

C. THE MEASUREMENT OF HEALTH STATUS

Samir Farid spoke about the use of surveys to gather information on health status in developing countries. He noted that health indicators were necessary, among other things, to assess performance in the attainment of goals set by the Health for All Programme of the World Health Organization (WHO). However, many of the countries which had to make significant strides in improving the health status of their populations were precisely those lacking adequate sources of information on health. To fill that gap, some countries were using surveys to measure a variety of health indicators. There were, however, no established guidelines for the design and implementation of health surveys in developing countries and practices could vary widely from one survey programme to another. If cross-country comparability was to be attained and if comparability was to be maintained over time within countries it was important to establish internationally validated guidelines for the design and implementation of such surveys as well as standard concepts and procedures for the measurement of health status using survey data. Ideally, an international effort in that regard would produce model questionnaires containing modules addressing specific priority areas, such as the prevalence of morbidity or long-term disability or the utilization of health services. In addition, guidelines were needed about sampling design, the training of interviewers, the adaptation of questionnaires to specific contexts, and the effects that seasonality might have on survey results.

Farid noted that over the past ten years three survey programmes had conducted comparable surveys in countries of Northern Africa and Western Asia: the Gulf Child Health Survey Programme (1987-1989); the Pan Arab Project for Child Development (PAPCHILD, 1989-1996); and the Gulf Family Health Survey (GFHS, started in 1995). A more ambitious health survey programme was being developed under the title Pan Arab Project for Family Health (PAPFAM). The first two had focused mostly on children, but the GFHS had gathered information on the health status of persons of

all ages. It included four questionnaires recording: (a) the health status of household members; (b) the socio-economic status and environmental conditions of the household; (c) the reproductive health of all women aged 15 to 49; and (d) the health status of all children under age 5. Model questionnaires had been developed for each of these purposes and the experience gained in their use would be helpful in improving their design and effectiveness.

The first questionnaire, focusing on health status, was meant to be answered by the head of household who provided information about the health of each household member. The questionnaire included a module on chronic conditions, including high blood pressure, heart disease, asthma, diabetes, ulcers, kidney disease, liver disease, stroke, epilepsy and mental problems. For each individual who was reported as having one of those conditions, it was ascertained whether a medical doctor had diagnosed the condition, the age at diagnosis, and the current use of medication. Another part of the questionnaire recorded current morbidity by inquiring about perceived health status, and illness or injury during the two weeks preceding interview. Those reporting illness or injury were asked about the utilization of health services, the use of medication and the duration of the illness. The health status questionnaire also included questions on the survivorship of close relatives to permit the derivation of indirect estimates of mortality levels. The information recorded permitted the calculation of a wide array of health indicators, some of which were presented for the Gulf countries. Farid also presented in some detail the information on reproductive health for Gulf countries obtained from the third questionnaire used in the GFHS.

Jennifer Madans provided an overview of the official sources of information on health status and morbidity in the United States. Although the National Center for Health Statistics (NCHS) was described as the principal and official agency producing, analysing and disseminating health statistics in the United States, health information was also collected by other departments of the Federal Government and by the research community.

The main role of NCHS was to provide consistent time series data that fulfilled multiple purposes and could serve as basis for both demographic and epidemiological applications. A key use of NCHS data was the monitoring of trends. All data systems managed by NCHS tried to cover different aspects of four health dimensions: (a) health status; (b) the use of health services; (c) environment and behaviour; and (d) insurance coverage and use. In relation to health status, several dimensions were of potential interest, including physical and mental health status *per se*; functional ability and disability; biological and physiological attributes; and genetic make-up and risk factors. Not all were covered as yet by the data collection systems of NCHS.

Madans reported that NCHS operated four major data collection systems. The first was the National Vital Statistics System that produced data on births, deaths and foetal deaths for the whole country. NCHS compiled the data gathered at the state or county levels, where the basic data were collected according to state or county rules. The data had achieved complete coverage but were not free from error. A problem faced in deriving rates was the lack of consistency between numerators obtained from the Vital Statistics System and the denominators obtained from census data, especially in the case of ethnic minorities.

The second system operated by NCHS was the National Health Care Survey, an integrated family of seven record-based surveys that was used to monitor the utilization and content of medical care in the United States. The surveys collected data on the characteristics of providers and patients, as well as on services provided, diagnoses, payment sources and outcomes. The data gathered were used to enhance and expand measures of the prevalence of disease. Madans noted that there were two other sources of the incidence of disease that were not operated by NCHS: the cancer registers maintained by the National Cancer Institute and the reporting system of specific conditions operated by the Centers for Disease Control (CDC). The cancer registers were not representative of the whole population. The CDC system focused on rare

conditions and its completeness depended on physicians abiding by the reporting rules established by the Department of Health and Human Services.

