## **European Data Watch**

This section will offer descriptions as well as discussions of data sources that may be of interest to social scientists engaged in empirical research or teaching courses that include empirical investigations performed by students. The purpose is to describe the information in the data source, to give examples of questions tackled with the data and to tell how to access the data for research and teaching. We will start with data from German speaking countries that allow international comparative research. While most of the data will be at the micro level (individuals, households, or firms), more aggregate data and meta data (for regions, industries, or nations) will be included, too. Suggestions for data sources to be described in future columns (or comments on past columns) should be send to: Joachim Wagner, University of Lueneburg, Institute of Economics, Campus 4.210, 21332 Lueneburg, Germany, or e-mailed to (wagner@uni-lueneburg.de).

## Health Data in Germany

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### 1. Preliminary note

Adults mention health as the most important human request for the well-being (e.g. Habich, 1999, 2). On the average 2,900 euro are spent annually in Germany per capita of the population on the preservation and the restoration of health. In the year 2003 this were altogether approximately 240 billion euro respectively 11.3 % of the gross domestic product.<sup>1</sup>

In Germany the available data on the state of health of the population and its health care are collected in mostly different forms particularly for the information demand of single institutions. This is assignable to the historical grown structure of the health care sector and the distributed responsibilities of the actors in the health care sector. The health care sector takes a high

<sup>&</sup>lt;sup>1</sup> See Federal Statistical Office, Health Expenditure Accounts, www.gbe-bund.de, keyword health expenditure 2003.

value in the political discussion. Despite of this, there are gaps in the available data and analyses measured by the information demand as well as the international comparison. With which contents the health term is filled, depends quite substantially on the respective interest situation of the data producer respectively the data user. The following representation is prior thematically aligned. The data of commercial, private-economical providers remain unconsidered.

#### 2. Data according to partitions of the health care sector

For the description of the health situation two regular total data collections are essentially available in Germany: mortality data from the cause of death statistics<sup>2</sup> as well as diagnostic data of the hospital patients from the hospital statistics<sup>3</sup> of the Federal Statistical Office and the statistical offices of the Länder. At the beginning of July 2005, results on the diagnoses of the patients discharged from prevention/rehabilitation facilities with more than 100 beds have been published for the first time by the Federal Statistical Office.<sup>4</sup> From these data, indications can be extracted, by which preventive and curative-medical measures for example the life expectancy and the quality of life of the population can be increased. A comprehensive evaluation of the state of health of the population respectively the occurrence of illness is, however, not possible on basis of these data. Data on incidence and prevalence are available only for quite few diseases (e.g. AIDS, cancer and notifiable infectious diseases). And/or they are regionally defined data sources (e.g. stroke and cardiac infarction).

The extent and development of the number of deaths as well as the structure of the causes of death are still considered as important indicator but are no longer sufficient to describe the health situation of advanced industrial nations. For this, the disease spectrum but also the awareness of health of certain population parts changed too much. The description of the quality of life, the subjective state of health, the health behaviour and the health risks as well as the social and economic consequences of illness and disability are becoming more and more important. The life expectancy is supplemented by a healthy respectively handicap-free life expectancy. In particular to the quality of life and to the social consequences of illness systematic and periodically repeated surveys are missing.

<sup>&</sup>lt;sup>2</sup> See Fachserie 12 "Gesundheitswesen", Reihe 4 "Todesursachen in Deutschland" (www-ec.destatis.de).

<sup>&</sup>lt;sup>3</sup> See Fachserie 12 "Gesundheitswesen", Reihe 6.2.1 "Diagnosen der Krankenhauspatienten" (www-ec.destatis.de).

<sup>&</sup>lt;sup>4</sup> See Fachserie 12 "Gesundheitswesen", Reihe 6.2.2 "Diagnosen der Patienten und Patientinnen in Vorsorge- oder Rehabilitationseinrichtungen" (www-ec.destatis.de).

