany and in Finland (when needed). In UK the examinations were carried out in the participants' home. Home visits (or visits to the institution) were also made in Finland if the participant was unable or unwilling to come to the examination site (5% of the main HIS/HES sample). An abbreviated/adapted protocol was used for these examinations if needed.

Nurses carried out the examinations in all surveys. Other personnel groups employed in one or two surveys were physicians, dentists and dental hygienists, laboratory technicians, and medical-technical assistants or receptionists. In UK nurses carry out most of the examinations, and interviewers were trained to measure height and weight. Special survey personnel was employed in all surveys, except in the Netherlands where regular health care personnel (in local health centres) was used.

The results of the examination were explained to the participants during and/or at the end of the examination, and the informants were given forms with results of the measurements. Copies of the recordings (e.g. ECG), were also given to participants in Finland. In UK the informants were later sent (if they wished) the results of their blood sample analyses, and the results of their measurements (BP, ECG and blood samples) were mailed to the participant's own doctor/GP (with the consent of the subject). In Germany and in Finland the participants received a detailed letter/form of their results comparing them with the reference/normal values of blood/urine tests and other measurements. In the Netherlands the participants did not receive any results from the laboratory analyses.

The interaction between the survey personnel and the feedback given to participants seem to be important elements in motivating the subjects. The complex relationships between non-response phenomena must be addressed. Decisions made throughout the study process have a cumulative effect upon the different sources of non-response. There seems to be no evidence that any single element in the survey process would decisively increase or reduce response. Intensive training of fieldwork personnel seems to be a key element for good survey participation and quality.

5.2.8. Quality assurance

Arpo Aromaa

Quality assurance is essential in health surveys. Ethically and technically high quality implementation has been described in several guidelines (Guidelines for Good Epidemiology Practices... 1991, International Society of Pharmacoepidemiology 1996). It is important to ensure validity and reliability of the survey as a whole and of all measurements. In this report quality assurance encompasses all methods used to ensure good quality of the data collected and of the results. The available means cover a wide range starting from sampling and selection of methods through training of personnel to quality control based on data management and analysis, and recorded results.

Good quality starts with design and methodological features resulting in well-defined samples, high-class implementation and high participation rates. These features lead

also to comparable samples and findings. The foundation of good quality is laid by the use of good proven methods. Key components of quality assurance related to implementation and measurement are standard operating procedures and manuals, control, maintenance and calibration of equipment, observer training and reference observers and laboratory standardisation. For international comparison one of the key determinants is culturally valid translation and formulation of questions. Additional elements are built-in estimation of validity and reliability and estimation of between observer and within observer variability. National and international references should be used when feasible and so should external standards and reference determinations. Some of these methods are only applicable in examination surveys.

5.2.8.1. Interview and questionnaire surveys

The interview survey is the standard method for collecting health data in most EU member countries. Trained lay interviewers perform the interview in the subject's home. The interview may be computer assisted (CAPI) and its alternatives are a computer assisted telephone interview (CATI) or a mailed questionnaire. The interviews may be complemented by self-completed questionnaires. It is often assumed that results obtained by interviews and self-completed questionnaires are similar. However, empirical comparisons have shown that results obtained by these methods may differ (e.g. Siemiatycki et al 1984, Galobardes et al 1998) and that the differences depend on contents. Differences are thought to be small in regard of factual information. For very sensitive issues (sex life, drug taking) the self-completed questionnaire is the method of choice.

The implementation of the survey may affect findings. Thus, trained non-provocative interviewers and calm surroundings free of disturbances help to set a relaxed tone for the interview. Subject matter interesting to the interviewee helps to keep him/her motivated. Amongst others the following implementation features influence results:

- **Season:** time of the year affects symptoms, acute diseases (infections, allergy), use of services and medicines. Some surveys try to overcome this by using a rotating design and others by long recall periods.

- **Epidemics:** if an influenza epidemic or comparable occurs it will affect estimates of the occurrence of acute diseases, respiratory and other symptoms, use of some medicines and use of services
- **Context:** a lone interview may produce different results than an interview followed by a health examination due to the feedback expected from the latter.
- **Interviewer-interviewee interaction:** some interviewers may provoke reactions in some interviewees resulting in biases. Some interviewers are able to create a positive atmosphere with more interviewees than others.
- **Interviewer's own understanding:** For factual information a knowledgeable interviewer may obtain more accurate results than an interviewer who does not know well the subject matter.
- **Repeated observation and training:** Those having trained the interviewers should also observe their performance in the field work and provide additional training.

The interviewed person may influence the accuracy of replies. The person's state of health and state of mind, motivation and concentration, cognitive ability, influence of alcohol and medication are examples of factors affecting replies.

Formulation, adaptation and translation of questions influence validity. Valid replies are most likely when the questions concern actual facts such as numbers of visits, medication used, surgical operations performed or diseases diagnosed. The same is true of personally experienced symptoms and of regularly reoccurring activities. However, the memory period may affect replies. It has been shown that for medical care utilisation the past 14 days yield estimates closest to the true frequency of visits. A longer memory period leads to underestimation. The drawback of the short period is that it is uninformative on the level of individuals. For this purpose 12 months is a better choice. Therefore, using both two months and 12 months seems to be a sensible approach.

To understand the findings one should also have an idea of the reliability (repeatability and inter-observer differences). Unfortunately, reliability tends to be question specific just as validity. Reliability also depends on the implementation i.e.

on the surroundings and on the way questions are presented. In interview surveys there may be considerable subject-interviewer interaction. Therefore, it is important to obtain in each survey setting assessments of the reliability of the most important questions.

Validity and reliability cannot be assumed to be similar in different subgroups of the population. Typically, reliability of data on health may diminish with advancing age and improve with increasing education, although such findings are not universal.

Different types of questions tend to have different validity and reliability (see table 5.2.8.1). In general, the quality of factual information is best provided that the memory period is optimal. Long memory periods tend to lead to underestimation of frequency measures. However, the validity criterion must be established for each specific use.

Questions of the following type yield quite accurate results.

- How many times have you visited a doctor during the past 2 weeks/30 days/12 months?
- Do you smoke cigarettes currently?
- Do you take any prescribed medicines currently?

Although the nature of the information is different the same can be said of questions on the person's current symptoms, emotions or opinions. As a rule, the closer to everyday experiences the more accurate are the replies.

A rather special category are questions on the person's functional ability. The first problem is that the environment and its requirements may be different for different persons. Second, even in uniform environments only some persons have experience of all of the activities inquired about. Questions concerning the person's activities: 'do you walk at least one kilometre every day?' tend to result in more accurate replies than questions of the type 'can you walk ...'. On the other hand they relate to activities and not to functional capacity. When a person does not have recent personal experience of an activity he/she will tend to reply to a question of the latter type regardless of how the question has been formulated. Particularly when inquiring about potential abilities (can you ...) optimists tend to overestimate and pessimists (or the depressed) to underestimate their current abilities. In order to reduce this

effect some surveys ask the respondent to compare his/her ability with that of other persons of the same age. Unfortunately, any individual bias and poor reliability is unlikely to be reduced. The problems mentioned above are of major concern both when comparing time trends and population groups. To overcome this independent assessments and measures are necessary as discussed under health examination surveys.

The way to reduce problems is to formulate questions very clearly and to present them in a supporting way. It is not enough that the researcher thinks the questions are clear, they must be tested in suitable groups of persons to make sure that they are understood in the intended way. Furthermore, such tests should be carried out in each of the countries (and cultural environments).

Table 5.2.8.1 Typical levels of validity and reliability of different domains in interview surveys.

Domain	Levels of validity and reliability
Social and demographic data	+++
Use of services	++
Chronic conditions	++
Use of medicines	+++
Health behaviour	++
Living conditions	+++
Symptoms	++
Perceptions	+
Functional limitations	++
Activities	+++

+ = relatively poor, ++ = intermediate, +++ = good

Assessing validity and reliability

To assess validity in the traditional sense requires an external criterion against which interview and questionnaire findings can be compared. It is practical only if comparative more valid information can be obtained from other sources or by other means. Obviously, the meaning of validity in the respective context must be defined first. Possible approaches are to obtain comparative data from

- a) statistical sources (use of services, consumption of medicines, consumption of alcohol – however, statistics may be incomplete)
- b) observer assessments (functional limitations – may also be labeled a reliability estimate)
- c) tests of performance (functions – falls into HES domain)
- d) comparative measurements (established scales compared to brief interview scales – falls into HES domain)
- e) laboratory tests (smoking, alcohol use, some medicines – falls into HES domain)

Although not comparable to the above validity criteria, two other approaches can be used. First, the variation with age, sex, education, occupation and income of some interview findings can be compared with data from other sources. A similar variation supports the idea of good validity although it does not give any direct indication of the degree of bias. Second, when there is a number of interviewers their findings can be compared. Big differences in means or prevalence suggest that there may be interviewer-related biases. Unfortunately, such results tend to be difficult to interpret.

Reliability has been much more frequently assessed than validity. One approach has been to measure the internal consistency of scales. The other to perform repeated measurements. The most straightforward way is to ask respondents to reply to the same questions twice after an interval of say two to four weeks and after six months or a year. For obvious reasons reliability is better when the time interval is short than when it is long. However, part of this within subject variation may be due to true changes over time and only part to measurement error. Comparisons of results by interviewers either in a survey at large or in separate or built in experiments allow estimation of interviewer differences (these include validity and reliability). If one or several interviewers can be regarded as superior to the others they can be use as a yardstick to which others are compared.

5.2.8.2. Health examinations and HIS/HES surveys

National health examinations or at least examination components added to national interview surveys are being regularly carried out in a few European countries only. Trained observers, usually health care personnel, carry out the examination.

Equipment for various measurements is used in field work. Nowadays it comprises both sensitive instruments and data processing apparatus. Blood samples are drawn, processed, transported and finally analyzed in central laboratories. X-rays and ultrasonic images may be taken, evaluated during the examination and sent for central analysis. All this indicates that not only is logistics of a HIS/HES much more complex than of a HIS but that there is need for more and much more variable quality assurance methods. On the other hand, although more things could go wrong the opportunities for preventive maintenance and controls are also better.

Much said above about interview and questionnaire surveys holds for those components in HIS/HES surveys. However, a general feature is worth pointing out: experience suggests that sensitivity and validity of questions on chronic conditions, medicines and use of services may be better in the HES context probably due to different expectations of the people.

There are two types of questionnaires usually included in HES. One is the diagnostic somatic symptom questionnaire (such as chest pain, chronic bronchitis), the other the psychic symptom or short diagnostic questionnaires (examples are the GHQ and the BDI). When used for screening or probable diagnosis these questionnaires separate the examinees into those with a disease and the healthy ones. Several of the well-known questionnaire scales have been validated against clinical diagnoses and then their sensitivity and specificity are known. Finally, there are the extensive diagnostic tools (CIDI) simulating the psychiatric diagnostic process. In all these cases the prerequisite of usefulness is sufficiently good validity i.e. the capability to separate cases from non-cases. This goes hand in hand with the requirement for good reliability since the separation should be sufficiently valid at all instances. It must be re-emphasised that interviewer effects may be considerable particularly when sensitive issues are examined as in these cases. Some of the mentioned screening instruments may perform better as self-filled questionnaires.

In addition to what was said under HIS the implementation, characteristics of observers and subjects and the quality of instruments in HES affects findings in several ways.

Season and temperature: many measurements vary with these

Time of day: time of the day affects many bodily functions and due to blood plasma volume changes many laboratory determinations

Fasting: the length of fasting affects e.g. blood sugar, insulin, triglycerides, partly due to plasma volume changes, partly due to metabolic influence

Physical activity: recent physical activity increases heart rate and blood pressure

Mental stress: concurrent mental stress raises blood pressure and heart rate and the excretion of some hormones

Smoking: recent smoking provokes several symptoms and increases blood pressure

Alcohol consumption: recent alcohol consumption affects many bodily functions and it may affect cognitive performance

Fatigue: particularly in elderly persons fatigue may reduce functioning

Observer-subject interaction: Observers may provoke reactions in subjects leading to changes in bodily functions

Subject's position and duration of rest: important for blood pressure measurement

Instructions to the subject: good instructions help the subject to perform as intended leading to correct measurements

Measurement technique: a correct technique is a prerequisite for correct results

Calibration of instruments: many instruments must be calibrated initially and from time to time to yield correct readings

Drawing and handling samples: thorough instructions should be given to avoid contamination and spoiling of the samples

Analytical techniques: in the laboratory the use of up-to-date methods using good techniques should result in valid determinations. This requires quality assurance and quality control methods with both internal and external control samples.

Storage: biological samples deteriorate unless temperature is low enough, now generally -70 °C.

Instructions should be given to subjects on eating, drinking, fasting, smoking and the like in the letter of invitation to avoid unwanted variation. Measurements should be

carried out in a calm relaxed atmosphere with a minimum of disturbances and strictly according to recommended procedures. Also, the order of measurements should be planned so that they do not influence each other. Calibrated equipment and high quality analytical methods should be used. Whenever feasible external controls should be employed. Standard operating procedures should be employed in all phases and manuals and protocols should be complete. Repeated self-instruction by booklets, videos etc. should be employed when feasible. When analysing and reporting results any deviations should also be reported.

To achieve improvements in comparability between surveys and countries requires international collaboration by experts in the field and joint training procedures. In regard of laboratory analyses external control serum must be used to establish validity. Such a scheme existed previously in Europe for serum cholesterol but the future scope should be much wider.

Validity and reliability can be studied by repeat measurements and parallel (observers and outside reference observers) measurements built into the survey proper. They can also be studied in separate experiments allowing e.g. for estimation of measurement level differences between all observers. Some times it is extremely useful to obtain separate estimates for biological variation (short term and long term) and for analytical variation. Sometimes these sources of variation can be used to correct the measurement results.

Other quality assurance during field work

Expert observers can be used to assess performance and give guidance when needed. Also, experienced observer's findings can be compared to the regular observers and when deviations are found, they should lead to corrective action. Atmospheric pressure and temperature should be recorded as they affect some measurements. When the performance of instruments can be tested using standards, these should be regularly used and the results recorded. Examples are comparing automatic sphygmomanometers with a mercury manometer, measuring a known volume with a spirometer, using a phantom to make an x-ray image, using a standard ECG-signal to check the calibration of the ECG instrument, using standard weights to check and calibrate a scale etc.

It is common knowledge that laboratory determinations carried out in different laboratories tend to vary. However, it is also well known that a system based on internal and external quality control sera helps to yield comparable results. It also enables corrections to be performed on the results. In order to ensure comparability on the European level it is essential to establish a network of reference laboratories providing control sera to each other. Such a scheme should be set up immediately.

5.2.8.3. Quality control for HIS and HIS/HES

Here quality control is understood to comprise methods employed after the data have been gathered. Such measures for interviews have traditionally comprised examination of means, ranges and prevalence of recorded findings. Their variation between observers and between consecutive time periods has been examined. Comparable methods have been used in health examinations for blood pressure measurements, height, weight, and BMI, and several laboratory determinations. If these controls reveal big differences it is often possible to identify their cause. However, the typical small differences generally remain inconclusive.

When measurements of standards can be used it is possible to estimate biases in the results, and perhaps also to correct them. This can sometimes be done successfully in regard of laboratory determinations. A similar approach may be used when 'standard' observers or 'standard' subjects (e.g. field personnel) have been measured. However, in regard of many measurements inherent errors are much bigger thus making conclusions uncertain.

The final step in all surveys is checking and cleaning the data obtained. If field work and built in quality assurance have been carried out according to high quality procedures the data should be rather good. However, it is well known that there are always some errors such as missing data and erroneous recordings. Cleaning of the data sets is important but one should note that in regard of quality most has to be done prior to and during fieldwork.

5.2.8.4. Examples of quality assurance in surveys in Europe

Some examples of quality assurance are presented, focusing on interviews and some examination components.

External quality control by another organisation (external observers during examinations) was organised in the German HIS/HES, while all other examination surveys used internal quality controls i.e. observers from the organisation implementing the survey. All surveys reported training of survey personnel and the use of written instructions. In addition, several quality assurance/control procedures were used. Repeated measurements of the same subjects were carried out in the German and the Finnish HIS/HES. In all countries the findings reported by observers (survey personnel) were monitored at regular intervals. Calibration of equipment was also used as part of quality assurance in all HESs. Some examples of other quality assurance methods/systems are presented below, based on the information available from the seven surveys selected for the detailed study on participation and representativeness.

Pilot runs of the examinations were carried out in Finland, in the Netherlands and in UK. In Finland two full-scale pilot surveys tested the feasibility of survey protocols and developed guidelines and manuals for the survey proper. The performance of the fieldwork staff was observed by those responsible for the survey planning, preparation of manuals and training of survey personnel. In Finland data were recorded into laptops and the programmes had built-in checks for non-permissible values. The main method for quality control in Finland were “quality assurance days”. Some measurements were repeated with different techniques (e.g. different BP-devices) and two observers carried out the same measurements. In Germany site visits by experts from an external organisation were carried out using special checklists for each measurement.

In Belgium (HIS) a sub-sample of the households was re-contacted later by phone to verify some information given during the interview. A specific Quality Control Board acted as a critical reflection chamber in the Belgian survey, giving advice to the survey director. During data collection the progress of data entry and data consistency checks were reviewed. The interviewers' performance was reviewed by

e.g. progress report forms with information on the number of realised interviews and the number of refusing households.

In Italy (HIS) supervisors attended some of the interviews during the pilot surveys to identify the difficulties in understanding and administering the questionnaires. The day after the interview during the actual fieldwork phase, some households chosen at random were contacted again by telephone by ISTAT (institution responsible for the survey) staff. The household was thanked for their collaboration and a rapid check on the interview was conducted on all its parts. Each day a monitoring group analysed e.g. reports from the interviewers and the notifications given to the free-phone number.

In UK (HIS/HES) recalls to check on the work of both interviewers and nurses were carried out in 10% of participating households. The computer program used by interviewers had built-in checks, including messages querying uncommon or unlikely answers. At the end of each survey month, the measurements made by each interviewer and nurse were inspected. E.g. if a nurse had obtained a number of abnormally low measurement values, the supervisors discussed these with the nurse.

5.2.8.5. Conclusions

Quality assurance is an essential prerequisite of good quality in surveys. Both interview surveys and examination surveys need to employ systematic quality assurance. They begin from high quality design and protocols, and go to clear manuals, good and repeated training, references and standards and expert observers. Final stages are traditional quality control measures based on the data obtained and corrections when feasible.

Although current European national surveys employ some quality assurance and quality control methods, there is large variation in the methods and their usefulness. European surveys would benefit from collaboration starting from devising designs, methods and protocols through to training and other elements of quality assurance. Organising joint planning, joint drafting of quality assurance and joint training and quality control would be particularly beneficial. All health examination surveys would benefit from a joint reference laboratory system to be set up as soon as possible.

5.3. Indicators typically measured in health surveys

Jean Tafforeau

5.3.1. *European Community Health Indicators (ECHI)*

The list of common health indicators at the European Community level (Kramers et al 2001) has the following structure:

1. Demographic and socio-economic factors
 - 1.1 Population
 - 1.2 Socio-economic factors
2. Health status
 - 2.1 Mortality
 - 2.2 Morbidity, disease-specific
 - 2.3 Generic health status
 - 2.4 Composite health status measures
3. Determinants of health
 - 3.1 Personal and biological factors
 - 3.2 Health behaviours
 - 3.3 Living and working conditions
4. Health systems
 - 4.1 Prevention, health protection and health promotion
 - 4.2 Health care resources
 - 4.3 Health care utilisation
 - 4.4 Health expenditures and financing
5. Health care quality/performance.

The total number of indicators included in this ECHI-list is 251. Half of these can be measured by health surveys (see the detailed list of these indicators in annex 11); for a lot of indicators alternative systems of registration can not produce national population-based figures. Health surveys thus play a central role in the health information system.

The indicators of the ECHI list, which can be covered by means of survey questions have been compared to the health topic code list in the HIS/HES database (see annex 1 for the HIS health topic code list).

A review was made in the HIS/HES database to check how many countries have included specific questions for each European Community Health Indicator. This helps to identify the domains that are well covered by health surveys and for which comparison of the results should be performed. For example, 49 out of 60 surveys have questions on self-perceived health, and 44 out of 60 surveys have questions on smoking.

It is also interesting to pinpoint the domains not yet sufficiently covered by health surveys and for which additional work is needed to develop instruments and/or promote the use of these instruments. For example:

- residential environmental exposure (only 13 out of 60 surveys have questions on this domain)
- knowledge and attitude on health (only 14 out of 60 surveys)
- breast – cervix cancer screening (only 14 out of 60 surveys).

Some ECHI indicators do not have their correlate in the HIS/HES health topic code list :

- Infant mortality (in category 2.1): is usually measured in Europe from vital registration and not through health surveys
- Energy from food (category 3.2.2): is not included in the list of health topics; these indicators require more than a set of specific questions, and need to be tackled by nutritional surveys or by extensive questionnaires in HIS/HES. The current topic codes need to be reorganised with the help of a nutrition unit. The new list should take into account both foodstuffs and nutrients.
- Consumption of bread/cereals and of fish (category 3.2.2): is not included as such in the topic list but such topics could be added in the future; for the moment the questions on these domains are classified into topic 407 (diet and nutrition)
- Consumption of calcium, or consumption of contaminants (category 3.2.2): are not included in the list of health topics; these indicators require more than a set of a few questions, and need to be tackled by nutrition surveys.
- Traffic behaviour (category 3.2.3). There are a few questions related to traffic behaviour (use of safety belts) in the database; these are classified under health topic 416 (knowledge of (un)healthy life styles).
- Violence (category 3.3.3). Questions on violence occur more frequently in recent health surveys. Violence is however not included as such in the topic list but it

should be added in the future; currently these questions are classified in topic 499 (other life style factors).

Concerning ECHI indicators which can be covered by means of HESs the following domains are covered in the 12 national HES in Europe:

- Personal and biological factors: BMI and blood pressure (all 12 surveys), and serum cholesterol (10 surveys)
- Prevalence of diseases, e.g. diabetes (five surveys), asthma (five surveys), dementia (two surveys), and depression and generalised anxiety disorder (two surveys).
- Functional limitations (two surveys)

Further work is needed especially to develop the measurement of functional limitations. Currently the HES topic list is not structured according to the ECHI list. Further work is also needed to link the ECHI list and the ICF-codes (WHO 2001) for the future development of the topic codes in the HIS/HES database (see chapter 5.4.4).

5.3.2. Indicators proposed by the Health Monitoring Program

During the period 1998-2002, a series of projects have been funded by the European Commission. The final reports of these projects (when available) have been reviewed and discussed in the HIS/HES core group. The aims of each project and its possible relevance for the HIS/HES database have been considered systematically.

Recent recommendations, or HIS instruments and HES protocols tested and/or proposed by other EU HMP-funded projects and projects under the WHO organisation are listed in tables 5.3.2.1 - 5.3.2.5 Some comments on these are given in this chapter.

The European Food Consumption Survey Method, EFCOSUM group (EFCOSUM group, 2001) emphasises the need for co-ordinating nutritional surveillance activities within the EU. Data at the individual level are recommended. There is a broad consensus on two points: 1) the need to carry out an European Food Consumption survey, and 2) in the meantime, any country that will carry out a

(national) food consumption survey should follow the recommendations made by the EFCOSUM project. Food consumption in detail may not be a natural part of general HISs and HESs. If it is, a special instrument should be developed.

