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DATABASES AND CODE SYSTEM USED IN HEALTHCARE

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1. HEALTH INSURANCE DATABASES (TÍMEA CSÁKVÁRI, IMRE BONCZ)

1.1. INTERNATIONAL DATABASES

In the chapter below databases containing health insurance data are presented by the example of three countries. First the *SEER-Medicare* database, developed together by the *Medicare* programme and the *National Cancer Institute*, and the *Medicare Coverage database* are introduced, both from the United States. Then the scope of the data collected by the National Health Service *(NHS*) of the United Kingdom and the versatile healthcare database of Germany are treated.

1.1.1. The United States of America

1.1.1.1. SEER-Medicare database

In the United States the percentage of people insured was much lower than in countries with the Bismarck or Beveridge models for a long time. Before the *Obamacare* reform the people receiving publicly funded health care only included the members of *Medicaid* and *Medicare;* the first covers the care of low-income families, while the latter that of old people (over 65), people suffering from end-stage renal disease and disabled people. The programme has covered various forms of health care for taxpayers fulfilling at least one of the conditions since 1966. At present *Medicare* consists of four parts:

- Part A: this means the funding of hospital care up to 60 days, after which a co-payment is required till the 150th day.
- Part B: upon request the insurance can also cover outpatient specialist health care subject to a coinsurance of approx. 20 %.
- Part C: also by payment of extra fees beneficiaries may also receive ophthalmological and dental care or health care in a foreign country and drug benefits for prescription drugs, decreasing the coinsurance mentioned in part B if possible.
- Part D: Since 2006 those who signed up for Part A+B plans have been able to enjoy a prescription drug benefit in the framework of this part. It is a precondition that beneficiaries have to determine the range of drugs that they require benefits for as well as the degree of the benefits.

The **SEER-Medicare** database [Figure 1/1.] consists of basically two collections of data: the SEER (Surveillance, Epidemiology and End Results) contains the demographic and healthcare data of patients from the cancer registry of the *National Cancer Institute*, while the financing agency, *Centers for Medicare and Medicaid Services (CMS),* provides data

about the insured concerning funding and services used. The two databases were first linked in 1991 [1], ever since it has been done every 2-3 years. The rate of success of coupling people's data is over 90 % every year.

The database thusly created is a good basis for researches: comparative studies can be conducted thanks to the group of people without disease, the efficacy of treatments can be investigated, and cost analyses and longitudinal studies can also be done due to the continuity of data collection.

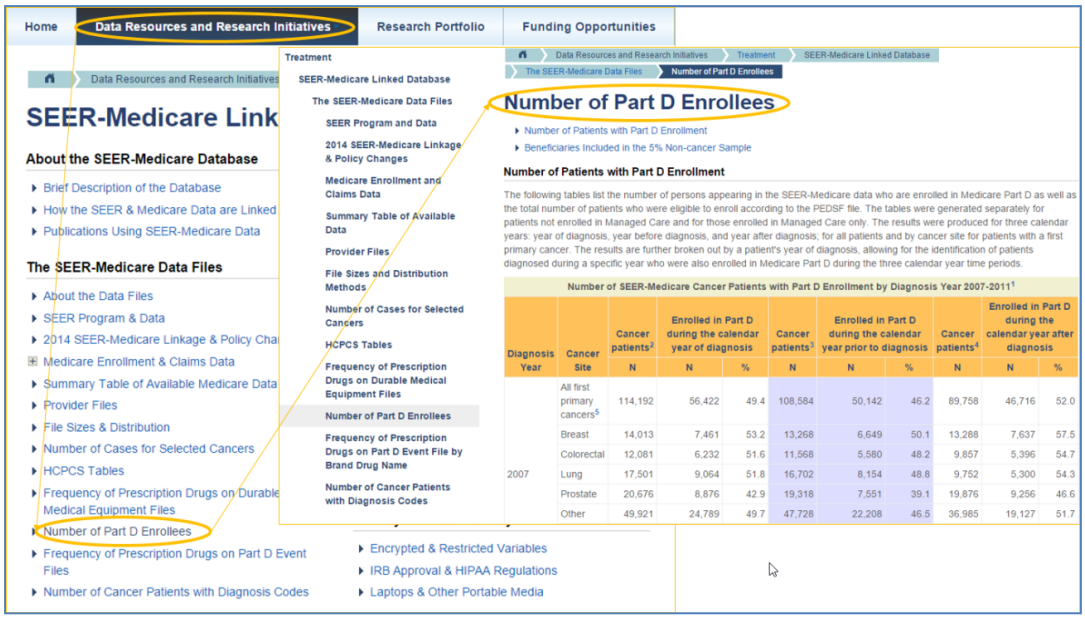

Figure 1/1: The SEER-Medicare database search interface

(www.healthcaredelivery.cancer.gov/seermedicare)

1.1.1.2. Medicare Coverage database

Medicare determines the range of procedures it finances for the contracting parties. These covered procedures are listed in documents (Coverage Determinations) of local and national competence. Medicare makes the database containing these contracts available, so that patients associated with it can be aware of the range of health care covered by Medicare.

The database is regularly, weekly, updated and the contracts can be sorted by keywords, the identification of the documents or areas (national or local, in the latter case by selecting state), and reports can also be downloaded from the CMS website. Without any doubt the database is useful in the healthcare system of the USA, where patients could not plan the costs of their health care without being familiar with the range of covered and not covered services and the conditions of subsidization.

1.1.2. The United Kingdom

In the United Kingdom the National Health Service is responsible for distributing the tax revenues among the facilities, and it is also the operator and owner of the healthcare facilities. The NHS is divided into four organizations according to the countries of the UK. In this chapter the database of the NHS is introduced by the example of the organization of NHS England.

Together with the HSCIC (*Health & Social Care Information Centre*) [2], which became an independent executive organization in 2013, NHS England forms an enormous healthcare database It determined its goals as ensuring the quality and transparency of social care, the more effective organization of patient paths, decreasing waiting time; in other words, supporting the work of researchers and decision-makers.

On behalf of the NHS England the HSCIC collects the data by processing questionnaires filled in by patients, audit results and hospital reports submitted to it. These are updated separately according to data topics with varying frequency: annually, quarterly or monthly, but the database may also be enlarged ad hoc.

The database is available to everybody at the *hscic.gov.uk* website, by the main types of care in *.xls* files, which can be filtered by years and topics.

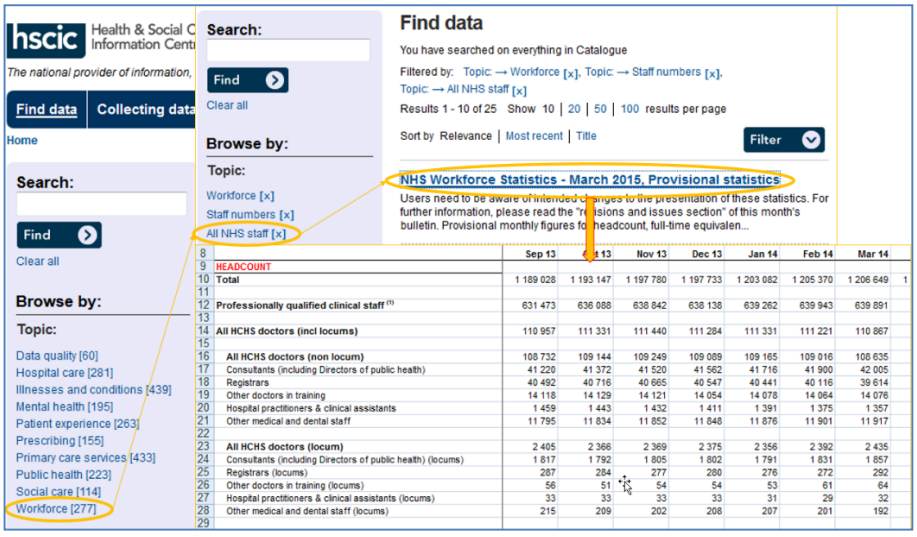

Figure 1/2: The search interface of the database operated by the NHS and the HSCIC (*hscic.gov.uk*)

1.1.3. Germany

Germany is the prime example of multi-insurance systems, where social insurance companies are organized on a regional or sectoral basis and, in a way unique in the EU, social and private insurance companies operate alongside one another, and the latter can also be taken as a supplement or replacement. As time passes their number continuously decreases; in 2000 nearly 450, while in the year 2014 132 sickness funds operated in the country [3], of which the AOK (*Allgemeine Ortskrankenkasse*) had the most clients.

Performance in health care is measured by several institutions in the country. A great amount of data from surveys is provided by the Robert Koch Institute (*Robert-Koch Institut*). These data are available individually or in an aggregate form by topics on the website (*gbe-bund.de*) of the Federal Health Reporting (*Gesundheitsberichterstattung des Bundes)*.

The WidO (*Wissentschaftlichen Institut der AOK*) has collected subjective data about the healthcare system and its quality by telephone interviewing the clients of the AOK sickness fund since 1998. These complex databases can effectively help with the right health policy measures and they also support research activities in the sector with relevant data. Several other organizations also gather data in the sector, which are summarized in the table below. The table does not include the various patient registries and projects dealing with surveying the population with questionnaires.

Table 1/1: Organizations collecting healthcare data in Germany

Organization	Dimension	Organization of data	Scope of collected/managed data
Statistische Bundesamt DESTATIS	Health status	Aggregate	birth rate, fertility rate, death rate, life expectancy, cause of death statistics
	Economy, efficiency		Annual reports about the number of beds, patient paths, medical instruments, HR data (from 1991)
	Availability		Annual collection of income and living conditions data
Gesundheitsberichterstattung des Bundes (GBE)	Health status	Aggregate	Disease, accident statistics Risk factors
	Use of health services		At national and regional levels: interventions, number of cases, number of discharges, HR data, duration of care, number of

			operations
	Costs, expenses		Inpatient and outpatient care, medicines, healthcare research expenditure
AOK WidO Monitoring (Wissenschaftliches Institut der AOK)	Quality	Individual	Annual questionnaire surveys Opinions, expectations related to health policy, sickness funds Expenses, taking medication, health status
	Use of health services		Use of health care Screening test attendance
AOK	Quality	Individual	Quality of publicly funded health care (only among AOK clients)
Deutsche Krankenhaus Gesellschaft (DGK)	Economy, efficiency	Aggregate	Hospital infrastructure
Deutsches Krankenhaus Institut (DKI)	Use of health services	Aggregate	Annual surveys among hospitals about the situation of health policy
Institut für das Entgeltsystem im Krankenhaus	Costs, expenses	Aggregate	It manages the catalogues of DRG

(*Health Data Navigator*)

1.2. HUNGARIAN DATABASES

As the sole insurer in Hungary, the National Health Insurance Fund (hereafter: OEP or health insurance) is responsible for insuring the population and contracting, financing and supervising healthcare facilities and thusly provide them with a basis for their existence. Consequently, as Hungary's health insurance database the following are presented below: the Social Security Identification database, managed by the OEP, which comprises the data of the insurees and their personal care data, the records of care from the reports of health care providers and, finally, the detailed registries of drugs and medical accessories.

Every month the health facilities send reports with data contents prescribed by law [4,5] in electronic form to the Fund, from which the OEP prepares and publishes databases of funding and use indicators in its website. It is enough to think of the OEP's reports on the numbers of hospital beds and patient numbers, which is an annually published report at health care facility level about active and chronic in-patient care as well as the performance of health care facilities providing same-day surgery. Other background institutions also gather healthcare data: the Health Registration and Training Center, for example, has been entrusted with the basic and operational records and healthcare wages and salaries and personnel statistics of the National Statistical Data Collection Programme. Also, on the website of the State Healthcare Management Centre (ÁEEK, earlier GYEMSZI=National Institute for Quality- and Organizational Development in Healthcare and Medicines) versatile demographic, public health, and service use data are made available in its Internet (IMEA) and Thematic (TEA) healthcare databases (http://tea.gyemszi.hu/), where the data can be seen and downloaded in time series and also broken down to national, regional and county levels. These are not data acquired in primary data collection but data supplied by the National Health Insurance Fund of Hungary. [6]

In 2011 the Family Support and Social Security Departments of the County Government Offices (earlier known as Health Insurance Fund Administration Agencies) overtook some responsibilities from the OEP, among others, the keeping of records and handling affairs related to monetary support, earning capacity and social security identification numbers. The performance of these transferred tasks is supported by a complex data system, the Social Security Identification database comprising personal and special data handled by the OEP. The following chapter presents the range of data collected and handled.

1.2.1. The range of personal and special data handled by the OEP

1.2.1.1. The TAJ-BSZJ database

In the database that records the Social Security Identification numbers of the population the Social Security Identification (TAJ) numbers and personal data of people alive in and after 1995 are stored. For the purpose of the lawful use of health insurance services, apart from the Identification Number, individuals' personal data, marital status, gender, nationality and place of residence are also listed in the database.

The records of the Registered Persons' Legal Relationship Data are to be collected separately in theory. However, in the case of employees it appears as a completely unified database combining the above-mentioned data with the names and FEOR codes of the insurees' employers or organizations providing them with care, the precise duration of each legal relationship and even the weekly working hours, and all this from 1998. Keeping the records is also necessary for determining and inspecting monetary health insurance payments (sick pay, sick pay for accidents, maternity pay, childcare allowance). The legal relationships are reported by employers and other organizations (e.g. MÁK). That is why the database may sometimes have 'holes' in it because of the imperfections of reporting, which can be remedied by the clerical staff subsequently by contacting the responsible authorities.

For the Department it is also important to know the existence or lack of legal relationship behind the Social Security Identification (TAJ) numbers - which is made possible by using colour coding.

- Green: TAJ valid, legal relationship is in order;
- Red: TAJ valid, there is no legal relationship behind it;
- Blue: TAJ is temporarily invalid, it can be revalidated later (e.g. in case of moving abroad);
- Brown: TAJ is invalid (e.g. dead person, faulty identification).

1.2.1.2.Keeping records of the data of funded health-care services

Every month the healthcare providers with funding contracts with the Fund report their performance including a range of data determined by law. The data serve as a basis for the funding of the services performed by the health care facilities and they are also conducive to creating funding procedures; they play a role in determining individual health insurance services if it also requires familiarity with the individual's health status; they also serve as

a basis for the supervisory activities of the health insurance and the National Public Health and Medical Officer Service. [7]

The following are legally required to report:

- Providers of general practitioners' services
- Providers of out- and inpatient [Table 1/2.] specialist services
- Providers of diagnostic imaging and laboratory diagnostic services
- Organizations of emergency medical services and medical transport,
- Providers of dental care
- Providers of home care, hospice care
- Providers of haemodialysis treatments
- Users of medicines subject to detailed accounting
- Providers of healthcare to 'E' category patients

Each of the above, of course, provides data according to different record forms.

Table 1/2: Record form of hospital inpatient report

Name	Length	Appellation
MUNKAHELY_AZON	9	Identification of the healthcare provider's place of work (institute+task+ward code)
SZAKMAKOD	**4**	**Code of profession of the place of work providing healthcare**
TORZSSZAM	9	Patient identification number
SORSZAM	2	Number of health care event
RESZ_SOR	2	Number of partial invoice within ward care
SZEMELYAZ	9	Personal identification number
AZ_TIPUS	1	Type of personal identification
BETEG_NEME	1	Patient's sex
SZUL_DATUM	8	Date of birth
ALLAMPOLG	3	Country of valid insurance or patient's nationality
BET_KISOK	1	Reason for escorting patient
KIS_TORZSSZAM	9	Patient identification number of escorted patient
IR_SZAM	4	Post code of patient's residence
LAKCIM_TIP	1	Type of address
TER_KAT	1	Charge category
RESZ_TER	8	Legal title of partial charge
RESZ_DIJ	8	Partial charge
BEUTALO	9	Identification of place of work of doctor issuing referral
BEUT_ORVOS	5	Stamp number of doctor issuing referral
ELL_IG_ADAT	9	Data proving previous care
FELV_IDO	12	Time of admission
OSZT_TIPUS	1	Type of admitting ward
FELV_TIPUS	2	Type of admission
FELV_JELL	1	Nature of admission

TAV_IDO	12	Time of leaving
TOV_SORS	1	Patient's further fate
BETEGSEG	16	Diagnoses
BEAVATKOZ	10	Healthcare interventions
UJSZ_SULY	4	Weight of newborn in grams
BALESET_MIN	2	Category of accident
FELHASZN	30	Fields at users' disposal
ORVOSKOD	5	Code of doctor responsible for care
REKORD_TIP	1	Type of record (correction, deleting, normal)
E-ADATLAP	1	0 = no E-FORM, 1 = there is E-FORM
ELSZ_NYIL	2	Statement of account settlement
TARTALEK	**15**	**Set aside for future development**
CR/LF	2	"CR/LF" characters indicating end of record

(*govt decree 43/1999, Annex 14*)

1.2.1.3. Data handled during procedures connected to monetary support by health insurance, sick pay due to accidents and travelling costs

Finally the OEP database also includes data on the insurees' children and employers for the purpose of granting and inspecting monetary support. These data are kept for 5 years.

1.2.2. Public drug and medical accessories registries

The OEP keeps databases of both subsidized and non-subsidized drugs and medical accessories for the information of the actors of health care (consumers, manufacturers, distributors, system developers) as well as for the purposes of analyses, the transparency of price-volume agreements, technological developments and pricing.

1.2.2.1. The Public Drug Registry (PUPHA)

The database is accessible in two forms: the working version is published on the 15th of every month by the Price Subsidization Department of the OEP. Its purpose is to inform distributors and IT system developers of the changes in the database as soon as possible (e.g. price changes) and to correct any errors without any delay. The final version of PUPHA, however, provides data to everyone.

The final registry is accessible in different forms to professional users and the public - to the first in *.dbf* or *.mdb*, while to the latter in *.xls* format - on the OEP website, providing detailed information - among others - on drug data; manufacturers' and distributors' prices; the forms of normative, increased and special subsidization and its degree; availability in public healthcare and the distributors.

1.2.2.2.The Public Medical Accessories Registry (PUPHAG)

Its structure is identical with that of the drug registry. It is available in both final and working versions. The up-to-date data are published on the 15th day of every month in a format that both professionals and the public can use. The lists of new and deleted products and monthly changes are shown in separate databases.

The PUPHA and the PUPHAG are also available as one file. Below the search interface of the database opened in *.mdb* format can be seen.

Figure 1/3: The search interface of the Public Drug and Medical Accessories Registry

1.2.3. OEP database analysis possibilities

Besides the accounting of health care funding, the funding database of the National Health Insurance Fund Administration (OEP) of Hungary also provides great opportunities for sectoral political and scientific analyses.

The importance of the OEP database in sectoral policy is the result of the coexistence of several factors. On the one hand, in the case of systems with a single funder (single player) or a single insurance it is natural that the only funder is responsible for the financing of the whole publicly funded health care system as well as the data collection associated with it. On the on the other hand, there is also need for a funding technique that provides a suitable basis for detailed data collection. In Hungary performance-based funding techniques are often used, e.g. in the so-called ‘German point’ system of outpatient specialist care or in the financing of in-patient specialist care based on homogeneous disease groups (HDG) [8].

Table 1/3: The data collection system of the National Health Insurance Fund of Hungary

FORM OF CARE	use of health service	diagnosis (ICD-10)	COST	intervention	ordering/referring/prescribing physician	other
GP	yes	yes	--	--	--	
General medical care for not registered insurees	yes	--	--	--	--	
dentist	yes	yes	yes	yes	yes	
home care	yes	yes	yes	yes	yes	
hospice care	yes	yes	yes	yes	yes	
outpatient specialist care	yes	yes	yes	yes	yes	number of prescriptions
active inpatient specialist care	yes	yes	yes	yes	yes	patient's further fate
chronic inpatient specialist care	yes	yes	yes	yes	yes	patient's further fate
CT-MRI	yes	yes	yes	yes	yes	
haemodialysis treatments	yes	yes	yes	yes	yes	amount of erythropoietin (EPO) used
medical transport	yes	yes	yes	--	yes	odometer reading
emergency medical services	yes	yes	--	--	--	odometer reading, health facility receiving the patient
devices subject to detailed accounting and expensive surgical interventions	yes	yes	yes	yes	yes	device used/code of intervention performed
medicines subject to detailed accounting	yes	yes	yes	yes	yes	quantity of medicine used and unused
prescribed drug	yes	yes	yes	--	yes	
prescribed medical accessory	yes	yes	yes	--	yes	
prescribed spa therapy	yes	yes	yes	yes	yes	
Sick leave	yes	yes	--	--	yes	
medical research	yes	yes	yes	yes	yes	OGYÉI protocol number, authorization number

The database of the National Health Insurance Fund of Hungary makes numerous health political and sectoral political analyses possible. Carrying out such analyses is only possible in compliance with very strict privacy regulations, which are dealt with in a separate chapter.

By the analysis of regional inequalities the differences in the availability and utilization of health care can be detected. Such studies can be carried out at the levels of the settlements, micro-regions, districts, counties or regions [9, 10, 11, 12, 13].

With the help of the OEP database the health insurance costs related to the care of individual diseases can easily be studied in the framework of so-called disease burden surveys. These can provide an overview on the annual expenses the funder incurs in connection with the treatment of the individual disease groups. [14, 15, 16, 17]

From the perspective of health policy planning the mapping of patient paths is of paramount importance. With the help of the OEP database the patient paths between the individual forms of care (primary care, out and inpatient specialist care) and the various levels of progressivity (municipal, metropolitan and county hospitals, university clinics) can be demonstrated well. [18, 19, 20]

The database makes it possible to follow various health policy and public health programmes and to analyse them based on monitoring. An outstanding example of the use of the OEP database in the last decade was the follow-up and monitoring of the organized mammography screening for the population [21, 22, 23, 24, 25, 26].

In many cases the data on the use of health services and health insurance expenditure in the OEP database serve as input data for health economic analyses. [27, 28, 29]

Methodologies for the measurement of the quality of health care have been developed in many countries. Several concepts for the measurement of health care quality have also appeared in Hungary. One of these, the quality indicator programme of the National Health Insurance Fund of Hungary, deserves mentioning at any rate. Within the framework of this programme the OEP elaborated an indicator system that is suitable for the measurement and assessment of the quality of health care. Unfortunately the programme has been discontinued in recent years. [30, 31, 32, 33]

The question of validity is often raised in connection with databases created as the result of data collection for the financing purposes. Generally speaking it may be said that data collection with any purpose may involve the distortion of the data reported. Most probably certain distortions also appear in the OEP data collection system. Nevertheless, there is no scientific evidence that the collection of financing data by the National Health Insurance Fund of Hungary or any other country contains more serious distortions than any other data collection for statistical purposes. [34]

Today the database of the National Health Insurance Fund of Hungary still represents a great asset and bears international comparison. A possibility for further development would be if the results of certain tests (e.g. laboratory, imaging) could also be recorded in the database.

