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(including Clinical Studies)

Bertram Häussler and Elke Hempel

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Contact: Council for Social and Economic Data (RatSWD) | Mohrenstraße 58 | 10117 Berlin | office@ratswd.de

Health

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Bertram Häussler and Elke Hempel

IGES Institut GmbH (kontakt[at]iges.de)

Abstract

Politics, science, research and the public base their discussions on comprehensive, valid and systematic health care data. Data based information is needed in order to measure the results or success of a policy of procedure. In Germany, the Information System of the Federal Health Monitoring (IS-GBE) comprises of a comprehensive health system data collection. Currently, the information system contains health data and information from over a 100 different sources, for instance surveys done by the statistical offices of the federation or the Länder, as well as many other surveys done within the health care system.

Apart from the IS-GBE additional official and non-official health care data sources exist in Germany. Within this expertise changes made from 2001 on to existing health data sources as well as newly established data sources are presented. Data sources dealt with in other expertise are not considered.

The up until now one time insuree sample collected in 2001 was, for example, collected in the course of the reform of the risk structure adjustment within the statutory health insurance is one of the more recent samples. From our point of view we highly recommend an update of this representative sample.

Keywords: Information System of the Federal Health Monitoring (IS-FHM), Microcensus, Inpatient Diagnosis Data, Hospital statistics by Diagnosis Related Groups (DRG Statistics), Cancer Registries, Kidney Replacement Therapy Statistics (QuaSi Niere), External Comparative Quality Assurance of the In-patient Sector (BQS), Structured Reports on Quality (SQB), Compulsory Health Insurance (CHI) Claims Data: Insuree Sample, GEK Claims Data

These data sources give information on:

- General framework of the health care system
- Health situation
- Health behaviour and health hazards
- Health problems and diseases
- Health care measures
- Health expenses, costs and health care funding

1. Introduction

A comprehensive data base is a prerequisite for political decision making, as well as for the establishment and evaluation of the effects of health care policy measures. Data based information are needed for the performance review of the implemented measures and support the development and evaluation of goal attainment in health care. Only by providing adequate data, it is possible to create transparency on the present state of affairs, on the possible need for action and on the deficits. Already at an early stage there was consent that in the field of health care comprehensive, valid and systematic data infrastructure was needed in order to use for the discussion of health care issues in politics, science and research as well as public. Within the framework of a perennial research project established in the nineties, concepts of the Federal Health Monitoring (FHM) were developed. At the beginning of 1999, this project was conveyed from the research phase into the routine use. Since then a permanent, standardized report scheme is available for easy and free access to official and in particular non-official data sources: The Information System of the Federal Health Monitoring (IS-FHM). Today, with the help of the IS-FHM a broad overview of the German health care system is possible. There is information on the health situation and the health care measures provided to the German population, the topics are chosen in a way that all areas of the health care system are covered:

- General framework of the health care system
- Health situation
- Health behaviour and health hazards
- Health problems and diseases
- Health care measures
- Health expenses, costs and health care funding

To portray the high dynamics of the health care system, the provided health data and information are updated on a regular basis and continuously enhanced, in accordance with the data holders and users.

Politically responsible for the IS-FHM is the Federal Ministry of Health. The Robert-Koch-Institute (RKI) is in charge for the scientific management whereas the Federal Statistical Office is in charge for the operation of the information and documentation centre "health data". Data and information from about one hundred different sources are held centrally, among those are collections of the Statistical Offices of the states (“Länder”) and the federation, but also those of numerous other institutions in the health sector. The IS-FHM also refers to health related information sources run by OECD and the WHO, where data from Germany are included. IS-FHM can be accessed online (www.gbe-bund.de) without charge. It provides a multitude of significant parameters, individually designed charts, texts, figures or publications. Besides the data itself, one can find documentation on the data sources, their census criteria, about the methodology and contact persons. Information is completed by the consecutively RKI published booklets on specific topics of health reporting. Among standard themes like demographical and epidemiological issues there are various topics relating to current health care problems like nursing. Up to now this service is for free, except the specific report on allergies. The booklets, mainfocus reports as well as the currently available report „Health in Germany“ from 2006 are easily accessible via the IS-FHM.

The statements of the FHM apply to the national, federal level. They are a reference for the health reporting of the Länder. Moreover by now, chosen indicators for the health reporting of the Länder, can be accessed over the IS-FHM.

The basis for the Länder health reporting is the third revised version of the indicator set for the health reporting of the Länder, which was enacted by the working committee of the highest public health authorities (AOLG) in the year 2003.

All indicators follow the systematics of core, federal, and Länder indicators. Federal and core indicators are adjusted to the IS-FHM, to the indicator sets of the WHO, OECD and the EU. Answers on methodological key questions are found in coordination with the RKI, the Federal Statistical Office, Eurostat and the WHO.