Statements on the frequency and distribution of diseases in the population are normally possible by primary collections (surveys) only. In contrast the discussed morbidity can be analysed on the basis of anonymised process data. This is reflected, for example, in the settlement data of the sources of funding. Here there is i.e. the ADT-panel (patient-physician-panel) of the Central Research Institute of Ambulatory Health Care in Germany as generally accessible sources. It covers the most frequent diagnoses in practices of general practitioners. The Central Institute also disposes of data for the acceptance of the legal early detection examinations of cancer and health examination. Results from insuring samples, for example, of the Association of Panel Doctors of Hesse/General Local Health Insurance Fund of Hesse are only reduced and against payment accessible. All in all it lacks of data on the health situation and the occurrence of illness which is service-independent and representative and can be extrapolated for the population. With health surveys of the Robert Koch Institute this lack will be met with.

Substantial economic consequences of diseases such as disability to work, frequency of ambulatory and stationary treatment and inability can in contrast be derived from the statistics of the social security institutions. For example: statistics of types of diseases on insured persons of the Local Health Insurance Funds and statistics of the pension admissions of the Association of German Annuity Insurance Institutions (VDR).

As resources of the health care all providers in the health care sector, the employees working in these providers as well as the used appliances are to be counted. Thereby, the type and number of resources, their application and the appropriate supplying structures stand in the centre of consideration. The human resources are of great importance in the service industry "health care sector". With the health personnel accounts of the Federal Statistical Office differentiated data on the number and structure of persons employed in the health care sector are available. They are differentiated according to age, sex, occupation and provider.

The representation of the services in the health care sector usually happens quantity-related: number of the physician contacts, prescriptions, hospital cases, hospital days. A conclusion on the number of treated persons is due to potential multiple utilisations of the same person on the basis of these data not possible. The hospital statistics delivers important information on the structure of the stationary care in the hospitals and preventive care or rehabilitation facilities and the services rendered by them. Structure and service data of the hospitals, which settle according to Diagnoses Related Groups – DRG, are published by the Institute for the Remuneration System in Hospitals (InEK) starting from the reporting year 2003.

Comprehensive and differentiated information on expenditure, costs and financing of the health care sector is available with the health-related account-

ing systems of the Federal Statistical Office on the health expenditure and costs of disease.<sup>5</sup> By the classification of the costs of illness according to age, gender and providers, the costs can be analysed before their demographic, epidemiological and provider-specific background. The data are systematic connected for the purposes of the accounting systems and close matched as regards contents. Thus the evaluation and analysis possibilities on financial aspects of the health care sector have improved substantially.

Altogether it is to be stated that one does not have to generally complain about a lack of information on health. So far, however, not yet all possibilities of an intensive data use are exhausted, which could be realised without additional stress of the respondents. An example is a further systematic consolidation of existing data. The synthesis of process and questioning data should here also be taken into consideration. Recurring data requests could be more strongly standardised, in order to reduce the effort with the respondents. In this context the regulations in the second so called "Fallpauschalenänderungsgesetz" (law for changing case flat rates) from 15 December 2004 on the supply of structure and service data are to be judged as a positive development (see future prospects). Most official health statistics furthermore contain no social criteria and thus no information on the internationally recommended minimum characteristics education, position in the occupation and income. Expert groups therefore also demand a substantially closer integration of health and social reporting (e.g. Bardehle, 2001, A1107 ff./C883 ff.). The coherences between socio-economic status and health currently form one of the focuses of the consideration in the expertise 2005 of the German Advisory Council on the Assessment of Developments in the Health Care System.<sup>6</sup> In addition, certain health-related data stocks are not accessible for the public or only against payment.

The health-related data landscape is also subject to a constant change. Various efforts and initiatives of the federation and the Länder, like the setup of systems of the health monitoring system and public health portals contribute to the disposal of more and better information for the citizen, patients and physicians. They are flanked by initiatives on European and international level.

<sup>&</sup>lt;sup>5</sup> See footer 2 and Federal Statistical Office, Costs-of-Illness Accounts, www.gbe-bund.de, keyword costs of illness 2002.