2. PUBLIC HEALTH DATABASES (ZSUZSANNA HORVÁTHNÉ KÍVÉS)

Public health databases primarily provide demographic data and data related to the health status of the population. There are databases limited to such data only such but in most cases they make also further economic data available. International databases receive data from statistical offices gathering data according to unified methodological principles. Then they harmonize them to make the data of various countries comparable. While using data from different databases simultaneously, one has to consider what year the data are from and what population the database regards as the standard population, since different data may be obtained in the case of the same indicator on the basis of these. The methodological principles of collecting and providing data are available in every database.

2.1. INTERNATIONAL PUBLIC HEALTH DATABASES

2.1.1 European health for all database (HFA-DB)

The HFA-DB provides access to the demographic, mortality, morbidity and risk factor data as well as data related to the resources and expenditure connected to healthcare from 53 countries of the European Region.

The data come from various sources, including data published by the WHO, the UN, the statistical office of the European Union (EUROSTAT) and the Organisation for Economic Cooperation and Development.

The database is accessible via the website of the Regional Office for Europe of the WHO under the databases menu item or by the following link: http://data.euro.who.int/hfadb/. The database is available both in *online* and *offline* versions. The first is mainly suitable for accessing information quickly, but if one would like to use the result tables, graphs and maps also in other applications, it is more reasonable to use the offline version. The data are updated twice a year. Data are available starting from 1970 but the years of data availability may vary from country to country. The standard indicators are shown projected to 1000 or 10000 people.[35]

By clicking the *Select parameter* option in the opening page you can access the search interface, where the required indicator can be chosen. Indicators:

- demographic and socio-economic indicators,
- mortality (by 67 causes of death and sex),
- morbidity (common communicable diseases, tumour diseases, and the common diseases of the main organ systems),

- life style factors (alcohol consumption, smoking, traffic accidents, energy intake, vegetable and fruit consumption),
- environmental indicators (pollutants, microorganisms),
- health care resources (hospitals, hospital beds, number of nurses and doctors),
- healthcare expenditure,
- maternal and child health (vaccination, abortion, mother's age at giving birth, developmental disorders).

After selecting the indicator(s) the country(ies) and year(s) can be chosen. By clicking OK you get back to the starting page, where you can select the form of displaying the data: maps, tables and different graphs. (Figure 2/1) The obtained results can be printed, copied as image or saved. In the case of selecting more than one countries and/or years the individual indicators and countries can be displayed with the help of the icons in the upper left corner of the results window. (Figure 2/2)

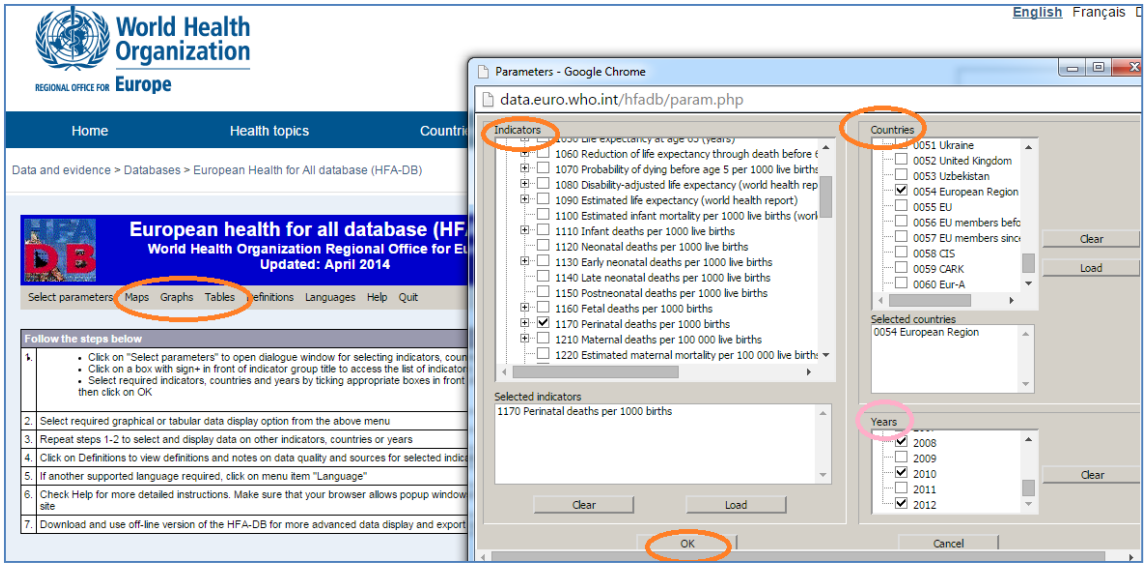

Figure 2/1: The search interface of the HFA-DB database

http://data.euro.who.int/hfadb/

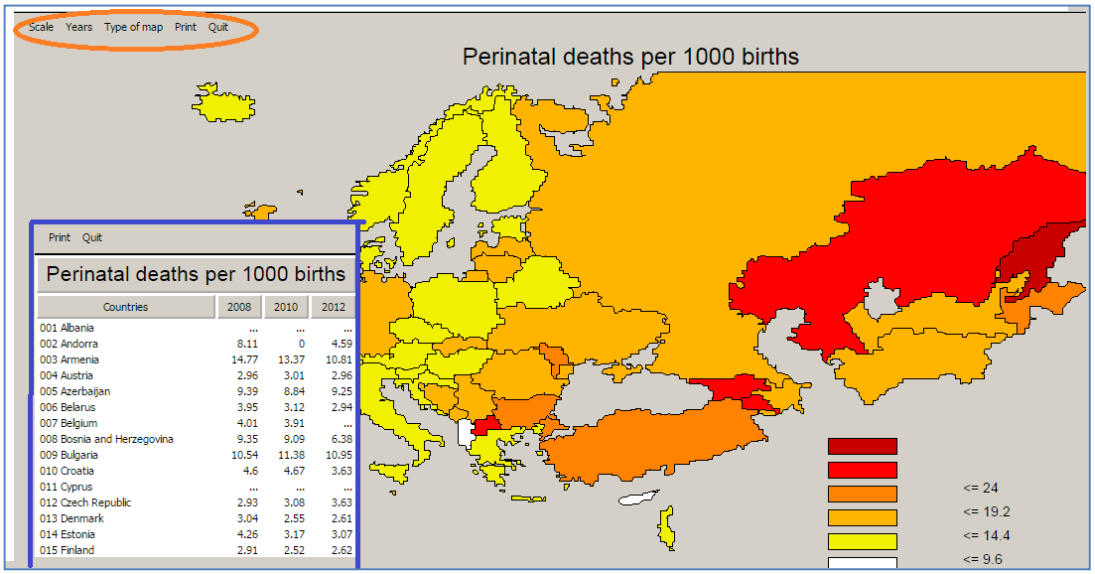

Figure 2: Displaying data in map and table formats in the HFA-DB database
http://data.euro.who.int/hfadb/

2.1.2 The statistical office of the European Union - EUROSTAT

The responsibility of EUROSTAT, based in Luxembourg, is the compilation of high quality statistics at a European level, which allows the comparison of countries and regions. The data can be widely used by decision makers for assessing the current situation and making decisions at the levels of the European Union, the governments, the enterprises, the education sector and the local governments. The EUROSTAT does not gather data directly; the data are provided by the statistical authorities of the member states. It is the task of the EUROSTAT to make the obtained data comparable by unifying and harmonizing them.

The office was established in 1953 to satisfy the information needs of the European Coal and Steel Community. Later the scope of its responsibilities was enlarged further and further and when the European Community was established in 1958 it became one of the Directorates-General of the European Commission. All the information published in the website is available free of charge but the EUROSTAT as its source must always be indicated.

The database is accessible by the following link: http://ec.europa.eu/eurostat/data/database. The data are updated continuously. The years of the oldest and most recent data are displayed by clicking the letter 'i' next to the selected indicator.

In the database data can be searched for with the help of the *Data Navigation Tree* or alphabetically (*Statistics A-Z*). In the navigation tree one can search by themes (*Database by themes*) or tables (*Tables by themes*). In the first option data of a wider range are available than in the case of the tabular form. Data related to healthcare and health can be

found under the menu point *Population and social conditions.* In the menu point one can browse demographic data and - in connection with health - data on health status, health determinants, health care, disabilities, causes of death by age and sex and, finally, data related to health and safety at work. (Figure 2/3) [36]

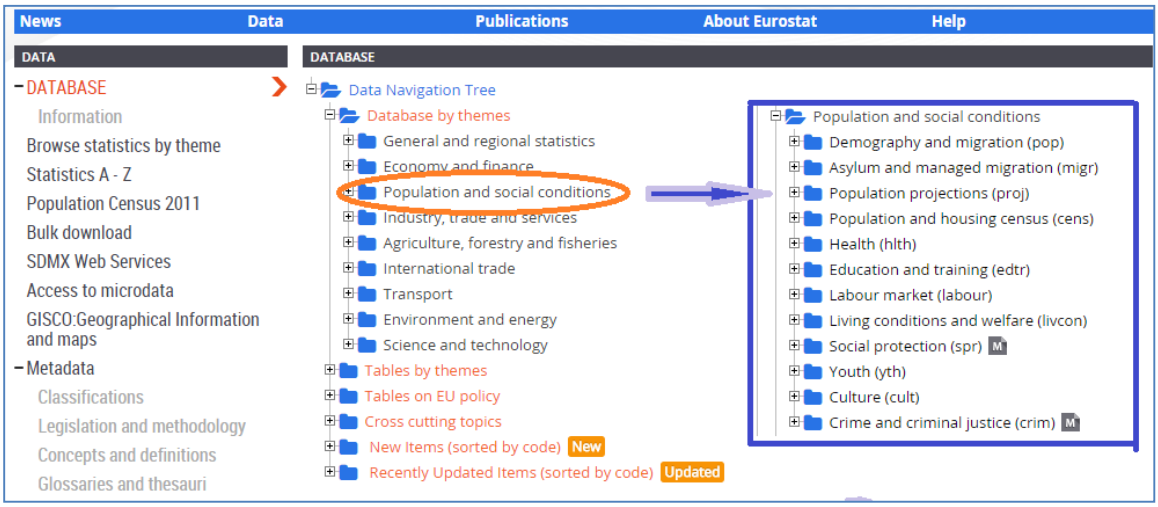

Figure 2/3: The search interface of the opening page of EUROSTAT
http://ec.europa.eu/eurostat/data/database

By clicking on the icon (*data explorer*) before the selected indicator the opening results window offers further options. One can select: age (*Age*), format of the data (*Unit*), e.g. percent, year (*Time*), individual countries also separately (*Geo*), gender (*Sex*) and - depending on the indicator - even frequency (*Frequency*), e.g. for alcohol consumption the options 'daily', 'weekly', 'monthly' or 'never' can be chosen. (Figure 2/4)

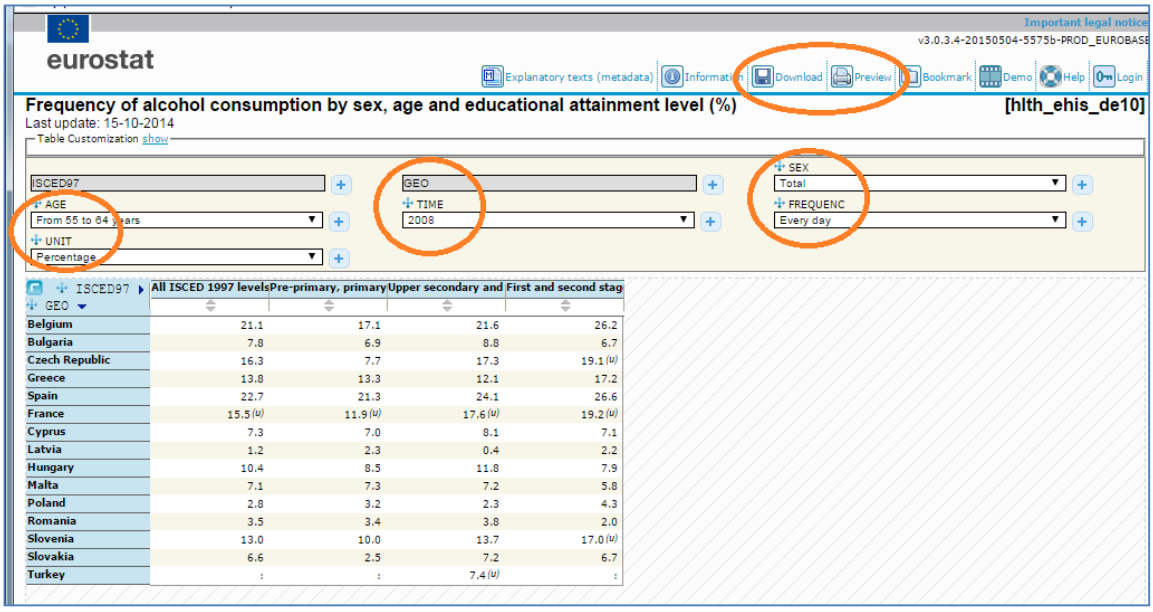

Figure 2/4: The thematic search interface of the EUROSTAT
http://ec.europa.eu/eurostat/data/database

In the results interface of search by tables the data can be displayed in tabular, graph or map formats. Filtering is possible by country, year and value; the results can be saved and printed. (Figure 2/5)

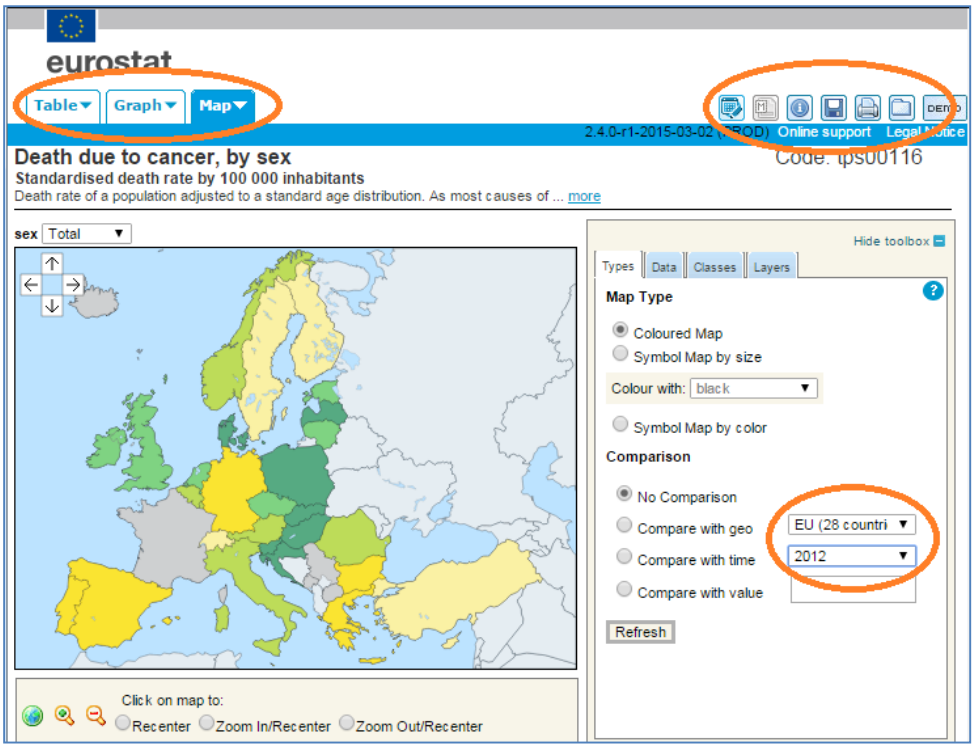

Figure 2/5: The table search interface of EUROSTAT

http://ec.europa.eu/eurostat/data/database

2.1.3 Organisation for Economic Co-operation and Development (OECD)

The Organisation for Economic Co-operation and Development (OECD) was officially established in 1960. Besides data related to health the database provides information in several economic themes to support making decisions necessary for economic development and financial stability.

The OECD does not collect data directly, they are provided by the statistical offices of the member states according to standard guidelines. The database is accessible by the following link: http://stats.oecd.org/#

The various themes are found on the left-hand side of the opening window. After the selection of the theme and the indicator within that, it is advisable to customize the data. That is necessary because by default all the variables related to the theme as well as all the units and countries are selected, which makes the table of data confusing. In such a case

graphical representation is not even possible due to the too many data. Exporting data in several formats and also their graphical representation are possible. A detailed user guide is also available in the upper right corner of the page. (Figures 2/6 – 2/7) [37]

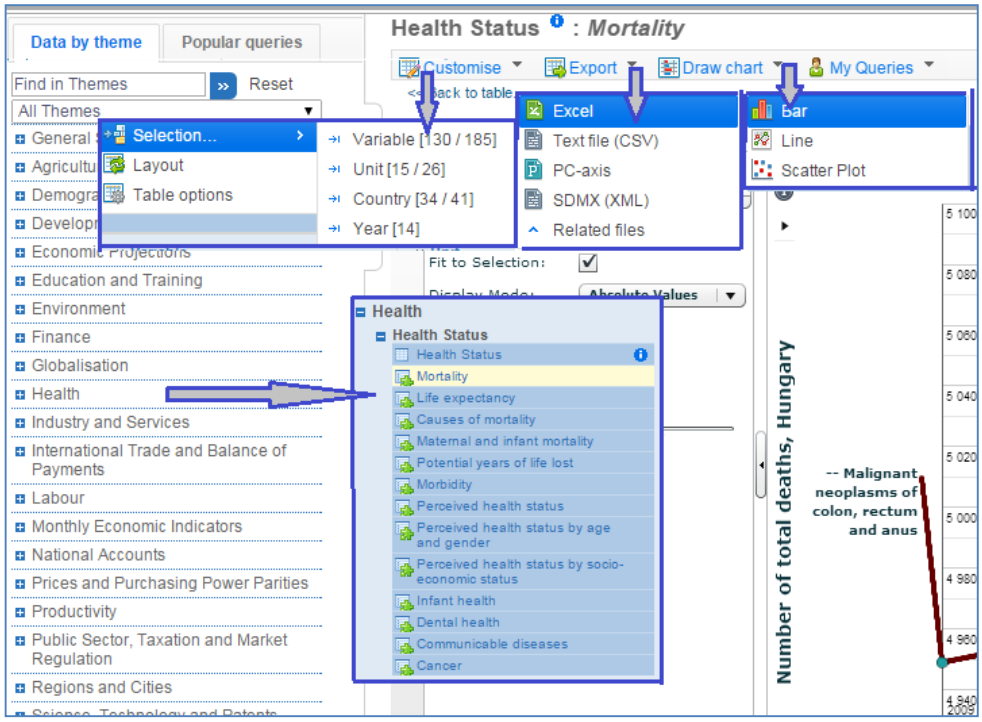

Figure 2/6: The search interface of the OECD database with options for filtering and formats for displaying results

http://stats.oecd.org/#

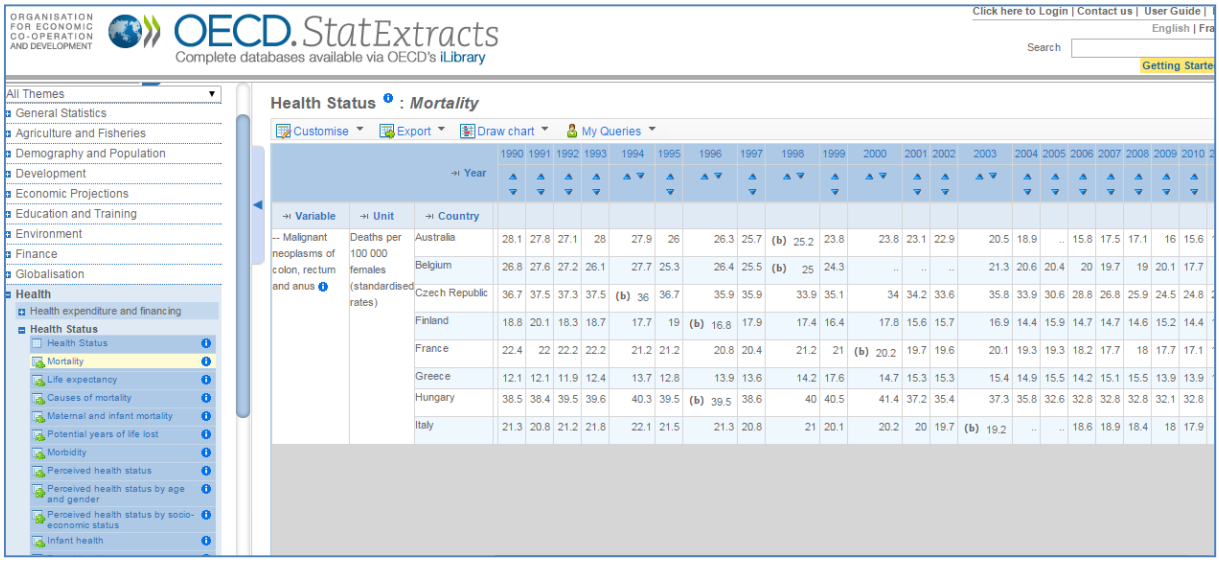

Figure 2/7: The results interface of the OECD database with filtered results in a tabular format

http://stats.oecd.org/#

2.1.4 The United Nations Economic Commission for Europe (UNECE)

The database is operated by the Statistical Division of the UNECE and it provides free access to the data of 56 member states in Europe, Central Asia and North America in English and Russian. The data come from various official national and international sources. Extra care is taken to ensure that the data are suitable for international comparisons and immediate analytical purposes and are also easy to handle.

