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Efforts towards improved coordination of data collection at the international level

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A. Introduction

1. The World Health Organization (WHO) is constitutionally mandated to establish and maintain statistical services and to provide information in the field of health. A detailed report of the activities undertaken by WHO in relation to the health statistics is reported each year to the United Nations Statistical Commission and the most recent one is available at <http://unstats.un.org/unsd/statcom/sc2003.htm>

2. This paper summarizes the work undertaken by the Epidemiology and Burden of Disease Team in relation to the collection of cause-of-death statistics by the World Health Organization. These statistics have been regularly shared with the United Nations Statistical Division and disseminated in the *Demographic Yearbook*.

B. Collection of cause-of-death statistics

3. In accordance with its mandate, WHO interacts with its Member States on different types of health statistics on an almost daily basis. The Epidemiology and Burden of Disease team is responsible for contacting the Organization's 192 Member States to obtain the latest cause-of-death data from their vital registration sources. In the absence of a complete and accurate vital registration system, countries are requested to submit data from other reliable sources as well.

4. In order to standardize data reporting, WHO has developed a set of electronic file specifications and record layouts for reporting mortality and population data. Comparability of cause-of-death data has been made possible worldwide through the development and revisions of the International Statistical Classification of Diseases and Related Health Problems (ICD). The Tenth Revision of the ICD (ICD-10) was adopted in 1990 by the World Health Assembly and came into effect as from 1995 at the country level. Out of the total of 115 Member States currently reporting data to WHO, there are 71 Member States reporting data using ICD-10. There are still about 40 countries reporting data using ICD-9.

5. The World Health Organization has six Regional Offices in the world covering the African, American, Eastern Mediterranean, European, South-East Asia and Western Pacific regions. In order to facilitate and coordinate the data collection at the country level, there is an agreement between WHO Headquarters and three of our Regional Offices.

6. Data collection responsibility for the WHO European Region consisting of 52 Member States is shared between Headquarters (WHO-HQ) and our Regional Office for Europe (WHO-EURO) in Copenhagen. WHO-EURO regularly contacts all the countries of Central and Eastern Europe and a few other countries to obtain their latest cause-of-death data. WHO-HQ is responsible for the collection of data from the remaining countries of Europe. WHO-EURO collaborates with WHO-HQ for contacting countries to resolve data inconsistencies and improve reporting.

7. With regard to the countries in the Americas, the WHO Regional Office for the Americas (WHO-AMRO) takes the entire responsibility for collecting the data for all the 35 Member

States in the region. It also ensures the validation of the data and undertakes regular consultation with the countries to resolve inconsistencies and improve reporting.

8. The WHO Regional Office for the Eastern Mediterranean (WHO-EMRO) coordinates with HQ in collecting data from the 21 Member States in their region.

9. As for the other three remaining WHO Regions (African, South-East Asia and Western Pacific), WHO-HQ collects the data directly from the countries. Data from the African Region is virtually non-existent and account for the major difficulties in assessing the level of mortality in that area.

10. Data received through WHO Regional Offices are shared with WHO Headquarters and vice versa. Those data submitted by Member States become part of WHO's unique historical data base on causes of death (WHO Mortality Database) which contains data as far back as 1950. The WHO Mortality Data base contains 3649 countries-years of data with a total of over 2 million records. Computerization of data at country level and electronic transmissions to WHO have considerably improved the timeliness of the information received.

11. The Statistical Office of the European Commission (Eurostat) collects data on causes of death disaggregated into several administrative levels from its Member States. Since 2002 it has extended its collection of cause-of-death data to the Central and Eastern European. WHO-EURO has collaborated with Eurostat in the collection of these data. This collaboration ensures that there is one focal point in each country and that the same data sets are being sent to both organizations. In order to facilitate reporting, the electronic file specifications used by Member States to send data to WHO-EURO and Eurostat are fully compatible. The considerable experience of our Regional Office in the collection of data from those countries has made this collaboration very fruitful.

12. WHO-EURO is currently collaborating with Eurostat in the design of a questionnaire on the reporting of hospital data.

C. Dissemination of cause-of-death statistics

13. The World Health Organization started the dissemination of cause of death statistics in 1948 in its publication entitled Annual Epidemiological and Vital Statistics. The 1962 and subsequent editions were renamed as the World Health Statistics Annual. The 1996 edition was the last to appear in printed form and was until then a priced item. With the advent of new technology, mortality statistics reported by Member States have been made available on the WHO Web site in an aggregated form since July 2000 with a user-friendly interface.¹ The entire mortality database containing all historical data since 1950 is made available free on the web site for outside users.² An estimated 25,000 users access the database in a month. Data from the WHO Mortality Data base are incorporated by the Organization for Economic Co-operation and Development (OECD) in their annual CD-ROM "OECD Health Data". International

¹ <http://www3.who.int/whosis/menu.cfm?path=whosis,whsa&language=english>

² http://www3.who.int/whosis/mort/text/download.cfm?path=whosis,whsa,mort_download&language=english

organizations, scientists, research and academic institutions, private companies and university students use the WHO Mortality Database as valuable inputs to their work.

D. Collaboration and agreement with the Demographic Yearbook group

14. The World Health Organization provides the cause-of-death statistics to the United Nations Statistics Division for publication in the *Demographic Yearbook* on a yearly basis. Those statistics have been published in the *Demographic Yearbook* since its 1951 edition and are generally presented according to an aggregated list of causes with the number of deaths and death rates.

15. In the past, WHO also provided relevant information such as completeness of the data to the *Demographic Yearbook* team to guide the user in the comprehensive use of the data. However, such information has not been provided for recent years on a regular basis alongside with the mortality data sets to the *Demographic Yearbook* team.

16. In the past, following an established agreement, at the completion of each issue of the *Demographic Yearbook*, the United Nations Statistical Division sent a number of series of demographic statistics on tape to WHO. However, in recent years demographic statistics were only sent to WHO on CD-ROM following ad-hoc requests.

17. Last year, the Epidemiology and Burden of Disease Team and staff responsible for the International Classification of Diseases met with the newly appointed editor of the United Nations *Demographic Yearbook* on his visit to Geneva. This meeting helped to establish an improved working relationship and clarify some fundamental issues related to the exchange and provision of mortality data.

E. Proposals for improving collaboration with the Demographic Yearbook team

18. Collaboration with the *Demographic Yearbook* team has long been an established procedure. It has worked satisfactorily though there are still issues that need to be improved.

19. Although for bureaucratic reasons it is necessary for the United Nations Statistics Division to follow some established procedures when contacting WHO, it is important that all requests related to data should be copied to the Epidemiology and Burden of Disease Team (EBD), the technical team responsible for cause-of-death data. As the EBD time schedule for producing the annual World Health Report analyses is very heavy, it is essential that requests for data should be made well ahead of time. EBD also has to respond to requests from a wide variety of other organizations.

20. The Epidemiology and Burden of Disease Team is in a position to provide guidance on the most appropriate aggregated list of diseases to the United Nations Statistics Division for use in data presentation. It should also provide information systematically on the completeness, coverage and quality of coding to help in the interpretation of the data.

21. Since WHO is also interested in data quality and collection characteristics for mortality information provided by Member States, it would be useful to collaborate with the United Nations Statistics Division in the questionnaire on vital statistics. WHO and the United Nations Statistics Division should set up mechanisms whereby questions related to deaths and causes of death data could be harmonized and meet the information needs of both organizations.