The EuroREVES project (Robine et al 2000, 2002) has proposed five instruments (see table 5.3.2.2). The new sets of questions, including physical limitations, need to go through a good validation process to ensure that the proposals are conceptually sound. However, strong statements are made by the project as far as the recommendation of instruments: Any instrument recommended to facilitate international harmonisation, should have relevance for policy-makers both at the international and at the national level. Any untested recommendation should be accompanied by a plan of practical testing, of implementation as well as regular evaluation of the quality of the information collected.

This emphasises the central role of the HIS/HES database: keeping an updated inventory of instruments used in each country, and evaluating the quality of the information collected. It also stresses the need for international efforts to gather experiences, test and recommend new instruments. In the future the HIS/HES project could offer assistance to the users (people/institutions in charge of national health surveys who often do not have the required resources to perform in depth studies on the quality of the instruments proposed) in the tasks mentioned. It is imperative to analyse the instruments proposed by special groups and give recommendations concerning their use in the framework of European health monitoring.

The project "**Monitoring socio-economic inequalities in health in the European Union: guidelines and illustrations**" (Kunst et al 2001) has identified the socio-economic indicators that can best be used to monitor socio-economic inequalities in health in Member States. It has also given recommendations for measurement (see table 5.3.2.1). These recommended instruments should be evaluated in detail before inclusion in the HIS/HES database. However, on face value they are likely to be the best possible choice. For practical reasons, standard ways of measuring and classifying these indicators are recommended. For theoretical reasons, however, the report considers a number of alternative measures for future data acquisition and monitoring. These are e.g. life-course based measures, such as occupational class measured at different points of time, measures of wealth, accumulated life-time

income, such as house ownership, and measures identifying disadvantaged groups, such as ethnic minorities. The project also gives recommendations on the way in which health indicators can be presented and analysed in relation to these socio-economic indicators. These guidelines are useful for all persons in charge of health surveys in the Member States.

Finally, the report emphasises that data from HISs suffer from a number of problems having the potential to bias estimates of socio-economic inequalities in health. Special attention should be given to the effects of a) high non-response rates in some countries, b) the exclusion of institutionalised populations from most surveys and c) problems with comparability (both over time and across countries) of some health indicators.

In **the EUPASS Project** (European Physical Activity Surveillance System, Rütter et al 2000) IPAQ was proposed as a comparable instrument for national physical activity surveillance (see table 5.3.2.3). However, the validity and the reliability of the instrument has to be further tested. Applications of the IPAQ in three national surveys have not been successful. Thus, the value of the data on physical activity already available at country level should not be underestimated. For example, one of the old indicators used in the national Finnish health survey for many years (physical activity in leisure time) turned out to be a stronger predictor of subjective health status than the IPAQ indicators.

The project "**Establishment of a set of Mental Health Indicators for European Union**" (Lehtinen et al 2002) recommended several instruments for the measurement of mental health (see tables 5.3.2.2 - 5.3.2.4). Not all of these have been fully tested in the context of national health surveys, while others have been widely used and tested for validity and reliability.

The European Health Risk Monitoring (EHRM) project (Tolonen et al 2002) has given several recommendations for indicators, international collaboration, protocol and manual of operations for chronic disease risk factor surveys (see tables 5.3.2.2 - 5.3.2.5). In addition to recommended questions and protocols, recommendations have been made on the methodology of CVD risk factor monitoring in the age group of 35-74 years: sampling, response rate, survey interval and quality assurance. The

feasibility of these recommendations in the framework of comprehensive national health surveys should be further evaluated.

The Child Health Indicators of Life and Development (CHILD) -project (Rigby et al 2002) emphasises that surveys on child health need to ensure collection of child-centric data, and to seek children's views rather than solely adults' views. It is recommended to measure the following indicators with specific survey instrument for children: prevalence of asthma, dental health, breastfeeding, passive smoking, parental support (HBSC/WHO survey), physical activity (HBSC/WHO survey), tobacco smoking (HBSC/WHO survey) and alcohol abuse (HBSC/WHO survey), substance misuse (ESPAD survey), overweight and obesity. The feasibility of these instruments within the framework of comprehensive health surveys should be evaluated, as well as the need to add to the HIS/HES database specific surveys for children and adolescents.

The Reproductive Health Indicators in the European Union (REPROSTAT) - project (see <http://www.reprostat.com>) is working on indicators and recommendations for measurement but no final results are available. Health surveys are indicated as data source for the following indicators: chlamydia prevalence, age and contraceptive used at first intercourse (youth survey), condom use during last intercourse, contraceptive use (at 15-49 years of age), HRT use (women aged 50-59), time and treatments needed to get pregnant, hysterectomy, urinary incontinence, and sexual violence/well-being. Most of these questions are already included in the HIS/HES database. In the future the feasibility of different questions on reproductive health within comprehensive health surveys should be evaluated. A specific topic on reproductive health could also be included in the database.

The European Comparative Alcohol Study, ECAS II, (Leifman et al 2002) has given no direct recommendations on instruments and methods. Currently the HIS/HES database contains the health topic "alcohol use and abuse" which covers drinking patterns. The ECAS II project shows the necessity of measuring alcohol-related problems, and an additional topic "alcohol related problems" could be introduced.

European Disability Measurement (EDM) project (de Kleijn-de Vrankrijker & Bonte 2002) aimed at consistent disability statistics in Europe with the development of a minimum set of items, with reference questions and the collection of data by 2006. Specific disability modules have been included in the ECHP 1994-1999 and in the Labour Force Survey in 2001. Emphasis should be on common disability items, not on common instruments. A distinction can be made between a reasonable short list of core items which should be available at regular intervals in all MS and at EU level and items needed on an ad hoc basis. The ICF should be the conceptual framework while realising that some topics and items of ICF cannot be measured in practice. More emphasis should be put on developing practical measurement methods.

Further steps in development comprise the following proposals:

1. Functioning/Disability in terms of body functions/structures and activities
2. Cognitive functioning
3. Self-Care
4. Domestic life activities.
5. Functioning/Disability in terms of participation and environmental factors.

As noted also by the report the majority of the proposed items go back twenty or thirty years and many have been widely used in national surveys. However, their validity and comparability on the international level has not been fully established. Also, the full proposed set is vast and a major part of it has so far been included only in comprehensive disability surveys and in a few HESs. In particular, the proposed cognitive items and mobility items can only be included in HES type surveys. The most recent national example is the Finnish Health 2000. An important development step would be to carry out joint analyses of data from national studies.

Our review of the recommendations from **the EUROHIS project** is based on the draft report (Nosikov & Gudex 2003). The project aimed to recommend indicators for eight topics (see tables 5.3.2.2 - 5.3.2.4). Further experiences and assessments are needed before there is an internationally widely accepted measurement method for all these topic areas. Despite some questionable choices in the disease list for chronic conditions and some differences in wording in the follow-up questions the adopted principles resemble those applied in many surveys in Finland since the 1970s. Similar lists have also been used in other countries. The principle should be

endorsed but needs to be examined further. The sound proposals on mental health are a possible choice for a set of questions. The recommendation on alcohol consumption is based on sound principles and needs to be taken into account in further work. The only drawback is that it has no direct links with the many varied ways used previously in HISs to assess alcohol intake. This proposal is a basis for developing questions on alcohol use; it should be included into the database as a recommendation. A new understanding of health enhancing physical activity has been developed and new survey instruments are needed. The IPAQ instrument is in the background of the current proposal, but field-testing of the instrument revealed difficulties in some countries. Therefore, the measurement of physical activity is still in a developmental stage. As far as use of curative medical services is concerned the recommended common instrument includes a minimum set of 10 core items and a number of optional items. The proposal is a reasonable compromise and it should be referred to in the HIS/HES database. However, it cannot take into account different features of national health care services and must therefore be modified for national use.

Other HMP-funded projects have also arrived at conclusions relevant from the point of view of HIS and HES. The project on **Health Indicators in the European Regions, ISARE** (Grimaud et al 2001), has shown that the lack of available data regarding health status and morbidity at regional level is a challenge to national health surveys. The HIS/HES inventory should verify in each member state if sample size and data collection methods are adapted to the need of regional health indicators.

The project "**Methodologies for producing EU-wide comparable disease-specific morbidity data**: development of an electronic inventory of data sources" (ONS, UK 2001) has two key recommendations very close to methodological problems faced by the HIS/HES database: 1) using the Internet to make the database easily accessible within the EU, and 2) ongoing commitment and resources to be set aside to ensure that the database is continually updated and thus retains its relevance as a reference tool. The close relationship between this project and the HIS/HES project should be maintained. Besides this methodological aspect, the two databases are complementary. The aims of each of the two specific projects are quite different and

the ONS database should just refer to the HIS/HES database as far as health surveys are concerned.

The project on **response conversion** (van Buuren et al 2001) gives an example of a new technique for comparing existing health information. It can be used to repair any trend gaps that are inevitable when a new instrument replaces an older one. The proposed method could smooth the transition from current to common instruments.

The project "**Health monitoring in sentinel practice networks**" (Fleming et al 2001) is not directly related to health surveys; it has demonstrated however that primary care based sentinel practice networks can be a valuable source of information for selected health indicators. The methodological approach of this project is similar to what the HIS/HES project has been doing: building a database with the inventory of the network and its data collection methods, studying the comparability between Member States, evaluation of and recommendation for data collection methods. Both projects should thus learn from their mutual experiences. The role of an Expert and Documentation Center is emphasised in the project report to provide support and to ensure comparability between networks and Member States. The same lines one can be followed to propose the establishment of an Expert and Documentation Centre for health surveys in Europe.

Other HMP projects, not yet finalised, are possibly having relevance to HIS/HES database:

- Nutritional monitoring (Sjöstrom)
- Cardiovascular conditions (Giampaoli)
- Locomotor conditions (Bruusgaard)
- Cancer indicators (Micheli)
- Respiratory indicators (Duran)
- Dental health (Bourgeois)
- Intellectual disabilities (Noonan-Walsh)
- Health promotion indicators (Davies)
- Work-related health (Bödeker)

These should be taken into account in the HIS/HES database development and other further work on HISs and HESs.

In addition to the above mentioned proposed instruments and recommendations, there are other recent International instruments and protocols to be taken into account in future development. These include e.g. the WHO STEPS Instrument developed for the surveillance of risk factors for non-communicable diseases (WHO 2001, http://www.who.int/ncd/surveillance/surveillance_publications.html.)

Table 5.3.2.1 Recent EU HMP and WHO recommendations/proposed instruments on demographic and socio-economic factors.

Area/topic	Recommendation's /project's name/ reference	Organisation/project responsible for the recommendation (and co-ordinator)	Year	Included in the HIS/HES database	Topic/Content (name of instrument tested, proposed and/or recommended)
Demographic and Socio-economic factors	(Kunst et al 2001)	HMP (Erasmus University Rotterdam, The Netherlands)	2001	No	Education, occupation, income
	EHRM (Tolonen et al 2002)	HMP/EHRM (KTL, Finland)	2002	No	Education, employment status, income, household size
	WHO (de Bruin et al 1996)	WHO, Copenhagen/ Statistics Netherlands	1996	Yes	Education, occupation, economic position, income

Table 5.3.2.2 Recent EU HMP and WHO recommendations/proposed instruments on health status.

Area/topic	Recommendation's /project's name /reference	Organisation/project responsible for the recommendation (and co-ordinator)	Year	Included in the HIS/HES database	Topic/Content (name of instrument tested, proposed and/or recommended)
Health status/perceived health	WHO (de Bruin et al 1996)	WHO Copenhagen/ Statistics Netherlands	1996	Yes	Perceived health
	EuroHis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	
Health status/temporary limitations of activity	WHO (de Bruin et al 1996)	WHO Copenhagen/ Statistics Netherlands	1996	Yes	Temporary disability
Health status/Chronic conditions	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	Open ended question on any long standing illness or health problem Disease specific questions (list 15 disease or conditions + other)
	EHRM (Tolonen et al 2002)	HMP/EHRM (KTL, Finland)	2002		Awareness and treatment of Hypertension Diabetes mellitus
Health status/limitations of functional ability and ADL	Euro-REVES (Robine et al 2000)	HMP/Euro-REVES (INSERM, Montpellier, France)	2002	No	ADL (feeding, transfer [bed],dress/undress, use toilets, bath or shower) IADL (telephone, shopping, prepare meals, light housework, heavy housework, laundry, finance) Physical and sensory functional limitations (seeing, hearing, walking, stairs, speaking, biting/chewing, arm use, fine arm use, bending/kneeling, lifting/carrying), GALI

Area/topic	Recommendation's /project's name /reference	Organisation/project responsible for the recommendation (and co-ordinator)	Year	Included in the HIS/HES database	Topic/Content (name of instrument tested, proposed and/or recommended)
	EDM (de Kleijn-de Vrankrijker & Bonet 2002)	HMP (TNO, the Netherlands)	2002	No	Recommends common items and relies on recommendations of Euro-REVES
	OECD (McWhinnie 1981)	OECD	1981	Yes	Long Term Disability Questionnaire (vision, hearing, speaking, carrying, walking, cutting toenails, pick up a shoe from the floor, cutting food, biting/chewing)
	WHO (de Bruin et al 1996)	WHO Copenhagen/ Statistics Netherlands	1996	Yes	Long term disability (physical: mobility, locomotion, transfer, dressing, washing, feeding, toilet, continence, hearing, seeing)
Health status/Quality of life	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	WHOQual
Health status/mental health	Lehtinen et al 2002	HMP (Stakes, Finland)	2002	No	Sense of mastery/seven item scale (modified from Perlin et al) Optimism/LOT-R, 6 items Psychological well-being and distress and impairment/SF36 Negative life events/short list of threatening events (LTE) Depression/CIDI-SF Suicide attempts Generalised anxiety disorder/CIDI-SF

Area/topic	Recommendation's /project's name /reference	Organisation/project responsible for the recommendation (and co-ordinator)	Year	Included in the HIS/HES database	Topic/Content (name of instrument tested, proposed and/or recommended)
	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	Positive mental health (SF-36) Psychological distress (SF-36) Role limitation (SF-36) Depression/CIDI-SF Generalised anxiety disorder/CIDI-SF Suicidal thoughts and behaviour
	Euro-REVES (Robine et al 2000)	HMP/Euro-REVES (INSERM, Montpellier, France)	2002	No	GHQ 12
	WHO (de Bruin et al 1996)	WHO/Statistics Netherlands	1996	Yes	Chronic conditions, mental: dementia (Iowa dementia test), mental retardation (MMSE, Benton visual retention test, MC version), anxiety disorders, schizophrenia, affective disorders (DIS)
Health status/sleeping disturbances	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	Sleep problems (WHO Health and Responsiveness survey)
Health status/social support	Lehtinen et al 2002	HMP (Stakes, Finland)	2002	No	Social support/Oslo 3 item social support scale Social isolation/4 item scale (Statistics Canada)
	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	Social support/Oslo 3 item social support scale

Table 5.3.2.3 Recent EU HMP and WHO recommendations/proposed instruments on personal and lifestyle factors.

Area/topic	Recommendation's /project's name /reference	Organisation/project responsible for the recommendation (and co-ordinator)	Year	Included in the HIS/HES database	Topic/Content (name of instrument tested, proposed and/or recommended)
Personal factors	EHRM (Tolonen et al 2002)	HMP/EHRM (KTL, Finland)	2002		Awareness and treatment of Hypertension High cholesterol
	WHO (de Bruin et al 1996)	WHO Copenhagen/ Statistics Netherlands	1996	Yes	BMI (self-reported height and weight)
	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	Blood pressure measurements Blood cholesterol
Life style factors/Smoking	WHO (de Bruin et al 1996)	WHO Copenhagen/ Statistics Netherlands	1996	Yes	Current smoking Reduced smoking Ever smoked Stop smoking
	EHRM (Tolonen et al 2002)	HMP/EHRM (KTL, Finland)	2002		Ever smoked Current smoking Advised to stop smoking Passive smoking
	EMCDDA (2002)	EU/EMCDDA	2002	No	Ever smoked Current smoking
Life style factors/Alcohol use and abuse	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	Alcohol dependency/CAGE-measure Alcohol consumption
	EMCDDA (2002)	EU/EMCDDA	2002	No	Drink/use alcohol
	Lehtinen et al 2002	HMP (Stakes, Finland)	2002	No	Alcohol dependency/CAGE-measure
Life style factors/Drug use	EMCDDA (2002)	EU/EMCDDA	2002	No	Use of illicit drugs: cannabis, ecstasy, amphetamines, cocaine, heroin, relevin, LSD Opinions on illicit drugs

Area/topic	Recommendation's /project's name /reference	Organisation/project responsible for the recommendation (and co-ordinator)	Year	Included in the HIS/HES database	Topic/Content (name of instrument tested, proposed and/or recommended)
Life style factors/Diet and Nutrition	EFCOSUM (2001)	HMP (TNO Nutrition and Food Research, The Netherlands)	2001	No	24-hour recall (EPIC-SOFT program)
Life style factors/Physical activity	EUPASS (Rütten et al 2000)	HMP (Technische Universität, Chemnitz, Germany)	2000	No	IPAQ
	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	IPAQ
	WHO (de Bruin et al 1996)	WHO Copenhagen/ Statistics Netherlands	1996	Yes	Leisure time physical activity (two items)
Life style factors/breastfeeding	WHO (de Bruin et al 1996)	WHO Copenhagen/ Statistics Netherlands	1996	Yes	Breast feeding at age 6 weeks, 3 months and 6 months

Table 5.3.2.4 Recent EU HMP and WHO recommendations/proposed instruments on prevention, and health and social services.

Area/topic	Recommendation's /project's name /reference	Organisation/project responsible for the recommendation (and co-ordinator)	Year	Included in the HIS/HES database	Topic/Content (name of instrument tested, proposed and/or recommended)
Prevention	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	Vaccinations (influenza) Changed eating habits Mammography Cervical smear
Health and social services/medication	EHRM (Tolonen et al 2002)	HMP/EHRM (KTL, Finland)	2002	No	Use of Acetylsalicylic acid Hormone replacement therapy
	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	Prescribed medicines Non-prescribed medicines Hormone replacement therapy
	EMCDDA (2002)	EU/EMCDDA	2002	No	Use of sedatives or tranquillisers
Health and social services/mental health care	Lehtinen et al 2002	HMP (Stakes, Finland)	2002	No	Use of services due to mental health problems
	Eurohis (Nosikov & Gudex 2003)	WHO Copenhagen	2003	No	Hospitalisation General practitioner Accident or emergency centre or casualty department Occupational health care Specialists Dentists and orthodontists Other health services (e.g. physiotherapist, nursing care, alternative practitioners)

Table 5.3.2.5 Recent EU HMP and WHO recommendations/proposed protocols by HES topic.

Area	Recommendation's /project's name/ reference	Organisation/project responsible for the recommendation (and co-ordinator)	Year	Included in the database	Topic/Content of proposed/recommended protocols
Risk factors	EHRM (Tolonen et al 2002)	HMP/EHRM (KTL, Finland)	2002	Yes	Anthropometric measurements: Body height Body weight Waist and hip circumference Blood samples: Blood lipids (total cholesterol, HDL, LDL, triglycerides)
Cardiovascular function and diseases	EHRM (Tolonen et al 2002)	HMP/EHRM (KTL, Finland)	2002	Yes	Blood pressure measurement
	EHRM (Tolonen et al 2002)	HMP/EHRM (KTL, Finland)	2002	Yes	Blood samples: Blood glucose Glycated hemoglobin
Nutrition	EFCOSUM (2001)	HMP (TNO Nutrition and Food Research, The Netherlands)	2001	No	Blood samples: Folate, vitamin D, iron, iodine, sodium

5.4. Definitions, instruments and recommendations for survey measurement of ECHI indicators

5.4.1. Sociodemographic factors

Jean Tafforeau

The coverage of topics on demographic and socio-economic factors in the HIS/HES database is shown in table 5.4.1.1. Results on all 60 surveys are biased because only the health modules have been included in the database from general surveys such as population censuses or surveys of living conditions. The results are shown separately for the analysis of the 33 health surveys.

Table 5.4.1.1 Coverage of topics under area demographic and socio-economic factors in health or health related surveys during the period 1998-2002.

Topic	Number of surveys (all 60 surveys)	Number of surveys (33 health surveys)
Marital status	30	26
Household composition	28	25
Income	31	27
Education	34	30
Employment status	34	27
Population subgroups	21	7
Nationality		17

Marital status

The majority of the health surveys investigate the marital status of the respondents. The usual response categories are: not married, married, divorced, widowed and separated. The exact formulation of the answer categories varies from one survey to the other.

The conceptual background of this item is not clearly defined. This has important consequences on the comparability of the results: it is not clear if we refer to the legal situation of the respondent or to his current actual situation. A person can for example be legally divorced but is living together with another partner. Some recent

surveys (FR, UK , FI) take this issue into account by including the alternative “living together”. Recommendations on this item are needed.

Household composition

The objective of these questions is to identify people living together in a same household and their familial links with the reference person. Most of the surveys investigate this topic but the wording of questions and the answer categories vary greatly from one survey to the other. Also, the conceptual background of this item is not defined and clear recommendations would be needed.

Income, Education, Employment status

The HMP project ‘Monitoring socio-economic inequalities in health in the European Union: guidelines and illustrations’ (Kunst et al 2001) aimed at the development of guidelines for the monitoring of trends in socio-economic inequalities in morbidity and mortality. A set of guidelines were developed by explicitly taking into account practical and theoretical considerations: proposed data sources have to be available for most Member States, analytical methods have to be easy to use, socio-economic indicators have to be applicable to data from various sources ranging from mortality registries to health interview and multi-purpose surveys.

Guidelines were given in five steps: (1) identification of data sources, (2) measurement of socio-economic variables, (3) tabulation of health indicators by socio-economic variables, (4) statistical data analyses and (5) evaluation and interpretation of the results.

Data sources currently providing comparable data on health inequalities in most Member States were identified. Recommendations were developed on how to improve the availability, reliability and comparability of these data sets in the future. Guidelines were given on how to analyse these data in such ways that the results are maximally robust to problems of data comparability. The project identified the socio-economic indicators that can best be used to monitor socio-economic inequalities in health.

Three core socio-economic indicators (education, occupation and income) were recommended. For practical reasons, standard ways of measuring and classifying these indicators were recommended. The project also gave useful recommendations on the way in which health indicators can be presented and analysed in relation to these socio-economic indicators.

Finally, it was emphasised that data from HISs suffer from a number of problems that have the potential to bias estimates of socio-economic inequalities in health. Special attention should be given to the effects of (a) high non-response rates in some countries, (b) the exclusion of institutionalised populations from most surveys and (c) problems with comparability (both over time and across countries) of some health indicators.

Population subgroups

Only a few health surveys (UK, Canada, USA, Australia) include questions on population subgroups; these are aimed at investigating religious affiliation, or social class, ethnic group or cultural background.

Nationality – country of birth

About half of the health surveys record the nationality of the respondents, a few surveys retrieve information on the country of birth and some include both questions. Again the conceptual background of the item is not defined and clear recommendations would be needed. Some of the variations of this question are also to be found in the HIS/HES database under the topic code 111: “geographical information” and 199 : “other demographic and socio-economic factors”.