The database is accessible by the following link: http://www.unece.org/stats/stats_h.html

In the opening page indicators in six themes can be selected: about all the collected variables of a chosen member state (*Country Overview*); in the theme of population and gender, among many others, migration, certain demographic data and fertility indicators are shown. Further data are also accessible about the economy and in the themes of forestry, transport and the 'Millennium Development Goals'. Upon clicking on a theme the particular indicators can be selected in the pop-up window. For example, let us select causes of death by sex in the theme Health and mortality. (Figure 2/8) [38]

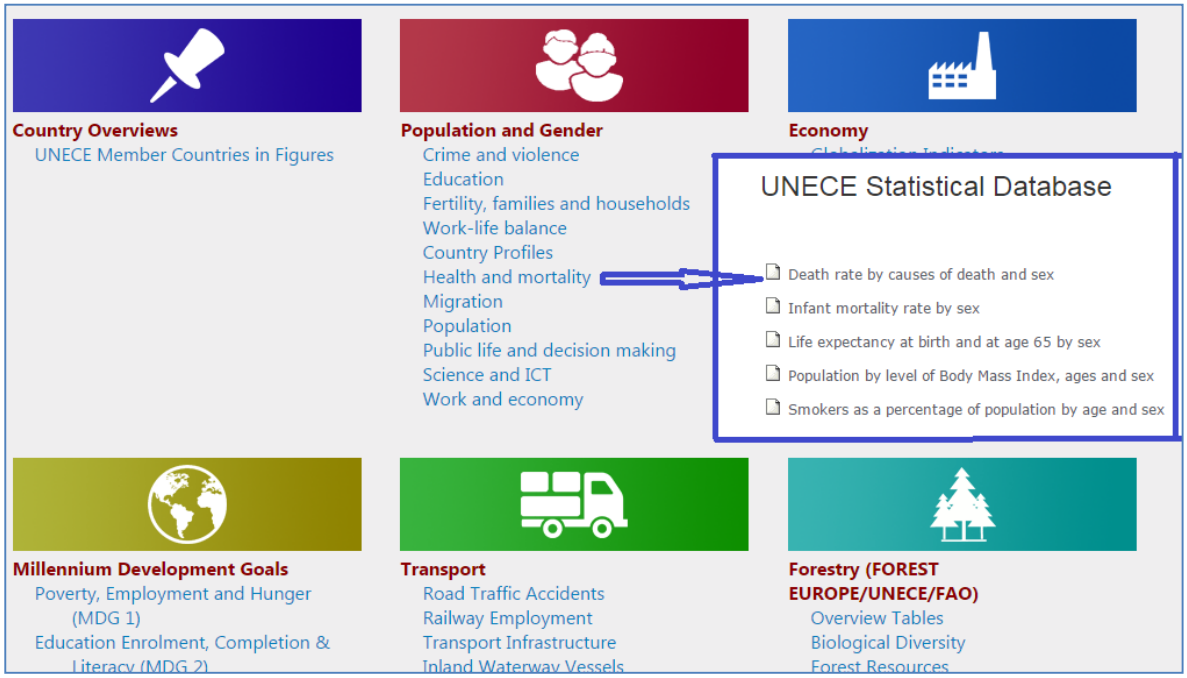

Figure 2/8: The search interface of the UNECE database

http://www.unece.org/stats/stats_h.html

In the pop-up window one can choose from 25 causes of death and select sex, country(ies) and years from 1980. Finally, the results are shown in several formats of representation, such as charts and tables. (Figure 2/9)

The other mode of search is using the icons in the upper left corner of the opening page. By choosing *Ranking* the selected indicator is shown in a horizontal chart in descending

order or in a tabular form. After clicking *Profiles* one has to select a given country to see all the indicators from the latest year known. In the *Charts* menu a line chart of the selected indicator appears with the countries below it. By clicking on the individual countries their data appear in the chart or they can also be shown in a tabular form if needed. In the *Maps* menu the selected indicator is represented in a map, showing all the countries. Moving the cursor over the country of your choice the exact values also appear in the upper right corner of the image. (Figure 2/10)

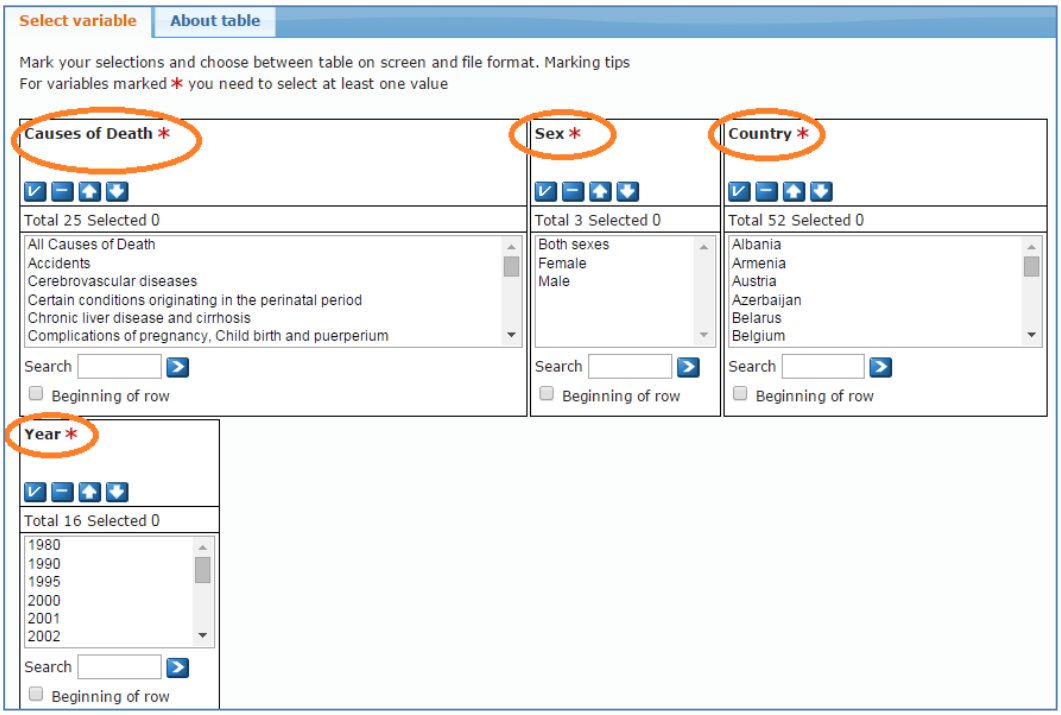

Figure 2/9: Filtering options of the UNECE database
http://www.unece.org/stats/stats_h.htm

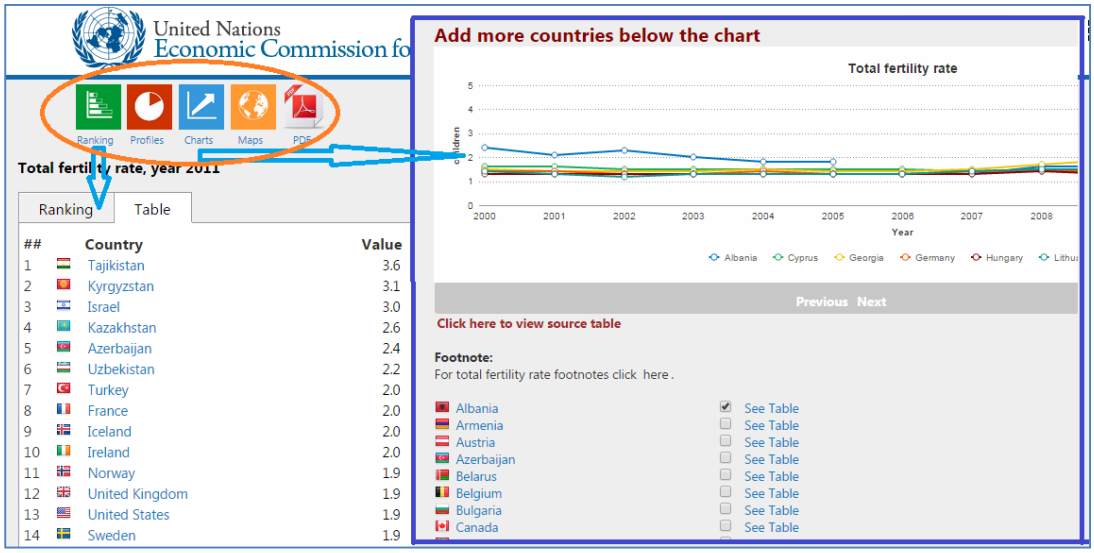

Figure 2/10: The search interface of the UNECE database using icons
http://www.unece.org/stats/stats_h.html

2.1.5 Global Health Observatory (GHO)

The GHO Data Repository provides access to data of more than 1000 important health indicators, such as mortality and burden of disease, the Millennium Development Goals (child nutrition; child, maternal and reproductive health; immunization; HIV/AIDS, tuberculosis, malaria; water and sanitation), non-communicable diseases and risk factors, infectious diseases, health systems, the public health and the environment, injuries and violence and violence prevention. Also, the GHO provides its member states with on-line access to WHO's annual summary of health-related data (World Health Statistics 2014). [39]

The database is accessible by the following link: http://apps.who.int/gho/data/node.main

In the *By theme* menu it is possible to search by the related topics; the results are shown in a tabular form. Search *By indicator* displays all the available indicators in alphabetical order, while in search *By country* one has to select the required country from the alphabetical list of nations. In the latter case the indicators are found in the rows of the table of data, while in the column one sees the years from the most recent to earlier ones. (Figure 2/11) In addition to results tables there is also a graphical display option (*Interactive graph*), moreover, the data can also be downloaded in Excel format.

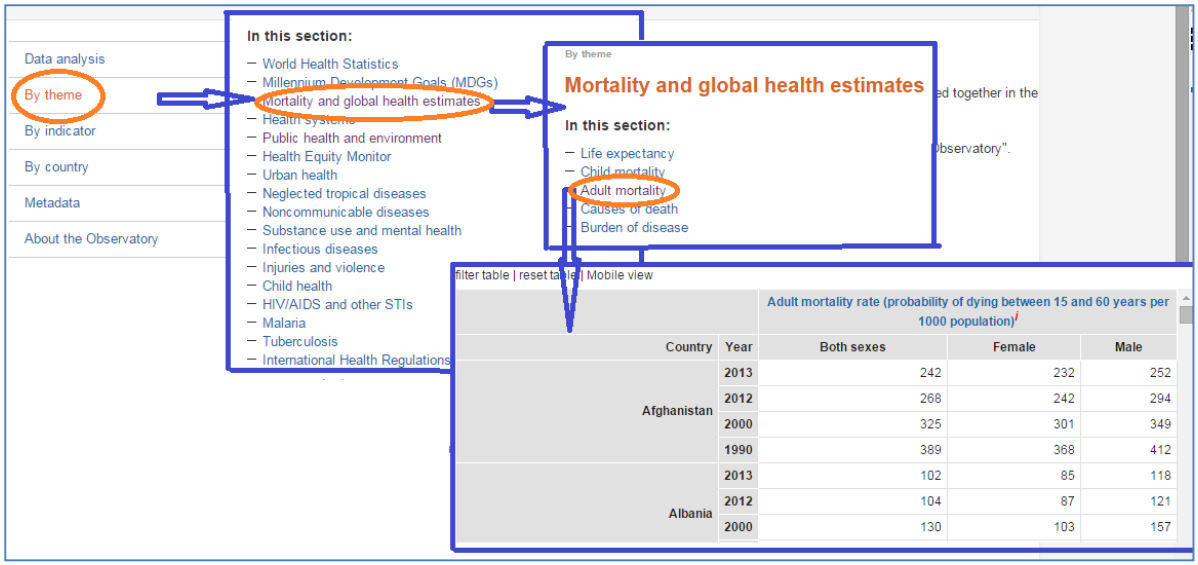

Figure 2/11: The search interface of the GHO database

http://apps.who.int/gho/data/node.main

2.1.6 International Agency for Research on Cancer (IARC)

The IARC provides access to databases containing information in connection with tumour diseases worldwide.

- Via the GLOBOCAN the latest information related to tumour diseases, such as morbidity, mortality and prevalence, are available from 28 countries of the world .
- The **CI5** (Cancer Incidence in Five Continents) provides access to the incidence indices of tumour diseases via national and regional cancer registries.
- The **ACCIS** (Automated Childhood Cancer Information System) provides information about children's tumour diseases and survival based on European cancer registries.
- The **DIICC** (The International Incidence of Childhood Cancer) informs about the incidence of childhood tumour diseases on the basis of cancer registries worldwide.
- The **ECO** (European Cancer Observatory) is a web-based tool for accessing data related to European tumour diseases for analysis and downloading.
- **NORDCAN** (the database of the Association of Nordic Cancer Registries) presents the morbidity and prevalence data of 40 kinds of tumour diseases with long-term time series analyses for the Scandinavian countries.
- On the basis of cancer registries **SurvCan** (Cancer survival in Africa, Asia, the Caribbean and Central America) gives tumour survival data concerning the low- and middle-income regions of the world.

The databases are accessible by the following link: http://www-dep.iarc.fr/

In the opening page of the **GLOBOCAN** one can search globally or by individual continents (*Population Fact Sheets*), and as a result the incidence, mortality and prevalence values of the most common types of tumours appear in a graphical or tabular format. In the *Cancer Fact Sheet* the particular tumour types can be selected and as a result one receives data about the incidence and mortality of a given tumour broken down to sexes in graphical, tabular and map formats. (Figure 2/12)

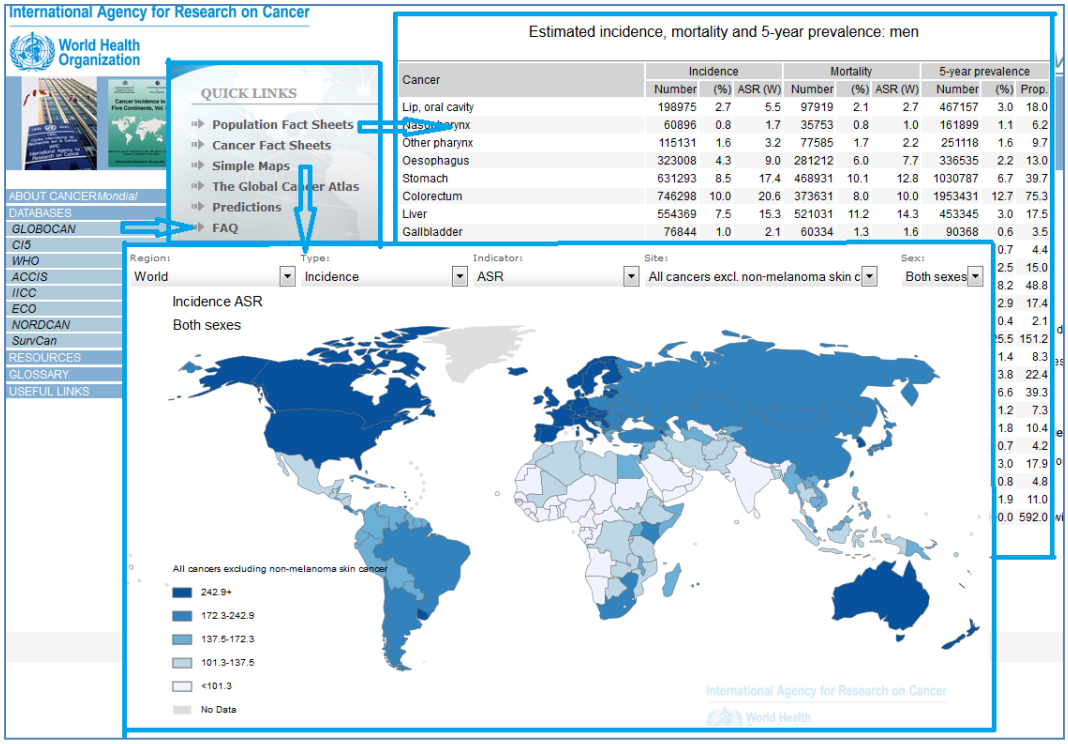

Figure 2/12: The search and results interface of the GLOBOCAN database

Clicking *Simple map* the required continent (*Region*), the type of data (*Type*), i.e. incidence, prevalence or mortality, the indicator (ASR), the tumour type (*Site*) and gender (*Sex*) can be chosen in the pop-up window. (Figure 2/13)

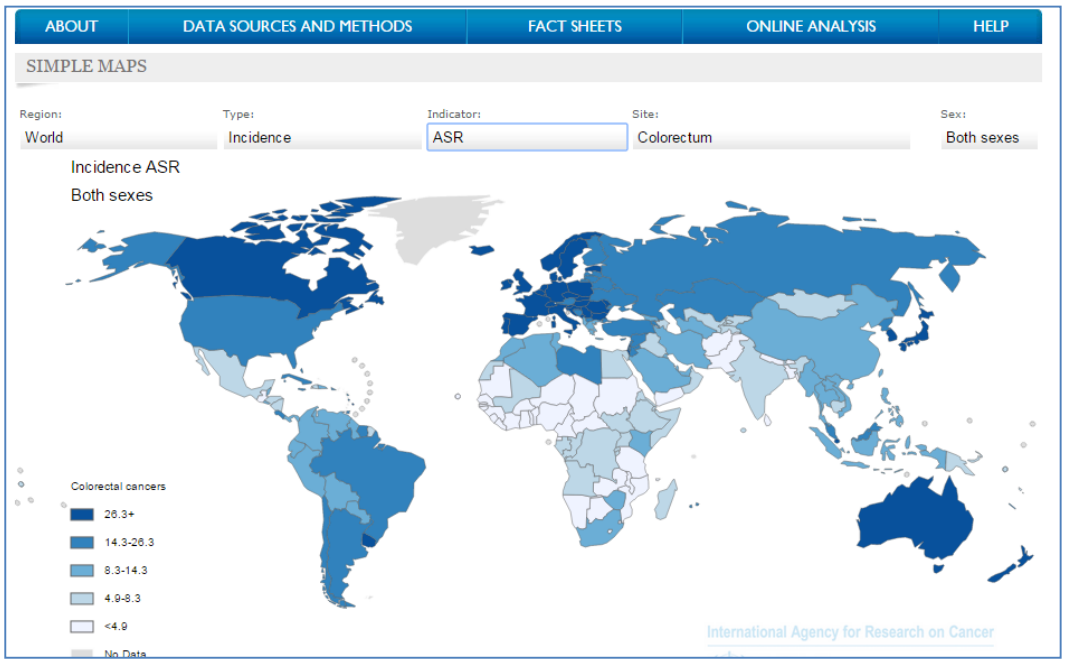

Figure 2/13: The map display interface of the GLOBOCAN database

http://globocan.iarc.fr/Pages/Map.aspx

2.2. HUNGARIAN PUBLIC HEALTH DATABASES

2.2.1. Hungarian Central Statistical Office (KSH)

The KSH is a professionally independent government agency that processes official data related to the social, demographic and economic situation of the country. Its responsibilities include planning data recording, processing, storage, analysis and publication. Besides demographic data from censuses, health statistics are also available and can be purchased in printed book or CD forms.

The website is accessible by the following link: https://www.ksh.hu/. By selecting the *Health care, accidents* menu point on the left-hand side of the opening page time series data become available, most of them already from 1990. (Figure 2/14) [40]

Figure 2/14:The thematic search interface of KSH

https://www.ksh.hu/egeszsegugy_baleset

In the **list of publications** further data on public health are available, e.g. *Morbidity data* and several studies of the *Heal survey of the European population.* The *Health statistical yearbook* is also available with a CD-ROM. Its annually published tables provide detailed data on demographic changes, the main demographic characteristics, primary health care, home care, outpatient specialist care, nursing homes, inpatient care, the activities of the Hungarian Ambulance Service, medicine and blood supply and health care personnel, also making international comparisons possible.

In the data menu one can access a collection of ready-made tables, the **STADAT**, which contains the most important data and indicators collected by the KSH or acquired from other organizations. Regional data are displayed broken down to counties and regions - sometimes even micro-regions and settlements- while the most important international data are shown related to the members of the European Union and some other countries. The tables are printable, may be downloaded free of charge in Excel format and can also be displayed in interactive maps.

From the data menu one can also access the **Dissemination database**, which shows the data stored in the non-thematic statistical data storage of the KSH in a cross-tabular manner, providing quick and easy access to the data through its interactive user interface. The tables shown can be rearranged and modified according to wish, and the tables and graphs, thusly customized, can be saved, printed or exported in Microsoft Excel and Adobe Acrobat PDF formats.

By clicking **International data** one can reach annual and interim indicators for comparing various countries and regions. Data tables from EUROSTAT provide data about the EU countries as well as countries outside Europe on a wide range of topics. The ***Interactive graphs and maps*** present certain indicators broken down to nations and regions.

By the http://www.ksh.hu/nepszamlalas/detailed_tables?lang=en link one can access the latest ***census data***, broken down to country, regions and counties -and for some indicators even micro-regions- in Excel format. The related publications can be downloaded or purchased in print.

2.2.2. Death data information service

The database has made Hungarian mortality data available (number of deaths, standardized mortality rate -SHH) in territorial breakdown (region, county, micro-region, district) by age group and sex since 2005. The database can be accessed via the website of the National Institute for Health Development (NEFI): **http://www.oefi.hu/halalozas/**

In the opening page the year of data collection, the territorial unit, the indicator (case or rate) and, finally, the total mortality or mortality by disease groups, for the whole population (0-X years) or people aged under 65 (early death 0-64 years) can be selected. The appearing results table can be downloaded in Excel format and the required indicator can also be shown in a map. The map uses colour coding to represent differences in mortality, moreover, the data from areas with the highest and lowest indices are also displayed numerically below the map. Maps are also available after selecting the year, the cause of death, the indicator, the age group and the sex. (Figure 2/15) [**41**]

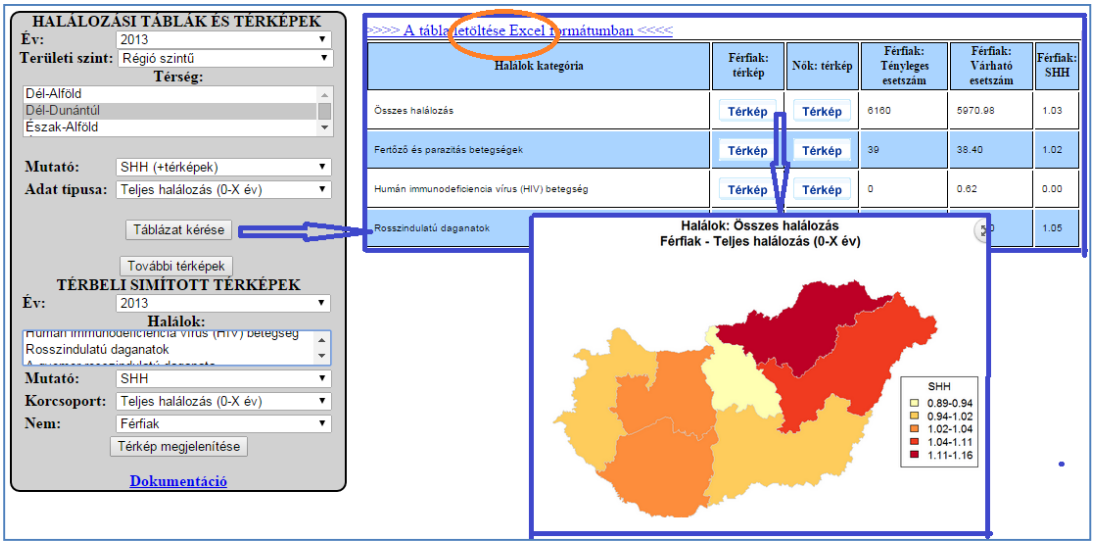

Figure 2/15: The search interface of the information system of mortality indicators

http://www.oefi.hu/halalozas/

2.2.3. Internet-based Hungarian Health Datawarehouse (IMEA)

Currently the database publishes data which have been collected by the State Health Care Management Centre (ÁEEK) related to some of its tasks (e.g. international reports, data of the Regional Health Datawarehouse) or are provided by other institutions for the purpose of Internet publication on the basis of some programme or agreement (Hungarian Health Datawarehouse).