NCHS also operated two major population-based surveys: the National Health Interview Survey (NHIS), which was the principal source of information on the health of the non-institutionalized population in the United States, and the National Health and Nutrition Examination Survey (NHANES) which gathered information on the health status of the population by conducting standardized medical examinations as well as blood and urine tests. Together these surveys produced a good picture of the health status of the population of the United States.

The NHIS had been conducted annually since 1957 and every year it gathered information from some 40,000 households covering about 100,000 persons. African-Americans and Hispanics were oversampled. Until 1996 the approach used to determine health status was based on a subject's self-assessment of health status; information on the prevalence of selected conditions, including heart disease, diabetes, cancer, pulmonary diseases, depression and arthritis; and information on limitation of activity, that is, the subject's ability to perform age and sex appropriate roles and activities of daily living. Focusing on the limitation of activity because of ill health was thought to provide a more "objective" indication of health status than a self-assessment of that status. Such an approach was appropriate as long as ill health was primarily the result of acute conditions where the onset was clear and there was a direct association between the conditions and behaviour. However, as a result of the epidemiological transition, acute conditions were being replaced by chronic conditions. Given the greater difficulty in diagnosing chronic conditions, longer periods were being spent in the disease state both prior and after diagnosis, making the traditional approach used by NHIS problematic. For that reason, in 1996, investigation of the prevalence of chronic conditions changed: respondents were asked first if they had ever been diagnosed with a condition or if they had symptoms

associated with specific conditions and, if they had, follow-up questions were asked about the date of onset, use of medical services and medications. Since data on functioning were still gathered as before, the availability of more complete information on chronic conditions could potentially allow a better assessment of the interrelations between the social and biological aspects of health. Madans thus underscored that health status was much more than the causes and progression of disease; social, cultural and economic characteristics conditioned the perception of symptoms, the adoption of health-related behaviours, and the use of health care, and thus determined self-perceived health status. Surveys such as the NHIS were considered the best suited tools to obtain information about both the social and the biological aspects of health status.

In comparison to the NHIS, the NHANES focused on the biological aspects of disease by incorporating standardized physical and medical examinations, laboratory tests, nutritional assessments and an in-depth questionnaire. The NHANES was described as costly and demanding. It required the use of mobile testing units, covered 5,000 persons annually and took 6 years to be completed. It was useful for the study of trends in the prevalence, treatment and control of selected diseases; for the investigation of risk factors associated with selected diseases; for the analysis of trends in risk factors; and for the study of the relation between diet, nutrition and health.

To enhance the usefulness of the data sources it operated, NCHS had been engaged in creating linkages between different data sets and exploiting the potential for longitudinal coverage. For instance, the results of cross-sectional surveys were being linked with mortality records to obtain some sort of "longitudinal" coverage. Similarly, sub-samples of the populations covered by certain surveys were being traced and re-interviewed. Lastly, attempts were being made to carry out "statistical matching" of persons covered by the NCHS surveys and those covered by Census Bureau surveys or censuses, so that more detailed socio-economic characteristics

could be studied in relation to health. However, the protection of confidentiality was hindering the use of such matching.

The discussion focused on a number of ethical issues related to the investigation of health status. When surveys involving medical examinations were carried out, the question of what to do if a serious condition was discovered was raised. In the case of the NHANES, written guidelines existed. Interviewers were instructed to contact the persons tested and to refer them to appropriate health care providers if certain conditions were detected, but not all conditions were disclosed to the persons tested. NCHS was considering the possible use of genetic testing as part of the health surveys it conducted but discussions were going on regarding the ethical issues involved and the need to ensure informed consent. Because such testing, if done, would cover nationally representative samples, it was not expected to yield useful results regarding rare gene mutations. Instead, it would provide information about the relative frequency of commonly occurring polymorphisms, some of which were already known to have specific implications for health prospects. The issue of whether to inform the individuals tested about the results of genetic testing was far from resolved.

It was noted that, although the population-based surveys of NCHS had large sample sizes, they were insufficient to cover certain minorities in the United States, such as American Indians or the populations of Asian origin. NCHS considered that over-sampling such populations would be too costly. A possible alternative and more cost-effective approach could be the use of regional surveys that took advantage of the fact that such minorities tended to be concentrated in certain geographical areas.

Regarding the use of surveys to measure health status in developing countries, questions were raised about the accuracy of information provided by the head of household on the health status of other members of the household. It was also noted that, in the Gulf countries, most

nationals had access to medical care so that questions focusing on medical diagnoses and utilization of health services were appropriate. However, in countries lacking similar health services, there were doubts that such questions would yield usable information.