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Demographic and social statistics: health statistics

Report of the Statistical Office of the European Communities

Note by the Secretary-General

The Secretary-General has the honour to transmit to the Statistical Commission the report of the Statistical Office of the European Communities on health statistics. Points for consideration by the Commission are contained in paragraphs 11 and 69.

* E/CN.3/2003/1.

Report of the Statistical Office of the European Communities on health statistics

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I. Introduction

1. Projects on health statistics were launched in the European Union (EU) some decades ago. The projects were not yet grouped together but operated either within demography (e.g., statistics on groups of causes of deaths by region) or within other fields in social statistics (e.g., statistics on health and safety at work).

2. In 1993, with the adoption of the Maastricht Treaty (in particular article 129) the EU obtained for the first time a legal basis for its actions in the field of public health. A prerequisite for such actions is knowledge about the nature and extent of existing problems, so that the Maastricht Treaty was a starting point for the revision and extension of a range of social statistics in the EU in general and in the Statistical Office of the European Communities (Eurostat) in particular. Health statistics were mentioned for the first time as a separate area in the community statistical programme for 1993-1997.

3. Various specific programmes in the field of public health (one of which was the programme of action on health monitoring (1997-2001)) and also in other social fields came into being and contained explicit references to the need for collecting information and data, such as on health status and its determinants, on social participation and on equal opportunities.

4. These policy developments created an urgent need for more and better statistics on health status and its determinants and on the use of social and health services and the resources involved in such services.

5. Recently, the framework of EU action on public health was reviewed, resulting in a new strategy that was endorsed by the European Parliament and Council in a decision dated 23 September 2002 on a new programme of action in the field of public health (2003-2008).

6. Thus, since 1994, member States and Eurostat have gradually set up, in the framework of the European Statistical System (ESS), networks of partnerships to bring together expertise and efforts for the harmonized development of health statistics at both the EU and member State levels. The 10 candidate countries which will become members of the EU in 2004 have already started to join those networks.

7. The above-mentioned efforts were developed while also drawing on the expertise and experience of international organizations, such as the United Nations Statistics Division, the World Health Organization (WHO), the Organisation for Economic Cooperation and Development (OECD) and the International Labour Organization (ILO), in whose work many experts from EU member States are involved.

8. Over the years, practical working arrangements for the collection of data and statistical methodology, e.g., on classifications, have been established between Eurostat and other international organizations active in the field of health information, such as WHO and OECD.

9. The current state of the art and the increased attention given to public health require the increasing assistance of qualified and experienced statisticians in the many specific domains of health statistics; hence, an even more pressing need becomes apparent for more efficient collaboration between statistical agencies active at the international and supranational levels.

10. One instance of that need for collaboration arose with the intentions of WHO to launch the World Health Survey: the issue of the Survey was brought to the attention of the Commission at its thirty-third session, when the EU member States' heads of statistical authorities, together with Y. Franchet, Director-General of Eurostat, explicitly requested WHO to ensure careful coordination of its activities with current and planned future work of EU member States before launching a new worldwide survey on health and in any case before any formal arrangements for participation of member States were requested.

11. We have been informed that the Survey was launched during the last months of 2002 and the beginning of 2003. According to the information available through ESS, the responsible services in national statistical offices/authorities have, with rare exceptions, not been involved or consulted in the preparation phase. WHO approached the national ministries of health but did not ascertain that all responsible services within national statistical offices/authorities in the Economic Commission for Europe (ECE) region were involved, as requested by the Statistical Commission and the Conference of European Statisticians (CES) plenary and Bureau. That situation emphasizes the need to again bring the issue of international cooperation on health statistics to the attention of the Statistical Commission.

II. EU policy programmes and information needs

12. At the national level, EU member States face challenging policy and social developments that put a heavy burden on the health and social services and on the resources to finance those services. The structure of national health-care services is different in every member State. Not only are there variations in terms of levels of in-patient, out-patient and ambulatory care but also, in member States with traditional national health-care insurance, there is a tendency towards more private care and/or more limited reimbursement.