The database can be accessed from the opening page of the State Health Care Management Centre (earlier known as the National Institute for Quality- and Organizational Development in Healthcare and Medicines - GYEMSZI) by clicking on the *GYEMSZI archive* menu in the pop-up window within *Health statistics* or by the following link: http://imea.gyemszi.hu/IMEAIndex.jsp (Figure 2/16)

In the website of the **Internet-based Hungarian Health Datawarehouse (IMEA)** one can access the *Regional Health Datawarehouse Online (REA)*, the *Hungarian Health Datawarehouse Online (MEA)* and the *data reported to the OECD and the HFA* in various themes. In the case of the latter two, national data are available. Thus, for the required index only the year has to be selected. (Figure 2/17)

In the above-mentioned databases one can select region(s), county(ies) and years after choosing the required indicator. By clicking on the RT or MT headings above the data row in the results tables the series of data appears in regional or county maps using colour coding. The tables can be opened in Excel and can be analysed even further.

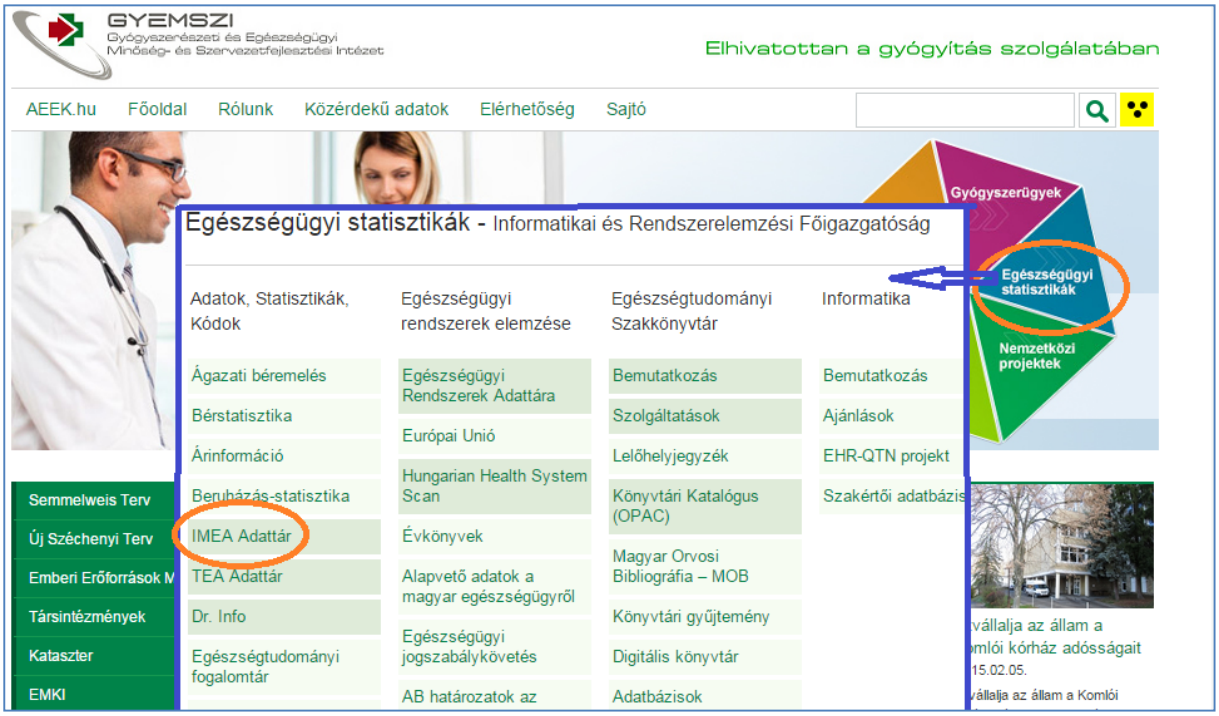

Figure 2/16: Accessing the IMEA database

http://www.gyemszi.aeek.hu/gyemszi/home

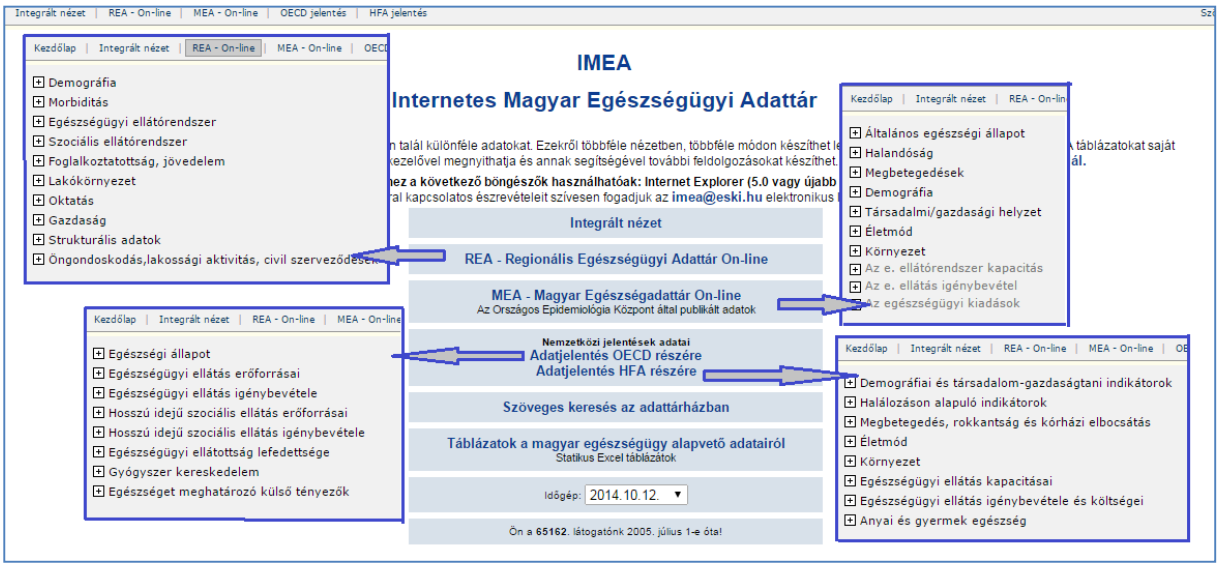

Figure 2/17: Search interfaces accessible within the IMEA database

http://imea.gyemszi.hu/IMEAIndex.jsp

3. THE COCHRANE LIBRARY (TAMÁS DECSI)

3.1. THE ROLE OF THE COCHRANE LIBRARY IN HEALTH CARE

Among the databases used in health care the database of the Cochrane Collaboration, the Cochrane Library, plays a special part due to the fact that it serves as a kind of link between the technical databases of the operation of health care and the databases that contain scientific information related to health care.

Today the best-known part of the Cochrane Library is the Cochrane Database of Systematic Reviews (CDSR), which primarily deals with review articles on questions connected directly to clinical care. However, meanwhile special sub-libraries have also been separated within the Cochrane Library that contribute not only to the solution of particular clinical problems by providing systematic data, but also serve as effective tools for the operation and development of health care systems. On the one hand, they contain technical data necessary for the quality assurance of clinical research activities in an easily accessible form, while, on the other hand, they also provide high quality data for the economic assessment of patients' clinical care. The structure of the Cochrane Library is summarized in *Table 3/1*.

Table 3/1: The databases of the Cochrane Library

	Name	Number of documents
1.	Cochrane Database of Systematic Reviews (CDSR)	*8841*
2.	Cochrane Central Register of Controlled Trials (CENTRAL)	861602
3.	Cochrane Methodology Register (CMR)a	15764
4.	Database of Abstracts of Reviews of Effects (DARE)b	36795
5.	Health Technology Assessment Database (HTA)	17397
6.	Economic Evaluation Database (EED)b	15015

a = Due to the lack of resources the database has not been updated since July 2012.

b = Due to the lack of resources the database has not been updated since April 2015.

(http://www.cochranelibrary.com/about/about-the-cochrane-library.html, 29 June 2015)

3.2. THE CREATION OF THE COCHRANE LIBRARY

The paradox that brought about the foundation of the database called Cochrane Library in its current form emerged together with modern medical literature. Although an increasing number of high quality clinical trials that produced results applicable in the practice of health care had been conducted, the reviews of these research results had been sporadic and even if they had been published it had happened with considerable delays. Although information necessary for improving the quality of medical care had already existed 'somewhere' in the literature of medical science, most of the practising physicians had no access to it. Consequently, it could not be utilized in health care. It was a book published in 1972 by an English epidemiologist, Archibald (Archie) Cochrane, [42] that drew attention to the problem the most effectively. In his book the author explains why the indicators of healing had not improved in spite of increasing healthcare expenditure by pointing out that the health care system had been slow in getting to know and utilize the latest achievements of medical research. The Cochrane Collaboration and the Cochrane Library got their name from the formulator and influential promoter of this historical idea.

Today the Cochrane Collaboration dates back more than 20 years. The first Cochrane Centre was established in Oxford in 1992 followed by one in Canada the next year, and later the Scandinavian Nordic Cochrane Centre and finally the Cochrane Collaboration was also formally established in Oxford in 1993. At present 14, mostly regionally organized Cochrane Centres form the backbone of the Cochrane Collaboration, which is present also formally and organizationally on every continent. Today Hungary also participates in the Cochrane Collaboration officially.

The Hungarian Cochrane Branch was established on 16 October 2014 at the Clinical Centre of the University of Pécs. The Hungarian Branch operates in close cooperation with the German Cochrane Centre with its methodological help and official support. **The main goals of the Hungarian Cochrane Branch include:**

- providing information about the Cochrane Collaboration,
- participation in international Cochrane-activities,
- training professionals capable of creating systematic reviews and writing up-dated Cochrane review articles.
- furthermore, it provides language-specific services (e.g. the collection of data from Hungarian journals for writing Cochrane review articles and the translation of the abstracts of review articles into Hungarian),

- dissemination of the results of Cochrane reviews in Hungary and the promotion of a more and more wide-spread use of Cochrane reviews in Hungary. The further aims of the Hungarian Cochrane Branch also include:
- facilitating knowledge transfer of high quality healthcare evidence by establishing formal and informal partnerships and
- promoting access to the Cochrane Library and to Cochrane systematic reviews.

The first element of the Cochrane Library, the CDSR database, was founded in 1995. The practical importance of the CDSR, already evident at that time, was well indicated by the fact that it was the Secretary of State for Health of Britain who established the database, which according to the report of the Lancet was an initiative whose importance was comparable to that of the Human Genome Project. Later the Cochrane Library was enlarged by further databases listed in *Table 1*. It is a dynamically changing structure; the practical importance of the individual units changes from time to time with the changes in the demands of health care and other external circumstances. This database - library is one of the main bases of scholarly literature and evidence-based Medicine (EBM).

3.3. THE DATABASES OF THE COCHRANE LIBRARY

3.3.1. The Cochrane Database of Systematic Reviews

The Cochrane Database of Systematic Reviews (CDSR) is surely the most frequented and most cited part of the Cochrane Library. Nowadays the CDSR is the leading database of systematic reviews in medical science. The average impact of the CDSR, which can also be regarded as a scientific journal, is increasing continuously: its value is around 6 at present (impact factor2014: 6.032), which is a remarkably high value in medical science. (The impact factor is a measure based on the average number of citations of scientific journals. The impact factor of a journal is calculated by dividing the number of citations in the given year by the number of papers published in that journal during the two previous years. The higher that value is, the more influential and, consequently ,more “valuable” the given scientific journal is.)

In the MEDLINE database the number of publications found by using the search term ‘Cochrane review’ has shown a dramatic increase over the past 20 years: while during the 5-year period between 1995-1999 the database contained only a couple of hundreds of systematic reviews, in the 5-year period between 2010-2014 nearly 20 000 systematic reviews were found by using the same search term *(Figure 3/1)*.

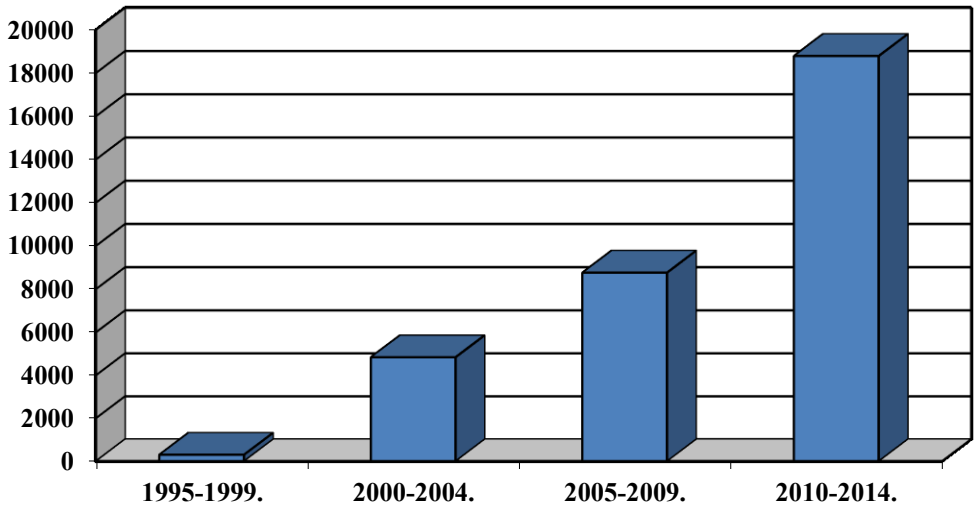

Figure 3/1: 'Cochrane' systematic reviews in the MEDLINE database

2015.(the data search took place on 28 June 2015 via PubMed access using the search term 'Cochrane review'.)

It must be emphasized that in the CDSR database the publications on any given issue are regularly up-dated. Thus, the current size of the database is smaller than the total of publications that have appeared during the various periods. At the end of 2014 the CDSR database contained 8 532 publications, 6 180 of which were systematic reviews, while 2 352 were protocols43.

Conceptually the Cochrane Review is a systematic review that summarizes the results of human trials concerning various issues of clinical health care and health policy based on the highest standards of evidence-based health care. The clinical questions may concern different stages of health care, which are usually answered by different types of trials. Concerning issues regarding diagnostic information necessary for recognizing clinical pictures, normally cross-sectional studies provide information. The questions of medical treatment today usually mean having to choose from several available therapeutic procedures; such problems can be answered by randomized controlled clinical trials. Prognostic information necessary for prognoses mainly come from cohort studies and case control studies based on observations. For dealing with all three types of questions primary studies describing the particular trials, whose results the systematic review summarizes, are of profound importance.

Although the type of scientific publication called review was first designed and became common for summarizing the results of randomized controlled trials, in the last decade it has been more and more widely used for the structured summary of the results of not only randomized controlled trials but also various other scientific studies based on observation. Regardless of what health care issue is concerned the basic condition for creating a systematic review of suitable quality is the formulation of the problem as an unambiguous question. Almost without exception all systematic reviews included in the CDSR database comply with the structure of the PICO (i.e. Patients, Intervention, Control, Outcome) model for clinical questions. The unambiguity of the research question is a fundamental element of the high professional quality of the systematic reviews of the CDSR.

Another component of ensuring high quality is the standard system of requirements for the community of authors producing the systematic reviews. The so-called Cochrane Review Group Editorial Team, on the one hand, scrutinize and authorize the writing of a Cochrane systematic review in a particular topic in advance and, on the other hand, they also support the writing process by providing computer software and reference books. An indispensable element of the authorisation process is the approval of the protocol of making the systematic review. This protocol has to contain not only the exact question the planned systematic review is addressing but also the methodological elements of finding and critically assessing the literature serving as the basis of the publication. As a result, it is easy to understand why the Cochrane Systematic Reviews are those scientific publications in medical science that have the greatest practical influence. Nowadays the CDSR publications are considered an almost unquestionable authority not only in answering concrete clinical questions but also in making decisions on health policy and health economics.

If one searches for a CDSR review in a given topic, there are at least two different ways of accessing - at least a short abstract of - the articles. The search function of the database at http://www.cochranelibrary.com can also be used but one may also make use of the search facilities offered by the MEDLINE database. While the abstracts are freely available to everyone, access to the complete articles is limited. Earlier access was mainly subject to subscription. However, it has been a favourable development of the past few years that certain articles in the database now appear as ‘open access’ thanks to authors who pay an extra fee for that purpose. Another great achievement is also that the CDSR database has become accessible for the citizens of certain countries as a result of the decisions of the governments of those nations.

At present, besides India and Australia the European countries of Denmark, the United Kingdom, Ireland and Norway belong to that group. Also, the database is freely accessible to the residents of 100 so-called low- and middle-income countries; in Europe Albania, Bosnia, Kosovo, Macedonia, Moldavia, and Ukraine are in this category.

3.3.2. The Cochrane Central Register of Controlled Trials

The verification of causal relationships of great significance in medical science can only be achieved by active interventions, so-called controlled trials. One group of the participants in such trials is exposed to some effect, e.g. they receive a drug treatment, while the other group is not exposed to the same effect. Provided the two groups were similar in every other respect at the beginning of the experiment, the differences perceived at the end of the test can be attributed to the intervention with good reason. (The description of the characteristics of controlled clinical trials and their roles in making health care decisions is beyond the scope of this book chapter. For further reading on the topic we recommend a textbook published earlier44.)

The Cochrane Central Register of Controlled Trials (CENTRAL) is a concentrated warehouse of randomized controlled clinical trials. The database contains the authors, titles, bibliographic data necessary for identification of the publication as well as a short abstract (however, the full text is usually not available). The CENTRAL database is monthly updated and has been expanding dynamically since the beginning. Today the database dates back more than 20 years. The project, officially launched in 1992, was enlarged by about 300 000 publications in the first decade and by more than 500 000 in the second decade of its operation.

Concerning their sources, approximately two thirds of the publications of the CENTRAL database come from MEDLINE, while almost one third of them from the EMBASE database. The unique feature of CENTRAL is, however, that it does not only contain information from electronic databases but even so-called handsearch results, such as conference proceedings that are not in the databases of MEDLINE or EMBASE. According to the practical needs of medicine, apart from randomized controlled clinical trials (RCT) in the strict sense of the term, CENTRAL also contains a great number of controlled clinical trials (CCT) in which randomization did not take place according to the standard professional principles of today but being controlled still allows reaching conclusions of a scientific standard.

3.3.3. The Cochrane Methodology Register

The Cochrane Methodology Register (CMR) provides methodological guidance for writing systematic reviews in social care and health care. The database is primarily aimed at informing researchers and health care professionals with relatively little experience who wish to produce systematic reviews on a given topic area. The great advantage of the database is that it provides quick and specific reference on the details of formulating clinical questions, identifying information, assessing the quality of evidence, mathematical expression of data or the methodological aspects of publishing results. Although the database has not been updated since July 2012 due to the shortage of funds, it is still an indispensable tool for writing systematic reviews even in its present form.

3.3.4. The Database of Abstracts of Reviews of Effects

The Database of Abstracts of Reviews of Effects (DARE) is a storehouse of information based primarily on systematic reviews dealing with health interventions and the organizations and health care systems performing them. In addition, it also contains systematic reviews concerning issues that are not directly related to health care but influence the health status of the population significantly, e.g. the conditions of housing and transportation or the various aspects of the social safety net. The DARE database includes all the CDRS review articles but it also draws on the great wealth of electronic systematic reviews on health care. However, the DARE database only accepts systematic reviews that comply with the quality requirements of writings of this genre in every aspect. Thanks to the strict inclusion criteria the DARE database is especially useful in the process of preparing decisions on health policy, which generally require comprehensive knowledge. Although the DARE database has not been updated since April 2015 due to the lack of funding, at the time of writing this chapter the database can still be used without any methodological reservations and limitations.

3.3.5. The Health Technology Assessment Database

The separate subchapter of evidence-based medicine is a complex analysis of techniques used in health care considering not only their aspects which are strictly related to medical science but also economic, sociological and ethical ones. The Health Technology Assessment Database (HTA) contains publications appearing in this particular area of science, complemented with the descriptions of the most important elements of numerous current projects. A special feature of the database is that besides the conventional approaches of medical research it also contains other sources of health care information and economic analyses. Practical users should, however, be aware that -party because of the heterogeneity of the documents included- the publications in the Cochrane HTA database do not go through such rigorous preliminary critical assessment as those in the CDSR and the DARE databases.

3.3.6. The Economic Evaluation Database

The NHS Economic Evaluation Database (EED) contains the economic assessments of various health interventions. In health-economic analyses usually the results and costs of two (possibly more) different methods of patient care are compared. The results are normally expressed by indicators typical of the given disease in the form of health benefit, while costs are represented by individuals' and the society's expenses expressed in money. The EED database contains various types of health-economic analyses (cost-benefit, cost-utility, cost-effectiveness) complemented by critical commentaries in the case of questions of special importance for health care. Unfortunately, this database has not been updated either since April 2015. Nevertheless, it is still available via the Cochrane website.