Conclusions

Clear recommendations have been made in the framework of the Health Monitoring Program for measuring three core socio-economic indicators (education, occupation and income). Also, guidelines have been given on how health indicators can be presented and analysed in relation to these socio-economic indicators.

For other socio-demographic items such as marital status, household composition, population subgroup and nationality, the conceptual background has not been defined and clear recommendations are needed. Where should such recommendations come from? It would be useful to make recommendations taking into account the instruments already used in Member States.

The recommendations for the three core socio-economic indicators (education, occupation and income) should be compared with the Eurostat agreements in the field of social statistics. Recommendations for other socio-demographic items (marital status, household composition, ...) in the framework of Eurostat social statistics should also be taken into account.

5.4.2. Perceived health

Jean Tafforeau

The HIS/HES Database covers more than 90 HISs and a period of 10 years. A lot of changes were seen in health surveys administered during the last five years. Among the 60 surveys carried out between 1998 and 2002, 50 surveys included questions on perceived (subjective) health. The surveys without such questions were mainly population censuses or socio-economic surveys (e.g. labour force survey, household panel). Only four health surveys included no questions on subjective health (FR, IT, NL).

One recommendation (WHO) has been made on perceived health measurement (de Bruin et al 1996): How is your health in general (very good, good, fair, bad or very bad)? The conceptual background of this recommendation has not been well described. As far as we know there has been no validation process, nor validated translations of the question. The question has never been fully field-tested and there may be some problems in comparability between countries. Despite these shortcomings this question or its variants have been very widely used in surveys and research settings. Its validity and reliability have also been studied. The validity criterion has often been mortality, and poor perceived health is clearly related to increased mortality (e.g. Jylhä et al 1998, Helmer et al 1999).

The Euroreves group (Robine et al 2000) recommended the use of the WHO question as part of what they call the 'mini health status module' (with a question on chronic conditions and one on disability). Despite of a very good conceptual description of the module, it has neither been translated nor validated.

The EuroHis group (Nosikov & Gudex 2003) in the quality of life module (WHOQoL), recommended the following question on perceived health: How satisfied are you with your health (very dissatisfied, dissatisfied, neither dissatisfied nor satisfied, satisfied, or very satisfied)? It is not clear so far if this question can be used only within a quality of life module, or if it can be used as an individual question and interpreted as a general tool for perceived health. The conceptual background of the EuroHis proposal has not yet been published. There are some translations and a few field-tests have been carried out. This question has already been used in a few health surveys in Europe (e.g. the Survey of Lifestyle, Attitudes and Nutrition in Ireland). The EuroHIS question is quite different from the WHO recommendation.

The question recommended by WHO has been most widely used in health surveys. However, some variations in the wording impair comparability:

- Changes in the number of response categories (3, 4 or 6 instead of 5) or even changes to different scales (varying from 0-10, 0-100, 1-5 or 1-7)
- Introduction of a reference period (currently, at the moment, these days, during the last 12 months)
- Comparison with another person of the same age.

Other questions related to perceived health were totally different than the recommendation. Some were based on the SF-36 question and compare the current situation with that one year ago. However, the reference period was sometimes different from the SF-36 standard: 5 or even 7 years ago. The remaining questions did not follow any standard and thus there is no possibility to compare between Member States. The situation is even worse in countries where different instruments have been used in successive health surveys, excluding also the possibility of looking at time trends at the national level.

The Eurostat decided to gather the data on 12 items included in health surveys in the Member States. The question on perceived health was among the items compared.

The results show large variations between countries despite of good comparability of the formulation of the question. Part of the variations may be related to cultural differences attached to the wording.

Conclusions

Despite of the wide spread use of the WHO recommended instrument for measurement of perceived health, additional work is needed particularly on the validation and the translation. Many studies have demonstrated that the simple question is reasonably reliable (test - re-test) and that it is also related to mortality (Helmer et al 1999, Martikainen et al 1999). Still some countries need to adapt their question to the standard. Additional research should be performed to better understand the large variation of the results and their interpretation between the countries.

5.4.3. Chronic physical conditions and morbidity

Lidia Gargiulo, Emilio A. L. Gianicolo

Chronic diseases are one of the main public health concerns. Measuring the prevalence of diseases is an important issue for evaluation and policy formulation on health. There is a general agreement on the following characteristics of the definition of longstanding/chronic illness/diseases: they are permanent and can be expected to require a long period of observation or care. However, within this definition the question arises whether a certain minimum duration should be defined as e.g. three months or a year or not.

Over the last five years (1998-2002), all EU countries have used questions on longstanding/chronic diseases in HISs. The only exception is Luxemburg, investigating only the limitation of functional ability caused by chronic illness. In surveying chronic conditions in HISs, the questions follow two types of approaches: a global approach and/or a specific one. In the first approach respondents are questioned whether they have a long-standing/chronic illness or condition. The answer categories are "Yes" and "No". In the specific approach the respondents are asked which disease they suffer from (without or with a check-list or card that has to be shown).

Out of the 60 HISs considered (see Table 5.4.3.1), including the national surveys in Europe, the national surveys in Australia, Canada, USA and some international surveys carried out in the last five years (1998-2002):

- 20 surveys included both approaches. In these surveys all the respondents, whether or not they had declared that they suffer from a chronic condition, answered both the general and the disease-specific questions. Sometimes the general question was a filter for the disease-specific (open-ended) question.
- 23 surveys included only the disease-specific questions and did not refer to an overall chronic condition, however in a third of these surveys the answer option 'other (specify)' is also given.
- 9 surveys included only the global approach questions, and these questions usually included mental health problems and/or disability. In addition, respondents were sometimes asked to define and specify which condition they are affected by.
- 8 surveys did not include either of the two approaches, even though three of them included a global question on limitations in the daily activities associated with chronic conditions.

The global approach

Comparability of the global approach was analysed in respect of the wording (i.e. use of the following words: longstanding/chronic, disability/handicap, injury and mental) and the reference period. Most of the surveys (22 out of 29 surveys with a global approach) referred to chronic or longstanding illnesses in the wording. Most of the European surveys (17 surveys / 8 countries) used both words *chronic/longstanding* and *disability/handicap*. Generally the question was "Do you suffer from (*do you have*) one or more (*any*) longstanding illness, chronic conditions or handicaps (*disability*)?"

The UK included also the word "infirmity" and four surveys (DK, NO, SE) referred to injury. A few surveys (e.g. FI, IE) referred also to mental diseases in the global approach. A different formulation was found in one survey (FR): "Are you regularly monitored for a serious or chronic illness (including consequences of an accident, disabilities)". Countries outside Europe, such as Australia, Canada and USA, did not use the global approach.

Table 5.4.3.1 Overview of the global and specific approaches in questions on long-standing/chronic illness (Number of surveys/country, years 1998-2002).

Country	Global approach	Specific approach	
		Open question	Check list
Austria			1
Belgium	2	1	1
Denmark	1	1	1
Finland	1	1	4
France	5		2
Germany			2
Greece	1		1
Iceland			2
Ireland	3		4
Italy			3
Luxembourg			
Norway	1	1	1
Portugal			1
Spain			2
Sweden	2	2	2
Switzerland	1	1	1
The Netherlands	1	1	3
United Kingdom	7	4	4
Total in Europe	25	12	35
Australia		1	1
Canada			1
USA			1
International surveys	4	1	1
Total in all surveys	29	14	39

It is important to point out that the most recent approach, discussed in the EuroHIS group (Nosikov & Gudex 2003) and adopted also in EuroReves (Robine et al 2000, 2002), is to separate in two different questions the concept of chronic conditions and the concept of disability, intended as limitation in the daily activities. The recommended instrument for a global approach on chronic condition, included in the proposal of MEHM (Minimum European Health Module), and under testing in a pilot (Statistics on Income and Living Conditions, EU-SILC), is: "Do you have any long-standing illness or health problem?".

With regard to the reference period, every survey referred to present, but in some surveys the words long-standing, long-term and chronic were defined in relation to

time. Six British surveys gave a generic definition of long-standing illness as something “that has troubled you over a period of time”. Two French surveys defined chronic disease as a disease “which will continue to affect you in the future”. One French survey referred to a period in the past of at least 6 months. One Dutch survey referred to “a situation that has lasted or is expected to last for 6 months or more”.

Some surveys (8) were not considered to use a global approach because the concept investigated was not chronic/longstanding diseases but the limitation of functional ability due to chronic illness. For example the question addressed in a Finnish survey was: “Do you have some permanent or chronic illness or some defect, trouble or injury, which diminishes your working capacity or functional ability?”. Another survey (DE) has been excluded because the main question referred only to acute illness occurred in the “last four weeks”. However, the former formulation can also be regarded as a variant of the global chronic disease questions with the purpose to obtain high sensitivity. It would also be interesting to study in detail how much the formulation really affects the replies.

The specific approach

More problems were found when comparing the disease-specific questions. The checklists included different types of conditions: physical and/or mental and/or disabilities and the wording varied widely including medical terms and/or symptoms and/or complaints. Different reference periods were used (e.g. present and past for the estimate of life time prevalence, or past 12 months, etc.). Some surveys (e.g. F03) addressed a list containing groups of diseases (e.g. respiratory diseases). Most of the surveys (33) included a check-list, which often contained the answer option “other (specify)”.

The number of diseases in the check-list varied between 5 and 43. If we consider illness and complains together one Dutch survey reaches 46 (19 illness and 37 complains). Half of the surveys with a check-list contained at least 15 diseases. Where the formulations are similar and the diseases are well-defined it may be possible to make comparisons between countries.

In over half of the surveys (17) the question was formulated so that it asked whether the condition had been **diagnosed by a doctor** (item suggested by EuroHis as well). The typical question was “Have you ever been told by a doctor that you have or have had *this disease*?”. One Finnish questionnaire specifies also the year it was diagnosed for the first time. Some countries (Austria, Belgium, France, Switzerland) did not ask if the disease was diagnosed, but if it is treated. Belgium and The Netherlands specify also if the treatment was given by a general practitioner or by a specialist. Switzerland asks “Have you been to a doctor for treatment in the last 12 months ... for one or several of these diseases?”. Obviously treatment by a doctor and diagnosis are different concepts, even if the first is not possible without the second one. The consequence is that the questions are not comparable. No diagnosis was requested in Germany and Greece.

The reference periods varied greatly. In the specific approach 10 surveys considered the last 12 months. Another group of countries referred to the present or to the present and past. The Netherlands used both, so they may be able to calculate the life-time prevalence and the prevalence in the last 12 months. This can be done also for some diseases when for each disease there is a single question and detailed information is asked (e.g. UK after the first question “Have you ever had angina?” a more detailed question asks “Have you had angina during the past 12 months?”). Countries like Germany and Italy can calculate the incidence (new occurrences in last 12 months) for the diseases detected in the check-list. However, for each disease one must be careful to take into account its natural history. In many cases it is not feasible to separate the notions 'ever' and 'in the last 12 months'.

Concerning the **check-list of diseases**, questionnaires with a long check-list covered the main disease groups. The German questionnaire included in the check-list also different wide categories for physical disabilities.

All check-lists included *hypertension (or high blood pressure)* and *diabetes* (30 surveys for *hypertension* and 28 for *diabetes*), with the exception of one Swedish survey, using a very short list and mainly open-ended questions.

Heart attack appeared in most of the lists (20 out of the 33 surveys considered). Note that we considered *heart attack* and *myocardial infarction* as a similar wording. In

seven surveys the illness has been included in a wider category (e.g. in Belgium the item refers to heart attack together with other serious heart diseases).

Stroke (cerebral haemorrhage) was covered in 19 surveys, and it was present in all countries except for Portugal, Greece and Sweden.

Asthma was another frequent item. It was present in half of the check-lists. Comparison could be possible among the following countries: Austria, Finland, Greece, Portugal, Iceland, because they used the same reference period (twelve months), but Austria and Greece didn't ask about the diagnosis. Denmark, France, Iceland (IS03) and Italy were comparable, using the same reference period (present and past).

Allergy was covered in 17 surveys but in a comparable fashion in 13. More details of the kind of allergy were included in the German, Portuguese, Finnish (FIN03) and Danish questionnaires.

Even if the *respiratory diseases group* was investigated in most of the surveys, it is very difficult to compare the recommended item *chronic bronchitis and emphysema*. A similar wording is present in only five of thirty check-lists. This problem occurs also for the item *Arthrosis, etc.*, comparable for eight surveys or four countries, and for the "*Malignant tumour...*", comparable in five surveys, but included in fourteen check-lists.

Chronic anxiety or depression were generally investigated in separate items. In some surveys they were investigated as symptoms or troubles, often considering a shorter reference period (e.g. 30 days).

Other investigated aspects: In many countries (BE, IT, NL, FR, FI, UK) other more specific questions were included: e.g. use of medicines and hospital admissions due to the diseases, and whether the disease was under treatment. The Danish questionnaire specified whether the people were restricted by their illness in their work or usual activities. Other questions linked to the specific disease were often included. This was particularly true for some diseases (e.g. diabetes, cancer, asthma and allergy). In one Finnish questionnaire on average ten specific questions were included for each of the diseases.

Chronic diseases in the health examination surveys

Morbidity may be accurately investigated using HES instruments, with clinical and medical tests. In the last five years (1998-2002) 12 HESs have been carried out in five European countries (Germany, Finland, Ireland, The Netherlands and United Kingdom).

The main domain covered for the chronic conditions was “cardiovascular function and diseases”. Blood pressure was measured in all HESs to investigate hypertension. Only two countries, Finland and England used also Electrocardiography (ECG), sometimes for a sub-sample of the participants. Finland used clinical physical examination for CVD, and United Kingdom and Finland carried out laboratory measurements related to blood clotting.

Other topics were less frequent. Regarding diabetes mellitus and metabolic function, five surveys (DE, FI, NL, UK) tested blood glucose and also, (except for NL), other indicators used in diabetes surveillance (e.g. Glycated Haemoglobin).

“Respiratory function” was included in six surveys, but only two countries, Finland and United Kingdom, used the Spirometry or PEF test.

Four surveys (DE, FI, UK) investigated “Kidney and urinary tract and thyroid function and diseases” with exams of blood or urine samples. The same surveys included also measurement of liver function, measuring Gamma GT in blood samples and in Germany also a Glutamate-Pyruvate-Transaminase test.

Five surveys (DE, FI, UK) investigated “Haematological system functions and diseases” with blood count. More detailed exams were included in the German HES. Finland and UK selected a sub-sample of the HES participants for these exams (e.g. for elderly people, or for adolescents).

For the measurement of allergy, Germany, Finland, and England carried out a IgE test, but in the last country only a sub-sample of young people was selected for this test.

“Mental disorders, mental and cognitive functions”, were measured only in Germany and in Finland, investigating depression, psychosis, alcohol /drug dependence, phobia, anxiety and other disorders using the M-CIDI instrument. For the cognitive functions Finland and UK administered the MMSE instrument.

Conclusions

As a basis for national health policy, monitoring the prevalence of chronic diseases represents one of the most important issues. The growing importance of chronic morbidity is due not only to the ageing of the population but also to the fact that it is the main reason for health services' utilisation.

At present, most often HISs are used to investigate this topic. Sometimes chronic diseases are under-reported or over-reported in HISs, in particular for specific diseases (Heliövaara et al 1993). However, HISs are still the most practical and cost-effective tool. A HIS is very useful to investigate health inequalities considering the background characteristics and socio-economic aspects. The challenge could be to reduce bias through improving the instruments commonly used. A way to reduce over-reporting could be to use in all countries a specific question on the diagnosis by a doctor. An Italian experience shows that the interviewed assert in less than 10% that the chronic disease has not been diagnosed by a doctor. Obviously this percentage varies by disease. A combination of HIS/HES surveys, carried out periodically, could be a good approach also to correct eventual bias in HIS for the prevalence of chronic diseases.

Concerning the comparability with ECHI indicators, all countries, except for Luxemburg, cover a general indicator of chronic disease (illness not specified; per cent with at least one chronic disease); but the comparability among countries has to be improved. For countries not using a global approach, the percentage of people with at least one chronic disease can be different because of the different number or types of diseases included in the check-list.

According to the analysis made further work is needed towards a better harmonisation of the instruments to investigate chronic conditions with HISs. Some results can be achieved with the recent instrument MEHM, which is currently tested

in the EU-SILC pilot in several EU countries, just only to compare chronic conditions using a global approach.

The global approach should be included in all surveys. Agreement on the concepts and definitions is a first step towards harmonisation. Nevertheless, comparisons between countries may also be affected by, for instance, proportional differences in the numbers of institutionalised persons and the total population. It is very important to be aware of the whole process of information production (see chapter 5.2).

5.4.4. Physical and cognitive functioning

Sanna Rätty, Arpo Aromaa & Päivikki Koponen

This inventory is based on a search for all questions measuring physical, sensory and cognitive functioning as well as self-care and domestic life items in the HIS-HES database. The results have been analyzed in keeping with the approach of the International Classification of Functioning, Disability and Health (ICF, WHO 2001). Functioning (physical, sensory and cognitive) will be discussed here in terms of ICF:

- 1) Body Functions/Structures and Activities (sensory motor and cognitive functions),
- 2) Self-care Activities (activities of daily living (ADLs) such as bathing, dressing, eating, and toileting etc.), and
- 3) Domestic life Activities (instrumental activities of daily living (IADLs) such as shopping, telephone use, preparing meals etc.).

All the questions have also been compared with recent recommendations. Detailed results are given in a separate report (Rätty et al 2003). In addition to the surveys examined here, there are several other topic-specific national surveys in Europe (e.g. on cognitive functions among the elderly). The European national comprehensive HISs and HESs (N=57) during the last five years (1998-2002) and their items on the area of functioning are summarised by country in table 5.4.4.1.

Recommendations and further needs

The ECHI-list (Kramers et al 2001) proposes on Generic Health status a limited number of indicators related to functional items. These include measures of functional limitations, activity limitations, a global activity limitation indicator and short-term activity restriction. The European Disability Measurement (EDM, de Kleijn-de Vrankrijker & Bonte 2002) project emphasises the need for common disability items rather than for a common instrument. The EDM-report relies on recommendations of Euro-REVES for the three general disability/health items but further work is needed to develop relevant instruments and questions.

Euro-REVES (Robine et al 2000, 2002) listed ten instruments to be used in European health surveys. Five of these concern either functional limitations (physical, sensory and cognitive) or activity restrictions (ADL/IADL). In addition, OECD (McWhinnie 1981) as well as The Regional Office for Europe of WHO (de Bruin et al 1996) have recommended common health instruments. Besides these recommendations many generic health measures including items on functioning, such as the SF-36, have been used in national health surveys.

There have also been initiatives to develop a common instrument for cognitive functioning. The Division of Mental Health of WHO has developed the WHO Cognitive Assessment Battery. Also OECD has developed measures of literacy and numeracy for cross-national comparison. However, these batteries and measures are not commonly used. Recent European initiatives, involving harmonisation of cognitive measures, are the Study of Health and Retirement in Europe (SHARE, www.share-project.org) and the Euro-REVES recommendation for cognitive functioning. However, several population studies have used tests originating from clinical settings such as the Mini Mental State Examination, and tests of short term memory or linguistic fluency.

The coverage of functional topics in Europe

Altogether 47 of the 57 European surveys included at least some functional topics. However, the coverage of questions on functioning varies greatly. Several HISs in Europe include almost all functional topics (BE, FR, FI, SE, NL, IT and UK). The two French disability surveys and the Spanish disability survey have been most comprehensive from the functional perspective. These three are disability surveys and thus the items are naturally well represented. Ten of 57 (18%) surveys did not include any questions on functioning. Most of these were multipurpose surveys such as the Eurobarometer. In Austria, Greece and Iceland only a limited number of relevant functional topics have been included (table 5.4.4.1).

HESs including functional measurements are rare in Europe. Measurements of sensory functions have been conducted only in Finland, whereas physical functional measurements have been included in Finland and in The Netherlands. The Finnish Health 2000 survey is the only European survey covering both comprehensive interviews and examinations of sensory, physical and cognitive functioning.

Sensory functions (ICF codes: b210 seeing function / b230 hearing function)

Of all European surveys 26 (46%, in 15 countries) included questions on hearing or seeing. Three countries did not include these items in HIS (see table 5.4.4.1) Information on seeing and hearing function has been obtained by asking the respondents to judge their capacity rather than to report their actual performance. Questions related to eye diseases and other diseases affecting seeing have been collected only in a few surveys. In contrast, questions on general hearing functions or hearing problems are relatively common in European surveys. In addition to interview questions sight was tested at short and long distance and hearing was examined by an audiometer in one Finnish survey.

The long-term disability questionnaires of both OECD and WHO-Europe recommend questions on seeing and hearing. The use of these has been wide spread in Europe. Even when following the recommendations, countries did not follow them exactly: Instead they modified the wording of recommended questions or selected different items.

5.4.4.1. Functioning topics covered in national surveys in Europe categorised according to ICF.

Country	Sensory functions	Mobility	Self-care	Domestic life	IADL others	Cognitive
Austria			HIS		HIS	
Belgium	HIS	HIS	HIS		HIS	
Denmark	HIS	HIS			HIS	
France	HIS	HIS	HIS	HIS	HIS	HIS
Finland	HIS/HES	HIS/HES	HIS	HIS	HIS	HIS/HES
Germany	HIS	HIS	HIS	HIS		HIS
Greece						HIS
Iceland		HIS	HIS	HIS	HIS	
Ireland	HIS	HIS	HIS		HIS	
Italy	HIS	HIS	HIS	HIS	HIS	HIS
Luxembourg	HIS	HIS			HIS	
Norway	HIS	HIS	HIS	HIS	HIS	
Portugal	HIS	HIS	HIS			HIS
Spain	HIS	HIS	HIS	HIS	HIS	HIS
Sweden	HIS	HIS	HIS	HIS	HIS	
Switzerland	HIS	HIS	HIS			HIS
The Netherlands	HIS	HIS/HES	HIS	HIS	HIS	HIS
United Kingdom	HIS	HIS	HIS	HIS	HIS	HIS/HES
Number of countries	15	16	15	10	14	10

HIS= health interview surveys / HES= health examination surveys

A main source of poor comparability in the questions on sight is variation in distances used. For example, long distance is defined as 3 to 4 meters or 4 yards. The differences in wording reduce comparability also between questions related to hearing. The largest variation in wording concerns the number of people talking in a conversation (from 3 to 4 persons).

It is of course possible that some of the apparent wording differences may not have any major impact on the findings. If so, this needs to be demonstrated. Research is needed to establish the most valid way to measure sensory functions by interviews and questionnaires. Existing recommendations must be taken into account. Although the use of recommended questions has been wide spread, there are problems with scales. For example the results concerning reliability and validity of the OECD instrument are poor (McDowell & Newell 1996, 106). Serious consideration should be given to including measured eye sight and hearing in more countries, since it is

rather easy to gain more information about actual performance. These tests should definitely be included and at least eye sight could well be tested in typical HISs as well as in HESs.

Mobility (ICF-codes: d410 – d499)

Questions concerning mobility are the most frequent questions on functioning. Of the surveys 61 % (35) included these items (in altogether 16 countries). Three European surveys have included examinations and tests on mobility: two Finnish surveys and one Dutch survey.