13. Basic principles that are widely accepted in society, such as the principles of equal opportunity and accessibility to social and health services, lead to demands for specific policy measures and services. The known negative impact of certain lifestyles, e.g., smoking or unhealthy eating habits, require much attention, and many health promotion campaigns have been put in place.

14. Population ageing has its implications, both in terms of more demand for care in the older segments of the population and in terms of the type of treatment and care needed. To which must be added the demand for more sophisticated and more expensive yet innovative treatments. In fact, the demand for care for elderly persons is increasing faster than the actual total number of elderly persons, while the necessary resources to respond to those increased demands are not increasing proportionally, either in monetary terms or in terms of manpower. On the contrary, in some member States there is a great shortage of qualified staff, leading to a closedown of hospital wards.

15. Developments in member States are reflected in different EU programmes, in which issues of common concern and policy are elaborated. Programmes also clarify very specific roles for member States and the EU and, whenever appropriate, the roles of national and international agencies and the research community. In the case of programmes on statistics and/or information, the roles of national statistical authorities and Eurostat are also described.

16. As mentioned above, between 1996-1997 and 2002, there were eight specific programmes of action in the field of public health, ranging from specific areas, such as rare diseases, communicable diseases, cancer and drugs, to health promotion and health monitoring. On 23 September 2002, the European Parliament and Council adopted a new public health programme, which will run for the period 2003-2008 and combines the commonly agreed health policy issues and actions in the EU into one single programme of action.

17. The programme has three general objectives:

(a) To improve information and knowledge for the development of public health;

(b) To enhance the capability of responding rapidly and in coordinated fashion to health threats;

(c) To promote health and prevent disease through addressing health determinants across all policies and activities.

18. The first and last objectives in particular make a special appeal for health statistics, and the programme explicitly refers to the statistical element of the programme to be developed, in collaboration with member States, using, as necessary, the community statistical programme to promote synergy and avoid duplication (this is included in the community statistical programme 2003-2008).

19. Appropriate arrangements will thus be made between the working parties to be established under the new public health programme and the structures under the community statistical programme.

20. One of the topics to support public health policy is the development of health indicators, which will partly be statistical indicators but may also be deduced from administrative systems and research findings. The programme will be implemented through annual programmes for financial support to networks of institutes. Several projects aim to improve statistics or fill gaps in the statistical system.

III. A system for health statistics in the EU

21. From 1994 onwards, together with experts from member States, Eurostat developed a comprehensive and durable system of health statistics. At its first meeting in early 1996, the Eurostat working group on public health statistics recommended developing further work along three lines: cause-of-death statistics, health and health-related survey data, and health-care statistics.

22. In 1997, statisticians from four member States took the initiative to create a partnership with Eurostat to support the new work based on the terms of reference agreed in the working group on public health statistics. That first experience of working through a partnership group (LEG Health) was established by the Statistical Programme Committee, to which the partnership is accountable. Each partner contributed manpower resources and the exercise was financially supported by Eurostat, with a contribution to finance participation in meetings in particular. Task forces were established for each of the three above-mentioned statistical areas — cause-of-death statistics, health and health-related survey data (to gradually also include morbidity and disability statistics), and health-care statistics — and were steered through LEG Health. Each partner, together with Eurostat, took the

responsibility for one of the task forces, and together they made the synergy for the system of health statistics as a whole. Each member State contributed by means of active participation in the work of the task forces.

23. At the start, each task force designed a framework for the domain in question, established priorities and agreed on actions to be included in the annual work programmes for approval by the working group on public health statistics. In 1998, the proposals of the task forces and the working group resulted in a framework for comprehensive and durable health statistics for the EU, which the Statistical Programme Committee approved in the same year.

24. Step-wise development of work in the task force resulted in the development of methodology, mainly through different projects financed by Eurostat or other Commission services, the implementation of the methodology through regular data collection, and analysis and dissemination.

25. Work is currently shifting from the development of the methodology towards implementation and data collection, which, together with the need to prepare for enlargement, for a revised form of partnership health, the Directors of Social Statistics, at their meeting in April 2002, endorsed to become effective in 2004.

26. The new form of partnership envisages a revised structure, whereby the different groups take different roles, from steering to development and practical implementation.