4. CODE SYSTEMS (ICD, ICF) FOR THE CLASSIFICATION OF DISEASES (DÓRA ENDREI)

4.1. THE HISTORY OF THE ICD

The early beginnings of the International Classification of Diseases goes back to the 18th century. At first it was created for the purpose of statistics on the causes of death. The set of data, which was compiled by John Graunt, rather resembled just a list at the time, and did not show any particular organization. In the 19th century Culen's Synopsis Nosologiae Methodicae, created for the classification of diseases, was the most popular literature on the subject. However, it did not contain the latest development of medicine. In 1855 in a congress held in Paris a list of 139 items was accepted. Later it was revised in 1864, 1874, 1880 and also in 1886. According to Farr's recommendation the classification differentiated between general diseases and diseases limited to a certain organ or anatomical area. [45]

In 1898, at the meeting of the American Public Health Association, held in Ottawa, the Bertillon Classification of Causes of Death was accepted and a recommendation was also made for revising the classification every ten years. [46] On 21 August 1900 the detailed classification of the causes of death, containing 179 groups and 35 groups of brief classification, was accepted.[47] In 1948 the classification was also extended to non-lethal clinical pictures. In 1975 at the International Conference for the Ninth Revision it was realized that the ten-year interval had proved to be too short. At present the tenth revision, which has gone through several modifications, is used. The eleventh revision is expected to take place in 2017.48

The International Statistical Classification of Diseases and Related Health Problems (International Classification of Diseases) is published by the World Health Organization (WHO). This system of classification is used widely for preparing statistics related to mortality and diseases. Since 1994 the member states of the WHO have used the tenth revised version (ICD-10).(48)

In Hungary it was Decree 42/1995. (XI.14.) of the Ministry of Welfare that prescribed the introduction of the tenth revision of the International Classification of Diseases 49. According to Section 1 of the decree, instead of the Ninth Revision of the International Classification of Diseases "the tenth revision of the International Statistical Classification of Diseases and Related Health Problems shall be applied" from 1 January 1996 in every document, in which codes related to the particular diseases are to be indicated according to

the law. The greatest innovation in the tenth revision is the use of the alphanumeric code system. Thus, at the four-character level in the first digit there is a letter followed by three numbers. This change has increased the possibilities available for coding more than twofold, and also allows assigning separate letters to each main group. Altogether 25 letters have been used and the letter U has been put aside for future additions.

The code system, which has gone through significant changes, was based on Bertillon's classification from 1893. The sixth revision of the ICD was elaborated under the supervision of the WHO. The repeated revisions are justified by the more and more precise descriptions of the individual diseases.

The original goal of creating the ICD was the aspiration of the WHO to show the health statuses of every country and continent and to make the data suitable for determining interventions (e.g. epidemic prevention) and to decide which diseases have significance for public health. Since every condition must be classified somehow, it is also possible to use the categories, such as "other specified" and the "without separate specification" or "not elsewhere classified".

4.2. The STRUCTURE of the ICD

The ICD code system has a hierarchic structure where the highest level is that of the chapters. Below the chapters there larger units, so-called ICD groups, which are made up of three characters and are necessary for the collection of international health care statistics data. The further divisions, the so-called four-character subcategories, are not used in international statistics and the levels even further below that only serve national classification purposes.

Verbal descriptions do not belong to the ICD categories, except in the case of psychiatric diseases, in other cases the individual disease codes and/or the codes of disease groups have verbal descriptions.

(e.g. F07.8 Other organic personality and behavioural disorders due to brain disease, damage and dysfunction)

Besides medical terminology, Latin and English (in the Hungarian version Hungarian) wording is mixed. In certain verbal specifications exceptions are also given.

(e.g. Enthesopathies of lower limb, excluding foot)

Some categories also include anatomical terminology.

(e.g.: M79.4 Hypertrophy of [infrapatellar] fat pad)

Apart from rules at the levels of groups and chapters, there are also global rules, which regulate the use of the code system as well as the preparation of ICD-based morbidity and mortality statistics.

Number of ICD versions

Currently version ICD-10, which features several innovations compared to the ninth version, is in use. The greatest novelty in the tenth revision is the use of the alphanumeric code system, according to which there is a letter and three numbers at the four-character level. As a result, the number of coding options has been increased by more than 100%, allowing the association of letters or groups of letters with chapters. The original ICD-10, published by the WHO, appeared in three volumes in book form.

1. The first volume provides information on the whole system and also contains morphological codes besides verbal descriptions and rules.
2. Volume 2 or the instruction manual presents the use of the code system and the rules for making mortality and morbidity statistics.
3. Volume 3 is the alphabetical list of the names of the diseases with the codes also displayed next to them.

The ICD-10 comprises 21 chapters, which are presented in detail in the table below.

Table 4/1: Structure of the ICD code system [50]

Chapter number	**Chapter title**	**ICD code**
I	Certain infectious and parasitic diseases	A00–B99
II	Neoplasms	C00–D48
III	Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism	D50–D89
IV	Endocrine, nutritional and metabolic diseases	E00–E90
V	Mental and behavioural disorders	F00–F99
VI	Diseases of the nervous system	G00–G99
VII	Diseases of the eye and adnexa	H00–H59
VIII	Diseases of the ear and mastoid process	H60–H95
IX	Diseases of the circulatory system	I00–I99
X	Diseases of the respiratory system	J00–J99
XI	Diseases of the digestive system	K00–K93
XII	Diseases of the skin and subcutaneous tissue	L00–L99
XIII	Diseases of the musculoskeletal system and connective tissue	M00–M99

XIV	Diseases of the genitourinary system	N00–N99
XV	Pregnancy, childbirth and the puerperium	O00–O99
XVI	Certain conditions originating in the perinatal period	P00–P96
XVII	Congenital malformations, deformations and chromosomal abnormalities	Q00–Q99
XVIII	Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified	R00–R99
XIX	Injury, poisoning and certain other consequences of external causes	S00–T98
XX	External causes of morbidity and mortality	V01–Y98
XXI	Factors influencing health status and contact with health services	Z00–Z99

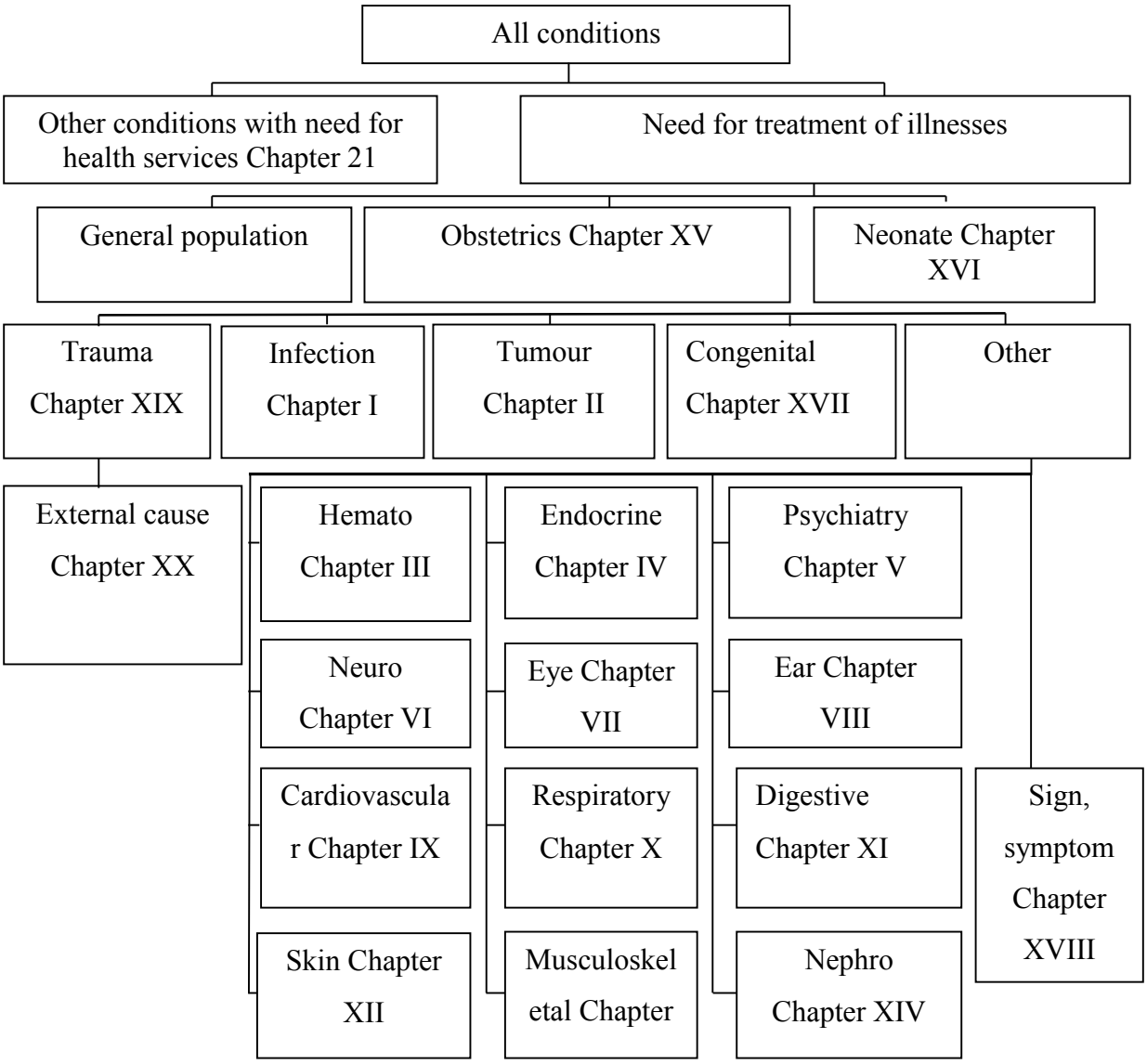

Figure 4/2. Figure of Nitsuwat and Paoin on ICD chapters [51]

4.3. DESCRIPTIONS OF THE CHAPTERS

I. Certain infectious and parasitic diseases

The chapter contains diseases caused by living pathogens: bacteria, viruses and parasites, on which the internal structure of the chapter is based. The chapter mainly includes pathogens causing lesions significant from an epidemiological point of view. Secondarily, it also contains organ specific localization, since a considerable part of pathogens cause lesions in certain organs only.

II. Neoplasms

They are classified according to whether they are benign or malignant (dignity). After the categorization of the dignity of a tumour it is localized.

III. Diseases of the blood and blood-forming organs and certain disorders involving the immune mechanism

Classification here takes place on the basis of the blood constituents (blood cells, blood-clotting factors, immunologic cells and immunoglobulins). A large part of the chapter also includes the various forms of anaemia.

IV. Endocrine, nutritional and metabolic diseases

First the chapter treats diseases related to the various endocrine glands and the hormones produced by them followed by nutritional and metabolic diseases. The most detailed part of the classification includes the categories connected to diabetes.

V. Mental and behavioural disorders

In this chapter the individual clinical pictures are grouped according to the various mental functions, which also appear from an aetiological perspective. Due to the lack of information related to the clinical pictures verbal descriptions also belong to the ICD items.

VI. Diseases of the nervous system

The chapter includes the various groups of the diseases of the nervous system, starting with the diseases affecting the central nervous system to the disorders of the cells, nerve roots and the plexus.

VII. Diseases of the eye and adnexa

The classification begins with the diseases of the eyelid, the lacrimal system and the orbit, followed by the lesions of the smaller structures of the eye (e.g. the lens). The categorization deals with the diseases of the blood vessels, neural pathways and the ocular muscles as well as the reasons of the various visual disturbances and blindness separately.

VIII. Diseases of the ear and mastoid process

The chapter contains the classification of the diseases of the external ear, the middle ear, the mastoid, the inner ear and also other diseases affecting the ear.

IX. Diseases of the circulatory system

This chapter provides a detailed categorization of the various circulatory diseases and the lesions affecting the veins.

X. Diseases of the respiratory system

The major groups comprise the lesions of the upper and lower respiratory tracts and the pleura. The classification of the lung diseases caused by various external agents is also of a significant extent.

XI. Diseases of the digestive system

The chapter contains very wide classifications since the structures of the digestive system are complemented also by the lesions affecting the oral cavity and the jaws as well as the various types of hernia.

XII. Diseases of the skin and subcutaneous tissue

This chapter includes, among others, the grouping of the infections, inflammations, and radiation-related disorders of the skin and subcutaneous tissue.

XIII. Diseases of the musculoskeletal system and connective tissue

Here the disorders of the structures of the joints, the connective tissue, the spine and soft tissue are dealt with in detail. Furthermore, the chapter also treats the lesions that affect bones and cartilage.

XIV. Diseases of the genitourinary system

This chapter contains the diseases of the kidneys, the urinary system, the male and the female genital organs as well as the disorders of breast and the inflammatory and other diseases of female pelvic organs.

XV. Pregnancy, childbirth and the puerperium

Here one finds a mixed classification according to whether the pathological state is related to the mother or the foetus and according to the stages of the process of pregnancy, labour, delivery and puerperium.

XVI. Certain conditions originating in the perinatal period

Classifications based on the causes or the processes of the diseases or on the organ systems are found mixed in this chapter.

XVII. Congenital malformations, deformations and chromosomal abnormalities

The diseases here are categorized according to the organ systems and/or organs affected, while the chromosomal abnormalities comprise a separate group.

XVIII. Symptoms, signs and abnormal clinical and laboratory findings, not elsewhere classified

The chapter contains classifications based on localization (circulatory and respiratory systems, digestive system, skin, nervous and musculoskeletal systems, urinary system), on functionality (perception, behaviour, emotion, speech) and also categories according to the processes of examination.

XIX. Injury, poisoning and certain other consequences of external causes

The main criterion of classification is the type and localization of the injury. The sequelae of burns, poisoning and injuries comprise a separate group.

XX. External causes of morbidity and mortality

The grouping classifies the circumstances of the injuries. In version 9 of the ICD this chapter was still regarded as a supplementary classification.

XXI. Factors influencing health status and contact with health services

Here one finds categories of occasions when a person receives health care or services for a reason other than disease (general examination) [52]

4.4. USING THE ICD CODE SYSTEM

The ICD code system serves numerous purposes thanks to the information it provides. Its use is widespread, among others, in the financing processes of health care institutions as well as the preparation of public health statistics. The currently effective ICD code system is traditionally managed by the health insurance (OEP, Gyógyinfok). Healthcare providers have to carry out a continuous coding activity for the purpose of performance inspection and settling their performance accounts with the insurance company, which is the task of the coding administrators in close cooperation with ward doctors. During coding the ICD code(s) that corresponds to the known status of the patient and is associated with the care event is determined. This is based on the diagnosis in the patient's documentation, which can be found in the data sheets of both out- and inpatient care.

That is followed by the classification of the disease; it has to be decided which chapter the disease belongs to. It is a general rule that if several chapters may be involved, classification based on organ systems is only justified if no other suitable category is available (e.g. colon cancer is not found in the chapter of the diseases of the digestive system but in that of neoplasms).

After that the category is recorded, i.e. instead of a verbal denomination a quasi-numeric datum is recorded (conversion). That is followed by the selection of the main disease and/or the determination of other "labels", e.g. in the case of death it is necessary to indicate the direct cause of death, the complications and the attendant diseases. The detailed rules of labelling keep changing; it is important to stay up-to-date.

Mistakes may occur in the coding process, which may be caused by several factors. The activities performed by the health care provider are recorded in separate forms and, by combining these, reports are made for the health insurance. The reports, however, do not always correspond to the findings of the health insurance, since care/service providers are often prone to under- or overcoding. Another source of mistakes is the errors during the recording of the cases, in which case the insurance withholds the money payable for the

given performance. In the background of the mistakes generally coding errors, confusing in- and outpatient care and the guarantee rule are found.

In order to be able to settle their performance accounts with the health insurance as precisely as possible, care providers must be aware of and follow the relevant legislation closely. It is common that care providers contract certain consulting firms which help with their coding activities either by "selling" their employees expertise (e.g. consulting) or by providing them with software.

4.5. The International Classification of Functioning, Disability and Health (ICF)

The International Classification of Functioning, Disability and Health (ICF) was created by the WHO in order to provide unified terminology for the classification of health and the statuses related to health. Similarly to the two code systems mentioned above, it classifies health conditions with numbers and letters according to different criteria, applying the health-related subdomains of both health and well-being. These subdomains are listed in two main domains both from the perspectives of the individual and the society (1 Body functions and structures, 2 Activities and participation). From the initial form of 1980 -"the classification of the consequences of diseases"- the system has developed towards the direction of the classification of "the components of health". Both functioning and disability are umbrella terms referring to all body functions, activities and involvement, on the one hand, and all types of damage, disability and limitation of participation, on the other hand. The classification system also lists the environmental factors that are in interaction with the above-mentioned items. Thus, a possibility is created for the user to assess the degree of functioning and disability. The ICF, as a system of classification, categorizes the subdomains related to persons living with pathological health conditions (in the case of the presence of a given pathological health condition what a person does or is able to do). Thanks to the standardized form, the ICF code system allows people working in different fields or disciplines to compare various health services and to address the individual factors of different health conditions. [53] While, the ICD code system mainly describes the diagnoses of pathological health statuses, the ICF provides further information on the functioning ability related to the diseases. As a result, the ICD and the ICF code systems complement each other and it is advisable to use them together [54]. Due to information obtainable about the health conditions of individuals or groups, the code systems can also have a role in decision-making. The results of these classifications (ICD, ICF) can be combined, which makes monitoring of health conditions possible.

Furthermore, the distribution of characteristics in the background of morbidity and mortality can also be investigated. The code system divides the information into two main chapters: the first one deals with functioning and disability, while the second one with the contextual factors. In the first chapter the functions of the systems of the body and the structures of the body are classified. The chapters are arranged according the systems of the body. The activities and participation contain the subdomains which describe the individual aspects of functioning from an individual perspective, on the one hand, and from a social one, on the other hand. The chapter of contextual factors begins by listing the environmental factors which affect every component of functioning and disability. The environmental factors follow one another from the environment of the individual to the wider environment. Generally, it may be said about the ICF classification system that its use is universal. [**55**] Two versions of different detail of the ICF have been made, and its complete version contains the classifications in four-character detail. This, however, can be condensed into a higher level classification system, which includes the subdomains up to the second characters. This is called the ICF Pocket Version. The table below presents the classification of the ICF code system and the list of chapter titles of the classification.

Table 4/2: The ICF code system

Body functions	**Appellation**	**Code**
Chapter 1	Mental functions	b110-b199
Chapter 2	Sensory functions and pain	b210-b299
Chapter 3	Voice and speech functions	b310-b399
Chapter 4	Functions of the cardiovascular, haematological, immunological and respiratory systems	b410-b499
Chapter 5	Functions of the digestive, metabolic and endocrine systems	b510-b599
Chapter 6	Genitourinary and reproductive functions	b610-b699
Chapter 7	Neuromusculoskeletal and movement-related functions	b710-b799
Chapter 8	Functions of the skin and related structures	b810-b899
Body structures	**Appellation**	**Code**
Chapter 1	Structures of the nervous system	s110-s199
Chapter 2	The eye, ear and related structures	s210-s299
Chapter 3	Structures involved in voice and speech	s310-s399
Chapter 4	Structures of the cardiovascular, immunological and respiratory systems	s410-s499
Chapter 5	Structures related to the digestive, metabolic and endocrine systems	s510-s599
Chapter 6	Structures related to the genitourinary and reproductive systems	s610-s699
Chapter 7	Structures related to movement	s710-s799
Chapter 8	Skin and related structures	s810-s899
Activities and participation	**Appellation**	**Code**
Chapter 1	Learning and applying knowledge	d110-d199
Chapter 2	General tasks and demands	d210-d299
Chapter 3	Communication	d310-d399
Chapter 4	Mobility	d410-d499
Chapter 5	Self-care	d510-d599
Chapter 6	Domestic life	d610-d699
Chapter 7	Interpersonal interactions and relationships	d710-d799
Chapter 8	Major life areas	d810-d899
Chapter 9	Community, social and civic life	d910-d999
Environmental factors	**Appellation**	**Code**
Chapter 1	Products and technology	e110-e199
Chapter 2	Natural environment and human-made changes to environment	e210-e299
Chapter 3	Support and relationships	e310-e399
Chapter 4	Attitudes	e410-e499
Chapter 5	Services, systems and policies	e510-e599

5. FINANCING (ICPM, DRG) CODES (DÓRA ENDREI, RÓBERT PÓNUSZ)

5.1. INTRODUCTION – THE SIGNIFICANCE OF FINANCING CODES

At first, the introduction of code systems in health care was justified by statistical-epidemiological reasons. However, no computers existed back then. The use of code systems, the purpose of which was to make individual identification possible, had become necessary because of the increasingly complex conditions of patients. Nowadays the most important reasons for the existence of the various code systems are the necessity of unambiguity in identification and the suitability of data for processing. The chapter treats the most significant financing code systems used in Hungary -HDG, ICD, ICPM, ICF- in detail.

5.2. THE INTERNATIONAL CLASSIFICATION OF PROCEDURES IN MEDICINE (ICPM)

For the identification of the various medical procedures the code system called the International Classification of Procedures in Medicine (ICPM), developed by the WHO, is used in Hungary. The original publication by the WHO appeared in 1978, as an experimental version. Its purpose was to prepare the final version taking the feedback of the various countries into consideration.[56] As it has never been realized, the WHO deleted it from its programme. The compilation of the International Classifications of Health Interventions (ICHI) has begun recently. In Hungary -similarly to other countries- a national version has been created for the classification of medical activities. In Hungary, depending on whether outpatient or inpatient specialist care is concerned, two intervention code systems have been made, and they serve as the basis of accounting of health care services towards the health insurance and financing. The list of codes associated with the various interventions is made available in an electronic form by Gyógyinfok. During the development of the system special care was taken to avoid diagnostic statements - they are described by ICD codes. The domain of the ICPM code system consists of the various medical activities. In addition, it also allows the identification of expensive equipment, whose financing takes place afterwards, based on invoices.[57] The domain of the code system comprises five-character numeric codes. The alphabetic characters are used to identify the valuable equipment used for the particular interventions. Table 5/2 shows the chapters of the ICPM code system, while Table 5/3 the structure of the ICPM codes and

the number of points (so-called 'German points') that provide the basis of billing for each intervention and examination.

Table 5/1: The chapters of the ICPM code list

Examinations, interventions	**Range of codes**
examinations, diagnostic procedures	10000-19999
clinical laboratory, pathological tests	20000-29999
radiological and medical imaging examinations	30000-39999
preventive and screening procedures	40000-49999
invasive therapeutic procedures	50000-59999
not elaborated during the compilation of the ICPM	60000-79999
in the original (WHO) version medicines are listed in this chapter	
other therapeutic procedures	80000-89999
other procedures	90000-89999

source: National Health Insurance Fund of Hungary-FIFO

Table 5/2: Structure of the ICPM code system

Code	Name of activity	Points
11011	First aid	176
11041	Examination	750
21057	Identification of tumour necrosis factor alpha (TNFα)	1 610
31312	Medical imaging of chest, from two directions	923
34461	CT examination of pelvis following the administration of contrast agent	10 137
42110	Hip dislocation screening	141
42400	Mammographic screening	2 957
53416	Mediastinoscopia collaris sec. Carlens	1 840
54490	Endoscopic polypectomy in the upper alimentary tract	20 655
81020	Removal of foreign body from eyelid or orbit	291
8888H	Regional anesthesia	227

source: National Health Insurance Fund of Hungary-FIFO

5.3. HOMOGENEOUS DISEASE GROUPS (HDGS / DRG)

Historical overview

In Hungary the financing of in-patient specialist care is based on the Homogeneous Disease Groups (hereafter: HDG). The main characteristic of the Hungarian category system is that it is based on the system of the Diagnosis Related Groups (DRG), whose Hungarian adaptation was in use at first but later as a result of successive improvements it was adjusted to the special features of Hungarian active in-patient specialist care. It is not an exclusively Hungarian characteristic; other countries have also developed their national versions (e.g. Health Related Groups, HRGs, United Kingdom). The fundamentals of the DRGs system were laid down at Yale University (United States) in the 1970s in order that the quality of care could be monitored. A decade later, from 1983, it was already used for financing purposes in the hospitals belonging to the Medicare financing system.[58]

The Hungarian HDG system was introduced on 1 July 1993 as a tool for financing and coding hospital activities. However, the beginnings of the system go back to much earlier, since its introduction had been preceded by long preparations. The establishment of data collection systems, the analysis of costs data and the elaboration of disease groups all comprised integral parts of the preparatory work. In the history of the system three phases that have made it possible for institutions at different levels of progressivity to bill for their services in a standard way nowadays must be highlighted *(the particular phases of the Hungarian HDG system are illustrated by Table 5/1*).