<sup>&</sup>lt;sup>6</sup> Sachverständigenrat zur Begutachtung der Entwicklung im Gesundheitswesen "Koordination und Qualität im Gesundheitswesen, Gutachten 2005", S. 35 (http://www.svr-gesundheit.de/Gutachten/Gutacht05/Langfassung2.pdf as of 4 August 2005).

### 3. Specific data offers

#### 3.1. The Federal Health Monitoring

The Federal Health Monitoring (FHM) contributes with its information system www.gbe-bund.de quite considerably to the improvement of the on-line offer of data concerning the health care sector. So far, approximately 115 health-related data sources for the purposes of the FHM could be made available. From these sources approximately 825 million data and a multitude of data calculated out of them are presently displayed in the information system of the FHM. They are made accessible for the public free of charge. The data are predominantly represented in flexibly shapeable tables. Thereby various enquiry and analysis possibilities are offered to the system user. The data in the tables are supplemented by texts and illustrations, a glossary and selected background information such as methodologies, variables, definitions and contact persons.

The data offer of the information system was primarily aligned to the federal level. But also regionally differentiated data are made available. With the integration of selected indicators of the Länder-indicator set into the information system of the FHM, a direct reference to the Health Monitoring System of the Länder has been created. Further links lead the user to selected data of the Organization for Economic Co-operation and Development (OECD) or the World Health Organization (WHO).

#### 3.2. Medical registers and databases

Medical registers represent an important source of realisation to epidemiological questions, for quality assurance and for the practice of the therapeutic care. The following details are limited to a selection of registers with statistical information.<sup>7</sup>

The cancer registers rank among the most well-known medical registers in Germany. In most of the Länder they are equipped with predominantly areawide registration and constantly increasing integrity. The Federal Cancer Reporting Unit at the Robert Koch Institute evaluates the data of the population-related cancer registers in Germany recapitulating and spanning. On national level so far the new cases of cancer can however only be evaluated. The data are available in the Internet in a data base, which can be served interactively (www.rki.de) (see Schön, 2004, 429 ff.). A special register represents the German Childhood Cancer Registry Mainz at the Institute of Medical Biostatis-

<sup>&</sup>lt;sup>7</sup> On this, see also Bundesgesundheitsblatt – Gesundheitsforschung – Gesundheitsschutz, "Medizinische Register und Datenbanken", 47 (5), 2004 as well as "Medizinische Register und Datenbanken, Teil 2", 47 (6), 2004.

tics, Epidemiology and Informatics of the University Mainz. The speciality lies in the fact that it also covers numerous clinical information (www.kinderkrebsregister.de) (see Kaatsch, 2004, 437 ff.).

The *Bremen Mortality Index* is a data base, in which the complete contents of all certificates of death of persons is comprehended, who deceased after 31 December 1997 and had their first domicile in the federal state of Bremen (http://www.krebsregister.bremen.de/mortalitaetsindex.html) (see Gierspiepen, 2004, 451 ff.).

The Federal Central Office for Health Education accomplishes nationwide surveys on selected topic fields such as health promotion of socially disadvantaged persons, prevention of child accidents, movement promotion in the kindergarten (www.bzga.de) (see Meyer-Nürnberger, 2004, 464 ff.).

#### 3.3. Thematically specialised surveys

The National Health Survey 1998 of the Robert Koch Institute (RKI) is the first all-German survey. The core of the health survey could be supplemented by the modules on i. e. pharmaceuticals, nutrition and mental-health problems. The RKI supplements the analysis and questioning surveys by Telephone Health Surveys. The data are available as Public Use files (http://www.rki.de/→Gesundheitsberichterstattung und Epidemiologie→Datenerhebungen→Gesundheitssurveys).

The German Health Survey for Children and Adolescents of the RKI is a nationwide representative, comprehensive analysis on the health situation, on the spreading of diseases, health-affecting behaviour patterns and environmental strains of the population under 18 years. After the ending of the collection these data are also to be made available as Public Use File for further analysis (www.kiggs.de).

#### 3.4. Regular multi-topic questionings with questioning part of health

In the *Microcensus* of the Federal Statistical Office and the statistical offices of the Länder every four years an auxiliary questioning on health is conducted with questions on illness and accident injury, smoke behaviour as well as body size and weight (www.gbe-bund.de, keywords state of health, smoking, body measures).

