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Session 2 – Invited paper

WHAT SHOULD BE MEASURED IN RELATION TO HEALTH STATUS. THE EU AGGREGATE EXPERIENCE

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I. HEALTH INFORMATION SYSTEMS IN A GENERAL APPROACH

1. The aim of a European Union System of Information on Health and Knowledge (EUHIKS) is making accurate information readily available and accessible concerning the health status of the population to improve the health status of European citizens. Effective and timely use of information is crucial to achieving this objective.

2. In 1946 the World Health Organization (WHO) described health as *'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'* (WHO 1946). Health is an important part of wellbeing, of how people feel and function, and also contributes to social and economic wellbeing. Health is not simply the absence of illness or injury, and there are degrees of good health as well as of bad health. Many things determine and influence health. Indeed, the dominant view presently is a 'multicausal' one, in which disease, disability, quality of life and (ultimately) death are to be seen as the result of the interaction of human biology, lifestyle and environmental (including social) factors, modified by healthcare interventions.

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3. Disability, disease and death are aspects of health and wellbeing, and all can be seen as the result of a complex interplay of many determinants described as individual or environmental. These causes and effects can be modified to various degrees by health protection, prevention and promotion, or by treatment and rehabilitation; in the end stages of life, palliative care arises. Such interventions are supported by human and material resources, including essential information via research, monitoring and evaluation.

II. THE PROGRAMME OF COMMUNITY ACTION IN THE FIELD OF PUBLIC HEALTH (2003-2008)

4. Decision No 1786/2002/EC of the European Parliament and of the Council of 23 September 2002 adopting a programme of Community action in the field of public health (2003-2008), envisages the creation of a comprehensive and sustainable health monitoring and information system, building on work done in previous Community public health programmes, work in the Statistical Programme and other Community programmes such as the research programme, and taking into account the activities of related international organisations.

5. The annex of the programme establishes the need to improve health information and knowledge for the development of public health by developing and operating a sustainable health monitoring system to establish comparable quantitative and qualitative indicators at Community level on the basis of existing work and of accomplished results, and to collect, analyse and disseminate comparable and compatible age- and gender-specific information on human health at Community level concerning health status, health policies and health determinants, including demography, geography and socioeconomic situations, personal and biological factors, health behaviours such as substance abuse, nutrition, physical activity, sexual behaviour, and living, working and environmental conditions, paying special attention to inequalities in health.

6. The programme puts forward several specific major public health concerns that deserve EU level attention:

- Increasing life expectancy without disability or sickness
- Dealing with health threats particularly communicable diseases and bio-terrorism
- Reducing differences in health status and health outcomes – tackling inequalities in health
- Attention to major burdens of disease
- Addressing health determinants through promotion and prevention – e.g. tobacco, nutrition and alcohol
- Health protection in all EU policies and activities
- The citizens' dimension and equal access to information
- Needs of the new EU Member States

7. The programme of Community action in the field of public health is also intended to build on activities and the work of the eight programmes from the previous public health framework (Cancer, HIV/AIDS, Drugs, Health Promotion, Health Monitoring, Pollution-related Prevention Programme, Rare Diseases and Injuries and Accidents), as well as on relevant research projects funded under previous Community Research Frameworks.

8. The statistical element of the health information system will be developed, in collaboration with the Member States, using as necessary the Community Statistical Programme to promote synergy and avoid duplication.

III. HEALTH INFORMATION AND KNOWLEDGE SYSTEMS IN DG SANCO

9. On the basis of the foregoing, the objective of DG SANCO is to develop, on the basis of existing Health Monitoring Programme, Injury Prevention and Rare Diseases Projects as well as on the basis of the current work in DG SANCO, Eurostat, DG RTD and as well as the work of other EC and international bodies, an European Union System of Information on Health and Knowledge.

The main components of the system should be:

- The European Community Health Indicators (ECHI) system at national level
- The System of Regional Indicators on Health (ISARE) at sub-national level
- A system of sources and inventories on health information
- A system of information and knowledge on major and chronic diseases
- A system of networks and databases in the field of Rare Diseases
- The Epidemiological Surveillance and control of Communicable Diseases Network
- A system of tools for the analysis of events leading to unforeseen levels of mortality
- A system of information on life styles and health determinants
- The European Community Environment and Health Information System (ECOEHIS)
- The Injuries and Accidents Surveillance System (ISS)
- The European Health Survey System (EHSS)
- A Hospital Activity and Resources Information System
- The System of Health Accounts (SHA)
- A system of information on mobility of patients and health professionals
- Health Evidence Resources

10. DG SANCO is giving also a high priority to developments in other areas covered by existing Health Monitoring Programme projects, especially Reproductive and Perinatal Health, Oral Health and other issues in the new programme.