IV. Current status of health statistics in the EU

Health and health-related (interview) survey data

27. Data collection began about four years ago, after extensive inventory work on existing surveys in member States on the subjects covered by health and health-related (interview) surveys and the instruments used. At first, data were collected for 12 selected items; recently, coverage was extended to 18 items. Data on those items were collected using a common output format, with commonly agreed breakdowns by age, sex and socio-economic background variables, such as education and economic activity.

28. Work on the harmonization of instruments resulted in the application throughout the EU of a minimum European health module, which will be included in annual EU surveys, such as in the *Statistics on Income and Living Conditions*. Whenever appropriate, member States will include the module in national surveys to foster international comparability of a variety of survey results.

29. Larger modules for the harmonized measurement of health status, health determinants and background variables of persons and household should be ready in 2003. The modules are being constructed along the following lines: agreement on a common concept for use throughout the EU, with agreed, well defined items (variables) and with accompanying EU reference instruments. At the national level, EU reference instruments could then be adapted into operational instruments according to cultural specifications (e.g., calibrated when needed) and translated into the national language.

30. Apart from such input harmonization, adjustment of the results may be required according to strict rules and agreed techniques (ex-post harmonization).

Disability statistics

31. At first, extensive exploration was done of user needs, resulting in the adoption of two main lines. As a first “fast track”, ESS agreed on the minimum European health module as a minimum measurement to be used for measuring disability in general population surveys. Next, a list of topics was agreed, and further work on concepts and items and reference instruments will start in 2003, based on extensive available inventories. In the meantime, the disability variables available since 1993 in the European Community Household Panel 1994-2001 have been analysed and published, providing the first EU harmonized set of data on disability.

32. During the last decade, a multitude of population surveys, covering health, health-related topics and disability, have been conducted all over the EU, some of them subsidized by the EU. Also, new multinational surveys have been launched recently, such as the World Health Survey.

33. That proliferation of surveys will undoubtedly lead to differences in results for the same concepts, thus adding to confusion rather than solving the problem of comparability. In order to assist in building durable systems while making optimal benefit from scarce resources and expertise and with a view to achieving greater comparability and homogeneity and higher quality while avoiding overlaps and duplication of work, and also to develop instruments, the Directors of Social Statistics, at their most recent session, in September 2002, expressed a favourable opinion of the proposal for a new system, namely the European Health Survey System.

34. The European Health Survey System may be tentatively defined as a comprehensive and coordinated set of surveys, allowing inter-country comparisons, that is built around an essential core survey, according to a flexible and modular implementation, aiming to monitor potential changes in health and related subjects over time. The System is composed of three pillars:

(a) The European health interview survey, which is the core survey in the System for general statistical measurement in the framework of health statistics;

(b) A complementary set of special surveys (specific age groups, disease groups etc.), which should deal with specific user-oriented topics and which could be run by special networks of researchers and/or institutes;

(c) A database, including reference instruments and other recommended instruments, which is being established.

35. For the Survey, there is already in place the annual minimum European health module in the *Statistics on Income and Living Conditions*, and at least every five years member States should include during the same period four harmonized modules constructed around common concepts for which reference instruments are or will be available: the European background module, the European module on health status, the European module on health care and the European module on health determinants.

Morbidity statistics

36. Apart from the usual diagnosis-related data available through health services and specific networks, e.g., on communicable diseases or on cancer, no basic

framework actually exists for the generic approach and for the measurement of diagnosis-related morbidity data at the population level. Developmental work on methodology is still ongoing and will be given special attention in 2003, making use of existing work in that domain in the EU.

Cause-of-death statistics

37. The situation in the EU is characterized by national regulations on notification and by different national practices for applying the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) rules on classification and coding. Through the network of expert statisticians, substantial progress has been made in the exchange of experience to achieve better quality and comparability. The introduction of ICD-10 is spread over a period of about 10 years in the EU, hampering substantially detailed comparisons between member States. Therefore, a short list of 65 codes has been introduced, which can also be applied for data collection at the subnational level, allowing contributing to a better understanding of regional differences in mortality patterns.