The status of mobility questions in Europe is summarised in table 5.4.4.2 using ICF as a basis. In terms of activities and participation, mobility related questions can be divided into five main groups according to the content of the question: 1) changing and maintaining body position, 2) carrying, moving and handling objects, 3) walking and moving, and 4) moving around using transportation. In addition there were several questions on 5) other mobility related items.

Table 5.4.4.2 Mobility topics covered in the national health surveys in Europe categorised according to ICF.

Country	Changing and maintaining body position d410–d429	Carrying, moving and handling objects d435 – d449	Walking and moving d450-d469	Moving around using transportation d470–d489	Other mobility related items d498-d499
Austria					
Belgium	HIS	HIS	HIS		HIS
Denmark		HIS	HIS		
France	HIS	HIS	HIS	HIS	HIS
Finland	HES	HIS /HES	HIS / HES	HIS	HIS
Germany	HIS	HIS	HIS		HIS
Greece					
Iceland			HIS		
Ireland					HIS
Italy	HIS		HIS	HIS	HIS
Luxembourg		HIS	HIS		
Norway			HIS	HIS	
Portugal	HIS		HIS		HIS
Spain	HIS	HIS	HIS	HIS	HIS
Sweden			HIS	HIS	HIS
Switzerland			HIS		HIS
The Netherlands	HIS	HIS /HES	HIS / HES		HIS
United Kingdom	HIS		HIS	HIS	HIS
Number of countries	8 HIS / 1 HES	8	15	7	12

Most of the mobility questions were formulated so that they inquired about capacity (can you..?) rather than actual performance (do you...?). The most frequent topic areas were the ability to walk and move around as well as moving around in different places. Altogether 15 countries (29 surveys) had included these items. However, one main source of incomparability present in questions on walking arises from variation in distances. The distance varied between 100 and 400 meters, and between half and two kilometres (one block/ several blocks). In addition some questions did not include any distance at all, mentioning only a time limit for walking.

The great variability of questions is not surprising, since also the recommendations in this area differ greatly. Almost all the European surveys used either the OECD or the WHO-Europe recommendations as a basis for mobility questions. The SF-36 (physical part) served as a reference for two surveys (German and Belgium). However, even when the recommendations were followed in principle, the wording was modified or only some of the items were selected, making the questions non-comparable. The recommendation of Euro-REVES aims to improve the comparability of surveys within Europe by producing new reference questions/instruments. However, these questions/instruments have to be tested and validated before they can be recommended for wider use.

Finland and the Netherlands are the only countries including mobility tests in HESs. Both countries have used a similar joint function test. In addition, the ability to walk was measured in the Finnish surveys (6.1 meters walking test), which also measured the standing balance and/or sway of body's gravity centre and the handgrip strength.

The use of standardized performance based tests is a new alternative for comparisons of functional ability among different populations. The use of performance measures in cross-cultural and international studies has obvious advantages. Cultural, language, and social differences between populations may greatly limit the validity of comparisons of self-reported functioning and disability. Performance tests are much less influenced by cognitive impairments, culture, language, and education level compared to self-report methods (Guralnik 1989). There is already some evidence of validity of performance measures of functioning in non-disabled elderly persons (Guralnik et al 1994, 418). Furthermore, they are essential for understanding time trends in functional capacity. However, there are

only few standardised tests suitable for assessing physical performance in large populations (Rikli & Jones 1997, 257). The best option is probably to combine interview and questionnaire data with performance based test data. In addition, it is essential to develop both performance-based tests and questions on mobility for national health surveys. This requires international research collaboration.

Self-care (ICF-codes: d510-d599)

Altogether 23 (40%) surveys (in 15 countries) included questions on self-care activities (personal activities of daily living/ADL). The current state of self-care topics is summarised in terms of ICF in table 5.4.4.3 Self-care activities have been classified into seven main categories: 1) washing, 2) caring for body parts, 3) toileting, 4) dressing, 5) eating and drinking (here combined together), 6) looking after one's health, and 7) other self-care items.

Most of the surveys including self-care questions were based on the WHO-Europe recommendations (long-term disability questionnaire). However, there were differences in wording and in the selection of items. It is reasonable to recommend this quite widely used instrument. Scientific research is still needed to validate and develop ADL instruments for use in population surveys since most of the ADL-instruments have been developed for institutionalised persons. The proposals of Euro-REVES can be seen as a starting point for this development.

Table 5.4.4.3 Self-care topics covered in the national surveys in Europe categorised according to ICF.

Country	Washing d510	Caring for body parts d520	Toileting d530	Dressing d540	Eating and drinking d550/d560	Looking after one's health d570	Self-care other d589-d599
Austria							HIS
Belgium	HIS		HIS	HIS	HIS		
Denmark							
France	HIS	HIS	HIS	HIS	HIS	HIS	
Finland	HIS	HIS	HIS	HIS	HIS		
Germany	HIS	HIS		HIS	HIS		
Greece							
Iceland				HIS	HIS		HIS
Ireland							HIS
Italy	HIS			HIS	HIS	HIS	
Luxembourg							
Norway				HIS	HIS		HIS
Portugal	HIS		HIS	HIS			
Spain	HIS	HIS	HIS	HIS	HIS	HIS	
Sweden	HIS						
Switzerland	HIS		HIS	HIS	HIS		
The Netherlands	HIS			HIS	HIS		
United Kingdom	HIS		HIS	HIS	HIS		
Numbers of countries	11	4	7	12	11	3	4

Domestic life (d610 – d699), major life areas (d810 – d899) and global personal care and chore activities

Twenty (37 %) European surveys (in 10 countries) included questions on domestic life activities (IADL Instrumental activities of daily living). 42 % (24) of the surveys (14 countries) included questions on general tasks and demands (other IADL questions, mainly the global questions). The current state of questions in this area is summarised in Table 5.4.4.4 in terms of ICF.

Ten countries inquired about limitations in usual activities by using global questions. Most of the questions referred to usual activities in general and only a few referred to specific life situations such as leisure-time, school and work. Most of the questions used in European surveys referred to health-related problems (most commonly health in general, some to physical or mental health) as a source of activity limitations.

Existing European questions in this area are far from comparable. There is no definitive reference instrument that could have been recommended in comprehensive health surveys, and countries have chosen different instruments. Euro-REVES (Robine et al 2002) recommended both an instrument for IADL and a Global Activity Limitations Indicator (GALI). The GALI has not yet been evaluated but it has been translated into all European languages. The development work of GALI is important since the indicator can be linked to the codes of ICF.

Cognitive functioning (communication d350-d369, learning and applying knowledge d160 – d179)

Questions related to cognitive functioning were included in 11 European surveys (10 countries, see table 5.4.4.1). The ability to communicate was the most frequent question of cognitive functioning (7 surveys). Most of the questions dealt with speech and speaking difficulties and the rest with communication in general. Memory related questions (learning and applying knowledge in ICF) were included in five surveys. Orientation, the ability to monitor ones environment, was included only in two French surveys. The comparability of the questions on cognitive functioning between countries and surveys was poor.

The Finnish Health 2000 survey included during the home/institution interview the Mini Mental State instrument (MMSE), for those aged 55 and over. In England the MMSE test was used for those aged 65 and over in the household sample and in care homes. The Finnish HES included also two tests from the CERAD neuropsychological measures: word list recall and verbal fluency for all during the examination/clinic or home visit.

The adoption of a common instrument on cognitive functioning to be used across Europe requires a harmonisation process and co-operation of research and survey organisations. The work of Euro-REVES and the SHARE project need to be taken into account. The HES procedures may refer to the experiences of using MMES and CERAD in national surveys. The assessment of cognitive functioning is increasing in

Table 5.4.4.4 Domestic-life and major life area topics covered in the national surveys in Europe categorised according to ICF.

ICF	Domestic-life				IADL others				
	Shopping d620	Preparing food d630	Doing housework d640	Domestic Life other d660-d699	Major life area Finance d860	Work d845	Community Social and leisure	Communication Telephone d360	Global questions
Austria									HIS
Belgium									HIS
Denmark									HIS
France	HIS	HIS	HIS	HIS	HIS			HIS	HIS
Finland	HIS	HIS	HIS		HIS	HIS		HIS	HIS
Germany	HIS								
Greece									
Iceland			HIS			HIS	HIS		
Ireland									HIS
Italy	HIS	HIS	HIS		HIS			HIS	
Luxembourg									HIS
Norway	HIS		HIS			HIS	HIS		HIS
Portugal									
Spain	HIS	HIS	HIS	HIS	HIS			HIS	HIS
Sweden	HIS	HIS	HIS			HIS			
Switzerland									
The Netherlands	HIS	HIS	HIS						HIS
United Kingdom	HIS								HIS
Number of countries	9	6	8	2	4	4	2	4	11

epidemiological studies and in health surveys. The growing interest is partly due to the increasing number of elderly people in the population and to the high prevalence of cognitive problems in the elderly (McDowell & Newell 1996). Also, the increasing use of technologies at work and at home, as well as in managing money, and in social and leisure activities, require increasing cognitive abilities. Thus, brief cognitive screening is important in all health interview surveys. Euro-REVES (Robine et al 2002) recommends the use of at least a few key items assessing cognitive function, particularly orientation and memory, close to the beginning of the questionnaire to ensure that answers are reliable.

Conclusions

The number of topics on functioning varies greatly within European surveys. Some of the surveys covered all the relevant items while others had none. The coverage of topics depends partly on the nature of the surveys. Disability surveys are usually comprehensive from the perspective of functioning covering all functional limitations and activity restriction topics, while the multipurpose surveys such as Euro-barometer may include no items.

The idea of internationally standardised scales is commendable, but it has not been fully achieved. Both WHO-Europe and OECD have recommended common health instruments for European HISs. The use of these instruments has been wide spread but still the wording of questions in different surveys varies greatly. The development of standardised instruments, such as OECD, WHO-Europe or Euro-REVES, is a dynamic process and takes usually a long time. Some of the European surveys have included questions being under development. Thus these questions may differ from those in the final version of the instrument. Another source of incomparability arises from the history of the surveys. Countries with the longest experience want to keep time trends by continuing to use the questions they have been used to.

Many other factors affect comparability such as population coverage and non-response. These must be taken into account when making comparison between countries. The differences in language and in cultural contexts also need to be considered.

Improving comparability of health survey instruments and methods requires scientific co-operation between countries. Evaluation and development of the present recommendations is needed. Also, the role of the functional performance tests needs to be taken into account. ICF, describing functioning and disabilities, will certainly affect the functional items and in which way they are to be asked in future national health surveys. It is important to take this developmental work into account.

Linking questions already used to the codes of ICF is feasible as far as physical and cognitive functioning related questions are concerned. Using this internationally recommended classification system in the HIS/HES-database should be considered. The ICF linking rules developed and tested by Cieza et al (2002, 206) can be adapted to the needs of the database.

5.4.5. Mental health and quality of life

Ulla-Sisko Lehto-Järnstedt

Positive mental health is a value in itself and may be considered a health resource. Negative mental health is usually indicated and assessed by mental or behavioural disorders, symptoms, and problems. Mental health is a broader concept than lack of mental disorders. Often mental ill-health and disorders are the main concern in health surveys. Mental disorders are conditions which are not within the "normal" range (psychological), but clearly abnormal or pathological phenomena (psychiatric) (WHO, 2001), understood as clinically significant conditions with alterations in thinking, mood (emotions) or behaviour associated with personal distress and/or impaired functioning. Valid and representative epidemiological data on mental disorders in the population are needed as a basis for public health initiatives.

The variety of measurable mental health aspects is wide, ranging from very severe disorders to psychological well-being, quality of life (QOL), and personality traits. The latter ones are health resources. Psychometric measures provide the distribution of a domain in the population whereas diagnostic measures provide the diagnosis of disorders according to current international psychiatric classifications.

Depression (affective disorders) is the most commonly assessed single mental disorder in health surveys and along with anxiety it is a core component of the psychological distress syndrome. Psychotic disorders (schizophrenic and other), posttraumatic stress disorders, and personality disorders have also been measured. Also eating disorders, substance use disorders (alcohol, drugs, tobacco), and mental status deviance and psychogeriatric disorders (dementia) have in some studies been classified as mental disorders. Here we do not discuss measurements of the latter.

Rather recently there has been progress in consolidating the field of health measurement (McDowell & Newell 1996) and nowadays there are good methods for this. These are also being used more consistently in a growing number of studies. Thus, they provide genuinely comparable information. However, in current national surveys, the area of mental health is very heterogeneously covered. When mental health measurement is present, its contents vary, i.e., the targets of measurement differ.

Mental health and quality of life measurement in the European HIS and HES surveys are presented in the HIS/HES database. Both mental health and QOL instruments (section Examinations) and individual questions (section Questions) are covered. The questions are grouped into the topics QOL, Aspects of mental health, General mental health, Positive mental health (self-esteem, mastery, coherence, self-efficacy) and Social health, while also the topic Self-assessed perceived health includes questions describing these issues. Concerning these topics the database is under development. Detailed results on mental health measurement in national health surveys in Europe are presented in a separate report (Lehto-Järnstedt & Aromaa 2003).

Health-related quality of life (QOL)

The Short-Form Health Survey Index of Quality of Life (SF-36) is a multi-purpose generic measure of health status developed and internationally validated for survey use. An abbreviated version of SF-12 has been developed, and a still shorter version SF-8 is under development. SF measures are rather widely used: in more than 10 surveys and at least in the Netherlands, Norway, Germany and Denmark SF measures have been used more than once. Thus, this is a widely used measure and

there is material for comparisons. However, all eight dimensions of the SF-36 are not always included, and the use of this measure may be restricted to some dimensions only.

Other alternatives to measure QOL have been used only from time to time. *The World Health Organization Quality of Life Assessment (WHOQOL)* is a multi-dimensional 100-item profile of scores across six domains and 24 subdomains. Often shorter versions have been applied in surveys. It has been used in a Danish and an Irish survey. *The EuroQol quality of life scale (EuroQol)* is a generic health status measure with a single index score. It has been applied in 4 surveys in 3 countries: Ireland (repeated), Denmark and Finland. *The Duke Health Profile* is a 17-item generic health status profile with six health scales and five dysfunction scales. It has been applied in a French survey. Denmark had applied all first three of these QOL measures within a survey and Ireland the second and third within one survey.

Psychometrically measured general mental health and psychological well-being

The General Health Questionnaire (GHQ) is an old very widely used multidimensional, self-report screening instrument for use in general population surveys to identify potential cases of psychological distress (depression, anxiety, social impairment, and hypochondriasis). It has been widely used in the HIS/HES surveys: in 15 surveys from 8 countries and in one international survey, Belgium, Ireland, and UK (England and Scotland) have repeated it. Thus, there are possibilities for both cross-country and cross-survey (time-series) comparisons.

Symptom Check-List-90 (SCL-90) is a widely used 90-item self-report psychiatric symptom inventory for detection and measurement of symptom intensity. SCL-90 evolves from *the Hopkins Symptom Checklist (HSCL)*. SCL-90 was used in 4 surveys in an equal number of countries and HSCL in one survey. *The Affect Balance Scale* comprises ten questions designed to indicate psychological reactions of people in the general population to events in their daily lives. It is seldom used; half of it has been used in one European survey.

Depression

There is a strong tradition in measuring depressive symptoms with questionnaires and most of the scales have been thoroughly validated and have been used in numerous studies in many countries. However, there are very few measures developed specially for survey use, *The Center for Epidemiological Studies Depression Scale (CES-D)* is one of these. It is a 20-item, uni-dimensional, self-report, depression scale to assess respondent's perceived mood and level of functioning. Items for CES-D were selected from previously validated depression scales, including e.g., BDI. CES-D was used in a Greek HIS and in Spanish (Catalan) and Irish HESs. *The Beck Depression Inventory (BDI)* is an uni-dimensional, self-report depression measure, which has been in use over forty years. Its 21 items consist of several statements evaluating degrees of given depressive symptoms and attitudes. Within the time period, it was used in one survey in Finland (previously used in repeated surveys).

Current national health surveys do not present any true possibilities for comparison of depression between the Member States.

Mental ill-health and disorders by psychiatric diagnostic measures

There is a carefully validated instrument of psychiatric epidemiology, *The Composite International Diagnostic Interview (CIDI)*, which is a fully structured standardized diagnostic tool for trained non-clinical interviewers. Recent versions map the symptoms onto DSM-IV and ICD-10 diagnostic criteria and report whether the criteria are satisfied. The full CIDI package covers eating disorders, dementia, substance use disorders (alcohol, drugs, tobacco), schizophrenic disorders, affective disorders (several), anxiety disorders, posttraumatic stress disorders, somatization disorder, psychosexual disorders, pathologic gambling, and antisocial personality disorder. Computerized versions of CIDI have been developed (CIDI-Auto, M-CIDI). For survey purposes, the CIDI Short Form (CIDI-SF) assessing eight syndromes has been recently recommended by international projects (Lehtinen et al 2002) to be used also in health interview settings. Two national HESs (Germany and Finland) have recently employed the M-CIDI. Whereas findings from these two countries can now be compared, no overview of Europe exists.

Psychological concepts, psychosomatic concepts and social health

For psychological concepts such as coping ability, sense of mastery, coherence and optimism there is a wide variety of good and widely used instruments available. These have been included in some surveys. Also psychosomatic constructs have been measured, which may be relevant to obtain information on the possible psychiatric background of the physical complaints recorded in health surveys. In Finland, *The Toronto Alexithymia Scale (TAS)* has been used to assess the hypothetical personality construct alexithymia that has been associated with psychosomatic diseases, somatization disorders and some other medical and psychiatric illnesses.

Social health is less familiar than the topics physical and psychological health. Social health concerns how people interact with other people or social institutions (McDowell & Newell 1996, 122), and it highlights elements of social skills, personality, and the norms of the society. As psychological concepts, most measurements of social health do not deal with 'health', but instead well-being, adjustment, performance, or functioning. In health surveys, social health has been specifically targeted by certain countries only.

Projects aiming at recommendations

Recently, there have been efforts to reach consensus on the recommended measures for mental health in surveys, especially by Euro-REVES (Robine et al 2000), EuroHIS (Nosikov & Gudex 2003) and The Indicators for Mental Health Monitoring in Europe project (Lehtinen et al 2002). The measures considered most suitable have varied between the various projects. Some consensus has been reached on measuring:

- psychological distress: SF-36's MHI-5 if also CIDI-SF is used, otherwise GHQ-12,
- positive mental health/ psychological well-being: SF-36's energy/vitality items with Andrew's item on happiness,
- anxiety and depression: CIDI-SF.

Also on some specific indicators, such as substance use disorders, suicide attempts, dementia, and cognitive functioning there are recommended methods. Out of the validated instruments, there is agreement on the usefulness of GHQ-12, SF-36 (as parts), and CIDI-SF (or parts).

Conclusion

Mental health issues have been evaluated in a minority of comprehensive European national health surveys. There is no general agreement on that the psychological, social, or mental health dimensions of health should always be included in a comprehensive health survey. However, if mental health has been surveyed, there seems to be some agreement on the aspects – and even on some measures – to be included. General mental health (well-being) and quality of life (QOL) are the most commonly evaluated mental health domains, and GHQ and the SF measures the most commonly applied instruments. Also depression is rather commonly evaluated, although the instruments varied. Other targets of measurement are somewhat heterogeneous and cover areas from specific psychiatric disorders and psychosomatic complaints to personality traits, psychological concepts and aspects of social health.

Evaluated by individual questions, the areas of mental health and quality of life are more widely covered in the surveys than by looking at the use of validated measures, but the variety of these individual questions and sets of questions does not allow comparisons. The heterogeneity of the mental health and quality of life measurement and the variety of the instruments and especially the individual questions used results in poor between-study and international comparability. There is a considerable need to develop the field of mental health and quality of life in national HIS and HES surveys, especially the quality and comparability of the measurements.

5.4.6. Biological risk factors

Paola Primatesta

Blood pressure

Hypertension screening coverage has been addressed in ten HIS or HIS/HES surveys over the last 5 years (1998-2002), including Finland (4 surveys), United Kingdom (3 surveys), Ireland, Belgium, and Iceland. More generally, the topic of hypertension has been addressed in most surveys, to try to measure prevalence of awareness of hypertension and drug treatment. Countries that did not cover any of

the aspects related to blood pressure over the last 5 years were France, Sweden, Norway and Greece.

The Eurohis (Nosikov & Gudex 2003) and the EHRM (Tolonen et al 2002) recommendations focus on the importance of collecting information on awareness of hypertension and its treatment. The purpose of the four EHRM recommended questions is to provide information on the prevalence of blood pressure measurements, the awareness of raised blood pressure and the treatment of hypertension in the population. Treatment refers both to pharmacological treatment and non-pharmacological treatment, such as changes in lifestyle, to underlie the increasing importance of non-pharmacological treatment.

The Eurohis recommendations on hypertension screening coverage include five questions to deal with awareness and non-pharmacological treatment, while the issue of pharmacological treatment is covered in another section of the questionnaire, which deals with treatment prescribed for a list of diseases including high blood pressure.

Questions to elicit information on awareness of hypertension, and treatment in the last 12 months, are also included among questions on longstanding illnesses, which cover a list of conditions including high blood pressure.

Both the Eurohis and the EHRM acknowledge the importance of identifying the person taking the measurement in order to discard measurements taken by others than health professionals. The EHRM recommendations specifically state that casual blood pressure measurements (in shopping centres, drug stores etc) do not qualify as taken by health professionals.

Among the surveys that were identified as addressing the topic of blood pressure only a few cover all recommended aspects (screening, awareness, pharmacological and non-pharmacological treatment). In particular, the question about interventions other than pharmacological appears not to be covered in most surveys.

Among the surveys addressing the topic of hypertension screening coverage, the formulation of the questions varied. In particular, most surveys do not ask specifically

who took the measurement, and the question about the last time blood pressure was measured offered different time intervals in the different surveys. Most would nevertheless allow calculation of whether blood pressure was measured in the last 12 months. Other variations in questions formulation were observed, but the general comparability of the questions seemed to be high.

The question on awareness of hypertension is also formulated differently in those surveys that include it. Belgium, Finland, Ireland, England, Scotland, Portugal have a specific question, along these lines: When checking your blood pressure, have you ever [at time of measurement] been told you had high blood pressure?

Other surveys (as noted above) on the other hand include a question on awareness of hypertension among questions on longstanding illnesses, which cover a list of conditions including high blood pressure. Whether these two different approaches in assessing awareness of hypertension produce differences in the reported prevalence of hypertension would be an interesting point to assess. On the basis of the awareness questions it is possible to assess from most surveys the prevalence of self-reported hypertension. All HIS/HES surveys also include the direct measurement of blood pressure (see below) allowing comparisons between measured and self-reported hypertension.

Of the surveys addressing more in general the topic of hypertension some, but not all, surveys have questions on pharmacological treatment. This information is available from Spain, Austria, UK, Finland and Switzerland. These questions appear to be comparable between surveys. Some countries (e.g. the UK) also collect information about the name of the drug/s prescribed to lower blood pressure.

The question about intervention other than pharmacological is lacking from most surveys. The recommended Eurohis question attempts to establish the details of intervention: Because of your blood pressure did a doctor advice you to: Reduce salt intake, lose weight, decrease alcohol intake or Increase physical activity. The EHRM recommends a more generic question: Has a doctor in the past year ordered you to change your way of life, in order to lower your blood pressure?