1. The first stage, which was the phase of fee levelling, dates back to the years between 1993 and 1997. Back then the health care institutions were still financed using different HDG basic fees (HUF/weight number). That was the result of the different institutional budgetary positions experienced at the beginning of the 1980s and the 1990s, since the institutions overfunded earlier would have got into an economically impossible situation if standard basic fees had been introduced immediately.
2. The second phase was characterized by the nationwide introduction of the standard basic fees. The institution-specific HUF/weight number fees, typical earlier, were replaced by standard national basic fees. A common feature of these fees was that they were announced in advance, and thus the planning of institutional budgets became also easier for the managements.
3. The third stage began following the introduction of the Performance Volume Limit (hereafter: PVL) in 2004. According to that, the standard national basic fees announced earlier were modified, since health care providers' performance in excess

of the quantity determined by the PVL (given in weight numbers to the particular institutions) is not paid by the insurance in 100 % of the basic fee.

The main characteristics of the HDG

The HDG is a code system based on classifications that group care cases on the basis of ICD and ICPM codes. The basis of categorization are the groups of care cases with identical performance values which are also acceptable from a medical perspective. According to that, diseases are listed in the individual groups based on the professional knowledge and costs needed for their care. Health care providers report the data of the patients treated by them every month. Then the health insurance puts them in homogeneous disease groups taking the following factors into consideration: main diagnosis justifying care, interventions based on main diagnosis, disease(s) associated with main diagnosis (complication, comorbidity), patient's age and his/her further fate.[59] The activities of health care providers are influenced by both the number and the mix of cases. During the elaboration of the HDG system the individual weight numbers were elaborated on the basis of the operating costs, however no depreciation costs were taken into account. (According to the concept of two-channel funding capital costs are to be covered by the institution owners.)

Concepts related to active inpatient care cases

Lower and upper day limits

These are the minimum and maximum numbers of days of care necessary for the treatment of a given HDG. For the period between the two values the healthcare institution is entitled to the fee payable for the whole HDG weight number. Cases shorter than the lower day limit are financed as short-care cases, while those exceeding the upper day limit are financed as long-care cases.

Short-care cases

The duration of care of the case does not reach the day limit set in advance, so the fee payable for the given HDG cannot be billed for. In such a case the funder transfers the amount equal to the product of the number of the actual days of care and the daily fee of the given disease group, determined as the quotient of the current fee of the HDG and the normative days of care.

Long-care cases

Health care institutions also have the possibility to provide long-term care. If the duration of care of a given case exceeds the upper day limit of the given HDG but the patient is still in need of care, the weight number amount payable for the care of the given HDG can still be billed for. And the same applies to the daily fee payable for days of care exceeding the upper day limit, which is 75% of the chronic basic fee (excess day x chronic basic fee x 0.75), and in the case of intensive care it is four times as much (intensive excess day x chronic basic fee x 4).

Normative days of care

This is the duration of a given care case between the lower and upper day limits determined for the given HDG. The health care provider is allowed to bill the funder for the weight number determined for the given HDG.

Case Mix Index

The Case Mix Index (CMI) is an index formed from the weighted averages of the weight numbers of HDGs performed, and it can be calculated for either wards or institutions. The CMI shows the average performance of the unit examined. In the case of HDGs the higher the weight number is, the higher expertise and/or costs are necessary for the care of a given case, and it is also true for calculating the CMI. At the higher level of progressive care (e.g. university clinic) the value of the index is much higher than in the case of health care facilities providing care for less complicated cases (e.g. municipal hospitals).

Days of care

Within the normative days of care health care institutions can bill for the weight number to be charged for the provision of care for the given HDG. For example: in the case of ‘Groin, umbilical and femoral hernia operations over 18 years of age’ (HDG 5.0 code: 281B) the lower day limit is 1, while the upper one is 25 days for the disease group. Between the two extreme values the health care facilities can bill for the same weight number (0.43497), so hospitals are not interested in providing excess care for the patients.

Standardized Day Quotient (hereafter. SDQ)

The average days of care of an institution or ward can be compared to the normative days of care of the given HDG. The quotient of these two values is the standardized day quotient. If the value of the SDQ is lower than 1, the average time of care of the institution examined is shorter than the normative days of care belonging to the given HDG, in which case the hospital does not provide excess care for its patients.

Bed occupancy

Two types of bed occupancy are distinguished: actual and normative bed occupancy. In the case of actual bed occupancy the total of the days of care provided are compared to the days allowed, while in the case of normative bed occupancy the total of the normative days of care provided are compared to the days allowed.

A close relationship can be observed between the SDQ and bed occupancy; in the case of institutions with identical profiles and bed occupancies the institution that has a lower SDQ does its job more economically. This way it can also be established which institution maintains its bed occupancy artificially.

Table 5/3: The stages of the development of the domestic HDG system in Hungary

Version	Period (statute)	Validity	Characteristics
HDG 1.0	01/07/1993-30/06/1994 9/1993. (IV.2.) NM	12 months	The first Hungarian version. The operation-ICD code correspondence was not universal.
HDG 2.0	01/07/1994-28/02/1997 6/1994. (IV.1.) NM	32 months	It contains the correspondences of diagnoses-operations. From 1 January 1996 change due to the introduction of ICD-10. That did not mean any change in content, so no independent version was created.
HDG 3.0	01/03/1997-30/09/1997 3/1997.(II.13) NM	7 months	Significant change in the number of groups, the factors and process of classification and the prioritization of professionally preferred forms of care.
HDG 3.1	01/10/1997-31/031998 34/1997.(XI.7) NM	6 months	Modification of upper day limits for the appropriate application of guarantee rules
HDG 3.2	01/04/1998-30/04/1999 5/1998. 11.) NM	13 months	Creation of new groups in cardiac surgery, haematology and pulmonology
HDG 4.0	01/05/1999-31/05/2000 7/1999.(IV.7) Eü.M.	13 months	Fundamentally new version. The basis of the classification rules is not provided by foreign DRG systems any longer
HDG 4.1	01/06/2000-31/03/2001 13/1999.(IV.7) Eü.M.	10 months	New groups for short-term, emergency cases.
HDG 4.3	01/04/2001-31/01/2004 7/2001. (III.2.) Eü.M.	34 months	The number of groups of minor diseases marked with comorbidity decreased. New groups by age for some adult and paediatric HDG groups with higher funding requirements.
HDG 5.0	01/02/2004-to the present day 3/2004. (I.15.) ESzCsM		The incorporation of the average 50% public sector wage increase. Preference of surgical HDGs

6. IN- AND OUTPATIENT SPECIALIST CARE SPECIALTY CODES (ATTILA LÁNG, DÓRA ENDREI)

6.1. HISTORICAL OVERVIEW

The first information on specialty codes and their structure was presented in Annex 1 of the Decree 32/1997. (X. 28.) of the Ministry of Health on the registration of health care providers and their operating licences. Some of these are still in use. The contract of funding and the operating licence both comprise nine-character identifications, including the following codes from left to right. The first two characters contain the identification of the county followed by the number of the institute. Universities are marked using the number '4' in the third digit. The 5th character indicates the code of the type of care, e.g. the number '1' stands for active in-patient specialist care, and it may also be a letter, e.g. the letter 'C', which represents chronic in-patient specialist care. The 6th, 7th and 8th characters are used for codes according to the list of specialty codes in health care. The 9th digit (if necessary also the 8th) is an individual identification number determined within the specialty by the institute, and it marks a given unit of the health care provider with a number that is different from those of other units.

The decree presented above was amended by Decree 33/2000. (XI. 16.) of the Ministry of Health on the registration of health care providers and their operating licences. It was the decree which stipulated that health care providers and the specialist tasks they are authorized to perform as well as the operating licences permitting the provision of health services are to be registered. The registry is kept by the county (capital city) institutes (hereafter county institute) of the National Public Health and Medical Officer Service (hereafter ÁNTSZ) which are regionally competent for the location of operation of the service providers, while the national registry is the responsibility of the Office of the Chief Medical Officer (hereafter OTH). The data content of the registry was also set down. In addition, apart from the deadlines of registration and the recording of any modifications, their data content to be submitted electronically was also amended.

The currently valid specialty codes are included in Decree *2/2004. (XI. 17.)* of the Ministry of Health on the registration of health care providers and their operating licences and the registry of health care specialties. The decree has gone through several amendments. In 2009 the code *su* (specialized unit) still existed. Codes marked by that were only used for units specialized in a given specialty (activity) as a main profile; no other specialty appellation was allowed to be used for the given specialist activity. In April 2011 out-of-

hospital childbirth care and newborn care with specialty code 0404 and -under specialty code 73- midwife's care (in hospital) with code 7308 and out-of-hospital care by midwife with code 7309 were added as new specialties within obstetrics and gynaecology.
In June 2012 the code *su* was phased out and the appellations and codes of all existing health care specialties were changed. As a result, Annex 2 became much more user-friendly. In December 2013 neurological rehabilitation (0903), clinical dental hygiene (1307), internal medicinal rehabilitation (2202), gynaecological rehabilitation (2204) and haematological laboratory diagnostics (5002) were eliminated from the list. On the other hand, rehabilitation medical primary activities (2200), specialized clinical and mental-hygienic psychology (7101), psychotherapy (with specialized clinical psychologist's qualifications) (7104), neuropsychology (7106), specialized clinical addictological psychology (7107) and clinical dental hygiene were added to the list. In December 2014 gastroenterological rehabilitation with specialty code 2203 was removed from the registry of specialties.2014.

6.2. THE USE OF SPECIALTY CODES, LEGAL BACKGROUND

Specialty codes are necessary for issuing and registering operating licences for health care providers. The national database (hereafter: registry) is managed by the Office of the Chief Medical Officer (hereafter: OTH). During the authorization procedure the authority granting licences provides health care providers and organizational units with identifications created by the registry system. The identification is unique; it cannot be replaced by any other in the case of the same health care provider. The identification of a defunct health care provider may not be given to another health care provider. Apart from the identification of a health care provider, the identifications may not be used for any other purpose, and they do not substitute other identifications used in public administration. The unique identifications of health care providers and those of the organizational units are included in the operating licence. The authorization of operation is based on Act CLIV. of 1997 about health care. Only health care providers -regardless of proprietorship and funding- that have operating licences issued and registered by the competent health care state administration body are allowed to provide health care services. The purpose of the registration is to have a clear and reliable picture of the health care system, the health care providers and the health care specialties authorized for them and their changes. For the continuous operation of the registry and the availability of the data of health care providers registered in the country the OTH is responsible. The monthly changes in the registry are sent to the National Health Insurance Fund of Hungary by the

OTH no later than the 15th day of the month following the month of the change. The authorizing agency -in the course of granting new operating licences or modifying valid operating licences- records the changes of the data of the health care provider. The authorizing agency keeps the data on which the registration was based for at least 30 years from the date of the registration. The data are public, and upon request the OTH makes them available against the payment of a fee. The ministry responsible for the sector and the professional chambers can obtain the data of the registry upon request free of charge, and may use them for analysis and records prescribed by law. Similarly: the Hungarian Association of Hospitals and the Association of Economic Leaders in Health Care for the purposes of analysis, the Hungarian health care institutions for the purposes of planning, analysis and controlling, and the public administration bodies, people's representative bodies, prosecutors, courts of law for fulfilling their tasks under the law, the State Healthcare Management Centre for the purpose of health political analysis and parliamentary commissioners for their tasks under the law. The specialty codes of in- and outpatient specialist care also appear in operating licences, contracts of funding and Decree 60/2003. (X. 20.) of the Ministry of Health on the professional minimum requirements necessary for the provision of health care.

6.3. THE STRUCTURE OF THE SPECIALTY CODES

Only the health care sector is allowed to have specialty codes, which are subject to certain medical qualifications and the minimal professional requirements (personnel and material) set down by the law. These specialties are listed with individual specialty codes in the code registry. In the registry of specialties the two-character specialty code stands for the main health care specialty group. The four-character sub-codes listed under the main groups represent the health care specialties that can be individually licensed within the authorized units, e.g. 0101 - angiology, phlebology, lymphology. From other main groups further specialties can be authorized within a given organizational unit according to specific regulations. Sub-codes ending in -00 mean a general licence for performing activities that can be listed in the basic qualifications of a given main group, for doing activities requiring additional or special qualifications and/or exams specialties marked with independent codes are needed. The complete list is found in Appendix 7 of this chapter.

6.4. THE MAIN GROUPS OF HEALTH CARE SPECIALTIES

In the following chapter the the codes of the main groups of health care specialties are listed according to the current legislation, while their detailed breakdown can be found in

Appendix 6/1.

Code	specialty	Code	specialty
01	Internal medicine	02	Surgery
04	Obstetrics and gynaecology	05	Paediatrics
06	Otorhinolaryngology	07	Ophthalmology
08	Dermatology	09	Neurology
10	Orthopaedics and traumatology	11	Urology
12	Clinical oncology	13	Dental care
14	Rheumatology	15	Anaesthesiology and intensive care
16	Infectious medicine	17	Oral and maxillofacial surgery
18	Psychiatry	19	Pulmonology
20	Plastic surgery and the treatment of burns	22	Rehabilitation medicine
23	Child and adolescent psychiatry	25	Occupational medicine
26	Sports medicine	40	Cardiology
46	Emergency medicine	50	Laboratory diagnostics
51	Medical imaging and radiological therapy: X-ray diagnostics and therapy	52	Interventional radiology
53	Medical imaging and radiological therapy: Ultrasound diagnostics and therapy	54	Pathology and histopathology
56	Special therapy	57	Physiotherapy
60	Tissue bank and cell bank activities	61	Transfusion medicine and blood bank
62	Emergency medical services and medical transport,	63	General practice
64	Primary care of the military and police force	65	Nuclear medicine (isotope diagnostics and therapy)
67	Clinical genetics (human genetics)	70	Clinical pharmacology and distribution of drugs
71	Clinical psychology	72	Health care specialties that can be done with pedagogical qualifications
73	Nursing	76	Dietetics
79	Health visitor care		
80	Supplementary medical activities (with qualifications and content determined by special legislation) - non-conventional medical practices a) medical practices by medical doctors b) activities requiring special qualifications c) activities requiring qualifications acquired in a training ending with an examination.		
93	Military and disaster medicine	94	Public health and preventive medicine
95	Forensic medicine	97	Aviation medicine
ARMA	Activities related to medical accessories		

6.5. THE MAINTENANCE OF THE SPECIALTY CODES

Due to continuous further specialisation there is great need for the maintenance of the specialty codes. Besides the ÁNTSZ, the OTH and the Ministry of Health, the colleges of health care professions play a really important role in this. According to the *Ministry of Human Capacities' decree 12/2011. (III. 30.)* on these professional associations, the divisions - *according to the specialty of the given division* - express their opinions about the system of funding of the health care system; the allocation of the capacities; the progressive levels of care; the introduction, implementation and effectiveness of professional guidelines; the issues of health care and medical education; the system of data collection; the questions of strategic development and any other issues that legislation renders the task of the professional association. Upon the minister's request the divisions express their opinions on any other issue within the field of health care and perform the tasks set down in the request. The head of the division - for the formulation of the professional opinion of the division - may ask for the opinions of the Medical Officer for Health of Hungary or any person appointed by him/her, the permanent quality head physician working in the given specialty and/or the quality head of the specialty, the Chief Pharmaceutical Officer of Hungary, the national institutes, the institutions and councils responsible for medical and health care education and training, and he/she also coordinates the talks on the given professional issue. The divisions and councils observe the validity of the professional guidelines and make suggestions concerning their content and, in certain cases, prepare them. They make suggestions for the minimum requirements for health care providers, give opinions on new examination methods and the conditions of the application of curative and preventive procedures, they coordinate data collection within the given specialties, and cooperate in the elaboration of the professional requirements of the health care quality assurance system. At present 60 divisions/councils of professional associations are functioning with 5, 10, 15 members each.

6.6. ISSUES TO BE SOLVED RELATED TO SPECIALTY CODES

As it can be seen, the decree has been amended several times. Nevertheless, the list of specialties still raises a number of issues to be solved, which indicates the difficulties of conceptual classification. It has not been really clarified what is regarded as a specialty. The list includes some items which can be hardly regarded as such. For example 'work hygienic activities', which is even linguistically defective, since an activity should not be called a specialty. The specialties should be harmonized with the system of medical specialist examinations. Further specialty codes are necessary, especially for the field of

child care. It may also be mentioned as a problem that many of the specialties listed are specialties within more general specialties. That leads to a kind of conceptual hierarchy, which is also reflected in the code system by separating the concept of 'a group of specialties' and that of 'a specialty' in some cases. Such a case is that of obstetrics and gynaecology (04), within which one finds obstetrics (0405) and gynaecology (0406). There seems to be no solution for the problem either that children's ophthalmology (0508) is listed under paediatrics (05) in spite of the fact that is is done by ophthalmologists.

Appendix 6/2

List of health care specialties and their codes serving as the basis of issuing operating licences

01 Internal medicine
0100 internal medicine
0101 angiology, phlebology, lymphology
0102 haematology
0112 haemopoetic stem cell transplantation
0103 endocrinology, metabolism and diabetology
0113 endocrinology
0123 diabetology
0104 gastroenterology
0105 nephrology
0106 geriatrics
0109 allergology and clinical immunology
0110 dialysis
02 Surgery
0200 surgery
0202 lung and thoracic surgery
0203 vascular surgery
0204 neurosurgery
0214 paediatric neurosurgery
0205 cardiothoracic surgery
0215 paediatric cardiothoracic surgery
0207 ESWL
0208 organ transplantation surgery
0209 removal of tissue for the purpose of transplantation from brain-dead patients
04 Obstetrics and gynaecology
0400 obstetrics and gynaecology
0403 *in vitro* fertilization (IVF)
0404 out-of-hospital childbirth care and newborn care
0405 obstetrics
0406 gynaecology
05 Paediatrics
0500 paediatrics
0501 neonatology
0502 PIC
0503 paediatric cardiology
0504 paediatric pulmonology
0505 paediatric gastroenterology
0506 paediatric surgery
0507 paediatric gynaecology
0508 paediatric ophthalmology
0509 paediatric otorhinolaryngology
0510 paediatric radiology
0511 paediatric neurology
0515 paediatric intensive therapy
0521 developmental neurology

06 Otorhinolaryngology
0600 otorhinolaryngology
0601 audiology
0602 phoniatry
0603 otoneurology
07 Ophthalmology
0700 ophthalmology
0701 corneal transplantation
0702 removal of cornea for the purpose of transplantation from brain-dead patients
0703 sight-testing by specialist, ordering glasses
0704 optometry (with non-medical qualifications)
08 Dermatology
0800 dermato-venereology
09 Neurology
0900 neurology
0901 stroke care
0904 clinical neurophysiology
0905 sleep medicine
10 Orthopaedics and traumatology
1000 orthopaedics
1001 spinal surgery
1002 traumatology
1003 hand surgery
11 Urology
1100 urology
1101 andrology
1102 urodynamia
1103 neuro-urology
12 Clinical oncology
1200 clinical oncology
1201 radiation therapy
13 Dental care
1300 dental care
1301 dentoalveolar surgery
1302 orthodontics
1303 periodontology
1304 paediatric dentistry
1305 school dentistry
1306 dental X-ray
1308 conserving dentistry, prosthodontics
1309 dental intervention in general anaesthesia
14 Rheumatology
1400 rheumatology
1402 physiotherapy
1404 menopause and osteoporosis care
15 Anaesthesiology and intensive care
1501 anaesthesiology
1502 intensive care
1503 pain medicine
1504 long-term ventilatory assistance
16 Infectious medicine
1600 infectious medicine
1601 AIDS patient care
1602 HIV/AIDS screening (voluntary or compulsory according to separate legislation)
1603 tropical medicine
17 Oral and maxillofacial surgery
1700 Oral and maxillofacial surgery
18 Psychiatry
1800 psychiatry
1801 addictology
1804 psychiatric rehabilitation
1805 psychotherapy
1806 addictological rehabilitation

19 Pulmonology
1900 pulmonology
1903 pulmonary rehabilitation
1904 lung cancer screening (also including making individual images)
20 Plastic surgery and the treatment of burns
2000 plastic reconstructive and aesthetic surgery
2001 burn surgery
2002 paediatric plastic surgery and burn surgery
👉 *2222 Rehabilitation medicine*
👉 2200 Rehabilitation medicinal basic activities
👉 2205 paediatric rehabilitation
👉 2206 rehabilitation of patients with serious brain damage
👉 2207 rehabilitation of patients with spinal cord damage
👉 2208 rehabilitation of polytraumatized, burn and septic surgical patients
👉 2209 paediatric rehabilitation of patients with serious central nervous system damage, polytraumatized and burn patients
23 Child and adolescent psychiatry
2300 child and adolescent psychiatry
2301 child and adolescent psychiatric rehabilitation
2302 child and adolescent addictology
2303 child and adolescent addictological rehabilitation
25 Occupational medicine
2501 primary care in occupational medicine
2502 specialist care in occupational medicine
2503 work hygienic activities
26 Sports medicine
2602 sports medical care
40 Cardiology
4000 cardiology
4003 cardiological rehabilitation
46 Emergency medicine
4601 central call service
4602 specialist care organized in an emergency care unit
4603 clinical toxicology
50 Laboratory diagnostics
5000 medical laboratory diagnostics
5003 microbiological laboratory diagnostics
5013 epidemiological microbiological diagnostics
5006 molecular genetic laboratory diagnostics
51 Medical imaging and radiological therapy: X-ray diagnostics and therapy
5100 X-ray diagnostics
5102 mammography
5103 angiographic diagnostics
5108 CT diagnostics
5109 MRI diagnostics
52 Interventional radiology
5203 vascular interventional radiology
5204 interventional oncoradiology
5205 interventional neuroradiology
5206 other interventional radiology
53 Medical imaging and radiological therapy: ultrasound diagnostics and therapy
5301 complete ultrasound diagnostics
5303 echocardiography
5304 obstetric and gynaecological ultrasound diagnostics
5305 gastroenterological ultrasound diagnostics
5306 ophthalmological ultrasound diagnostics
5307 neurological ultrasound diagnostics
5308 urological ultrasound diagnostics
54 Pathology and histopathology
5400 anatomical pathology and histopathology
5401 histology, histopathology