The objective is that the EUHIKS information should be collected for these main components:

- in a routine register or survey basis when possible (with Eurostat as the main EU provider);
- on the basis of DG SANCO established systems (ECOEHIS, ISS, communicable diseases);
- from Community Public Health projects in a non routine basis;
- on the basis of future modules from the Eurostat /DG SANCO European Health Survey System (EHSS) for other health status indicators.

11. Outputs will be an EU Health Portal, supporting an easy access for citizens and professionals to thematic information resources on public health at EU level.

In addition, diffusion through regular EU health reports will be developed with use of thematic conferences to improve exchange of information.

IV. MEASURING HEALTH STATUS – WHAT WE WANT TO MEASURE?

12. Health status is a broad concept. It goes beyond the mere presence or absence of disease. However, currently available data do not allow for the systematic measurement of health status in

a way that does justice to the concept, by including measures of quality of life. Indicators as life expectancy, morbidity, premature mortality and disablement, could indicate that EU citizens are living longer than ever. The extent to which these gains in life represent gains in quality of life is variable. Nevertheless, significant preventable morbidity and mortality before 65 years of age still occurs. Old problems, mostly of an infectious nature, are persisting or re-emerging together with new degenerative disorders and social pathology. Many of these problems result in death or in survival with permanent disablement.

13. Also a number of social groups are considered in need of special attention. These include, *inter alia* , the elderly living in poverty, the unemployed, migrants, refugees, single parent families, the homeless, people in prison and out-of-school youth. The variation in health status across socioeconomic groups could be explained (OCDE, 2001) by the way in which social services such as health and education are distributed and resourced. In countries where social services are absent or income dependent (*e.g.* they are essentially private sector services, and they rely on fees and co-payments), health status is likely to reflect lack of access to health care by lower socio-economic groups and/or lack of ability to pay. By contrast, in countries where health care is publicly funded and available, the association between income and health is weaker. Distribution, geographical imbalances and accessibility for health services need also to be analysed when we refer to the health status of the EU population.

V. PUTTING INTO OPERATION THE ECHI SHORT LIST OF INDICATORS: MEASURING HEALTH STATUS

14. We will refer now only to some of the components of the EU information system more directly related to the more traditional concept of health status of the population.

15. The ECHI-1 and ECHI-2 (European Community Health Indicators) projects under the HMP, Health Monitoring Programme have developed a comprehensive list of indicators, in close co-operation with many of the other projects run under the programme. By March 2004, the list included approximately 400 items/indicators. There was a strong wish from the European Commission to extract a shortlist, in order to prioritize the work for harmonisation of EU member State's data collection. ECHI-2 undertook the work to select the indicators for the shortlist. This rationale coincides with an aim of the ECHI-2 work plan, namely that the comprehensive indicator list, which could be expected to grow steadily with the input of all the public health projects, would need some restriction to enable effective work on harmonisation of data collection, but not on too many topics at the same time.

16. There is no obvious reason to prefer one set of criteria against which to develop the initial indicator set, except perhaps to start from a *general public health policy perspective.* From this perspective, health policy seeks:

(1) To address the big health problems, as well as
(2) Unwanted health inequalities, and
(3) The best opportunities to improve health and reduce inequalities through appropriate interventions.

17. On this basis, indicators/issues should be selected which:

(1) Represent overall (negative or positive) health measures, or the largest health problems ('disease burden'), whether in terms of diseases or functional health at the population level,

(2) Contain the most important health inequalities (possibly to be implemented by stratification of other selected indicators), and

(3) Focus on determinants of health, which can be influenced by health and other policies and on associated interventions in health promotion, health protection, prevention and/or health care.

18. In the ECHI list, class 2 of the list corresponds to 'Health status' and contains indicators on various aspects of the actual health situation of the population. Disease groups have been selected because of their substantial share in the total burden of ill-health or because of their reference to known risk factors or to identified activities in prevention and health care (e.g. avoidable mortality). In this context we have not used the term 'Health outcomes'. We prefer to reserve this term for situations where a clear link can be made to an intervention. Class 3 corresponds to 'Determinants of health'. This group contains all factors determining health, outside the health care system. It includes (i) the 'personal and biological factors'; (ii) health behaviours (lifestyle factors) and (iii) living and working conditions, more to be viewed as the wider environment. For all these categories of determinants, selection criteria have been: their importance in determining a substantial share of (ill-)health; the degree to which they can be influenced, and the cost-effectiveness of the interventions involved.