Although questions on advice about changes in lifestyle received by doctors/health professionals are included in some of the surveys, none (with the exception of the Scottish Health Survey and the English Health Survey 1998) asked the question specifically in relation to high blood pressure.

Blood pressure measurement in HES

Table 5.4.6.1 summarises the main points of the protocol for blood pressure measurement in the HES, namely equipment and measurement procedure, comparing the EHRM recommendations with those followed in the countries with a HES.

Table 5.4.6.1 Protocol for blood pressure measurement.

	EHRM recommend.	HES				
		Germany	Finland	Ireland	Netherlands	UK
Number of measurements	3	3	3	2	2	3
Type of instrument	Sphygmomanometer	Sphygm	Sphygm	Random zero sphygm	Automated oscillometric device	Automated oscillometric device
Resting time before measurement	5'	3'	5'	5'	5'	5'
Time between measurements	1'	3'	2'	1'	5'	1'
Cuffs available	3-4	1	2	1?	2	4

As the table demonstrates, none of the methods is completely comparable with the EHRM recommendations, nor are methods comparable between HESs. Given these differences in protocol, a proper comparison of the prevalence of hypertension between countries based on HES data seems problematic. More efforts should be made by the member states to harmonise blood pressure measurement techniques. This may be complicated by the future prohibition of mercury meaning that only other devices may be used.

Cholesterol

Ten HISs (or HIS part of HIS/HES) in the last 5 years included the topic of cholesterol screening coverage to some extent: three in Finland, two in the UK, one in France, Ireland, Switzerland, Belgium, Denmark.

The recommended questions (EUROHIS and EHRM) on cholesterol screening coverage and awareness and treatment of high cholesterol closely resemble those on hypertension, with the purpose of providing information about the coverage of blood cholesterol screening in the population, the awareness of high cholesterol and the prevalence of treatment of elevated cholesterol. Few of the surveys cover all these aspects: the most commonly asked question is about cholesterol screening coverage, asked in all ten surveys, and of awareness of high cholesterol (seven surveys), with a high degree of comparability between the questions. Questions about treatment are less often asked (only three surveys) and none of the surveys addressed the important issue on non-pharmacological treatment, although one Finnish Survey included a question about having received any advice during cholesterol measurement.

A blood sample for the measurement of cholesterol (or complete lipid profile) was collected in the HIS/HES of Finland, UK, Germany, Ireland and Holland. The fasting/non-fasting status of the subject depends on the analyses. According to the EHRM recommendations if the full lipid profile is to be measured the samples should be collected after a fasting period (for triglycerides overnight fasting), while if the focus is on total/HDL-cholesterol a non-fasting sample is suitable. Fasting samples for cholesterol (total/HDL) were collected in Finland (4-hour fasting) and in Holland (9-hour fasting), non-fasting samples in the other HESs. All samples were examined in the country's central laboratories. Given differences in the protocol a comparison of cholesterol levels between countries may be problematic. The best way to improve comparability would be by creating reference laboratory activities in Europe.

Awareness and treatment of diabetes mellitus/blood glucose measurement

Six European HISs included specific questions about diabetes mellitus and/or measured blood glucose (Belgium, Finland, Portugal, UK, France, Switzerland). This topic was also covered in Australia, Canada and the US.

The EHRM proposes two questions to be used in surveys as a minimum requirement, since the problem of diabetes is addressed by a longer list of questions in the ongoing HMP project 'Establishment of Indicators Monitoring Diabetes Mellitus and its Morbidity'. The two questions aim to capture awareness and treatment of diabetes.

Questions about blood sugar screening, similar to those asked on blood pressure and cholesterol, were included in one Belgian and one Finnish survey. Questions about awareness of diabetes (sometimes also defined as 'high sugar levels in your blood or urine') were asked specifically in some surveys (Portugal and UK) while others included diabetes in a list of long-standing illnesses. The Portuguese survey also asked at what age the respondent was first told s/he had diabetes.

A question on whether the respondent was taking insulin injections every day was asked in all the surveys mentioned above, while only a few also added a question on any other medication for diabetes/high sugar levels (Belgium, Finland and UK).

On the basis of the questions included in the surveys it would be possible to compare prevalence rates of self-reported diabetes in the population, while a comparison of treatment practices would be more problematic.

Surveys in Finland, Germany, Holland and England measured blood glucose. One (the German survey) took a non-fasting sample, while all other surveys collected a fasting sample, with varying fasting times: 4 hours in Finland, 8-9 hours in England and Holland. The EHRM recommendations state that for glucose fasting of 4 hours is sufficient.

Anthropometric measurements

The protocol for measurements of weight and height (to derive BMI) and waist and hip circumference is included in the EHRM recommendations. When anthropometric measurements are taken directly it is recommended that self reported weights and heights should not be accepted. The WHO recommendations for HIS (de Bruin et al 1996) include self-report of height and weight. Several studies (e.g. Bolton-Smith et al 2000, Paccaud et al 2001) have shown that HES and HIS (self-reported)

measurements of height and weight are not comparable and HISs lead to substantially lower mean levels of body mass index.

Most HISs asked the respondent to report their height and weight (height without shoes; weight without clothes and shoes). All HESs included height and weight measurement. Most (with the exception of Ireland) also included waist and hip measurements.

Conclusions

Information about screening coverage, awareness and treatment for some biological risk factors (hypertension, blood cholesterol and diabetes) is included in some of the HISs. The subject of hypertension is the most common, covered in most national surveys over the last 5 years. The coverage of this and other topics varied by countries (especially the recall period), although most would allow calculation of screening coverage in the last 12 months, and of awareness of hypertension and of high cholesterol.

Information about awareness of diabetes mellitus/measurement of blood glucose is collected in fewer countries, and in a less harmonised way, suggesting that more efforts should be made to ensure comparability of data on this topic.

It is important to note that most surveys do not cover all aspects recommended by EHRM and the EUROHIS, in particular question addressing non-pharmacological treatment of hypertension and raised cholesterol are lacking from most surveys. The validity and reliability of these recommended questions may also need further evaluation.

The protocols of the HES still differed quite markedly between countries, this is therefore an area where harmonisation of methods should be pursued; this would enable comparisons of biological measurements between countries, which appears rather problematic at the moment.

5.4.7. Smoking

Lucie Viet

Smoking is world wide a major cause of serious diseases and death. Therefore, the number of smokers must be reduced by all available means ranging from health education to legislation.

The topic list used with the HIS-HES database includes five topics on smoking behaviour. An overview of the coverage of these topics in HISs is shown in table 5.4.7.1. Almost all national surveys in Europe included some questions on smoking, except for Luxembourg.

Table 5.4.7.1 Overview of the coverage of topics related to smoking in HISs (total 60 surveys carried out in 1998-2002).

	Number of surveys	Number of countries
Smoking, general (including present smoking)	44 (+ 3 international)	19
Former smoking	20 (+ 2 international)	9
Passive smoking	14 (+1 international)	7
Stop or reduce smoking	24 (+1 international)	15

Questions on smoking in national surveys

Questions about the prevalence of smoking (actual smoking) were included in almost all national surveys, and in almost all the countries. Among the questions on smoking prevalence, several aspects of smoking behaviour were distinguished:

- Questions in which different types of tobacco are explicitly asked
- Questions referring to the frequency of smoking
- Questions referring the quantity of smoking behaviour
- The used referenced period

In almost half of the surveys distinctions were made between different types of tobacco, mainly cigarettes, cigars or pipe. The frequency of smoking behaviour was most often measured by using answer categories like "daily", "occasionally", and "not

smoking". However the wording of these categories differed slightly in some surveys. Information on the number of cigarettes was gathered in a few surveys to determine the number of heavy smokers in the population.

Most of the questions on present smoking did not specify any reference periods, neither in the wording of the question nor in the answer categories (e.g. "Do you smoke?" or "Do you smoke currently / present?"). In seven surveys a reference period was used to determine the frequency or the quantity of smoking (e.g. "How many cigarettes per day" or "How many cigarettes on average per day in the last 30 days").

Only a few surveys included questions on passive smoking. These aimed to find out if the participant was exposed to smoke from other persons and if this was regular. The wording of these questions was comparable.

Questions on attempts to stop or reduce smoking can be used to evaluate campaigns to stop smoking. These questions typically indicated whether the subject ever tried to stop smoking. Reasons to stop smoking and use of nicotine replacements were also included in some surveys. Most of these questions were comparable.

Former smoking was studied by asking if the subject had ever smoked regularly or if he/she ever used to smoke (in general). In two Finnish surveys there were questions about smoking at least 100 times in the lifetime, to identify those who never progressed beyond being an experimental smoker.

It can be concluded that in the recent surveys included in the HIS/HES database, the measurement of smoking behaviour (the prevalence) is comparable between the surveys.

Smoking indicators in health examinations

Active and passive smoking can also be assessed in clinical examinations. Smoking indicators were measured in six HESs, five of them (all from UK) analysing cotinine from saliva samples. Blood cotinine levels were measured from a sub-sample of non-smokers daily exposed to smoking in one Finnish survey.

Recommendations

Since the adoption of the strategy of Health for all by the WHO in 1977, countries have become more aware of the need for adequate information for policy formulation, implementation and monitoring. To facilitate the development of common methods and instruments for HISs, a series of international consultations has been organised to develop common instruments to measure smoking behaviour. Recommended questions on smoking were published in 1996 (de Bruin et al 1996).

The European Health Risk Monitoring project (EHRM, Tolonen et al 2002) recommended a smoking questionnaire with two parts. The first part asks about personal smoking history and the second part about exposure to environmental tobacco smoke. The main part of the questionnaire is similar to the WHO recommendation (WHO 1998).

5.4.8. Alcohol consumption

Lucie Viet

In general harmful use of alcohol occurs when consumption exceeds a specified level. Unfortunately, there is no consensus on the exact level to be defined as risky alcohol consumption. A valid measurement requires that several aspects of alcohol consumption are measured. They should be measured so that they can be converted into international standard units (e.g. the measurement of quantity in pints, glasses, bottles etc.)

The HIS/HES database contains one topic on drinking behaviour (alcohol use and abuse). In the database 32 surveys in 19 countries cover this topic. In three countries (Luxembourg, Sweden and Austria) alcohol consumption has not been included. Most of the surveys start with the general question about usual intake (During the past 12 months, did you drink any alcoholic beverages? (yes / no).

Different aspects measured include:

- Frequency of alcohol use
- Reference period used

- Amount of alcoholic beverages consumed (quantity)
- Kind of alcoholic beverages consumed
- Abuse of alcohol and reduction of alcohol intake
- Problems related to use of alcohol

In general, the frequency of alcoholic intake relates to the number of days when the participant has consumed alcoholic beverages during a certain period. In most questionnaires frequency was asked by using pre-coded answer categories. Frequency depends on the reference period. The longer the reference period, the larger the underestimation of the consumption of alcohol. However, this effect also depends on several aspects of alcohol consumption, such as type of beverage or quantity. A reference period of 12 months was used for usual intake in most surveys. To measure frequency and quantity, 7 days (last week) has been used. Other questions have referred to a period of 6 months. These have mainly been questions about abuse of alcohol (more than 6 glasses per occasion). No reference period at all was used in six surveys, which referred only to a typical month or week.

The quantity of alcoholic beverages has been measured in most surveys. In some surveys pre-coded answer categories have been applied but in the majority of the surveys questions have been open-ended. In some surveys the number of drinks was measured separately for each type of alcoholic beverage. Other surveys inquired about the number of drinks of alcoholic beverages in general. In almost half of the surveys distinction was made between different types of alcoholic beverages: beer, wine, spirits and other (local) beverages.

With respect to the quantities of alcoholic beverages consumed, the following questions have been recommended (WHO / de Bruin et al 1996): "During the last six months, have you ever had six or more drinks containing alcohol in one day? " and " During the last six months, how often have you had six or more drinks containing alcohol in one day?". These questions identify persons who are at least occasionally heavy drinkers. Six surveys included alternative formulations of these questions. In other surveys the approach was subjective ("do you think that you drink too much"). Besides the abuse of alcohol (binge drinking) these surveys included questions about reducing alcohol intake. Questions on attempts to cut down or reduce drinking as well as questions concerning the respondent's view that he/she should cut down drinking

were included. There were several other types of questions about problems related to the use of alcohol, but their comparability was poor. In five surveys there were questions about alcohol use related to traffic.

In the surveys included in the HIS/HES database, the measurement of alcohol consumption shows variation in wording (frequency, quantity and reference period). However, it is possible to recalculate the answers to arrive at comparable figures between countries, e.g. per month or per year. After the recalculations it is possible to compare the results of alcohol consumption between the surveys.

Recommendations

The ECHI indicators (Kramers 2001) related to alcohol use are:

- Alcohol use (non-drinkers)
- Alcohol use – drinking pattern
- Total alcohol consumption
- Road traffic accidents involving alcohol

The instrument proposed by WHO Eurohis (Nosikov & Gudex 2003) can serve as a reference for evaluation of the national questions. This instrument is divided into 5 parts:

- Prevalence of use / abstinence
- Frequency of drinking
- Intake per occasion
- Binge drinking
- Drinking in specific contexts

An alternative approach was prepared for alcohol used during weekends and during working days separately.

In the European Comparative Alcohol Study (HMP project ECAS II, Leifman et al 2002) alcohol consumption was defined as the sum of recorded and unrecorded

alcohol consumption. The project advised to include questions on home made products. This may be especially important for some countries like Italy or Greece.

According to the ECASII project the most important indicators of drinking patterns are:

- the share of abstainers in the total population (male / female / adolescents/boys and girls).
- the share of heavy drinkers in the total population
- the share of total alcohol consumption drunk as intoxicant
- the frequency of heavy drinking occasions (binge drinking)
- the share of total consumption consumed with meals

The HMP Mental health indicators project (Lehtinen et al 2001) recommended the use of CAGE questions (Mayfield et al 1974) to measure alcohol dependence since excessive use of alcohol and alcohol dependence is commonly associated with mental ill-health. The CAGE instrument has already been used in some national surveys.

The present HIS/HES database contains the general topic “alcohol use and abuse”. In view of the need to measure alcohol-related problems this topic could be introduced. It could cover self-declared alcohol related problems in national surveys such as those presented in Table 5.4.8.1.

Table 5.4.8.1 Examples of questions on alcohol related problems in national health surveys.

Concept	Examples of questions During the past 12 months, have you
Drunk driving	
Alcohol-related accidents	Been in an accident of any kind when you had been drinking?
Marital and partner problems	Felt that your drinking harmed your home life or marriage?
Problems with family, children, parents	
Problems with friendship and social life	Felt that your drinking harmed your friendships or social life?
Work (school) problems	Felt that your drinking harmed your work or studies?
Financial problems	
Health problems	Felt that your drinking harmed your health?
Casualty problems	
Criminal behaviour, police responses	
Fighting and violence	Got into a fight when you had been drinking?
Sexual misbehaviour	
Risk-taking behaviour	Regretted something you said or did after drinking?
Mental well-being	Ever felt that you should cut down on your drinking?

5.4.9. Illicit drug use

Lucie Viet

Illicit drug use is identified as one of the leading health indicators because it is associated with multiple deleterious health outcomes, such as sexually transmitted diseases, human immuno-deficiency virus, viral hepatitis, and numerous social problems among adolescents and adults.

Consumption of drugs was a rare topic in the national HIS/HES surveys. In only 13 surveys in nine countries one or more questions on use of drugs were included. The main aim of these surveys was to measure any use of drugs (ever used).

Some of the different aspects of measurement of drug use are:

- Method of intake or administration
- Reference period used to measure drug use

- Type of drugs used

Consumption of drugs is an especially sensitive topic with special validity and reliability problems. Unconsciously, or even consciously, the respondents can give answers inconsistent with their true behaviour, attitudes or knowledge. Many factors can affect the answers. One of the best known factors is the role of the interviewer. Another well-known influence is social desirability, the desire to make a good impression on the person or organisation asking the questions or to give what oneself perceives as a socially or politically correct answer. The presence of other people during the interview can certainly affect the validity of answers. Mail surveys hold the greatest chance of others being present, but face-to-face interviews are also prone to this influence (EMCDDA 2002). In the HIS/HES database there were three surveys with a self-administrated questionnaire and five surveys with the face to face method for questions on illicit drug use. Because of the impact of the method on answers, the questions and their results are difficult to compare.

The longer the reference period, the greater the memory effects. In all surveys the reference period was lifetime, the last 12 months and last 30 days. In one French survey the reference period was last seven days.

In almost all surveys a distinction was made between different kinds of drugs (e.g. cannabis/hashis/marihuana, amphetamines, cocaine, ecstasy and LSD). The longest lists of different kinds of drugs were used in France and in Ireland.

In the present surveys in the HIS/HES database, the measurement of drug use shows a great similarity. However, it is only possible to compare the data if the same method was used (face-to-face or self-administrated).

Recommendation

Most of the questions in the surveys conform to the proposal of the E.M.C.D.D.A. about illicit drug use (EMCDDA 2002). A minimum set of questions on illicit drug use should be available for use in general population based health surveys as an alternative to this complete questionnaire. An age range between 15-64 years can be used for adults, for young adults the age range 15-34 has been suggested. There is a

risk that questions on illicit drug use may reduce response rates and the heavy drug users may not participate in health surveys.

5.4.10. Nutrition

Bärbel Kurth

Food consumption and dietary habits are important components of health behaviour. Several ways can be used to obtain information about food consumption of populations. Nationwide household food consumption surveys are the most common tools for assessing dietary behaviour. To study the relationship of diet and health and for a proper identification of risk groups, nutritional data are needed at the individual level. Therefore, questions about nutrition and dietary behaviour should be an integral part of HISs. However, it is a methodological challenge to achieve appropriate and valid information about food consumption through health surveys, and often the length of the dietary questionnaire is a problem. Usually, within the framework of HIS, a food frequency questionnaire (FFQ) is included. UK, Finland, Belgium, Ireland, The Netherlands and Germany use their own FFQs, which are part of the HIS. The United Kingdom and Ireland use semiquantitative FFQs, including frequencies as well as the portion sizes of the consumption of foods.

31 of the 60 surveys (during the period 1998-2002) comprise the topic diet/nutrition (in general), although the items included vary strongly (Table 5.4.10.1). Austria, Norway, Sweden and Luxembourg are the only European countries without any diet or nutrition topic in their surveys from 1998 to 2002.

Information from HIS/HES about nutrition components of ECHI

Eight of the ECHI indicators deal with diet/nutrition. These are:

1. Energy from food
2. % energy from protein
3. % energy from total fat and from saturated fatty acids
4. consumption of bread/cereals
5. Consumption of fish
6. Consumption of fruits
7. Consumption of vegetables
8. Consumption of calcium, intake of contaminants

9. (Breastfeeding)

While the information for the first three indicators must come from a detailed quantitative food consumption (nutrition) survey, indicators 4-7 can be included in HISs. Within the framework of HIS it is possible to ask for calcium substitution and for consumption of dairy products, which also means that crude information about the eighth indicator can be obtained as well.

Table 5.4.10.1 summarises the occurrence of ECHI relevant nutrition topics in the European health surveys. All the countries using a FFQ in their surveys have some information about the ECHI topics. Other countries, such as Belgium, Iceland, Italy, Spain and Denmark have single questions concerning fish, fruit, vegetable, cereals and fat consumption. Unfortunately the questions asked are totally incomparable. Even simple question such as the question about bread consumption has a wide variety of formulations. E.g. in Germany the question is “How often do you eat bread? Think about the last 12 months”. In Great Britain they ask: “What kind of bread do you usually eat? How many pieces of bread do you eat each day?” In the Finnish surveys people are asked: “How many slices of bread do you usually eat daily, dark bread, mixed bread...white bread.” Similar examples can be found for fruits, vegetables, fish and meat consumption. It would be a challenge to develop a European FFQ with comparable questions in different languages.

Information about dietary habits, special diets, attitudes

Some of the surveys included nutrition topics without assessing validly the amount and kind of consumed food. For instance, France only asks for special diets (vegetarian, etc), eating disorders and regularity of meals (where, how often). The surveys in Greece and Spain include questions on eating habits. Questions on milk consumption and the regularity of meals are included in Portugal.

Some aspects of nutrition consciousness and food safety are included in Ireland (are you reading food labels?). Switzerland, The Netherlands and UK ask the participants about their attitude and knowledge about healthy foods. Several surveys collect information about salt consumption and supplementation. More details for illustrating the variety of topics and questions can be seen in table 5.4.10.1.

Table 5.4.10.1 Coverage of specific nutrition topics by surveys (1998-2002).

HIS/HES	diet/ nutrition (general)	consumption of					breast feeding (passive)	remarks
		fresh fruits	vegetable	butter, oil	fish	bread/ cereals		
Austria	-	-	-	-	-	-	-	-
Belgium	x	x		x				regularity of meals, reduction of weight
Denmark	x	x		x			x	supplements
Finland	x	x	x	x	x	x	x	FFQ, special diets, salt
France	x							eating disorders, special diets, regular meals
Germany	x	x	x	x	x	x	x	FFQ, nutritional survey linked, special diets
Greece	x							eating disorders
Iceland	x	x		x	x			eating habits, regular meals, supplements
Ireland	x	x	x	x	x	x	x	FFQ, food safety
Italy	x	x		x				special diet, salt
Luxembourg	-	-	-	-	-	-	-	-
Norway	-	-	-	-	-	-	-	-
Portugal	x						x	regularity of meals, milk consumption
Spain	x				x	x		eating habits
Sweden	-	-	-	-	-	-	-	-
Switzerland	x	x	x	-			x	attitude to healthy foods, dairy products
The Netherlands	x		x	x	x	x	x	FFQ special diets, diet and health
United Kingdom	x	x	x	x	x	x		semiquantitative FFQ ¹ , special diet, attitude to healthy foods

FFQ= Food Frequency Questionnaire

Information from HESs about Nutritional Status

From HESs only a few biomarkers giving information about nutrition status are available. Vitamins and other markers of nutritional condition and metabolic processes can be analysed from blood samples, and minerals and trace elements from blood and urine samples. The German HES analysed the blood samples for Potassium, Calcium, Magnesium, Selenium, and Ferritin. The surveys in Finland and the UK included Ferritin analyses from blood. Furthermore in the German, Finnish and English HES folate in the blood was analysed. Other vitamins analysed were Vitamin D (Finland, UK), Vitamin C (Finland, UK) and Vitamin B12 (Germany). This list is not comprehensive, since other analyses can be carried out later from frozen stored samples.

Even a comprehensive list biomarkers can not replace the questionnaire information about food consumption, dietary behaviour and nutrition.

How to obtain comparable information about nutrition and dietary habits in Europe?

The aim of the European Food Consumption Survey Method (**EFCOSUM**) project (EFCOSUM 2001, EFCOSUM 2002) was to develop methods for monitoring food consumption in nationally representative population samples in a comparable way.

Careful consideration was given to available nation-wide food consumption surveys with nutrient intake data on the individual level. As a result, a lack of internationally comparable data was identified. Several pragmatic guidelines were developed for surveys in European countries. The EFCOSUM recommends the 24-hour recall method as the *best* and *most cost-effective* method, although this is more a result of consensus and of the lack of available standardised methods in different languages. For this purpose at least two non-consecutive 24-hour recalls are needed assuming that enough persons are included in the survey. EFCOSUM recommends to concentrate data collection on the age group of 11 years and older. It is recommended to use the EPIC-SOFT programme to collect 24-hour recalls in all European countries. This programme has been developed for the purposes of the EPIC study to obtain standardised interviews and it is already available in 11 European countries.