The analysis of health-scientific questions is also possible on the database of the *Socio-Economic Panel* of the German Institute for Economic Research (DIW; www.diw.de).

The Welfare Survey of the Social Science Research Center Berlin (WZB) and the Centre for Survey Research and Methodology (ZUMA) is a represen-

tative questioning, which was conceived particularly for the measuring of the individual welfare and quality of life in different spheres as for example health (http://www.wz-berlin.de/ars/usi/projekte/wohlfahrtssurvey\_ ausfuehrlich.de.html).

In the spring 2005 the Federal Statistical Office has set work on the collection of the data for the *EU-statistics on income and living conditions* (EU-SILC). It also comprises health-related variables. These refer to the state of health, chronic diseases or ailments and the access to health care. On first results from the EU-SILC is to be counted in spring 2006.

## 3.5. Federal facilities with medical and health-related specialised information

There is a set of federal facilities such as the Federal Ministry of Health and Social Security (www.bmgs.bund.de), the Federal Institute for Drugs and Medical Devices (www.bfarm.de), the Federal Institute for Risk Assessment (www. bgvv.de), the Federal Centre for Health Education (www.bzga.de), the German Institute of Medical Documentation and Information (www.dimdi.de), the Paul-Ehrlich-Institute (www.pei.de) and the Robert Koch Institute (www.rki.de) with own medical offers in the Internet.

# 4. Data in the regional, European and international comparison

For the health data of the official statistics regional data are available at least on the level of the Länder. Most of the Federal Länder have begun to collect data for the state-specific health monitoring system. In the last years Eurostat, the Statistic Office of the European Community (http://europa.eu.int/comm/eurostat/newcronos) and international organisations like the OECD (http://www.oecd.org/statsportal) and the WHO (www.euro.who.int/HFADB) intensify their efforts in the direction of a cross national, methodically better comparable data supply. The activities for the further development of the statistical aspect of the health information are continued in the context of the European Statistical System.

<sup>&</sup>lt;sup>8</sup> The Internet adress for the state-specific health monitoring offers are compiled under www.gbe-bund.de, Themen Gesundheitsberichterstattung, Gesundheitsberichterstattung der Länder.

#### 5. Future prospects

With the regulations to data transparency in the "Gesundheitsmodernisierungsgesetz" (GMG, law for modernisation of the statutory health insurance) from November 14, 2003<sup>9</sup>, the data situation concerning the events of services and the possibilities of the data use are to be improved. By the GMG, not only health insurance funds will routinely dispose of comprehensive personal or member-related data of their insurants. In the future they will also be provided with diagnoses to settle medical services. Furthermore, the research with health insurance company data will gain in importance in the future.

By the regulations in the second "Fallpauschalenänderungsgesetz" (law for changing case flat rates) of 15 December 2004<sup>10</sup>, selected structure and service data according to paragraph 21 Krankenhausentgeltgesetz (law for hospital pay) are conveyed from the Institute for the Remuneration System in Hospitals (InEK) to the Federal Statistical Office for the purposes of the hospital statistics. The aim is providing an official DRG-statistics. The Federal Statistical Office counts on first results at the end of the year 2006.

For the Federal Statistical Office, the extension of the offer of Scientific Use Files locates the centre of the development of the file access ways. The statistics of diagnoses of the hospital patients was selected primarily from the health statistics for adaptation. Accordingly, two factually depersonalised data records (to the patient and to the hospital) are intended. Both satisfy interests of research independently. The Scientific Use files will be available at the beginning of the year 2006.

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<sup>&</sup>lt;sup>9</sup> BGBl. I S. 2190.

<sup>&</sup>lt;sup>10</sup> Zweites Gesetz zur Änderung der Vorschriften zum diagnose-orientierten Fall-pauschalensystem für Krankenhäuser und zur Änderung anderer Vorschriften (Zweites Fallpauschalenänderungsgesetz – 2. FPÄndG) vom 15. Dezember 2004 (BGBl. I S. 3429).

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