19. The backbone of the scheme is that 'health' is what we are finally interested in to improve (class 2), 'health determinants' are the factors we want to influence to improve health (class 3), and 'health interventions' (class 4, now called health systems) are our means to do this.

20. The indicators for 'Health status' included in the so called ECHI short list (including also origin and justification) are:

CLASS 2, HEALTH STATUS
Mortality

Indicator	**Origin**	**Justification**
• Life expectancy at various ages	Originally selected	Basic indicator for population health
• Infant mortality	Originally selected	Important indicator for population health
• Perinatal mortality	Suggested by Peristat project; *also in shortlist ISARE*	Important indicator for perinatal health care and preventive care
• Standardised death rate Eurostat 65 causes, age 0-65)	Originally selected; *in shortlist ISARE*	The 65 causes list contains the most frequent causes of death, including all ICD chapters as a whole.
• Standardised death rate Eurostat 65 causes, age 65+)	Originally selected; *in shortlist ISARE*	The 65 causes list contains the most frequent causes of death, including all ICD chapters as a whole.
• Smoking-related deaths	Originally selected	Important group of preventable deaths
• Alcohol-related deaths	Originally selected Injury WP: take care that injury deaths are	Important group of preventable death

	explicitly included	
• Drug-related deaths	Suggested by EMCDDA	Important group of preventable death

Disease-specific morbidity

Indicator	Origin	Justification
• HIV/AIDS	Originally selected; *also in shortlist ISARE*	Novel disease with expansion potential and link to prevention
• Lung cancer	Originally selected	High-burden disease
• Breast cancer	Originally selected; *also in longlist ISARE*	High-burden disease
• Diabetes	Originally selected; NCA: specify for children	High-burden disease
• Dementia/Alzheimer	Originally selected	High-burden disease
• Depression	Added by ECHI meeting	High-burden disease; highlights mental health priority
• Acute myocardial infarction (AMI)	Originally selected	High-burden disease
• Stroke	Originally selected	High-burden disease
• Chronic obstructive pulmonary disease (COPD)	Originally selected	High-burden disease
• (Low) birth weight	Originally selected	Important indicator for pregnancy conditions; important cause for problems later in life
• Suicide attempt	Added by ECHI meeting	Highlights mental health priority
• Injuries by intent and sector, to include road traffic, workplace, home/leisure, suicide attempt, other violence	Originally selected: road traffic; Injury WP: add other sources of injuries; *no. of road traffic accidents in shortlist ISARE; work accidents in longlist ISARE*	Highlights all mains sources of injury; high-burden health problem

Perceived and functional health; composite Measures of Health Status

Indicator	Origin	Justification
• Perceived general health	Originally selected	Widely used measure of general health
• Prevalence of any chronic illness or condition	Originally selected	Widely used measure of general health
• General musculoskeletal	ECHI meeting wanted	High-burden health

pain	musculoskeletal indicator; MSD preferred this one	problem
• Limitations in seeing, hearing, mobility, speaking, biting, agility	Added by ECHI meeting	Physical disabilities are a high-burden health problem
• Limitations of usual activities, past 6 months, health-related	Added by ECHI meeting	Activity limitations due to health problems are widespread
• Psychological distress	Added by Mental health WP	Important to have a generalised measure on mental health status
• Health expectancies based on the above: • Perceived general health • Any chronic illness • Limitations in seeing etc. • Limitations of usual activities	Added by ECHI meeting, modified by Reves project	Health expectancies are important as composite measures, including both mortality and morbidity elements

VI. PUTTING INTO OPERATION THE HEALTH STATUS AND HEALTH DETERMINANTS INDICATORS: THE EUROPEAN HEALTH SURVEY SYSTEM

21. The general health status of populations, as measured by means of 'self-reports', by its nature changes only slowly over time. Improvements in prevention, nutrition, physical activity and other lifestyle factors may be reflected in the population's health only years later. Moreover, health status is not evenly distributed; with each step up the socio-economic ladder, groups are less vulnerable to disease, disability and premature death. Genetics, the physical environment and early childhood experiences all influence overall population health perception, in addition to the socio-economic environment. Perceptions also can differ for each culture, thus making comparison more or less irrelevant.