The EFCOSUM project proposes that biomarkers should be considered for the following micronutrients: Folate, vitamin D, iron, iodine and sodium. They recommend that the collection of biomarkers is combined with other pan-European HESs.

Two other European projects dealing with monitoring of food consumption are DAFNE and the Public Health Nutrition Monitoring (PHN) project. Until now there are no recommendations or conclusions available from these projects, relevant for HIS and HES in Europe.

Conclusions related to the HIS/HES project

The findings of EFCOSUM emphasise the need for co-ordinating nutrition surveillance activities within the European Union. The project demonstrated that there is a broad European consensus to carry out a specific European Food Consumption survey. In the meantime, it is suggested that any country that will carry out a (national) food consumption survey follows the recommendations made by the EFCOSUM project. An alternative to the European Food Consumption Survey could be a system of co-ordinating national surveys and to develop comparable methods for these.

There is an ongoing need to assess the relationship between nutrition and health within the framework of HISs and HESs. In some European countries it should be possible to have a link between health and nutritional (food consumption) surveys. This has been traditionally done in Germany during the last decade. This has the advantage that the information about health and nutrition is available at the individual level for the same people. Because this is the most expensive (but nevertheless the best for many health/nutrition related questions) solution the HIS/HES group recommends the following compromise: For serving the ECHI indicators, in a first step some common and comparable questions concerning fruits, vegetables, fat, fish and bread/cereals consumption should be established. In a second step, a European semiquantitative FFQ may be developed, which, in the same manner as the FFQ of UK and NHANES (USA), allows to estimate energy intake and percentages of fat and protein energy intake.

Nutrition/diet must be a component of HIS. For making data comparable, further work is needed. For HES at least a few biomarkers giving information about nutritional status are recommended. The HIS/HES group follows the recommendation of EFCOSUM to use biomarkers.

5.4.11. Physical Activity

Lucie Viet

The level of physical activity is an important protective and risk factor for many chronic diseases, such as coronary heart disease and diabetes. Most population studies examining chronic diseases include the assessment of physical activity. A valid and appropriate measurement of physical activity is a challenging task. To assess levels of physical activity, epidemiological studies often use questionnaires, because they are an inexpensive tool in categorising subjects into high and low level of physical activity.

In the HIS/HES database there are three topics about (physical) activities. A summary of the number of surveys including these topics is presented in table 5.4.11.1.

Table 5.4.11.1 A summary of the number of surveys including questions related to physical activity (Total 60 surveys, carried out during 1998-2002).

	Number of surveys	Number of countries
Daily activities	11 (+1 international)	7
Physical activities (including vigorous)	32 (+1 international)	18
Leisure time activities (excluding physical Activities)	18	13

Questions under the topic “Physical activity” were included in 32 national surveys and one international survey (Eurobarometer) containing questions about physical activity. Only in Luxembourg and Sweden there were no surveys containing questions on physical activity.

The survey approaches used to measure physical activity varied in their complexity, from self-administered, single item questions to interviewer- administrated surveys of lifetime physical activity.

Different aspects of physical activity are:

- Types of activity
- Intensity of activities
- Frequency and duration of physical activities
- Time frame / reference period.

The types of activity can be divided into four items:

- Activity at work,
- Household activity
- Leisure time activities
- Commuting.

In four surveys there were questions on all the first three activities, according to the so-called IPAQ questionnaire (the International Physical Activity Questionnaire). In the other surveys, there was a different approach to these items. Early studies in physical activity estimated activity performed **at work**. Of the 32 surveys only seven (in five countries) collected information about activity at work. Because of the difference in wording and answer categories it is not possible to compare these questions.

In five surveys (four countries) the focus was on **household** activity. Because the answer categories were almost the same, it is possible to compare these questions with each other.

Since physical activity levels at work have continued to decline in most countries, assessment of leisure time physical activity is often assumed to be the best indicator of physical activity in a population. Almost all surveys included questions on other **leisure time** activities. In general these questions contained different kinds of sports, physical exercise, walking and cycling. The questions included also different kinds of transport to work or school. **Commuting** activities (e.g. walking/cycling to work) were included as a separate aspect in only three surveys in Finland.

A more extensive physical activity questionnaire will not only measure the type, frequency and duration but also the **intensity of the activity**. In the IPAQ questionnaire the levels of vigorous, and moderate are used. Several surveys used the levels high, medium and low activity. Another approach to intensity is to ask about sweating. In seven surveys (seven countries) there was a question of the type “During your leisure activities do you work up to sweat...”.

In general, the **frequency of physical activities** relates to the number of days or times the participant was active in a certain period. In most surveys frequency was asked by an open ended question (... days). Frequency depends on the referenced period. Just like frequency the **quantity of the physical activity** was measured by duration. Almost all surveys used an open ended question (... hours / minutes).

The **reference period** of 12 months was used for the general question about sport. Measurement for frequency and quantity was based on the last seven days, or just a typical week. Questions about household activities were based on the last four weeks.

The two most common estimates of energy expenditure are derived from summing up the time spent or the time weighted by an estimate of the intensity of that activity (MET). Each activity can be expressed in MET-hours per week. In this way it is possible to compare the results from different surveys.

Several instruments have recently been developed to measure physical activity. The SQUASH questionnaire (Short Questionnaire to Assess Health Enhancing Physical Activity) was developed by the Dutch National Institute of Public Health and Environment (Wendel-Vos et al 2003). The basic assumption for the questionnaire was that it should be:

- ◆ Be reproducible and valid
- ◆ Be short (less than 5 minutes to fill in)
- ◆ Contain questions on habitual activities with respect to occupation, leisure time, household, transportation means and other activities.

The HMP project 'European Physical Activity Surveillance System (EUPASS)' aimed to develop and test a surveillance system for physical activity by providing a valid and

cross-nationally applicable list of indicators for health-enhancing physical activity, testing selected physical activity indicators, and investigating implementation structures of health monitoring on physical activity in the EU (Rütten et al 2000). A great variety of approaches to measure physical activity was identified in the Member States. No single dimension was covered so any comparison would fail due to the lack of comparable information.

The IPAQ instrument has been developed by an international consensus group (see <http://www.ipaq.ki.se>) and it has been tested during the EUPASS and EUROHIS projects. However, this method can not be recommended as a comparable instrument for use in national surveys, because these tests have shown that the validity and reliability of the IPAQ instrument as well as its international and intercultural applicability and adequacy have to be further tested (Rütten et al 2000). Also, it was included in the Health 2000 survey in Finland, and in the Danish and the Belgian interview surveys. All these large-scale implementations showed weaknesses by e.g. the instrument being too difficult for the subjects.

5.4.12. Other health-related behaviours

Jean Tafforeau

Several surveys performed in the EU Member States during the period 1998-2002 cover other health related behaviours in addition to substance use, nutrition and physical activity. Among these questions concerning sexual health and sexual behaviour are most frequent.

Sexual health and sexual behaviour

Nine surveys (in seven countries and one international survey / Eurobarometer) have included questions on sexual health and sexual behaviour with 66 questions. There is no recommendation for standardised instruments to be used in this domain in health surveys.

The analysis of the content of these questions showed that:

- More than half of the questions were related to sexual behaviour: sexual intercourse (ever, last 12 months), age at first sexual intercourse, number of partners, and details about the relation (duration, penetration, stable, sexual preference, paid sex).
- One fourth of the questions were directly related to HIV/AIDS: the questions dealt with knowledge about HIV/AIDS, attitudes towards HIV prevention and HIV testing. The respondents' assessment of the effectiveness of various current measures undertaken to control AIDS was included in one Eurobarometer. In agreement with all Eurobarometer questions these are to be understood rather as an opinion poll than information directly applicable to health care.
- 10% of the questions were related to prevention of sexually transmitted diseases (STDs): the use of a protection method against STDs (and sometimes specifically the use of condoms) or the use of a contraceptive method. In the database a specific topic is also dedicated to use of contraceptives; 20 surveys have questions on this domain with 90 questions.
- The rest of the questions were related to prevalence of STD's (e.g. ever had, currently suffering), and to satisfaction about sexual life.

A large number of items is included under this topic; and the questions are mostly not comparable.

Other health related behaviours

Among recent surveys, 13 contained questions on other health related behaviours (with 19 questions). These were e.g. related to:

- Motor vehicle accidents (e.g. means of transportation used, use of safety belts)
- Health promotion behaviours (e.g. dieting, relaxing)
- Violence (being a victim of)
- Preventive behaviour for dental health

These questions demonstrate the great variation of health related behaviours, but the conceptual and theoretical background of these items in national health surveys has not been defined.

The REPROSTAT -project (see <http://www.reprostat.com>) is working on indicators and recommendations for measurement for some of the items on sexual behaviour and sexual health (e.g. chlamydia prevalence, condom use during last intercourse, contraceptive use). Preventive behaviour for dental health has been covered in the WHO oral health surveys (Chen et al 1997). None of the other health behaviours mentioned above have been covered in international projects, which would be relevant for national health surveys.

A conceptual study of this domain is needed in order to define what should be measured and on how to measure it. In a second step a pragmatic approach may help to identify the questions that are as close as possible to the ones already used in the health surveys in the member states in order to make acceptable recommendations. There may be large differences due to cultural factors in perceiving these questions sensitive. Most questions on sexual behaviour may be feasible only in self-administered questionnaires.

5.4.13. Living and working conditions

Jean Tafforeau

The content of the 60 health or health related surveys performed in the EU Member States during the period 1998-2002 was reviewed for living and working conditions. Among these surveys 33 included 296 questions related to the occupational status of the individuals. The questions were mainly dealing with employment (yes/no), employment status (e.g. employer, salaried, self-employed), paid job and type of work. Seven surveys included questions on work force participation of disabled people (38 questions).

Altogether 28 surveys included 364 questions related to working conditions. The content of the questions referred to shift, night or weekend work, number of hours, stress and work related pressure, skilled work or repetitive work, job satisfaction and

other working conditions. Seven surveys included questions on work related exposures (15 questions).

16 surveys included questions related to the environment (with a total of 94 questions). The content of the questions varied extremely. The most frequent items were:

- Pollution and other harms
- Risks, hazards and inconvenience of the social environment
- Environmental noise.

Other questions dealt with problems of rubbish, the need for improvement of the environment, health problems due to environmental exposure, violence, and quality of the information provided on environment.

The comparability of questions related to living and working conditions seems to be poor. There are no recommendations on these items for general health surveys.

5.4.14. Health care utilisation

Arpo Aromaa and Päivikki Koponen

Several standard questions on the use of health care services have been used in health interview surveys since the 1950's. The questionnaire of the U.S. National Health Interview Survey (Gleeson 1972) has been used as a reference instrument in several European countries. Another traditional and widely used reference instrument is the WHO International Collaborative Study of Medical Care Utilization (WHO 1972).

5.4.14.1. Use of curative care

Questions on the use of curative health services were included in 47 HISs in almost all (17) EU/Efta countries (out of the total 60 surveys carried out during 1998-2002). The comparability of most of these questions was poor due to differences in reference periods, wording and types of services/service providers included or excluded.

GP or family doctor

Questions on the use of GP, family doctor or other corresponding doctor in the primary health care system were included in 32 surveys. The reference period for these questions varied from two to four weeks and from two to twelve months. Questions on when or how long ago the subject last used these services in addition to the number of visits during the defined reference period were included in 14 surveys. The number of visits was not specified in seven surveys, indicating only whether the subject had used these services during the reference period at all or not.

Several differences in the wording of questions limit comparability. Main differences lie in including or excluding home visits and/or telephone contacts and/or contacts via Internet or e-mail, and specifying visits for own behalf/own health (e.g. including/excluding visits with children) or for specific reasons. Some questions included contacts or visits without specifying the reason, others included or excluded visits e.g. because of check-up/screening and/or other examinations, and/or because of pregnancy or delivery. A few surveys included separate questions on the number of visits for each reason (e.g. for illness and for prevention). Even when the visits/contacts were specified as curative there were differences in wording, which may affect response, e.g. visits for treatment and/or symptoms of illness/complaints and/or accident/injury.

The reasons for the last visit to GP/family doctor were recorded in 20 surveys, with open-ended questions or using lists of reasons classifying preventive and curative visits and/or illnesses/complaints. In some surveys the answers were coded according to standardised international classifications, e.g. the International Classification on Primary Care (ICPC) was used in Belgium. Nine surveys included questions on having a regular, steady, particular or personal GP/doctor whom the subject primarily contacted.

Dentists

Questions on seeing, consulting or visiting dentists were included in 27 surveys. Some of these included services from other dental professionals such as dental hygienists or dental technicians in questions about dentists' services, while other surveys used separate questions for other dental professionals or included only visits

to a dentist. Other differences in the wording were also identified, e.g. specifying visits concerning the subject him/herself, for own teeth or for treatment and check-up. The reference period for use of dental services was most often 12 months, but it varied from two weeks to five years. Some surveys included also questions on when or how long ago the subject had used dental services. The reasons for the last dental visit/contact were recorded in seven surveys.

Other professionals and primary health care/outpatient services

Questions on the use of services of medical specialists' (other than GPs, e.g. gynaecologists, internists, eye specialists or surgeons) were included in 25 surveys. The speciality was not defined in 13 surveys, while other surveys included lists of 2-21 specialities.

Questions on visiting or consulting one or several groups of other health professionals such as nurses, psychologists, social workers, physiotherapists, occupational therapists, speech therapists, optometrists and dieticians were included in 19 surveys. Questions on use of alternative and complementary therapies, such as acupuncture, homeopathy, nature/traditional healers were included in 17 surveys. These lists of other health professionals and therapies varied as well as the question wording and reference periods.

Hospitalisation, day-surgery and emergency services

Questions on hospitalisations were included in 27 surveys. Differences in wording limit comparability, e.g. including or excluding ante- or postnatal visits and childbirth, emergency/first aid and/or outpatient visits and/or hospitalisation due to illness of other people, e.g. to accompany a child. The reason for (last) hospitalisation was recorded in seven surveys. In most surveys the number of nights spent in hospital (during last hospital stay or during the determined reference period) was recorded. The reference period for nights spent in hospital treatment was most often 12 months, but other reference periods such as 2-4 weeks or three months were also used. In a few surveys the number of admissions or days in hospital were recorded. Special questions on day surgery/day clinic (6 surveys), hospital outpatient clinics (4 surveys) and emergency clinics/departments (3 surveys) were also used. A few surveys also included questions on surgical operations.

Other services and aspects of the use of health services

Questions on the use of maternal and child health care were included in nine surveys, on mental health care in six surveys, on home care in 17 surveys and on rehabilitation in five surveys.

Other aspects of health services were questions on satisfaction with the care, expenditures and payments, using public or reimbursed vs. private or self-paid services, time spent travelling and waiting, and being on a waiting list (e.g. for surgical operations). A few surveys also included questions on referrals. These concerned the initiative for the last visit, and satisfaction of need, i.e. whether the subject had not received all the care/treatment he/she needed.

Existing recommendations and conclusions

Several differences in reference periods and wording limit comparability. Differences between the questions on the use of services by professional group or by type of service/organisation are partly due to differences in health care systems and such questions or data are difficult to harmonise.

EUROHIS (Nosikov & Gudex 2003) proposed a common instrument for use of curative medical services, including questions on hospitalisation (using a reference period of 12 months), specifying the number of admissions/stays, number of nights spent in hospital, reasons for hospital stay, and admissions as day patient. The total number of consultations to all types of medical doctors is asked with the reference period of 4 weeks. Special questions are proposed on GP/family doctor consultations, consulting a doctor in an accident or emergency centre or casualty department of a hospital, doctor at workplace, a medical or surgical specialist and visits to dentists and orthodontists. The question about the use of other health services (list of 12, including physiotherapist, homeopath, nursing care at home etc.) uses a reference period of 12 months. This questionnaire cannot take into account features of different national health services and therefore must be modified for national use.

It may also be reasonable to include both a shorter period (2-4 weeks) for an exact number of visits and a longer period (12 months). The long periods lead to

underestimation of visits, the short ones of the users. Therefore, where individual level analyses are to be carried out it is important to also have access to the 12 months data. The short period covers only a small share of health service utilisation and there may be seasonal variation and other problems with comparability linked to the short reference period. Further work is needed to achieve good comparability between countries.

The development of instruments on health care utilisation suffers from conceptual ambiguity. The aims of measurement have to be discussed. The aim may be to describe how people in general use health services, or to get a statistically representative picture of how health services are used within a certain time frame, or to evaluate how well people are treated and how they receive care for certain diseases or complaints. Health services utilisation can be measured e.g. as patterns of consumption or as care/treatment practices and resources used or needed.

5.4.14.2. Use of medicines

Questions on the use of medicines were found in 36 HIS surveys in 15 EU/Efta countries. The comparability of these questions was poor due to differences in the reference periods, in wording and types of medicines included or excluded.

Reference period

The reference period varied from 24 hours to 12 months. No exact reference period was given in six surveys using expressions like regularly or continuously, at present, at the moment, now or currently. Several reference periods were used in four surveys, first asking about a longer period, e.g. 12 months or two weeks and later specifying whether the medicine was used during the last week or the last 24 hours. In four surveys the subjects were asked first if they take any medicines regularly or continuously and next whether they have taken any medicines during a defined reference period. Four surveys included also questions on when the subject last took specified types of medicines.

Wording and types of medicines included

The wording differed in respect of inclusion of medicines prescribed by a doctor and of over-the-counter/non-prescription medicines (4 surveys) or asking about both separately and specifying which were prescribed and which were not (9 surveys). There were also differences in including or excluding vitamins, minerals, natural/herbal medicinal products, homeopathic preparations, medicines used during hospitalisation, medicines used externally (e.g. skin/dermatological products) and/or contraceptives. Two surveys included only medicines used for a long period of time (at least one month).

Five surveys used non-specified questions without recording the type of medicines used. The name of the medicine was recorded in three surveys, in one of them the interviewers were asked to check this from the package or prescription. A list of 3-18 different types of medicines/diagnoses/reasons for use was included in 17 surveys. In the lists medicines for hypertension or diabetes and painkillers were most often included. The wording in these lists differed greatly. Therefore the findings cannot be compared between surveys or between countries.

Six surveys were identified asking about HRT use. One of these was Australian, one Canadian. Among the European surveys two had been carried out in Finland, two in UK and one in Switzerland.

They all tried to find out whether the respondent was currently using HRT prescribed by a doctor, and in Finland the name of the preparation was also requested. In addition, in the UK surveys women who used to take HRT in the past but no longer took it were asked when they stopped taking it. A distinction between 'ever' used and current use can therefore be made. The nature of the questions is such that women using HRT are able to give a valid report. The few European surveys can be compared for the prevalence of HRT ever and the Finnish and Scottish surveys for current use.

Other aspects concerning use of medicines

Further questions on the following aspects were also included in a few surveys: how long the person had used the medicine, the form of the medicine (tablet, powder,

inhaler etc.), how often does he/she take the medicine, the dosage used, why does the subject use the medicine, why has he/she stopped taking it, who prescribed it or where did the subject get the medicines. Three surveys included questions on how many times the subject had been to the chemist/pharmacy (for advice on a health problem or in general). Difficulties in reading the instructions on the use of medicines, and questions on whether the subject (usually) takes medicines as prescribed were also included in a few surveys.

Existing recommendations and conclusions

There is a need for harmonisation of the reference period and the type of medicines included in the questions. The common instrument for use of medicines proposed by EUROHIS (Nosikov & Gudex 2003) suggests two weeks as the reference period and asks for prescribed medicines ("Have you taken any prescribed medicines, including contraceptive pills or other hormones"). The aim is to include all medicines prescribed by a doctor or used on a doctor's initiative or recommendation. A list of 18 types/groups of medicines is given (e.g. for high blood pressure, lowering the blood cholesterol level, diabetes). A separate question on medicines not prescribed by a doctor (including vitamins and minerals) is included in this recommendation, with a list of six options. This recommendation does not specify if natural/herbal or homeopathic products are included.

The EHRM project (Tolonen et al 2002) recommended a questionnaire about awareness and treatment of hypertension, high cholesterol and diabetes mellitus. It includes questions on medication, with a wording slightly differing from the EUROHIS recommendation ("Are you currently taking medication prescribed by a doctor to lower your blood pressure/blood cholesterol level/insulin or pills to control diabetes"). From the point of view of cardiovascular risk factor screening, the EHRM project proposed questions on hormone replacement therapy (HRT) and use of acetylsalicylic acid.

Two questions are recommended by EHRM to determine the prevalence of HRT use among post-menopausal women:

"Have you had any periods over the past six months?"

"Are you currently using hormone replacement therapy?"

Given its widespread use, health surveys in Europe should consider including questions on HRT, to assess prevalence of use and relationship to chronic disease risk factors.

The EHRM recommends using a question to assess whether the respondent uses medicines containing acetylsalicylic acid, prescribed to prevent or treat heart disease or stroke. None of the surveys examined included such a question. The information on use of aspirin/acetylsalicylic acid can be obtained in some of the surveys by the question asking which prescribed drug/s the respondent is taking, or under the section on cardiovascular diseases, by asking if the respondents is taking drugs for his/her heart condition. The formulation of these questions as they now stand may lead to an underestimation of the rates of use of aspirin for treatment or prevention of CVD; the introduction of the question recommended by the EHRM should therefore be considered.

Unfortunately, recommendations based on asking about some types of medicines only tend to miss a major part of use. Their great advantage is the subjects themselves clarify all their medicines according to reason of use. On the other hand, getting a full picture of all medicine use may be very relevant. The open-ended question separately for doctor prescribed and other medicines can be classified e.g. according to the ATC-classification providing detailed data on medicine use.

Conclusions

The two recommendations on use of medicines may lead to differences in responses and prevalence and an agreement should be reached. It needs to be defined what is the aim of these questions: to evaluate medical practice, to evaluate health behaviour, to measure consumption or something else. The feasibility of asking about medicines used during the last two weeks should be evaluated. Additional recall periods may be needed for certain medicines (e.g. to measure adequacy of treatment or compliance). The wording of conditions listed may also require modification. A combination of asking about the reasons of use and the name of the medicines may be the best way. This approach requires coding systems probably not available in all countries. For CAPIs the coding can be built into the questionnaire. There are good experiences on recording and coding product names in Finland and in Belgium.

Countries having a tradition of collecting data by brand name should continue to use it and add questions of the current proposal (EUROHIS) to their questionnaires for comparability.

5.4.14.3. Preventive activities

The coverage of surveys of concerning prevention topics varies greatly. Table 5.4.14.1 summarises the occurrence of different specific topics in the surveys examined. All of these topics have been included only in the Finnish Health 2000 survey and the Swiss survey covered all except a general question on any vaccinations. The Belgian HIS covered five topics (screening for breast cancer, for cervical cancer, contraception and vaccinations including flu).

Table 5.4.14.1 Coverage of specific prevention topics by European countries.