38. In this domain, there is still much to be done on the introduction of automated coding systems, which in the EU is especially challenging because of the existence of so many languages, which means that the widely accepted United States system of automated coding requires substantial national investments for adaptation. The automated transfer of medical terminology used on death certificates into ICD codes is the problem. The aim is to apply the automated coding rules in all member States by 2005, while training on manual coding and data entry will take place throughout the EU under the auspices of Eurostat and its partners.

Health-care statistics

39. Statistics on hospitals and manpower, which have existed for many years, have been drastically revised and extended, e.g., with data on discharge diagnosis in hospitals. The first large-scale project was to compile meta-information on the structure and organization of national health-care systems. The differences between EU member States are substantial and might seriously hamper data comparison in this domain. The types of hospital are different and the services they provide are different. For example, some member States have several categories of specialized hospitals; out-patient services are different; and most notably, long-term care facilities differ substantially (e.g., some member States have no nursing homes).

40. In addition, the boundaries of care are different and so are financing systems. Therefore, a very detailed meta-information system has been set up to cross-classify providers with functions, which gives a basis for functional comparability and for a truly comparable system of health accounts to be compiled according to the manual on that subject established by OECD, with significant input and support from ESS, for which additional guidelines are now being developed for EU member States.

41. The first functional breakdown of the system of health accounts in the EU will be by age and gender, and preliminary first results show promising developments. A prototype of statistics on manpower has been developed and a prototype of the system of health accounts is under implementation.

V. International cooperation

42. Significant international experience has already been gathered in the field of health data and the use of health indicators, in particular by WHO and OECD. Cooperation between those organizations and the EU (Directorate General on Health and Consumer Protection and Eurostat) on health monitoring and public health statistics is fostered through their participation at the meetings of the Eurostat task forces and their attendance as observers at meetings of the working group on public health statistics; often, representatives of WHO and OECD are also invited, either as participants or as observers, to attend meetings organized in the context of actions launched under the programme on health monitoring.

43. Regular exchange of information on the statistical activities of the respective organizations is given through ECE/CES, which designated OECD as the focal point on health statistics. In addition, the exchange of letters between WHO and the EU has established a new framework for cooperation and at regular intervals information is exchanged at the meetings of WHO-EU high-level officials.

44. During its discussion on health statistics, the Statistical Programme Committee has supported preferences for such a collaboration with international agencies on the basis of either “use of common questionnaires” or “territorial division” rather than a division according to subjects, e.g., mortality, surveys or cost of health care.

45. The reasons for such a preference are formal as well as practical: mandates cannot be transferred between international or supranational organizations, and Eurostat’s comprehensive approach requires regular and appropriate data for all components. The territorial and common questionnaire models are applied successfully for several domains, e.g., statistics on agriculture, education, population or environmental site assessment. These models already include other United Nations agencies, such as the United Nations Educational, Scientific and Cultural Organization and the United Nations Statistics Division, and they could also be applied for health statistics, including reporting to WHO and possibly to other agencies.

46. A further step could be to seek practical working solutions for avoiding the duplication of efforts and creating transparency. Working relations between the organizations could be further improved according to three technical pillars:

(a) The frameworks for statistical systems in member States, including general support to member States, standards and instruments for data collection, definitions and classifications;

(b) The data collection as such, collation and possible transmission;

(c) The use of data for management, planning, analysis and publications, research etc.

47. For the first pillar, the focal international point should be where expertise can best be mobilized, e.g., ICD and the International Classification of Functioning, Disability and Health (ICF) in WHO, health expenditure classification in OECD, which should not prevent other agencies from working together with the focal point.

48. The second pillar should follow the two models mentioned above (already adopted by OECD, Eurostat and some other organizations). Possible deviations from the standards in the application should be well documented.

49. For the third pillar, every organization must be free to act according to its mandate, e.g., *World Health Reports* for WHO and *Public Health Reports* for the EU.

VI. Existing working arrangements with international organizations

50. Based on the approach suggested above, practical working arrangements already exist as described below.

Cause-of-death statistics

51. ICD, which was established by WHO, is used as the basic classification for statistics on cause of death, and a procedure for a common approach for data collection on cause of death has been worked out with WHO-Geneva and with WHO-Euro.