22. One of the ways used by governments to assess the positive aspects of health is through population survey-measures of self-rated health status. Subjective or self-reported health status is not a substitute for more objective indicators but rather complements these measures: self reports of health introduce a consumer perspective into population health monitoring and reveal dimensions of health that may be inaccessible to the more traditional measures (NZ MoH 1999). Indicators of self-perceived health have been found to be a good predictor of future health care use and mortality and to have predictive value for decline of functional ability among the elderly and among the general population. The measurement of self-perceived health is, by its very nature, subjective. The EU is comprised of many different countries, each with its own languages and cultural traditions; even with agreement on the structure and wording of the self-rated health status question, it is likely that answers will at least partly reflect cultural differences in health perception (Robine 2002).

23. HIS also have some disadvantages, however. The sample method is not suitable for measurement of conditions with a low prevalence, and the subjective reporting may not always correctly identify the condition, e.g. people may have a disease but be not aware of it, or they

may have incorrectly 'diagnosed' a condition themselves. Furthermore, there is considerable heterogeneity in the concepts and definitions that are adopted in different countries when surveying chronic conditions.

24. Measuring the prevalence of diseases and health determinants is an important issue for evaluation and policy formulation on health status of the population. 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.

25. In EU Member States and EFTA/EEA countries, Health interview surveys (HIS), Health Examination Surveys (HES), combinations of HIS/HES and other population surveys with a significant health component to provide insight into the coverage of areas that are relevant for Health Monitoring by national and international surveys can be used to collect information on the self-assessed health of the population (perceived health, chronic conditions, disabilities, mental health), on a number of health-related behaviours (health determinants such as smoking, use of alcohol, physical activity, use of drugs, food consumption habits) and on the use of medical services (hospitalisation, consultation of doctors/dentists, use of medicines, preventive actions such as cancer screening tests). In addition these surveys collect comprehensive information on the personal characteristics of the interviewed persons, or – in a few countries – survey databases can be combined on the micro level with data from registries.

26. The methodological rules as well as the practical decisions for implementation of HIS in Member States have been normally discussed in the Task Force and in the Core Group HIS from Eurostat. The methodological production of these groups during recent years has been very good and very well welcomed in all the Member States and beyond the EU. For additional needs, DG SANCO has supported the creation of the 'HIS/HES database' but also, in the framework of the former Health Monitoring Programme, some methodological projects on HIS but also on HES and HIS/HES to complement and to inventory practices, guidelines and methods to improve quality of health surveys in the EU (The Response Conversion Project to compare health surveys, The Euro Reves-2: Selection of a Coherent Set of Health Indicators for the European Union Project, The 'European Health Risk Monitoring' project, The Phase 2 of the 'Health Surveys in the EU: HIS and HIS/HES Evaluations and Models' project) and specially the *HIS/HES database project*, coordinated by Statistics Netherlands, KTL (Finland) and Scientific Institute of Public Health (Belgium), started in 1998 under the EC Health Monitoring Programme. This database contains information on the methods and contents of HIS, HES and HIS/HES. The database covers more than 5 000 HIS questions, both in the original language and in English. Users of the database can search for specific information on particular surveys, or on particular topics like self-reported health, lifestyles, use of services. In order to facilitate the search on specific topics, a list of health topics has been developed.

VII. OBJECTIVES AND MAIN COMPONENTS OF THE EUROPEAN HEALTH SURVEY SYSTEM

27. It is proposed to develop a European Health Survey System (EHSS) combining existing national survey instruments with appropriately designed common modules of questions. The main objectives (Robine, Bonte, Jagger 2002) of a European Health Survey System (EHSS) are:

- To contribute to a solid standardised information base for a European Health Monitoring System (EHMS), as required by the new European Public Health Programme (2003-2008),

making possible basic comparisons between Member States including essential background variables for computing standardised rates (age, sex, level of education…);

- To validate and calibrate the annual data provided by Minimum European Health Module for the calculation of the structural indicators required by the Council;
- To validate and calibrate the data collected regularly in the framework of the EHSS, which will provide basic data for different modules or sets of indicators for health monitoring;
- To provide bridge variables in sufficient quantity and quality to refine comparisons between various European surveys by post-harmonisation techniques for the comparison of questions or topics not (yet) standardised;
- To provide basic modules and interfaces for complementary European surveys covering the many topics included in the European Community Health Indicators (ECHI) list;
- To oversee and support the co-ordination of health surveys in Europe to avoid duplication and multiplication *ad infinitum* of basic questions on health that make comparison difficult;
- To support exchanges between professionals involved in the various health topics and the professionals who collect the data.