1.1 The developement since 2001

Besides the official and non-official data sets which are accessible by the IS-FHM, there is a variety of other official and non-official data sources which cover health and health care issues in Germany. To follow, changes of the data sets and in particular new data bases will be presented from the time span since 2001. Information sources which are covered in other chapters of this volume are not taken into consideration.

1.1.1 Microcensus

The microcensus is the biggest annual official survey in the EU.All in all around 390.000 households with 830.000 persons take part in the microcensus, among those 160.000 persons in about 70.000 households in the new federal states and East Berlin. Due to the large sample size it supports highly differentiated analyses. Due to the high proportion of invariant questions, time response analysis which show historical developments are possible. In the framework of the additional microcensus programs, health care and health insurance criteria are integrated in a four year course. Individual annual data are available about three months after the termination of the respective census year. Individual data of the quarter are available approximately three months after the respective report quarter. Thanks to this annual basic routine, personal data (age, gender, citizenship), family history and household situation, professional criteria, the general and professional graduation, and in particular information on the social pension fund, nursing care insurance and the amount of household net income are available. In the framework of the quadrennial add on program on the population's health insurance, data are collected about the statutory health insurance membership according to statutory health insurance company type, private health insurance membership, insurance type, further health care entitlements or additional private health insurance cover. The latest additional micro census data for 2007 have been available since July 2008. Following topics are covered by the add on program "Questions on Health": state of health (diseases, injuries caused by accidents, outpatient and inpatient treatment), health risks (smoking habits), as well as body size (height, weight). The last survey was carried out in 2005, participation was optional and the proportion of people who were willing to answer was altogether 86,2%. A further survey will be carried out in the year 2009. The data will be published by the Federal Statistical Office.

As an additional source for micro data is the research center of the German Pension Fund (http://forschung.deutsche-rentenversicherung.de/ ForschPortalWeb/). Pension Fund micro data are offered here, these result from Process-produced Data. The sources for the micro data are employer information reported to the German Pension Fund as well as administrative data on insuree benefits reported.

1.1.2 Inpatient Diagnosis Data

Since 1993, inpatient diagnosis data are collected and published annually by the Federal Statistical Office. The reporting period equals one calendar year. In order to improve the comparability with other basic data of hospitals, health screening and rehabilitation institutions, diagnosis data for the year 2007 is offered in two versions (including day cases (“Stundenfälle”) or not). The reason was that it is no longer possible to disclose overnight staying patients in the basic data of 2002. Since 2001 diagnosis data are available more detailed (5-digits ICD-10). Detailed Iinpatient diagnosis data are annually collected all over the federal territory and published by the Federal Statistical Office (Fachserie 12, Reihe 6.2). For all four-digit ICD-10 the number of cases of inpatient hospital discharges is disclosed according to age cohort, gender and calculation and days of occupancy. A separated presentation on the level of the three-digit ICD-10 positions is carried out for: deaths; day cases; medical division and surgical procedures in combination with the primary diagnosis. In the 2004 survey year for the first time also the healthy newborn babies (Z38) were included.

1.1.3 Hospital statistics by Diagnosis related groups (DRG Statistics)

The inpatient diagnosis statistics is complemented by the DRG statistics which include information on surgical procedures and inpatient medical procedures. This secondary statistic is an annual collection of all hospital cases and the performed services, which are submitted according to the DRG-compensation system. The data collection is continually carried out by the hospitals in the reporting year (calendar year). The law on hospital reimbursements states that by July 1st of the subsequent year the DRG-data agency and the Institute for Hospital Remuneration System (InEK) is to forward data to the Federal Statistical Office. The annual results for the survey year 2005 which are available for the first time, were published by the Federal Statistical Office in April 2007 (Fachserie 12 Reihe 6.4). In future they will be continued annually and can be downloaded for free over the Federal Statistical Office publication service (www.destatis.de/shop). The data base is formed by all inpatients which have been discharged from hospital in the course of the reporting year. The data also include cases if loss of life results, but not outpatients. Additionally patients are excluded who are transferred to nursing homes as well as patient’s leave days. The continuous inpatient treatment is measured independently from the number of the departments passed. Besides scientific purposes, the DRG-data serve as planning criteria for the institutions which are involved in hospital financing and form a basis for decision making in health policy.

1.1.4 Cancer Registries

Because of the reunification process in the 1990s the GDR cancer registry was not continued in the New Länder systematically. There was no federal consensus to be found which was able to encompass data protection regulations aptly. On Länder level a registry working on voluntary basis was in place (f.e. in Brandenburg). In the Old Länder cancer registries had been set up in Hamburg in 1952 and in 1967 in Saarland. The Saarland cancer registry has been managed systematically since then and has up until now been used to estimate cancer rate incidences.