	Breast cancer screening	Pap smear	PSA screening	Contraception	Any vaccinations	Flu vaccinations
Austria	-	-	-	-	X	X
Belgium	X	X	-	X	X	X
Switzerland	X	X	X	X	-	X
Denmark	X	X	-	-	-	-
Netherlands	X	X	X	X	-	-
Finland	X	X	X	X	X	X
France	-	-	-	X	-	-
Ireland	-	-	-	X	-	-
UK	-	-	-	X	-	-
Germany	-	-	-	-	-	X
Spain	-	-	-	-	-	X
Italy	X	X	-	-	-	X

Breast cancer screening

Of the 60 most recent surveys eight (in seven European countries and Canada) contained questions on mammography and /or physical examination of the breasts. Typical questions inquired whether the interviewee had ever had a breast examination by a physician (or another health professional) and whether she had ever had a mammography. A few inquired about breast self-examinations. The Finnish Health 2000 survey differs in that its questions concern the past five years and the past year only. However, most European surveys contain additional questions allowing one to calculate the prevalence for comparable time periods such as five or one year.

The wording and contents of the question series varies greatly but the topic is rather clear cut. Women are rather familiar with breast cancer screening and replies can be expected to be valid. Therefore, it is likely that both the frequencies of mammography and of physical breast examinations can be compared between most current surveys.

Relatively few countries seem to collect information on this major screening programme by national health surveys. It is possible that they obtain the needed data from other sources. Nevertheless, the reasons for non-inclusion of this topic must be examined, e.g. coverage of register information on screening programmes.

Cervical cancer screening

The Pap smear is a well-established screening programme in many countries and the subjects can be expected to be aware of it. Of the most recent surveys on the data base ten contained questions on gynaecological examinations or Pap smears. Two of these were Australian and Canadian surveys, one inquired only about gynaecological examinations and two were Dutch surveys from 2001. Useful information is available from Belgium, Switzerland, Denmark, The Netherlands, Italy and Finland.

Typical formulations were either "Have you had a Pap test/cervical cancer screening during the past 5 years" or "how many times during the past 5 years" or "ever" and "when last" or "how many times during the past 12 months". A comparison can be

made on the level 'at least one Pap smear during past 5 years' between the Belgian, the Swiss, the Danish, the Dutch and the Finnish surveys.

Cervical cancer screening related information may in many countries come from other sources than national HIS/HES which may explain the limited number of surveys containing such information. However, it is important to examine the reasons for non-inclusion of this topic in national health surveys.

Prostate cancer (PSA) screening

Only five surveys, one from Canada, two from the Netherlands, one from Switzerland and one from Finland, inquired about prostate cancer screening. Of the European surveys the Swiss one asked about a preventive examination of the prostate, the Finnish survey separately about PSA and rectal examination and ultrasound examination and the Dutch surveys about PSA-tests alone. On the level of having had a blood test for PSA during the past five years the Dutch and the Finnish surveys yield comparable results and their findings can also be compared with the Canadian survey.

Since PSA testing is the most recent expanding development in European preventive care one would have expected that more countries would have up-to-date survey information on it.

Contraception and the contraceptive pill

Altogether ten European surveys and the Australian and Canadian surveys contained questions on contraception and/or the pill. When all contraceptive methods were asked the pill was one of the alternatives. Useful information on pill use is available from Belgium, Switzerland, France, Finland, Ireland, the Netherlands and the UK. Despite of major variation in the question series it is also possible to construct formally comparable prevalence figures for "current use of the pill" for the Swiss survey, the French survey, both Finnish surveys, for the Dutch survey, the UK Household survey and possibly the UK Health survey. In regard of the Belgian and Irish surveys the comparability is reduced since in the follow-up question after any contraception they inquire about the most frequent method thus underestimating use of e.g. the pill compared to other surveys.

The two Finnish HIS/HES surveys inquired also about current use of IUDs including hormones and about duration of pill and other hormone use in order to control effects of hormones on outcome of blood tests. At the same time up-to-date valid data on contraceptive methods used seems to be lacking in numerous countries.

Vaccinations

Australian, Canadian and US surveys contained questions on vaccinations and so did thirteen recent European surveys. The Danish and the French surveys were the only ones to contain questions about vaccinations of the subject's children. Most surveys asked whether the person had been vaccinated (either ever, during 12 months, during 10 years etc.) against specified infections. The Austrian survey asked whether the person has a valid vaccination, a quite difficult question for a lay person.

The most popular topic was asking about influenza vaccination, which was included in the Austrian (valid), the Belgian (ever, when last), the Swiss (ever, when last), the German HES (last winter), the Spanish (this season), the Italian (12 months), the Dutch (ever, when last), and the Finnish (past 12 months, earlier) surveys. With some reservations the findings of these surveys can be compared. The relatively recently available pneumococcal vaccination was only asked for in the Finnish survey (in addition Australia and US)

Other vaccinations were inquired only in a few European surveys. First, some included questions about typical immunisations carried out in childhood. In many countries information about their coverage is available from other sources.

Of typical adult vaccinations tetanus was asked for in the Austrian, Belgian, Italian and Finnish surveys. Hepatitis A was included only in the Finnish survey but the longer established Hepatitis B vaccination in the Belgian and the Finnish surveys (in addition the US). In addition to the frequency of vaccinations some surveys attempted to measure attitudes towards vaccinations.

Infections and coverage of vaccinations have also been analysed in HESs. In Germany blood samples were analysed for antibodies to respiratory antigens, helicobacter pylori antibodies, and hepatitis markers. In the Finnish HES antibodies

to viral antigens were analysed from blood samples, e.g. influenza virus A and B, RS virus and mycoplasma antibodies.

From a public health view point it is important to include information about influenza vaccinations in all national surveys. However, it is equally important to note other information needs related to established or emerging vaccinations such as Hepatitis A, Hepatitis B, pneumococcal vaccination, tetanus and polio (if vaccinations are offered). The German survey inquired about preventive measures taken prior to long-haul travel. Similar precautions might be necessary for Eastern Europe and States of the previous Soviet Union. It is important to follow these developments closely but it is not clear that a national survey is the way to do it.

Various other health promotion and prevention methods

The Finnish, Dutch, German and Irish questionnaires contained a variety of questions on other topics. Examples are health promoting and preventive measures, health examinations, doctor's advice on health behaviour and participation in health promoting measures, having received advice on health behaviour, or having received nutrition advice for the child in the health centre.

In addition to the Australian and Canadian surveys there were five European surveys containing topics not discussed above. However, the contribution of these questions to the overall development of the information system is limited.

The great variation suggests that health promotion at large continues to be a difficult subject also to survey. This is clearly an area for further development in all European countries.

Existing recommendations and conclusions on prevention

The EUROHIS (Nosikov & Gudex 2003) recommended common instrument for use of preventive health care covers questions on vaccinations against influenza, eating habits, blood pressure, cholesterol, hormone replacement therapy, screening for breast cancer, and cervical smear tests. These differ from the EHRM-project recommendations (Tolonen et al 2002). Furthermore they do not reflect the breadth

of health promotion. There is a need for further evaluation and testing of these questionnaires before they can be recommended for wider application.

The main specific prevention related topics covered in national surveys were screening for breast cancer, cervical cancer and prostate cancer, use of contraceptive pills, and vaccinations. Only influenza vaccinations were inquired in a larger number of surveys (8). Health promotion and prevention at large were tackled in very varying ways and in only a few surveys. Overall, the coverage of topics and of countries needs to be improved. The coverage of the main topics by surveys varied greatly.

A review of the existing contents suggests that there is much to improve both from the national and international public health point of view. The choice of topics should be based on current and emerging public health importance. This yardstick should be used for all topics to be included in national HIS/HES surveys. Important items should not be missed unless the data can be obtained from other sources (such as vaccination or cancer registries or special national surveys). This survey revealed that a particularly problematic area is health promotion and prevention at large. It is essential that joint work is carried out in this important area.

If the topics are comparable and if the information can be obtained from all European countries it is important to work with the question series and the wordings. The variation is still large between recall periods and formulation of the questions. Despite this the evaluation suggested that many data can be transformed to obtain reasonably comparable rates. Finally, true comparability can only be assessed by actually carrying out comparative analyses, which should be done for the promising topics mentioned above.

Future development of national surveys in this regard should be carried out as joint work between public health experts and survey organisations (if separate) and international experts and working groups (Eurostat and EU Sanco public health programme).

5.5. Other health indicators and items to be measured by health surveys

Jean Tafforeau

The content of the 60 surveys performed in 1998-2002 was reviewed for several domains such as:

- reproductive and child health
- adolescent health
- health of the elderly
- dental health
- knowledge and attitudes
- violence

5.5.1. Reproductive health

In addition to the modules on sexual behaviour and use of contraceptive methods (mentioned in chapter 5.4.12. and 5.4.14), some health surveys have also been used to investigate maternal and child health. 141 questions have been raised in 13 different surveys. A large number of different domains have been studied:

- Menarche and menstruation (10 questions)
- Gynaecological problems (2 questions)
- Fertility treatment (2 questions)
- Pregnancy termination (1 question)
- Pregnancy related problems and prenatal care (12 questions)
- Delivery (13 questions)
- Breastfeeding (36 questions)
- Maternity care (4 questions)
- Post natal care and help (6 questions)
- Newborn follow up (20 questions)
- Child health (25 questions).

It was difficult to find any common questions that could be compared between the member states. It should be interesting to verify if the health surveys are the best instrument to investigate pregnancy related items; the number of pregnant women in the general population is quite low even when questions relate to pregnancies during

the last five years. It seems however that extending the recall period does not lead to any major bias and women seem to be able to recall even distant pregnancies accurately (Tomeo et al 1999). In some countries surveys are specifically dedicated to maternal and child health; this is the approach used in France where a periodic survey of a sample of all births is organised.

Only one question concerns pregnancy termination; this may be a difficult topic to incorporate in general health surveys because of its sensitivity. However, in some countries like Finland such a question is not considered sensitive.

In conclusion, including questions on reproductive health in comprehensive health surveys can be recommended, but there is need to develop new instruments and to evaluate the validity, reliability and feasibility of these questions in different countries and cultures.

5.5.2. Child health

In this inventory, 20 questions about the follow up of the newborn were identified as well as 25 questions on child health. Half of the latter questions were from the Spanish survey on disability, containing specific questions on the child's health status and its consequences.

This inventory underestimates the importance of the child health topics in health surveys because many questions of the general questionnaires are also used to measure child health. For example, in most of the surveys questions about chronic conditions or the use of health services are not only applicable to the adult population but also to children. Some surveys may also have used special questionnaires for children, and those have so far not been included in the HIS/HES database.

In addition, in some countries like Germany, at least one special survey will be focused on children and adolescents. Such surveys are currently, however, not included in the database because they do not meet the inclusion criteria (the survey should not be restricted to a specific part of the population such as children and/or adolescents). This German survey started in May 2003 and it will include 18 000 children and adolescents aged 0-18 years. The experiences from this survey will be

important for future HIS/HES development in other countries. In future, such surveys may also be included in the database.

The Child Health Indicators of Life and Development (CHILD) project of (Rigby et al 2002) aimed to produce a set of indicators and to stimulate understanding of and commitment to their use by child health professionals and the child health community in each member state. Several of these indicators are based on HIS/HES data. The project clearly stated that surveys of child health need to ensure collection of child-centric data, and to seek children's views rather than solely adults' views.

Several recommendations were made comprising the following indicators:

- Children's socio-economic circumstances (parental occupation/highest of father or mother)
- Children in poverty (household income)
- Parental educational attainment (particularly maternal)
- Prevalence of childhood asthma (survey question)
- Child Dental Morbidity/DMFT index (decayed, missing, filled teeth for 12 year old children from school health services or surveys)
- Breastfeeding (exclusively breastfed at hospital discharge or immediately after birth, 6 month old exclusively breastfed, 12 month old receiving breastfeeding from hospital/child health service data and surveys)
- Exposure of children to household environmental tobacco smoke (does any member of the family smoke inside the house, at any time during the day at least once weekly)

Other indicators are between child and adolescent health:

- Parental support to children (questions in the Health Behaviour in School-aged Children, HBSC WHO survey for 11, 13, 15 years of age: children who find it easy or very easy to talk with their parents when something is really bothering them)
- Physical activity by children (HBSC/Undertake vigorous activity outside of school hours for at least two hours a week)
- Tobacco smoking by children (HBSC/smoke every week)
- Alcohol abuse by children (HBSC/have been drunk from alcohol consumption on two or more occasions)

- Substance misuse by children (European school survey project on alcohol and other drugs, ESPAD/15 years of age/used cannabis more than twice during the last 30 days, ever used heroin and ever used ecstasy)
- Child overweight and obesity (routine school health data or surveys).

In conclusion, child health is to some extent covered in most of the health surveys even if there is usually no specific instrument used for this. However, there seems to be an information gap about children's health in comparison with the information available on adults. It would be important to verify the validity and the usefulness of the data gathered through general health surveys on child health. If the conclusions aren't convincing there may be a need to develop a specific module to study child health, based partly on the recommendations of the CHILD project. Only a few comparable instruments are available on children's health. An instrument on health related quality of life for children has been developed by the KIDSCREEN project, in nearly all European languages (Ravens-Sieberer et al 2001). The results of this project can be useful for future surveys including children.

5.5.3. Adolescent health

Half of the 60 surveys have restriction criteria based on the age of the participant and not all surveys include adolescents:

- three surveys include only persons aged 12 or more; such an age limit still allows to study the health of adolescents
- six surveys include only individuals aged 15 or more; such a limit allows to study the health of adolescents but the youngest age groups are missing
- ten surveys include persons aged 16 or more; such an age limit only allows to study the health of the older adolescents
- eight surveys comprise individuals aged 18 or more; such an age limit precludes study of adolescent health
- in three surveys adolescents are entirely excluded.

In addition to the age limit of the survey, some topics may be limited to specific age groups. This is the case for example in the Belgian Health Interview Survey, where items such as smoking, drinking or use of illicit drugs have been limited to individuals

aged 15 years and over. Some surveys, e.g. in UK include separate self-administered questionnaires for adolescents, including e.g. questions on health behaviour.

The instruments used to investigate several topics may have to be adapted to adolescents. The database contains information about the type of questionnaire used for each question but it is mainly intended to distinguish between face-to-face, self-completed or computer assisted interviews. Therefore we do not know all special additional instruments used for the adolescent population in connection of the general health surveys.

As mentioned above specific surveys dedicated to adolescent's health, have not been included in the database. However, the Health Behaviour of School-aged Children survey co-ordinated by WHO should be noted. It is a periodic survey specifically dedicated to adolescent health and health behaviour with common standard instruments used in all participating countries. It is however not clear enough if the results of these HBSC surveys are satisfactory and whether there is a need to investigating adolescent health in the general health surveys.

In conclusion, a harmonisation in the age inclusion criteria for the health surveys in Europe would be useful. Similar instruments should be used. On the other hand, the use of generic instruments for all age groups has the major advantage of allowing comparisons between adolescents and adults. Finally, it is likely that adolescent surveys should be included in the HIS/HES database.

5.5.4. Health of the elderly

Several surveys have an upper age limits:

- 64 years in four surveys
- 74, 75, 79 or 80 years (in one survey/each age)
- 84 years in two surveys

The question of how surveys represent elderly institutionalised people will not be discussed here (see chapter 5.2.2). There seems to be some uncertainty if general health surveys are the best instrument to investigate health status and behaviour

among the elderly people. In some countries the number elderly people contacted in a survey for the general population has been quite low. However, an alternative to surveys dedicated to the health of the elderly are special protocols developed for the fieldwork among elderly people.

An additional question about this age group is whether the usual instruments can be used or is there a need to make adaptations for elderly people (one should however then retain the possibility to compare the results with those of the general population). The same instruments could probably be used for chronic diseases, functional limitations and disabilities. It is necessary to add special topics in order to be able to investigate typical problems for elderly people. Special instruments are probably necessary for home care and rehabilitation.

In conclusion, a conceptual approach may be useful in this area to better define the age limits of the group of elderly. This approach should also be used concerning any special instruments. Such theoretical work will be of great help for the Member States in order to better understand how to investigate the health problems of elderly people in health surveys.

5.5.5. Dental health status

Dental health status has been covered in the database by two topics: dental formula and dental prosthesis, there were 69 questions in 26 surveys. The contents of the questions varied, including e.g. dental formula, number of extractions, dental prosthesis, general condition of the denture, cleaning teeth, and dental problems.

In depth work is thus needed in this domain before being able to produce standard instruments and to decide if HISs are a suitable way to collect data. WHO Oral Health Surveys (Chen et al 1997) should be reviewed. Health examinations may well be the only suitable way to obtain information on dental health status. So far in the recent HESs in Europe, clinical dental examinations have been included only in Finland.

The minimal recommendation of the EUROHIS (Nosikov & Gudex 2003) project is as follows: "Do you still have teeth of your own?". This recommendation seems to be acceptable for some population groups and for some countries. However, in most

European countries the number of people without any own teeth is so low that is indicator is clearly insufficient. It reflects the past rather than the present. As far as dental health status is concerned, further work is needed for standard survey instruments.

5.5.6. Knowledge and attitudes

Nearly all the items included in health surveys are factual: questions concern specific health problems and health behaviour. Very few items investigate health knowledge of individuals; such as questions on the mode of transmission of HIV. Knowledge and attitudes on health prevention has not been investigated in the national surveys. Only one question related to this was found in the inventory, inquiring about “the reason why morbidity is so high in the country” (Finland).

Quite few questions relate to attitudes, for example the reason for not participating in the breast cancer screening programme. The same applies to attitudes towards these activities and towards health policies.

Very few questions were found on general attitudes of the participants towards their own health, e.g.:

- do you monitor your own health (Germany)
- would have a better health if ... (Ireland, Switzerland)
- do you do something specific to improve your health ... (Denmark, Finland).

Such items could be linked with the concept of locus of control.

This is a domain, which is almost completely ignored in current health surveys in Europe although theory suggests that it is important to know about attitudes and behaviour. It may be useful to investigate the reasons why these topics are not included in surveys. If these topics are found useful standard instruments for them should be used.

Violence is included in the ECHI list of European health indicators. The main sources of information are surveys and disease specific registers. Only two questions on violence (Belgium 2001) were found in the HIS/HES database for the health surveys

in Europe. The Finnish HIS/HES included several questions both on this topic and on consequences of accidents.

Violence may have long-term effects on health and well-being, and may generate deviating behaviours like alcohol consumption, suicidal ideas and other risk behaviours. The first WHO report on violence was made available in October 2002 (see http://www.who.int/violence_injury_prevention/worldreport.htm). The World Health Organization has published the definition of violence also in the publication: *Violence: A Public Health Priority* in 1966. (See http://www.who.int/violence_injury_prevention/methodology.htm). These two documents have been used as the conceptual framework for the development of the questions used in Belgium.

If violence including accidents and their consequences are accepted as important public health problems, they deserve being included in national health surveys and standard instruments for them should be developed and used.

5.6. Comparability of findings of current HIS and HIS/HES

Paola Primatesta

5.6.1. Comparison of HIS/HES data on health related quality of life and cardiovascular risk

As part of the HIS/HES project one of the subprojects was set up to examine the comparability of methods used in national HIS and HIS/HES. This included an exploratory comparison of some key health data already collected in the national surveys (detailed results will be given in a separate report, Primatesta et al 2003).

This was to point out the problems and practicalities of pooling and analysing existing data merged from several national health surveys. Data collected at national level by each member state may pose problems of comparability of information. Nevertheless data that already exist, and have in some instances been collected for long historic series by member states, seem to offer a starting point from which to provide relevant information about the health of the population, subgroups of subjects and

comparative information across member states, provided that problems of post-harmonisation can satisfactorily be addressed.

The comparison of measures of self-assessed health status was chosen as a working example. The aim of this study was to compare the self-assessed health status of people in 3 different countries – Germany, England and Italy – overall and with some chosen risk factors for cardiovascular disease, measured by questionnaires and by biological correlates. The effect of hypertension and obesity on the health of the population as a whole and by socio-economic status as a predictor of health behaviours was investigated.

SF-36 and SF-12 were the chosen measures of self-assessed health status. The 3 national surveys included in the analysis had different characteristics: the German and English surveys included both an interview and health examination (HES) where height, weight and blood pressure were measured directly, while the Italian survey consisted of interview only (HIS) and self-report of height, weight and hypertension were available.

In order to merge the data some reclassification of the variables was necessary. Education and occupation were chosen as the variables available in all 3 surveys and frequently used descriptors of socio-economic status. SF-36 was used in Germany and England, SF-12 in Italy as generic health status measures; the latter was calibrated in the merged dataset to reproduce the original SF-36 scales.

Overall there were similarities in the self-assessed health status measured by SF-36/SF-12 between the 3 national surveys. All aspects of physical health were perceived as worse as people got older, while this was less evident for mental health. Women tended to rate their health worse than men, as did those of low socio-economic status.

Regarding the CVD risk factors, differences emerged between HIS and HES. In Italy, where height and weight were not measured but estimated by the respondents, the derived mean BMI and the prevalence of obesity were lower than in Germany and England where height and weight were directly measured. The effect on self-rated health showed differences in mean SF-36/SF-12 scores between obese and non-

obese people, more marked in Italy than in the other countries, possibly indicating that people perceiving themselves as obese were more likely to assess their health as poor than people with excessive BMI as calculated by direct measurement.

People from lower socio-economic status also tended to perceive their health as poor. In fact the differences observed between countries among obese people were greatly reduced and no longer significant once differences in social class or education were taken into account.

This study highlighted the problems and restrictions encountered when trying to analyse data collected by different countries with different methodologies and non-uniformity in the wording of questionnaires and between HIS and HES measurements.

5.6.2. International projects and surveys aiming at comparability of health survey data

One of the main concerns of the European Commission is to provide comparative information across member states. Since national health surveys are mainly carried out to monitor the health of the population and to identify trends over time that are internally (nationally) relevant, there may be some reluctance to work towards achieving complete harmonisation of methods and criteria of collection and processing of data to fulfil international comparability, thereby somehow possibly compromising the comparability of historic data. Moreover, problems with comparability behind translation may still exist if cultural differences in the interpretation of the question prevent the translated version from being understood by everybody in the same way (problems of this nature may also exist within the same country, if cultural differences between subgroups exist).

To try and address these concerns international HIS surveys have been developed and carried out, some developed and managed directly by the EU (e.g. Eurobarometer), some developed by the EU but managed by member states such as ECHP, SILC (the successor of ECHP), LFS. All these surveys have a health element (see below ECHP health topics).

ECHP health topics:

- Perceived health
- Any chronic condition
- Hampered by chronic conditions
- Temporary 'cut down'
- Hospital admission in 12 months
- Consulted in 12 months:
- General practitioner/medical specialist/dentist
- Present smoking/former smoking (1998+)
- Height and weight (1998+)

Sources for lists of topics have been identified: topics that are usually measured in national HIS and survey items in the ECHI list are candidates for inclusion. A list of 18 HIS items (see below) are being evaluated and a report on the 18 items will be made available to Eurostat shortly.