28. We detail here some of the parts of the EHSS:

1) **The European Health Interview Survey (EHIS)** to be developed by Eurostat. The first round of the EHIS could take place in 2006 in all the EU Members States including the new members. As mentioned, the survey system could take various forms in the different Member States, but in all Member States the common elements could be: the annual *Mini European Health Module* (MEHM), this would be the annual component of the EHSIS, providing the data needed annually for the European Structural Indicators in the field of health, such as the Disability-free Life Expectancy (DFLE) as well as other modules such as a *European Survey Module on Determinants of Health* (ESMD) and a *European Survey Module on Care* (ESMC). This part will be developed by the European Statistical System (ESS). The other part to be held every five years will have core modules on health status (European Module on Health Status - EMHS), on health care (European Health Care Module - EHCM), on health determinants (European Module on Health Determinants - EMHD) and on background variables (European Background Module - EBM). All modules should be ready in 2005. These modules together will be conducted in all MS in 2007, 2012 and may be grouped in one separate national survey thought they may also be included in existing national surveys. In this way Member States have the maximum flexibility for implementation though across the EU the same data are collected and become available at the same time.

2) **The European Special Health Interview Surveys (ESHIS)** to be developed under the new Community Public Health Programme 2003-2008 of DG SANCO. A call for tender for inventory of practices and proposals will be launched by DG SANCO in 2004. The complementary surveys might address different topics or subject groups, e.g. nutrition, adolescents, mental health. On the basis of the indicators defined in ECHI and the currently available question sets or modules, initial priorities for recommended special question sets or modules to be used in practice shall be proposed on the basis of the 2003/2005 EU Public Health Work Plans. In this context of the complementary set of European Special Health Interview Surveys (ESHIS) a specific attention will be given to the development of survey instruments covering functional topics and Mental health and Quality of Life measurement.

3) A **European library (database) of standardised special Health Interview Survey Question Modules** and an **inventory of co-operating special Health Interview Survey**

Institutes to be developed under the new Community Public Health Programme 2003-2008 of DG SANCO.

4) **A pilot survey** with some of the priority special question modules in Member States and the Accession Countries as, if possible and necessary, a part of the Eurostat module EBM or other modules A call for tender will be launched in 2005 by DG SANCO. These priority special modules shall be chosen, in co-decision in a Steering Committee Eurostat/DG SANCO/national and international experts, for a pilot trial. The pilot trial will be primarily conducted to test the performance of the institutions inventoried and to prepare for more expanded special surveys in the medium term.

5) A **European Health Examination Survey (EHES)**. A call for tender will be launched in 2004 by DG SANCO to develop a feasibility study. A Health Examination Survey is more expensive and logistically more demanding than a HIS, as it requires a variety of highly qualified personnel, 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. One major advantage of the HIS/HES combination is in measurement of time trends and differences between population groups, since the different types of measures facilitate interpretation of the findings. There is a need to develop core modules for HES in Europe. A HIS/HES will include an interview with a few measurements and/or blood samples, or a comprehensive health examination taking several hours to complete (e.g. cardiovascular diseases, respiratory diseases, diabetes). Mental and dental health issues were often the subject of separate surveys and therefore rarely included in national general health surveys. 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.

6) **Inventory of 30 years of Eurobarometers on health (1973-2003)** to be developed under the new Community Public Health Programme 2003-2008 DG SANCO will be launched in 2003 a call for tender. A complete set of information on past experiences could be useful to determinate in which areas the Eurobarometer should be an auxiliary useful tool for the EHSS (e.g. in areas related to opinions, satisfaction, preventive measures or others).

VIII. SOME CONCLUSIONS

29. An aggregate EU measurement of health status cannot escape from the EU national and sub-national particularities and very well consolidated methods over the time. A consensus strategy, in the long term, defining and discussing at EU level things that are probably obvious at national level is a necessary step. Inventories of sources, methods and practices available for EU institutions and experts are also a significant part of the process. At EU level a lot of data from surveys and administrative registers including information about risk factors and other determinants of health are collected since years. To harmonise these data and to propose a common framework for health information (EUHIKS), for measuring the health status (ECHI) and for a use of common tools (EHSS) are the main challenges for a successful measurement of health status in the EU.

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