5402 cytology, cytopathology
5412 lung and/or thyroid cytology, cytopathology (with special cytopathological exam based on special pathological examination)
5403 needle aspiration cytology
5413 lung and/or thyroid needle aspiration cytology (with special cytopathological exam based on special pathological examination)
5404 immunohistology
5405 neuropathology
5406 handling and preservation of dead bodies (with non-medical qualifications)
5407 removal of tissue for the purpose of transplantation from dead bodies
56 Special therapy
5603 carbon dioxide therapy
5604 hyperbaric oxygen therapy
57 Physiotherapy
5700 physiotherapy-remedial gymnastics
5703 hydrotherapy
5704 electrotherapy
5706 balneotherapy (procedures with the application of medicinal water)
5707 thermotherapy (treatments with warm and cold effects)
5708 magneto-, phototherapy
5710 under-water remedial gymnastics
5711 remedial gymnastics
5712 medical massage (requiring medical massage therapist's qualifications)
5722 physiotherapy (as a medical assistant's activity)
60 Tissue bank and cell bank activities
6001 tissue bank and cell bank activities
6002 tissue bank activities
6003 collection of umbilical cord blood/part, cord blood stem cells
6013 taking
6023 transportation
61 Transfusion medicine and blood bank
6101 transfusion medicine
6102 blood bank service
62 Emergency medical services and medical transport
6200 emergency medical services
6201 premature infants' emergency medical services and medical transport
6203 guarded medical transport
6206 medical transport
6208 medical support events
6209 medical service at international airports
6210 emergency medical services connected to organ transplantation
63 General practice
6301 general practice
6302 paediatric general practice
6303 adult and paediatric (combined) general practice
6306 school and adolescent medicine
64 Primary care of the military and police force
6401 care of the military and police force
6402 correctional medicine
65 Nuclear medicine (isotope diagnostics and therapy)
6500 isotope diagnostics
6501 radioisotope therapy
6503 PET-CT
6504 SPECT-CT
67 Clinical genetics (human genetics)
6700 clinical genetics
6701 genetic counselling
6702 biobank activities (collection and storage)
70 Clinical pharmacology and distribution of drugs
7001 clinical pharmacology
7002 distribution of drugs on the premises of an institution (according to conditions prescribed by law)
71 Clinical psychology

7101 clinical and mental hygiene psychology
7104 psychotherapy (with special clinical psychologist's qualifications)
7106 neuropsychology
7107 clinical addictological psychology
72 Health care specialties that can be done with pedagogical qualifications
7201 speech-language pathology
7202 special needs education (and its specialties)
7203 conductive education
7204 therapeutic swimming (with qualifications prescribed by special legislation)
73 Nursing
7301 nursing in occupational health care
7302 psychiatric nursing and mental hygiene
7303 paediatric nursing
7304 home nursing
7305 nursing (with medical or health care degree and/or nurse's qualifications according to special legislation)
7306 adult hospice and palliative care
7307 district community health nursing
7308 midwifery (hospital)
7309 out-of-hospital midwifery
7310 paediatric palliativ care
7311 clinical dental hygiene
76 Dietetics
7600 dietetics
79 Health visiting
7901 district health visiting
7902 school nursing
7903 family protection service
7904 human milk bank, breast milk collection
80 Supplementary medical activities (with qualifications and content determined by special legislation) - non-conventional medical practices
a) medical practices by medical doctors:
8011 homeopathy
8012 traditional Chinese medicine (other techniques based on that)
8021 manual therapy (may be done also by physiotherapist)
8022 Indian (Ayurvedic medical procedures)
8023 detoxification methods
8032 Tibetan healing procedures
8004 psychological procedures
8041 neural therapy
b) activities requiring special qualifications
8016 acupressure
8026 oriental movement and massage therapy
8036 lifestyle training and counselling
8046 reflex zone therapy
c) activities requiring qualifications acquired in a training ending with an examination
8017 supplementary physiotherapeutic methods
8037 fitotherapy
8047 ear acupuncture addictological procedures
8057 kinesiological methods
8067 eye training procedures
93 Military and disaster medicine
9301 military medicine
9302 disaster medicine
94 Public health and preventive medicine
9400 public health and preventive medicine
9401 radiation medicine
9402 international vaccination venue and counselling
95 Forensic medicine
9500 forensic medicine
9501 forensic psychiatry
9502 forensic toxicology
9503 forensic psychology

9504 health insurance medicine
9505 forensic pathology (except expert's activities)
9506 forensic genetics
97 Aviation medicine
9700 aviation medicine
GYS Activities related to medical accessories
GYS1 distribution of medical accessories (in independent shop)
GYS2 distribution of medical accessories (in shop belonging to a chain)
GYS3 distribution of medical accessories (with independent workshop/factory)
GYS4 orthopaedic shoe manufacturing
GYS5 dental technology
GYS6 rental of medical accessories
GYS7 repairing medical accessories

7. Disease Registries: Hungarian, International (Tibor Gazsó)

7.1. About Disease Registries in General

In the past few decades different countries have had different experiences concerning the effectiveness of disease registries. On the basis of the practice it can be concluded that the data content and accessibility of the registries greatly depends on what their purposes are and in what area the data are used. In the case of most Hungarian registries this utilization is mixed.

Regarding scientific activities it is primarily medical data, besides the diagnoses also the values taken, that are important. These are usually typical of professional registries; from a scientific point of view the goal is the monitoring of groups of patients for this end. Health care systems are also suitable for this purpose.

The monitoring of data collection at a higher level also involves the data of patient paths, expensive medicines, devices and procedures, for the purpose of assessment. These are funding registries, in which data representing criteria for per case funding, mainly diagnoses and interventions, also appear. These systems have led to the possibility of accessing the application data of drugs subject to detailed accounting and of adding new treatments to the service system.

Compared to examination results, morbidity characteristics, which allow longitudinal patient monitoring, are more prevalent. The National Cancer Registry, for example, collects data necessary for making conclusions at population level, which is of remarkable significance from the point of view of public health.

Act XLVII. of 1997 regulates the treatment and protection of medical and related personal data (hereafter: the Law) The purpose of the Law is to determine the conditions and purposes of the handling of special personal data about health status and the personal data related to them. Personal data may only be handled in the cases and to the extent that is necessary for lawful purposes. According to the Law the registries, also accessible by the patients, are based on patients' voluntary consent. One of their typical features is that, besides providing the health care system with data, they are also advantageous for the patients in the registries. These advantages include that patients can be involved in studies of the given diseases more effectively, and they receive direct information about the details of their medical care and about new procedures and developments. In Hungary there is no registry that can be utilized that way.

Registries handle medical data enjoying special statutory protection. Thus, their legal regulation and centralization is an extremely important area in health care. In the future, it will become indispensable to elaborate the compulsory statutory procedures related to the registries as well as to update the present regulations and to modernize the legal references which are now outdated at places. The regular and automated inspection of access has to be made possible for the supervisory bodies by statutory background.

Patient registers make it possible to follow the qualitative characteristics of medical care, and at the same time can also create supporting services for that purpose, so that there will be even more professional information available for both the whole sector and the decision makers of the government.

7.2. HUNGARIAN DISEASE REGISTRIES

In Hungary certain disease registries have undergone centralized, statutory regulation due to the public health importance of the diseases of special significance. The forms of legal regulation differ in the cases of different diseases; some diseases are dealt with in separate statutes, while others are treated in regulation imbedded in higher legislation. These are the National Cancer Registry - the Registry of Paediatric Oncology -, the National Registry of Myocardial Infarction, the Haemophilia Register, the Registry of Rare Diseases and the National Registry of Congenital Disorders. In the beginning the health care sector did not see the possibility in these registries that the data presentations provided by them may result in heterogeneity and incompatibility. Following the results obtained by research (pilot system, the statutory enhancements were started in connection with the registries in the hope vested in them. By the legal regulation the system of health care reporting has arrived at a turning point and it opened new horizons for the registries. In the case of diseases of special importance for public health the diseases registries contain the diagnoses of the patients and the time of the diagnoses in general, while the locations of the morbidity, the evidence and the therapies are treated in detail. On the basis of data of special importance contained in the registries the changes in the numbers and geographical locations of patients can also be followed. The analysis of these data can help to draw conclusions about the causes of diseases and it also makes the necessary medical care and medication predictable. However, the registries do not only contain the basic morbidity data but they can also follow the processes of the registered cases and any side effects with the help of the continuously updated data. The registries can also help to establish the efficiency of the individual treatment methods.

In the Hungarian health care the data and the qualitative parameters related to care have to be constantly monitored. An efficient health care system can only be operated in the possession of the data reflecting the quality and effectiveness of the care provided. The Hungarian registries should be markedly separated from the drug trials required by the pharmaceutical industry and the systems of the health care providers in their durations, goals, funding and legal environments, since the data accessible by them have a much higher social significance and utility.

In Hungary, apart from the disease registries regulated by legislation, other domestic professional registries that are related to researches (pilot systems) have also developed within contractual frames. Some of these are still in a research phase (e.g. hypertonia e-register), while some have been successfully widened to national competence. The National Nosocomial Surveillance (NNSC) is a registry for the monitoring of nosocomial infections related to health care. Its purpose is the continuous and regular collection, analysis and evaluation of data and providing feedback based on the scientific evidence of the epidemiology of nosocomial infections.

The registries were created in connection with some special diseases or forms of medical care, expensive devices or drugs. Below the registries that have the greatest significance from the perspective of the public health of Hungary are treated in detail.

7.2.1. The National Cancer Registry

The regulations concerning the National Cancer Registry (hereafter: Cancer Registry) are set down by Decree 24/1999. (VII. 6.) of the Ministry of Health on the Regulations of Reporting the Cases of Cancers [60]. The decree was authorized by point a) of paragraph (2) of section 38 of Act XLVII of 1997 on the Treatment and Protection of Medical and Related Personal Data [61]. The operation of the Cancer Registry is the responsibility of the National Institute of Oncology.

The manner and time of reporting the various cancers as well as compliance with the obligation of reporting and the range of data to be reported are all regulated in detail by the decree for the purpose of the prevention and treatment of cancers, the follow-up care for patients and of the planning, organization, management and assessment of epidemiological studies.

The duty of providing information applies also to health care providers, the National Health Insurance Fund of Hungary (OEP) and the Hungarian Central Statistical Office. [62, 63]

On the health care provider's side every doctor who diagnoses a case of cancer, treats a cancer patient, furthermore, those who carry out histologic examinations and those who hold a post-mortem examination or give their opinions on that are obligated to provide information for the National Cancer Registry [64]. The obligation to report cancer applies to all cancer cases diagnosed or treated at every health care provider if the diagnosis - including the diagnoses of causes of death - is identical with one of items C00–C97, D00–D09 D30.3, D33 of the Tenth Revision of the International Classification of Diseases (hereafter: ICD-10) [65].

In order to comply with its obligation to report prescribed by law the health care provider transfers the data set down in Annex 1 to the Cancer Registry. Recording and forwarding data is done by the electronic application provided by the Cancer Registry. If the health care provider does not have facilities for electronic data transfer, obligation to provide data different from that stipulated in Annex 1 is to be carried out with a data content according to the form in Annex 2. For the coding of the data included in the forms the decree gives detailed instructions (Annex 3), which also contain the detailed definition of the concept of the required provision of data. Health care providers that also carry out pathological examinations have to provide further information with a data content determined separately. The provision of data includes the examination of histological samples and the BNO classification of the diseases caused by malignant tumours identified during post-mortem examinations (Annex 4).

The provision of data concerning minors under 18 years of age is regulated separately. In this provision of information for the Cancer Registry the following have to be reported: medical data about the detection, origin, spreading, histological type and prognostic factors of the disease; information about the mode and effectiveness of the treatment, the later fate of the patient and long-term follow-up as well as related personal identification data required by the provision of information.

The frequency and the deadlines of the provision of information by health care providers is regulated by the decree, according to which the data are forwarded to the Cancer Registry in every quarter and by the 15th day of the month following the quarter. The Cancer Registry has a possibility to compare the data with the providers of medical information once a year in order to ensure the quality and completeness of the provision of data as well as to check if their data are identical with those in the medical documentations.

The data of patients once included in the Cancer Registry by the provision of data may not be deleted, except for the rare cases laid down in separate paragraphs in the statute. Such a case is, for example, when it turns out that the diagnosis was clearly false or the case of the

personal identification data if a patient dies, except for his/her social security identification. Moreover, the data of registered patients can only be corrected if the time of the correction is recorded and the availability of the previous data is ensured.

Concerning the Cancer Registry the National Health Insurance Fund of Hungary has a double responsibility. On the one hand, it provides information for the Cancer Registry, on the other hand, it makes data available concerning passivated social security identification numbers and the reasons and the dates of passivating to ensure that their data match. The provision of data by the National Health Insurance Fund of Hungary includes detailed funding data on medical care that is justified by diagnoses including one of the items (codes) of Chapter II Neoplasms of the ICD. The circle of data on medical care and their format is regulated by the National Health Insurance Fund of Hungary and the Cancer Registry in a separate agreement. The National Health Insurance Fund of Hungary also has to comply with its obligation to provide data every quarter.

The Hungarian Central Statistical Office and the Cancer Registry set down the details of the obligatory provision of data in a separate agreement. The range of data has to include the information stipulated by section 16. § (8) of the Law, which also contains data suitable for the identification of the deceased. On the basis of this provision of data the Cancer Registry records the post-mortem examination and cause of death data of cancer patients already registered.

The Cancer Registry has to make an annual report of the data collection detailed above. Furthermore, the Cancer Registry also reports the distribution of cancer cases grouped according to patients' place of residence broken down to the capital and the counties of Hungary as well as ICD codes, gender and age group, every year. The reports are forwarded to the Office of the Chief Medical Officer (hereafter: OTH), the National Health Insurance Fund of Hungary and the National Centre for Patients' Rights and Documentation. The purpose of the reporting is the assessment of the organization, planning and operation of oncological activities.

7.2.2. National Registry of Myocardial Infarction

The National Registry of Myocardial Infarction (hereafter: the Registry of Myocardial Infarction) includes all acute myocardial infarction cases diagnosed or treated at any health care provider. The provision of data about these cases was made compulsory by the amendment (section 10. § (2). of Act CCXLIV. of 2013, in force since 1 January 2014) of Act XLVII of 1997 on the Treatment and Protection of Medical and Related Personal Data. The details of the provision of data were set down by Decree 15/2014. (III.10.) of the Ministry of Human Capacities on the Regulation of Reporting and Registering of Cases of Diseases Related to Myocardial Infarction.

For the management of the Registry of Myocardial Infarction the Gottsegen György Hungarian Institute of Cardiology (GOKI) was appointed [66].

In the past decades only limited information was available about patients treated with myocardial infarction in Hungary, and no information at all on the details and the quality of the care they received in spite of the extraordinary significance of myocardial infarction in public health. Hungarian data about the care of these people have been extremely incomplete for many years, primarily due to the lack of data collection activities concerning the qualitative parameters of medical care.

The Hungarian mortality statistics showed a decrease in the number of patients dying within 30 days after being diagnosed with myocardial infarction, but during the analysis of the financing database the patients treated in hospital with myocardial infarction and the 1-year mortality rate did not show any significant change.

In the case of cardiovascular diseases great changes have taken place in the past few years both in the diagnosis of myocardial infarction and its treatment. By the analysis of the five-year data of the funding database it has been proved that that wealth of information was not suitable for a professional assessment of care provided [67]. Realizing the need for validated Hungarian data in 2007, the myocardial infarction registry pilot project was launched under the coordination of the Ministry of Health, the Office of the Chief Medical Officer, the information and privacy commissioner, the professional associations (Hungarian Society of Cardiology, Society of Hungarian Cardiologists) and the Gottsegen György Hungarian Institute of Cardiology with the participation of 12 data providing centres in 2007. During the pilot phase more and more centres joined the project while the IT system was being developed.

According to the regulations the National Health Insurance Fund of Hungary and the Hungarian Central Statistical Office hand over the data related to myocardial infarction patients to the online database of the National Registry of Myocardial Infarction

(https://ir.kardio.hu), while health care providers continuously upload the data of their patients treated with myocardial infarction (BNO I21-I23). The data are constantly inspected and the necessary corrections are also done online. For the assessment of patients' long-term prognoses the data of the National Health Insurance Fund of Hungary, the Hungarian Central Statistical Office and the Office of the Chief Medical Officer as well as the results of the ambulatory examinations are also used. The Registry of Myocardial Infarction contains data that are of fundamental importance (the incidence of the disease, the territorial differences in incidence, patients' short- and long-term prognoses) and were not known earlier due to the lack of specific data collection.

Thanks to the Registry of Myocardial Infarction the collection of myocardial infarction data from several sources has created a financing database about myocardial infarction care, which has a paramount importance for public health and in which the diagnoses made during health care are recorded according to the International Classification of Diseases (ICD).

It is the physician making the diagnosis or treating the patient or the doctor doing the histological or post-mortem examination or the doctor who gives his/her expert opinion on that who provides the National Registry of Myocardial Infarction with information according to section 16. § (9) of the Law. According to the regulation "In the case of detecting a case diagnosed with myocardial infarction the provider of medical care forwards the patient's personal identification and medical data connected to myocardial infarction to the National Registry of Myocardial Infarction, which is defined and operates for the purpose stipulated by points b) and c) of paragraph 4. § (1) and point b) of paragraph (2) 4. § of the decree of the Ministry." The obligation to report applies to all acute myocardial infarction cases diagnosed or treated at any health care provider if the diagnosis - including the diagnoses of causes of death - is myocardial infarction.

According to the regulation the recording of data in the Registry of Myocardial Infarction takes place by the electronic system operated by the Registry of Myocardial Infarction. If no electronic provision of data is available at a given health care provider, a report with a specific data content has to be forwarded to the Registry of Myocardial Infarction. The data have to be filled in every quarter until the 15th day of the month after the given quarter. Its obligation of providing data for the Registry of Myocardial Infarction the National Health Insurance Fund of Hungary also fulfils every quarter. For this end the National Health Insurance Fund of Hungary forwards the detailed care data of the services whose provision is justified by diagnoses that include one of the items (codes) of Chapter IX Diseases of the circulatory system of the ICD and were collected according to the

stipulations of the government degree on the detailed regulations of funding of health care services from the Health Insurance Fund. The details and form of transferring the information is determined by the agreement between the National Health Insurance Fund of Hungary and the body operating the Registry of Myocardial Infarction complying with the statutes referring to data handling.

The Registry of Myocardial Infarction records the post-mortem examination and cause of death data of persons already registered, and registers the data of people in whose case it is justified by a disease originating in infarction detected during the post-mortem examination.

For compliance with the data handling regulations of the Registry of Myocardial Infarction the person in charge of information privacy or in the lack of that the physician, while for its implementation the head of the health care providing institution is responsible. The physician treating the patient and/or the doctor doing the pathological examination are responsible for the credibility of the data forwarded to the Registry of Myocardial Infarction. The data reported according to the regulations have to be identical with the data in the patient's medical documentation.

On the basis of the experience of the past few years the operation of the Registry of Myocardial Infarction is more and more complete thanks to the wide professional support and the statutory regulation. Currently every Hungarian health care institution and centre that provides acute care participates in the provision of data, but rehabilitation institutions are joining the programme continuously as well. It is a very important objective to improve and make the medical care of patients treated with acute myocardial infarction more goal oriented. Every year the Gottsegen György Hungarian Institute of Cardiology prepares a report about the principal data of care, which is made available to the centres participating in the programme and the decision makers. From the comprehensive data of the Registry of Myocardial Infarction a valid picture of the medical care of Hungarian myocardial infarction patients can be drawn. It is important to note that the database also serves scientific purposes.

7.2.3. The Haemophilia Registry

Haemophilia is a rare disease so its diagnosis and the comprehensive treatment of haemophilic patients requires special knowledge. That is the reason why the so-called haemophilia centres, where diagnostics, factor replacement therapy as well as specialist medical care (perhaps several specialties even) are all available, were established in Hungary.

At present 19 haemophilia centres (hereafter: User Centre) provide care and drugs for patients in Hungary. Based on the suggestions of the Hungarian Society of Haematology and Transfusion healthcare institution appointed by the National Health Insurance Fund of Hungary for providing pharmacotherapy or premises belonging to the Hungarian National Blood Transfusion Service are the User Centres, where insurees may receive their specially funded medication and the therapies done with them. These centre can also access the so-called Centre Report Programme, a patient database, containing the current condition and any additional diseases of haemophilic patients. The User Centres have to submit reports about their patients, the patients' conditions and the use of specially funded medication in the reference month together with a signed Accounting certificate by using the Centre Report Programme by the 10th day following each reference month.

It is a contractual duty of the User Centres to prepare reports about the treatment of haemophilic patients and any supplementary activities connected to that for the National Health Insurance Fund of Hungary by using the Centre Report Programme. The contracts are based on section 27. § (6) of Act XCVIII of 2006 on the General Provisions Relating to the Reliable and Economically Feasible Supply of Medicinal Products and Medical Aids and on the Distribution of Medicinal Products.

On the basis of the agreement of the National Health Insurance Fund of Hungary and the User Centres, they ensure the supply of specially funded medication for haemophilic patients together -complying with the contractual regulations- according to the indications stipulated in the Decree of the Ministry of Health 32/2004. (IV. 26.) on the Inclusion Criteria of Authorised Drugs and Food Supplements for Special Dietary Needs in Social Security Subsidization and the Modification of the Inclusion or the Subsidization. Specially funded medication means a medicinal product with an active substance listed in Annex 4 and purchased by the National Health Insurance Fund of Hungary by means of a public procurement procedure according to Government Decree 130/2004. (IV. 29.) on the Detailed and Special Rules of the Public Procurement of medicines and medical accessories.

By the use of the registry the User Centres can report the turnover of specially funded products and they can also store them up and make a register, which helps their cooperation with the National Health Insurance Fund of Hungary as well as makes their administration and the fulfilment of their contractual obligations towards the National Health Insurance Fund of Hungary easier.