18 HIS topics:

Health status

- Chronic conditions (general and specific)
- Self perceived health
- Activity restrictions (general question)
- Physical and sensory functional limitations
- Personal care activities
- Mental health
- Temporary cut down of usual activities
- Quality of life

Determinants

- Height and weight (BMI)
- Present and former smoking
- Consumption of alcohol
- Physical activity
- Diet/food consumption habits
- Use of drugs (specific items)

Use of services

- In-patient care (hospitalisations)
- Out-patient care (GP, dentist, out-patient specialists)
- Preventive care
- Use of medicines (prescribed/non prescribed)

Further reports are in preparation on the LFS data and on the longitudinal ECHP data. All these initiatives need the continuous support of all member states and a strong central co-ordination strategy maintained over time.

While pre-harmonisation may be the ultimate goal for comparability of data, parallel efforts are being carried out on post-harmonisation. To bring together data collected by different member states in a meaningful, interpretable way any difference in data collection methodology should be accounted for before these data can be used. Post-harmonisation is based on using existing data, trying to transform them (e.g. by recoding) in order to be able to compare them. A new technology for comparing existing health information has been proposed in one of the HMP projects: response conversion (van Buuren et al 2001). It relies on using a conversion key to convert information deriving from different instruments (a set of different questionnaire items) into a common scale and using the values on this common scale to compare and monitor health indicators in different countries.

The disadvantage of this technique is the lengthy statistical procedure to obtain the conversion key, and the fact that only if enough overlapping information on the items of interest exists a linkage map can be built to construct the conversion key. The application of this method may be wide, although it is currently only being piloted in two disability areas (walking and dressing disabilities) by its proponents. Other areas have been suggested, e.g. the EUPASS project on physical activity where response conversion is likely to be straightforward and useful. In principle this work is very promising, allowing setting up of a health monitoring system without the need of drastically changing established ways of working.

5.7. Development of current health surveys to improve validity and comparability

Arpo Aromaa

The purpose of this chapter is to assess how current health surveys should be developed to improve their validity and comparability. Most of the issues are similar in regard of health interview and health examination surveys. These issues are closely related to the usefulness of national surveys as elements of a European health survey system.

The cornerstones of improvements have been listed above in the previous chapters. The sample, implementation and quality assurance methods need to be comparable.

Also many of the topics must be comparable and the measurement methods of a similar and high quality.

These requirements can only be met by the following means. Whenever possible interview survey samples should be based either on individual or on household sampling, the choice being agreed on together. In health examination surveys national samples must often be multistage probability samples. Regardless of the sampling method it is important not to exclude institutionalised persons. The participation rates should be high, certainly higher than typically today. Therefore major international collaborative efforts should be directed to ensure high participation.

A lot of effort needs to be put into ensuring quality and comparability. This calls for international collaboration in the selection of measurements, in the training of field personnel or at least experts training field personnel, in developing manuals and guidelines for quality assurance and control. The efforts needed are comparable to those of a joint research project. To be successful these efforts should initially be started in standardising a few surveys and successful methods should be taken over for standardisation between a large number of countries.

Finally, it would be of great advantage to agree together on the most important topics and measurement methods as well as on data management and concentrate training and quality control on those.

A key to success is collaboration of national survey teams and experts so that they could together develop protocols, develop manuals, choose measurement methods and develop quality control methods. Although it will be difficult to avoid measurement bias it is likely that the methods mentioned will help reduce it. To mobilise the necessary expert resources should be possible if all parties gain from the collaboration. The most concrete result should be data and information that can be compared with reasonable confidence between many European countries. Such an outcome would be a major improvement in comparison to the current situation.

In practice, joint selection of measurement instruments implies that an agreement can be found on the best among currently used ones. A further step might involve

adding common, sometimes completely new modules. Since it is a value in itself to be able to continue time trends by retaining instruments already in use, the process toward improved comparability is likely to be slow. Many countries may just want to add a limited number of comparable questions and not delete any of the old ones. However, our evaluation suggests that many of the instruments used are not of such quality that they should be continued to be used. Open discussions between key persons of national surveys and international experts could lead to better comparability. The benefits of this to Member States is of course the possibility to compare their health to others.

6. MODELS OF HIS AND HIS/HES OF VARYING INTENSITY AND COST IN THE NATIONAL AND INTERNATIONAL SETTINGS

Arpo Aromaa

National surveys and international surveys employ varying methodologies. The most frequent method is the interview survey but mailed questionnaire surveys and telephone surveys as well as different combinations of methods are also commonly employed. Since it is well known that clinical measurements give important additional information there is growing interest in them. In the form of nationally representative surveys they are now being implemented only in a few countries. Particularly noteworthy are the Finnish surveys initiated already in the late 1970s. In practice, health examination surveys combine a few or numerous clinical measurements with interviews or questionnaires. The following examines possible alternative ways to implement national and international health surveys.

6.1. Health interviews

In many EU member states health interviews are being carried out as household interviews. This is obviously cheaper than interviews of national sample of the same number of individuals. The advantage is also that it is possible to analyse the influence of household/family characteristics. Furthermore, children and youth are included by definition. Although not necessarily due to the method, it is a rule that institutionalised persons are excluded. The description and analysis of health and disability suffers from this delineation. Considering international comparisons it is also

a drawback that the household samples are not necessarily representative of the population when analysed at the level of individuals. The final issue is that of greatly varying participation rates (see chapter 5.2.4.). The non-response is related to diseases, disabilities and adverse health behaviour. Therefore, relatively low participation rates typical of many national interview surveys, are a threat to their validity. Future use of interview surveys requires much greater efforts to improve participation to much better levels such as 80 – 95%.

In order to improve comparability of the information between countries it is necessary to include some common questions or modules as proposed by Eurostat.

6.2. Mail questionnaires and telephone surveys

Some MSs utilise mail questionnaire surveys often in addition to other surveys. Mail questionnaires are rather cheap and are usually carried out on samples of individuals. They can also be carried out frequently, i.e. every year, instead of every five years or so. It is possible to obtain much information comparable to that obtained by interview surveys. However, mail questionnaires may suffer from major non-participation. Typically non-participation is 10 to 20 % higher than in interviews. Recently, this has led in Finland to a combination of a mail survey and telephone survey resulting in raising the participation rate from 70 to over 80 %. As long as mailed questionnaire surveys have not been successfully tried out in all MSs it is probably safer to rely on interview surveys. However, the cost issue is compelling since low costs allow much more frequent surveys. Joint development is needed. Some countries, like USA use regular computer-assisted telephone interviews (CATI). The feasibility of such telephone surveys for health monitoring purposes in Europe should also be examined.

6.3. Health examinations and examination components

Some risk factors can only be identified by clinical measurements such as blood pressure, blood lipids, height and weight, blood glucose. These measurements can be combined with a home health interview and do not add much to its total cost.

However, more demanding methods are also more useful. This concerns specially other measurements such as resting ECG, bone density, spirometry or measurements of function. Some mental health measurements based on relatively long questionnaires can be equated to clinical measurements. More clinical information can be obtained by clinical examinations carried out by dentists and doctors and this makes it possible to assess the actual prevalence of many diseases. There are examples of all of these types of surveys. In the United Kingdom the national health interviews are supplemented by home visits to obtain blood samples and to measure blood pressure. In addition some other measurements such as ECG and spirometry have been included. In Germany, a large number of blood samples is combined with blood pressure measurements, a medical interview and a thorough psychiatric interview (CIDI).

These examples show that a comprehensive survey can include some in-depth components only. At present, the most comprehensive health examination survey is the Finnish Health 2000. It combines a 90 minute home interview and a 4,5 hour health examination. In addition to several standard measurements it includes some non-standardised, experimental tests/measurements and it will be useful to take its experiences into account. It was designed to assess health, major chronic diseases, functional limitations and activity restrictions, need for care, and health determinants.

Health examination methods need to be developed and some of them can be incorporated into national interview surveys. In addition, new HIS/HES combinations will emerge and this development should be supported by collaborative efforts.

6.4. International surveys

Research oriented surveys such as the WHO Monica employed a combination of questionnaires and some health examination methods in one or a few regions in each of the participating countries. It was carried out by research groups in each of the countries. Recently a few health oriented international interview surveys have been carried out: the Eurobarometer in 2002 and the WHO health survey since 2002. The former by EU DG Sanco and the latter by WHO Geneva. A major drawback of both has been that they have been implemented by international organisations

without contact to national actors in health monitoring. Fieldwork has been carried out by national and private organisations with insufficient quality assurance and control. As far as is known their participation rates have also been very low invalidating international comparisons but also national findings. The lesson is that no such surveys should be implemented without proper planning, proper contact with responsible national organisations and high quality implementation. A pressing need for internationally comparable data and information cannot be an acceptable excuse for poor quality.

6.5. Conclusions

Exciting developments are going on in Europe pointing to a way to the future. The best bet for future surveys is a combination of health interview methods with health examination methods. Although cost must be considered it is important to note that health examination methods have many advantages both in comparisons of population groups and in time trend comparisons. The examination component depends on proven methods and on available resources. However, the possible alternatives do not exclude each other.

In view of the health examination cost it would be advisable to carry out sole health interviews (or questionnaires) at intervals of a few years, say every 4 or 5 years, and a HIS/HES survey every ten years. When determining their contents it would be advisable to get acquainted with recommendations and current surveys in the HIS/HES database, with forthcoming Eurostat modules and with recent HIS/HES surveys that can serve as examples. In addition, international collaboration should be used to develop methodologies, improve implementation and help in setting up HIS/HES surveys.

7. WORK TO BE CARRIED OUT IN FUTURE

At least half of all the health indicators needed for European Public Health Policy can only be derived from health surveys. Therefore it is essential that the data obtained and the information based on them are representative of the different populations and of high quality and that data from different surveys can be compared. This report

has clearly shown that there are still many shortcomings and development needs ranging from definition of data and indicators and individual measurements through general methodologies and implementation of various parts of the work.

There are also interesting developments opening new possibilities and introducing new challenges:

First, Eurostat has been introducing the notion of a European Health Survey System comprising national health interview surveys. Comparability would be achieved by recommending common modules. Sometimes in the future, the developments may also lead to a common European survey. All work now put into improving methods and comparability of national surveys will benefit also any international survey.

Second, in addition to health interview surveys recent surveys in many countries have utilised health interview and health examination methods (HIS/HES surveys). Their range of measurements has been considerable from a few tests added to an interview to a comprehensive clinical examination. There has been growing interest in many countries in Europe in carrying out surveys of the HIS/HES -type.

Third, information and experiences of the accession countries need to be taken into account - and this is a two-way road. They will benefit from the experiences gained so far in Member States and Member States will benefit from their experiences.

Fourth, the database of all surveys giving easy access to methods and recommendations provides an excellent opportunity for improving quality and comparability of future surveys. At least the more important topic-specific surveys and those restricted to certain age groups should be added to the database in order to make those experiences and methods widely available.

Fifth, the combined experience of the HIS/HES team and its Europe-wide networks of experts together with networks of some other EU Health Monitoring Programme projects secures the necessary knowledge and manpower for an international expert work force to tackle improvement of quality, comparability and implementation of surveys.

Finally, the classification schemes for health survey data are not well developed. Therefore, there is a need also to revise the classifications and coding used in the database. In particular, the International Classification of Functioning needs also to be taken into account.

The above list stemming from experiences of the HIS/HES project and of parallel developments demonstrates opportunities and development needs. Furthermore, the way in which the EU Public Health Programme has been organised suggests that many vertical topic specific groups need to interact with experts with survey experience.

7.1. Development and maintenance of the HIS/HES database

The database needs to be up-dated by the following information:

- New health surveys carried out in the Member States, EFTA-EEA and all or some OECD countries
- Health surveys carried out in the Candidate Countries
- New international Eurostat surveys (SILC, LFS).

In addition it would be useful to revise the inclusion criteria and include also some surveys restricted to certain age groups such children or the elderly as well as selected regional surveys. It would also be a good idea to include selected topic-specific surveys such as cardiovascular or respiratory since their measurement methods may well be worth using in national surveys. To do all the above all questionnaires, information about other instruments and information about survey design needs to be gathered from all these surveys. This is a major undertaking.

The inventory of health surveys is believed to be complete for the years 1998 to 2001 but only part of the surveys carried out in 2002 have been included in the database. Thus, coding and keying in of the information must be continued. The plans of Members States are shown in Annex 10. Annually 15 to 24 surveys are planned for the years 2003 – 2007. Our experience is that to include one interview survey in the database requires three weeks of work (for an academic and a secretary). Therefore, to update 2002 and 2003 requires about 90 weeks of work. Up-dating and

maintenance can only be taken care of if the Commission funds the database work on a regular basis.

The coding scheme needs to be revised first by introducing improvements to topic codes and codes for question series such as scales and second by developing a coding scheme based on the International Classification of Functioning (ICF, WHO 2001) for suitable topics. The HIS/HES subproject on physical functioning was also a pilot study of linking questions to ICF codes and showed that this is well worth the effort (see also chapter 5.4.4.).

The database has been released in the Internet in May 2003. The address is <https://www.iph.fgov.be/hishes>. Feed-back on usability is important and will be taken into account. There are already a number of features requiring improvement. Examples are the need to enhance search capabilities, to improve the flexibility and quality of output and to enhance the coding system. The database originated during the first phase of this project when it was designed in MS Access^R. In order to make it readily available via Internet whilst conforming to the Commission's requirements it was migrated to SQLServer^R with Coldfusion^R as interface. This effectively meant redesigning the database and adding necessary functions. Unfortunately, there were no Commission funds available for this work. Currently the web-site is hosted by the Internet server of the Scientific Institute of Public Health in Brussels. In future it will be possible to install the database on the Internet server of the Commission if this seems the preferred solution.

7.2. Participating in the development of European surveys

The comprehensive information on current surveys and recommendations and the network of survey experts are valuable assets for the development of national and international surveys. Therefore one line of future work should be following and participating in the development surveys. First, the possible future developments must be considered.

Eurostat presents four scenarios in its document "Harmonized results from surveys and/or survey modules on health" :

- 1) Continuation of the Eurostat initiative i.e. collection of health survey data on a number of items from Member States
- 2) Initiation of a European Health Survey in addition to the MS HISs
- 3) Long-term expansion of health data collection in the framework of the Survey on Living Conditions (SILC) and the Labour Force Survey (LFS).
- 4) The development of a European Health Survey System (EHSS). Common modules would be progressively included in national health surveys of the Member States. The Eurobarometer would be used in addition. The Eurobarometer could be used for comparative purposes and quick data collection. However, it cannot replace national health surveys, at least not in its current form and small sample size per country.

The fourth scenario is the most realistic and practical one. A similar system of health surveys with a common core section and optional modules already exists in the USA (Mokdad et al 2003). However, the suggestion of a starting year of 2006 seems too optimistic particularly because all modules must be tested in all Member States. Also, not all current developments and needs have been mentioned in the document.

- Health examination surveys and methods are needed and their use is spreading
- Another development worth noting is the implementation of either mailed questionnaires or telephone interviews particularly in health behaviour surveys
- There is a need for regional level data which cannot be met by European nor by national surveys
- Any survey implementation must be based on sound design, methodology and methods including quality assurance. This requires joint efforts beyond common modules or questions.
- There is a need to guide and co-ordinate the EHSS by survey experts, information and support measures such as those mentioned in this report.

A logical step forward is for the network of experts of this and some other HMP projects to collaborate in supporting the development of systems to ensure that high quality comparable data can be gathered from all Member States mainly via their national surveys. Collaboration involves ECHI –project, remaining Health Monitoring Programme projects, Public Health Programme projects and Eurostat activities concerning surveys.

The information and expertise now available should be involved in developing the European survey system, the general methodologies, and contents i.e. methods and common modules. This work must be initiated early during the current Public Health Programme.

7.3. Developing and improving international comparability of Health Examination Surveys

The role and feasibility of comprehensive and less comprehensive models of health surveys should be assessed further. Evaluation of and recommendations on new methods are needed. Guidelines for quality assurance for HESs is required. Particular emphasis must be given to general implementation aspects such as sampling and recruitment, and to the development of recommendations for clinical measurement of functional ability.

Due to the complexity and special requirements of HESs it is essential to transfer experiences gained to those initiating their first national HES. This would also help to improve quality and international comparability of the data. The expertise for this support can only come from the HIS/HES network. All the above should be documented as guidelines easily accessible via the HIS/HES web-site.

Several measurements carried out in HES field examinations can be standardised and it may be possible to reach reasonable comparability. However, HESs have one particular aspect which can be standardised relatively easily. Blood samples are taken in all HESs and both the sampling technique and the laboratory analyses can be made comparable. In fact, there was a WHO Lipid Reference Laboratory in Prague but its activities were laid down some six years ago. The spectrum of determinations is today much wider than in the days when lipid standardisation began. An important initiative also proposed to the Commission two years ago is to create a network of reference laboratories with each specialising in some of the determinations. Determinations should comprise lipids and some risk and protective factors typically measured in national HESs and research surveys.

7.4. Feasibility of international monitoring by mailed questionnaires and telephone interviews

The health survey system of some European countries comprises of yearly mailed questionnaires and interviews and examinations every 5 to 10 years. When developing the survey system there is a need to test the feasibility of the cheapest alternative. The role and feasibility of the least expensive health survey model, the self-administered questionnaire, as well as the alternative of computer assisted telephone interviews (CATI), should be assessed focusing on health and health behaviour monitoring.

7.5. Other work toward a distributed survey system

Based on the database and the network of survey experts work should be continued to assess the feasibility of pooling data from national health surveys. This initiative could become the beginning of a distributed data and analysis system possible to be established in future.

Many questions and measurement methods have been and will be proposed for surveys by the EU Health Monitoring Programme and the Public Health Programme. Most of these developments are topic specific (vertical) and it is essential that the horizontal input of survey experts is taken into account. In addition to already existing methods and recommendations incorporated in the database there is a need to participate in the development of new methods and recommendations. The current network of experts enables interaction of survey expertise and topic specific expertise of the future projects. In addition to evaluation of methods and recommendations this network of experts should take part in the development of the common modules for the European Health Survey System.

It is also possible to review national surveys and their methods and, upon request, feed back on comparability can be made available.

7.6. Quality assurance for Health Surveys

To ensure high quality implementation training and quality assurance are a must. Yet, from the database information it is clear that they are currently very variable. The existing experiences should be joined to develop guidelines, partly method specific, and then to implement them on national and international basis. In fact, joint training and quality assurance should be carried out first for a few surveys and a few methods to develop guidelines. They could later cover numerous methods and as many surveys as possible. This aspect is particularly important for improving international comparability of any data obtained. Also these guidelines should be made available via the HIS/HES database.

During the Health Monitoring Programme the EHRM project recommended measurement techniques and training and work could start on a pilot basis on those recommendations. They would next be expanded to cover other HIS and HES methods and to develop training and quality assurance modules in a stepwise fashion.

On the basis of information collected and its own experiences the network should take the initiative to produce practical manuals and guidelines to improve the quality and comparability of HIS and HIS/HES. Outcomes could be materials and manuals for training, quality assurance and survey implementation. The emphasis should be on areas and topics where no acceptable international standards exist. A main product could be A Guide to Good Health Survey Practice.

7.7. Networking and international support structures

Networking should be enhanced between national survey experts since this is the only way to share experiences. For networking to succeed such an expert group needs one or several common projects. Projects could be in the major fields mentioned above. For many of the above tasks there is also a definitive need for a Community level support and advisory structure for health surveys, both HIS and HIS/HES. Such a structure can enable joint training and quality assurance, its experts can transfer knowledge and experience, and they may be able to carry out or at least

to guide international joint training. These survey experts may also be prepared to produce manuals and guides, which are prerequisites for improvement. As has been repeatedly stated above these activities are cornerstones of improving quality and comparability.

8. CONCLUSIONS AND RECOMMENDATIONS

8.1. Implementation of health surveys in Europe

Health interviews and health examinations are essential tools of public health and health policy. They can gather unbiased information on the whole population, information not available from any registration of health care use. However, the measurement methods must be well suited to the task and the samples must be representative of the population.

Current surveys

At present, almost all countries implement national health surveys carried out as face-to-face interviews in the subject's homes. About half are based on household samples and the others on samples of individuals. National health interviews combined with health examinations have so far been carried out in a small number of countries but interest in them is growing. Although not using national samples there have been numerous risk factor and examination surveys combining HIS and HES methods.

The comparability of current surveys is limited by overall design and methodological issues, by the choice of different measurement methods and by differences in the fieldwork proper. First, sampling frames differ between countries. More importantly, inclusion or exclusion of the institutional population has a decisive effect on the prevalence of functional limitations in older age groups.

Second, participation rates vary from unacceptably low to very high. Participation is known to be selective and low rates tend to lead to underestimation of unhealthy behaviours, diseases and disorders and functional limitations.

Third, both contents and the measurement methods vary. Although this source of variation seems to be diminishing over time it is still considerable. Even when the methods allow comparison it is not certain that the implementation is similar. Most surveys apply some degree of quality assurance and quality control but the methods differ. Therefore it is unlikely that quality assurance has a similar impact in different surveys. Also, many HES measurements are prone to such differences. It is true even concerning laboratory determinations since there is no European quality control scheme.

Surveys are being used to provide health policy relevant health data and utilisation data. They can serve this purpose well only if study populations are representative of the target population, if participation rates are high and if methods are suitable and their application is of high quality. Combined indicators such as healthy life years or disability free life years would be valuable for international comparisons. However, the underlying information on the prevalence of functional limitations and activity restrictions in different populations is not comparable at present. This stresses the need for much improved quality and comparability of data derived by national health interview and health examination surveys.

Future surveys

The future European Health Survey System should be built on the existing national surveys. All kinds of surveys should be taken into account from mailed questionnaires and telephone interviews through face-to-face interviews to full-fledged health examination surveys. Ways should be found to support establishing and developing surveys particularly in countries with less experience. An example is the emerging HESs clearly benefiting from the experience of others.

The three quality aspects mentioned above (sampling frames, participation rates, and contents and methods) should be tackled in parallel. First, all efforts should be made to cover the whole population, i.e. of not excluding the institutionalised population. Second, experiences should be shared in order to achieve high participation rates. Third, collaborative efforts should be initiated to develop and recommend common items and modules to be used in all countries. Fourth, an international work force should be established to design modules for training and quality assurance and for

helping with setting these up. In addition, for HES a network of reference laboratories should be set up. Initiating these efforts in national surveys will, in due course, enable setting up international surveys in Europe should they become necessary.

8.2. HIS/HES database: updating, maintenance and dissemination

The HIS/HES database has been under development for several years. It is a very useful tool for comparison of European surveys and should lead to better comparability. The HIS/HES database (Internet version) was released in May 2003. It will hopefully be used extensively so that feed back can be given for future development.

The database is one of the permanent elements of the EU information system. It needs to be updated and maintained from now on. The main tasks are including new surveys, first from the accession countries and next new surveys from all countries. New recommendations must also be documented. Using the current version has revealed needs to improve usability and to improve the classification scheme. Special coding needs to be introduced for scales and question series now handled as individual items.

8.3. Work to be carried out in future

Projects should be set up to continue the work of HIS/HES Project Phase 2. In particular, methodological work on implementation of surveys should be carried out to make sure that samples are more comparable and participation rates improve. There is also a clear-cut need to establish international collaboration to improve training and quality assurance. One part of this is the establishment of a reference laboratory network. Measurement methods and recommendations should be developed further in the European context and similar modules suggested for use in different countries. A network of health survey experts is also needed for co-ordination of health surveys and for pooling and analysing data from national surveys. Finally, the cornerstone of all these activities is the HIS/HES database, which should be continuously updated and maintained.

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