Disability statistics

52. At an international seminar on the measurement of disability organized by the United Nations Statistics Division from 4 to 6 June 2001 in New York and sponsored by and/or in collaboration with the United Nations Children's Fund, the United States Centers for Disease Control and Eurostat, all participants agreed that ICF, as established and endorsed by WHO in 2001, provides the necessary framework for the measurement of disability.

53. On the proposal of the seminar, the Statistical Commission created the Washington Group on Disability Measurement, in which Eurostat and its ESS partners working on disability statistics are actively participating.

Health and health-related interview survey data

54. Commonly agreed and tested reference instruments for health surveys, such as those established by WHO-Euro in its health interview survey project, are promoted by Eurostat for use in European and national surveys.

55. A first exercise for common data collection on 12 selected health items was launched in 1998; the second data collection on 18 selected health items was carried out in 2002. In both exercises, working arrangements were made with international organizations; the data collected will also be made available to OECD.

56. Through the task force on health-care statistics and the working group on public health statistics, ESS has actively supported the establishment of a manual on system of health accounts by OECD, and Eurostat is currently giving further guidance to member States for the implementation of the manual, which is actually being implemented through pilot projects.

57. In the framework of data exchange between OECD and Eurostat, it has been agreed that Eurostat will collect data on health staff and equipment directly from member States and send copies of member States' reply (original data files and documentation) to OECD.

VII. Further reflections on the improvement of international collaboration

58. Although there are good working relations between international organizations active in the field of health statistics, there is a need to explore ways to improve cooperation, mainly in order to better serve the wide range of users, who are confronted more and more with a growing and urgent need for reliable data to underpin the often far-reaching consequences of decisions and actions in the field. The main focus for better coordination is a better and more efficient sharing of work.

59. International organizations and bodies working at the global level (the United Nations Statistics Division, WHO, OECD) could focus more on the development of standards, e.g., concepts and classifications, frameworks and methodology by way of preparing “toolboxes” for data collection and analysis.

60. For their routine statistical data collection, the international organizations and bodies should only make use of secondary sources, i.e., aggregates as provided by the different countries.

61. International organizations working in specific regions in the world, e.g., WHO-Euro and the EU as a supranational organization, could concentrate more on the adaptation of the global toolboxes according to different regional situations. The regional organizations could strengthen their support for the global level with respect to toolboxes.

62. At the national level, the focus should be on the implementation of common concepts and reference instruments in the context of cultural and language differences. Countries should be the primary data collectors, and should themselves provide aggregates to the international/supranational organizations.

63. It is important to focus on the role of ESS, where agreements are made — in the context of the EU statistical programme — for the collection, processing and analysis of EU statistics in a harmonized way through Eurostat, in partnership with the member States.

64. From a global perspective, Eurostat could adopt a coordinating role in the provision of the necessary statistical data by EU member States to the international organizations.

65. Only when there is an urgent need for complementary data sets which are not embedded in the national and supranational/international statistical framework, should international organizations engage, as necessary, in direct primary data collections and/or data collections outside statistical gremia, but in such cases those initiatives should only be launched after thorough consultation with the national and supranational organizations in order to avoid duplication of work and deviating results.

66. All arrangements concerning international collaboration in the field of health statistics should be made in consultation and agreement with the competent statistical authorities in the different countries and with Eurostat within the context of ESS.

67. On many occasions, there is insufficient consultation with national statistical authorities. The international organizations should take the initiative themselves to

ensure that appropriate arrangements are made with the national statistical authorities responsible for health and social statistics.

68. If such arrangements are not respected and data collections are launched on similar topics by international organizations, there is a serious risk of inconsistency between various data sets. In such situations, in order not to endanger the credibility of other surveys, in particular large national health interview surveys, the data obtained should at first be thoroughly evaluated by a group of high-level experts on population surveys and statistical methodology, which should be jointly organized by the cooperating national authorities and supranational and international organizations before any dissemination of results.

69. Such cooperation could be set out in a charter (code of conduct) to be agreed and established by the Statistical Commission, the specialized international agencies (i.e., WHO), suprainternational organizations (i.e., the EU/Eurostat) and the competent statistical authorities of member States.