Since the Länder Cancer Registry Bill in 2006 in Baden-Württemberg to establish a comprehensive registry, a population based cancer registry has been installed in all of Germany. This has led to an improvement of illness mapping in the Länder. Apart from few exceptions, all Länder depict data on incidence and prevalence. Baden-Württemberg, Nordrhein-Westfalen and Hessen have limited data availability due to no data or collection of data on subregional level.

Coordination and cooperation of the epidemiological and the clinical cancer registries influenced quality and usability of their data.

In 2008 the brochure "Cancer in Germany" was published as series on health reporting. The main topic are the emerged cancer diseases in the years 1980 until 2004. In future the results will be available in this form every two years as a collective publication of the Society of epidemiological Cancer Registry (GEKID) and the Robert Koch-Institute (RKI).

1.1.5 Kidney Replacement Therapy Statistics (QuaSi Niere)

In 1995 a voluntary collection on information on kidney replacement therapy (transplantation and dialysis) begun. Therefore, the institution QuaSiNiere was founded. As of now almost all treatment centers offering kidney replacement therapies such as dialysis, transplantation, and aftercare report their cases treated in anonymous form to QuaSiNiere. Parameters on demography and morbidity are of key interest, additionally the treatment centers structural data is passed on (such as number of treatment beds).

The results are published as annual reports that can be accessed online (www.quasi-niere.de).

1.1.6 External Comparative Quality Assurance of the In-patient Sector (BQS)

Since 2002, all hospitals which want to serve statutory health insured patients and claim reimbursements, are obliged by law (§108 SGB V), to participate in external quality assurance measures, documenting and reporting all cases for therapies listed. Specifically, these are surgical indications as well as increasingly cases mostly treated conservatively such as pneumonias. Documentation is extensive with a number of variables, depicting the treatment process and the results meticulously. Due to the extensive data the medical and patient care can be analyzed and compared for all hospitals. The listed indication data currently reflects around 20 % of hospital treatments in Germany.

The Bundesgeschäftsstelle Qualitätssicherung (BQS) collects data centrally and produces non public reports for care and data quality meassures of the individual hospitals. Additionally, reports are produced that inform on treatment quality in Germany's hospitals in general.

The transmission and processing as well as the publication of the data is done annually. The results are published within the BQS-coverage and currently the documented years 2001 till 2007 can be accessed under the following address: http://www.bqs-outcome.de.

1.1.7 Structured Reports on Quality (SQB)

Another prerequisite for hospital services reimbursement of the SHI is a bi-annual publication of a "structured quality report". The reports are to inform the public on the structure of the hospital, especially on staff, edificial and technical infrastructure available. The report also informs potential patients on the treatment focus by publishing important treatments. In 2004 the first reports were compiled, since 2008 data on hospital structure reports are also available in electronic from to the public (written request and acknowledgement of general requirements in form of XML-data). This is used by independent portals in the internet to inform and help in choosing a suitable hospital (www.weisse-liste.de).

1.1.7.1 Compulsory Health Insurance (CHI) Claims Data

1.1.7.2 Insuree Sample

This is vast amount of data from a previous scientific evaluation which the choice of adaquate grouping, weightening coefficient and classification is based on. This was undertaken for the Compulsory Health Insurance in the course of the Risk Adjustment Scheme (RAS) reform. The SHI data from the year 2002 include information on 2,3 million statutory health insurees, on in- and outpatient treatment cases, diagnosis, prescribed medication, sick pay as well as sick leave. Furthermore besides socio-demographic criteria such as the year of birth, gender and jurisdiction, also information like number of days insured, as well as cost of the health care benefits, are included. This represents so far the only sample of the year 2001, which can be used with the help of the Federal Statistical Office on-site access.

1.1.7.3 GEK Claims Data

Since 1996 a cooperation agreement between the University of Bremen and the Gmünder Ersatzkasse (GEK) exists. The focus is on the supply of anonymous insured data for the purpose of scientific evaluation of traditional aspects of health reporting as well as of outcome and longitudinal studies at the Center for Social Policy. It is a third-party funded project of the research unit health policy and evaluation of medical care which runs until end of 2009. The project data basis are the longitudinal performance data as well as the according basic claims data of the GEK insured. The time span from 1989 on is on record. The GEK provides a prospective (10 years) full population survey of its insured (at the moment about 1,6 million) of the basic claims and performance data for purpose of evaluation. These are data sets on in- and outpatient measures, incapacity to work, prescription of medication, remedies and aids as well as care benefits according to SGB XI. Besides information on pension, death benefits and on the occupational career are available. All data can be connected with each other related to the individual.