According to its obligation stipulated in the contract the National Health Insurance Fund of Hungary undertakes to purchase by means of a public procurement procedure and to make available to the User Centres the specially funded medicines for the treatment of haemophilia according to the indications set down in Decree 32/2004. (IV. 26.) of the Ministry of Health.

Under the stipulations of the contract the User Centres provide the patients appearing at their institutions nationwide -regardless of their places of residence- with specially funded medication and treatment with the respective medicines, and they also ensure the occasional provision of specially funded products for institutions providing inpatient care that lie the closest to the respective User Centre.

7.2.4. Centre of Rare Diseases, the National Registry of Congenital Disorders

According to the regulation of the European Union diseases whose prevalence is below 1 : 2 000 are considered to be rare diseases. However, that ratio shows great variations in different parts of the world. Most of the rare diseases are genetically determined illnesses but they also include certain tumours, autoimmune diseases, congenital developmental disorders and communicable diseases. Persons suffering from rare diseases often become the ‘orphans’ of health care systems. Rare diseases occur so rarely among the population that the costs of the development and distribution of drugs for their treatment would not be covered by the income generated by their expected sales. The term ‘orphan medicinal products’ refers to the fact that these products are ‘orphans’ among other drugs.

In Hungary those products were listed as orphan drugs that are governed by Regulation (EC) No 141/2000 of the European Parliament and of the Council of 16 December 1999 on Orphan Medicinal Products [68]. In the drug subsidization system orphan drugs were listed in the special subsidization category subject to indication.

The Centre of Rare Diseases was established within the National Centre for Healthcare Audit and Inspection. In 2011 the Centre of Rare Diseases together with the Department of the National Surveillance of Congenital Disorders was placed under the auspices of the National Institute for Health Development.

The main duties of the Centre of Rare Diseases include the following:

- data collection and cooperation with other organizations collecting data in order to be able to establish the indicators regularly,
- keeping a registry about the screening practices of rare diseases,
- elaborating evaluation criteria and guidelines,
- audition of the practice,
- promoting the application of E-health care devices in the area of rare diseases.

The Department of the National Surveillance of Congenital Disorders operates the National Registry of Congenital Disorders (hereafter: VRONY) [69]. Decree 21/2014. (III. 20.) of the Ministry of Health on the Reporting and the Regulations of the Registration of Congenital Disorders governs the operation of the VRONY [70]. The detailed definition of the information to be reported to the VRONY is included in Annex 5 as stipulated by the statutes. The defined goals of the registry are: to survey the incidence of congenital disorders as precisely as possible, to provide basic data for the national and regional analyses of the efficiency of prenatal screening, to promote prevention, to check the results of preventable disorders, to provide basic data for scientific researches, to raise decision makers' awareness by informing them about the number of affected people in need of care and to promote participation in international cooperation. The data of the VRONY are available to professionals dealing with research.

The funding in connection with the diseases is the responsibility of the National Health Insurance Fund of Hungary. The patients and their medicines with special indications are registered on the basis of individual equity. According to point c) of paragraph (1) of 26. § of Act LXXXIII of 1997 on the Services of Compulsory Health Insurance (hereafter: Health Insurance Act) and section 11/D. § of the Government Decree 217/1997. (XII. 1.) on the Implementation of the Health Insurance Act the National Health Insurance Fund of Hungary may grant a contribution towards the price of a drug or food supplement for special dietary needs (hereafter together: medicine).

In medical care an individual request for equity has to be submitted for the price subsidization of a medicine. The National Health Insurance Fund of Hungary does not reimburse the insuree for the price of the care received but the health care provider, who has to verify and account for the care and or intervention. In connection with that, health care providers have to send the National Health Insurance Fund of Hungary any hospital discharge summaries or clinical summaries of the authorized care as well as the invoices of the costs of any materials and equipment related to or used for the intervention.

7.3. Registries Related to Diseases

In Hungary registries whose purpose is not the direct registration of diseases but the monitoring of the use of materials and/or equipment for healing associated with the diseases have also been created. Both the system of medicines subject to detailed accounting and the central implant registry have been established related to the healing of diseases.

7.3.1. Medicines Subject to Detailed Accounting

The system of medicines subject to detailed accounting are also managed by the National Health Insurance Fund of Hungary. The legal background for that is provided by Decree 9/1993. (IV. 2.) of the Ministry of Welfare on Certain Issues of the Social Security Funding of Specialist Health Care and the provisions of Government Decree 43/1999. (III. 3.) on the Detailed Regulations of Funding Health Care Services from the Health Insurance Fund[71, 72]. The National Health Insurance Fund of Hungary provides funding for the medicines for the appointed health care providers up to the annual limit determined on the basis of the available budget. At the end of 2011 the minister responsible for health determined the active substances that are supplied in kind for the institution entitled to it and the patients in the Annex of the decree of the Ministry of Welfare (Annex 6).

The National Health Insurance Fund of Hungary operates the system on its website. The National Health Insurance Fund of Hungary registers the use of the listed active substances with the help of the reporting system in the indications listed according to the stipulations of the declaration of inclusion in subsidization by the social security and the instructions of application.

7.3.2. Central Implant Registry

Concerning patients' medical technical equipment, also including implants, in order to facilitate quick and effective communication health care providers have to report every intervention involving implants to the Central Implant Registry after 1 January 2014 according to section 101/C § of Act CLIV of 1997 on Health Care. Every health care provider, either private or state funded, that inserts, replaces or removes implants is obligated to report. According to the law health care providers have to report the data of the person affected by the intervention; the data of the intervention: inserting, removal or replacement, the data of the implant and the data of the health care provider carrying out the intervention.

The technical background and operation of the Central Implant Registry is provided by the National Health Insurance Fund of Hungary. The website of the Central Implant Registry is available at the address impreg.oep.hu. The data are anonymized by the system, so the patients' data are only accessible by the health care provider having uploaded them.

7.4. International Disease Registries

With the appearance of information- or knowledge-based societies the health care sector was faced with the demand for the creation of high quality health care data handling in various parts of the provision of health-care. One area of the use of medical data is their use within the system, e.g. in insurance accounting, the organization of the provision of care, preparing reports, education, research and statistics. In recent years health care costs have grown faster than the economies everywhere in the developed world. This increase can be attributed to several reasons, such as the growth of the ratio of the elderly population, on the one hand, and the spread of continuously developing and increasingly expensive technologies, on the other hand.

At an international level it is believed that the solution of the problem caused by the lack of available data coupled with dramatically rising health care costs is the implementation of the concept of value-based health care (VBHC). Based on systematic data collection this solution examines what benefits one unit of health care expenditure produces; assesses the efficiency of the individual actors, interventions and technologies, and in possession of these data it continuously develops the treatment protocols, highlights the weak points of care and assesses the performance of the health care providers. The goal of the programme is not the reduction of expenditure at any cost but the achievement of the greatest 'value' possible.

In an international comparison Sweden has the greatest experience in the application of disease registries in the area of health databases. Currently more than 100 patient registries operate in Sweden. The registries contain at least 85 % of the patients diagnosed and/or treated with the given diseases, many of them containing the data of more than 95 % of the patients in the patient group. Sweden's health care expenditure is near the Western European average but its complex health care quality indicators are the best.73 It is a great advantage in Sweden that the use of registries is required by law; they are centralized, their quality assurance is thoroughly elaborated and access to the information is regulated at several levels.

Appendix 7/1

Data to be provided by the health care providers electronically

Identification of the health care provider:

Identification (stamp number) of the (treating) physician providing care

Name (institution, ward, practice) address and identification of employer

Identification of the patient

Patient's name, mother's name, name at birth

Post code and address of patient's residence

Patient's sex

The patient's Social Security Identification Number

Patient's date of birth

Patient's identification number/log number at the institution providing care

Date (year-month-day) of finishing the patient's medical care (examination/treatment)

Identification of tumorous disease:

Time of detecting tumorous disease (if known)

Code of clinical diagnosis of tumour according to ICD-10 Chapter II Neoplasms

Laterality of the tumour (codes 1-4, see guide)

Spread of the tumour (codes 1-6, see guide)

TNM classification of tumour (according to the TNM version determined as separate rule)

The morphological code of the tumour according to chapter 'Morphology of Neoplasms' in ICD-10

The highest level examination supporting the diagnosis (codes 1-9, see guide)

OENO intervention code of anti-tumour treatment (operation, radiation, medicinal)

Status of the disease at the end of treatment (codes 1-4, according to WHO or RECIST, see guide)

Patient's further fate (codes 1-5, see guide)

In the case of patient's death:

Time of death

Direct cause of death

Code of clinical diagnosis of primary disease leading to death according to ICD-10

Appendix 7/2
Form to be submitted in the case of provision of data in a non-electronic way

1 Physician submitting the report
employer: ……..……
address: ……. town/city…… street…… No.
ward/practice: ……
……
identification:
Identification (stamp number) of the (treating) physician submitting report
2 Patient's name: ……
Patient's mother's name: …….
Patient's name at birth: ……
The patient's Social Security Identification Number
sex (male = 1; female = 2):
patient's date of birth: year month day
address: …….
town/city…… street……
No.

3 Time of detecting tumorous disease (if known): month day year

4 Code of clinical diagnosis of tumour according to ICD-10 Chapter II Neoplasms
laterality:
spread:
TNM classification of tumour (according to the TNM version determined as separate rule)

5 Code of examination supporting the diagnosis:

6 Code of the morphological examination according to ICD-10 ('M' code)

7 OENO intervention code of anti-tumour treatment (operation, radiation, medicinal)

8 Status of the patient at the end of treatment WHO or (if known) RECIST

9 Patient's further fate:

…… STAMP
Signature of physician submitting the report

Appendix 7/3

Guide

for coding data to be reported according to Appendices 7/1 and 7/2

Laterality of the tumour:

1 = left 2 = right 3 = both 4 = systematic disease

Spread of the tumour:

1 = in situ

2 = within organ of origin

3 = spread in surrounding tissue, organs

4 = regional lymph node metastasis present

5 = metastasis to distant organs

6 = cannot be defined, systemic disease

The highest level examination supporting the diagnosis

1 = clinical examination only

2 = X-ray or other diagnostic imaging

3 = endoscopic examination without histology

4 = exploratio without histology

5 = special cytological, haematological examination

6 = histology from metastasis

7 = histology from primary tumour

8 = histology with post-mortem examination

9 = unknown

If there was a morphological examination, one of codes 5-8 can be written here. Mark '8' can only be used if the malignant tumour was only verified at the post-mortem examination.

Status of the patient at the end of treatment:

WHO 1980: 1 = complete remission of tumour

2 = partial remission

3 = no change

4 = recurrence or progression of tumour

RECIST CR = Complete Response

PR = Partial Response

SD = Stable Disease

PD = Progressive Disease

Patient's further fate:

1 = receives further treatment

2 = does not require further treatment

3 = has rejected further treatment

4 = receives further treatment elsewhere

5 = has passed away

Appendix 7/4

Data of tumorous diseases diagnosed during pathological examinations to be reported

Identification of healthcare institution:

Name, address and identification of reporting institution, ward or practice

Identification code of examining physician (stamp number)

Identification of patient:

Patient's name, mother's name, name at birth

Post code and address of patient's residence

Patient's sex

The patient's Social Security Identification Number

Patient's date of birth

Patient's identification number at the institution providing care

Identification of tumour:

Date of pathological examination

Code of clinical diagnosis of tumour according to ICD-10 Chapter II Neoplasms

The morphological code of the tumour according to chapter 'Morphology of Neoplasms' in ICD-10

Appendix 7/5

The data content of e-VRONY and VRONY REPORTING FORMS

Identification and medical data of person affected	
Name	
Social Security Identification Number	
Date of birth / miscarriage / abortion	(year, month, day)
Date of death (if applicable)	(year, month, day)
Sex	(male, female, unknown)
Number of newborns	(one, twins, triplets, quadruplets, quintuplets)
Weight at birth	(g)
Outcome of pregnancy	(live birth, stillbirth, spontaneous abortion, termination of pregnancy due to prenatal diagnosis, prenatally detected, but not terminated pregnancy)
Week of pregnancy	(at birth, at death)
Date of diagnosing disorder	(year, month, day, completed week of pregnancy)
Mother's data	
Mother's name at birth	
Mother's Social Security Identification Number	
Address of legal representative	(post code, name of city/town/village, street, house number)
Mother's residence during pregnancy	(post code, name of city/town/village, street, house number)
Mother's date of birth	(year, month, day)
Mother's age during pregnancy	(years old)
Number of previous pregnancies	
LMP	(year, month, day)
Data of disorder	
ICD code and name of disorder	(max 10)
Laterality	(right, left, both)
Name of syndrome	
McKusick Code	
ORPHA code	
Date of diagnosis	(year, month, day)
Method of prenatal diagnosis	
Date of prenatal diagnosis	(year, month, day)
Date of first positive prenatal diagnosis	(year, month, day)
AFP result	(MOM)
Chromosomal test done?	(yes, no)
Result of karyotyping	
Date of planned or already performed surgical intervention	(year, month, day)
Aetiological data	
Was any assisted reproduction technique used?	(yes, no)
if yes, its name	

Mother's occupation at time of conception	
Mother's illnesses in the 3 months prior to pregnancy	
Mother's illnesses during pregnancy	
Number of previous pregnancies	
Its/their outcome(s)	(live birth, stillbirth, spontaneous abortion, termination of pregnancy due to prenatal diagnosis, prenatally detected, but not terminated pregnancy)
Folic acid intake, if yes, its quantity	(mg)
Medication during pregnancy	(name, dosage)
Consanguinity	
Disorder(s) of affected sibling(s)	(yes, no)
if yes, its type	
Type of congenital disorder in mother's family	
Type of congenital disorder in father's family	
Data of twin	
If has a twin: twin's sex	
Zygosity	
Outcome of twin's pregnancy	
Occurrence and name of disorder	
Data of reporting person	
Name of reporting physician	
Stamp number	
Reporting institution	
Name of ward	
Address of reporting institution	(post code, name of city/town/village, street, house number)
E-mail address	

Appendix 7/6

List of medicines and active substances subject to detailed accounting

According to Annex 1/A of Decree 9/1993. IV. 2 of the Ministry of Welfare

The National Health Insurance Fund of Hungary provides the institutions with the following in kind		
OENO	**Name of active substance of medicine**	**Name of medicine**
06010	trastuzumab	Herceptin
06011	pemetrexed	Alimta
06013	gefitinib	Iressa
06014	cetuximab	Erbitux
06030	agalsidase beta	Fabrazyme
06032	agalsidase alfa	Replagal
06036	bevacizumab	Avastin
06038	nelarabin	Atriance
06040	ranibizumab	Lucentis
06041	verteporfin	Visudyne
06042	alteplase	Actilyse
06050	cetrolizumab	Cimzia
06051	etanercept	Enbrel
06052	adalimumab	Humira
06053	infliximab	Remicade
06054	tocilizumab	Roactemra
06055	golimumab	Simponi
06056	ustekinumab	Stelara
06057	abatacept	Orencia
06058	rituximab	Mabthera
06059	ibritumomab tiuxetan	Zevalin
06060	bortezomib	Velcade
06061	lapatinib	Tyverb
06065	alemtuzumab	Mabcampath
06071	panitumumab	Vectibix
06047	klofaribine	Evoltra
06046	erlotinib	Tarceva
06047	Plerixafor	Mozobil
06043	Palivizumab	Synagis
	Human normal immunglobulin	

8. DATABASES OF HEALTH HUMAN RESOURCES (DÓRA KIS-NEMES)

Building databases is especially important in health care, since the availability of data and information of sufficient quantity and quality is essential for creating health policies for the sector as well as the preparation of decisions. As health care affects the whole population, it is of paramount importance that the databases should contain valid data, which is the joint responsibility of the sectoral administration, institutions of education, health care staff and their employers.

Act CLIV of 1997 on Health Care (hereafter: Health Care Act) clearly sets down the duties of health care personnel, educational institutions and employers to participate in the database.

8.1. THE GENERAL REGISTRY OF PERSONS WITH HEALTH CARE QUALIFICATIONS

According to the Health Care Act any person who possesses health care qualifications either acquired in an educational institution in Hungary accredited by the state or acquired such qualifications abroad and had it later recognized in Hungary has to be registered in the general registry after receiving his/her diploma or certificate. The educational institutions issuing the diploma or the certificate or responsible for recognition have to report it to the central office in charge of the general registry within 30 days following the issue of the diploma or the certificate. Until a person with health care qualifications has not been registered in the general registry, he/she may not be employed in health care. The main purpose of the general registry is the credible certification of acquired qualifications.

8.2. THE REGISTRY OF ACTIVE HEALTH CARE PRACTITIONERS AND PROFESSIONALS

The goal of this registry is to certify health care practitioners' and professionals' data as defined in the Health Care Act in a legally credible way. Its validity is 5 years, after which it can be renewed by submitting the required certificates. Health care practitioners and professionals who have applied for inclusion in the registry of active health care practitioners and professionals have to acquire theoretical and practical training credits which are determined for each group of specialties within a period of 5 years, which is a condition of the renewal of registration.

Theoretical credits can be obtained by attending courses and various trainings, while one can get practical credits by the employer's certification of the qualifications one wishes to renew.

From 2015 the general registry and the registry of active health care practitioners and professionals are managed by the Health Registration and Training Center; the data are available to everyone on the website: http://kereso.eekh.hu/ [74]. Updating the database was preceded by the validation campaign of 2014. The objective of the campaign was to have up-to-date and valid data of every health care practitioner and professional both in the general registry and the registry of active health care practitioners and professionals. The database is being currently updated.

It must be emphasized that in Hungary only employees who possess valid operating licences and can certify the acquisition of both their theoretical and practical credits according to their specialties in the registry are allowed to perform health care activities.

8.2.1. The Health Human Resources Monitoring Project: TÁMOP 6.2.1-11/1

In order to get a complete picture of the databases of the health human resources one must get to know the current institutional and structural changes, their indicators and the tasks of the newly established and/or restructured systems, health care administration and public administration authorities.

The objective of the Health Human Resources Monitoring Project is to create a health human resources monitoring system and a database connected to it that can appropriately support the health care HR strategy, can serve as a basis for the Government's decisions with their valid data and facilitate the monitoring and modelling of the human resources characteristics of the health care sector. The more distant goal of the project is to elaborate the concept of a career model for health care practitioners and professionals in order to support professional development and keep them within the sector. The universal objective, however, is to ensure functional and sustainable health-care of the expected quality. In the design and implementation of the project the experts of the Health Registration and Training Center, i.e. the former Office of Health Authorisation and Administrative Procedures, the former National Institute for Quality- and Organizational Development in Healthcare and Medicines and the Ministry of Human Capacities - State Secretariat for Healthcare take part.

By analysing the data it became clear to the team of experts that a new registration system had to be created by merging and unifying the majority of the currently functioning databases.

That is why the validation campaign was started in 2013 in order to update the data of the general registry and those of the registry of active health care practitioners and professionals. Self-validation is done electronically and on a volunteer basis.

8.2.2. The establishment of the Health Registration and Training Center

On 1 March 2015 Government Decree 29/2015. (II. 25.) on the Health Registration and Training Center came into force [75].

The most important legal changes concerning human resources databases were the following:

1. § (1) The Health Registration and Training Center (hereafter: HRTC) is a central budgetary institution operating as a central agency controlled by the minister in charge of health care (hereafter: the minister).

2. § (1) Within its scope of activities the HRTC -in the framework of the minister's sectoral responsibilities related to health care - according to the stipulations of the statutes:

a) in connection with specialized tertiary education for health care

aa) operates the system of the state-financed specialized tertiary education for health care,

ab) cooperates in the tasks related to the budgetary support of participants in state-financed specialized tertiary education for health care,

ac) in connection with the grants of the Resident Support Programme it fulfils comprehensive coordinating, communication, information and financial-managerial tasks,

ad) it fulfils the tasks related to the institutional accreditation of specialized tertiary education for health care,

ae) it operates the specialized tertiary education for health care and the National Examination Board in charge of the organization of specialist examinations concluding specialized professional further training for health care,

af) it determines the credit values of optional further trainings for specialist physicians, specialist dentists, specialist pharmacists and specialist psychologists,

b) in connection with the vocational training of health care practitioners

ba) within the minister's scope of competence, it elaborates, prepares and supervises the vocational and examination requirements of vocational qualifications belonging to the health care sector,

bb) it performs adult educational activities, organizes health care vocational trainings outside the school system and fulfils the organizational tasks related to the examinations concluding the vocational training of health care practitioners stipulated in the statutes,

bc) it organizes health care vocational further trainings,

bd) with the exception of the further trainings organized by itself, it determines the credit values of health care practitioners' optional further trainings,

c) it provides the operating conditions for the Council of Vocational Education and Further Training for Health Care,

d) considering certain certificates and diplomas entitling their holders to perform health care activities laid down in the statute (hereafter together: diplomas) - according to the act on the recognition of foreign certificates and diplomas -

da) it recognizes diplomas,

db) it issues official certificates,

dc) in the cases laid down in the statute it fulfils tasks in connection with the cross-border provision of services,

e) it operates the human resources monitoring system of the health care sector,

f) it performs tasks as an authority and market authority in connection with medical devices, as an authority related to the authorization of the clinical trials of medical devices and as an appointing authority in connection with the appointment of bodies entitled to assess the conformity of medical devices,

g) it performs the authorization procedures related to psychoactive drugs and psychotropic substances and the activities new psychoactive substances may be used for, and it keeps registries related to these,

h) it certifies medical certificates for use abroad,

i) it cooperates in data collection based on legal regulations and international agreements, it collects and analyses the statistical data on the numbers and salaries/wages of the health workforce, and it also fulfils tasks of preparing decisions and system analysis in the sector in connection with the health care provision system.

(2) The HRTC cooperates in performing tasks laid down in the decree on the rules of the domestic operation of the inner market information system and the rules of participation in it.

3. § (1) According to Act CLIV of 1997 on Health Care (hereafter: Health Care Act) the Government appoints the HRTC:

a) as the government agency responsible for the general registry,

b) as the government agency responsible for the registry of active health care practitioners and professionals,

c) as the agency responsible for the registry of health care experts,

d) as the health care government agency responsible for the accreditation of institutions of the education of specialist physicians,

e) as the health care government agency responsible for the unified human resources monitoring system of the health care sector,

a) as the health care government agency responsible for the registry of post-mortem examination consultants,

bd) as the health care government agency that determines the credit values of the optional theoretical further trainings for specialist physicians, specialist dentists, specialist pharmacists, specialist psychologists and -with the exception of the further trainings organized by itself- health care practitioners.

8.2.3. Changes in the employment of residents

A further function of the HRTC is the centralized employment of residents together with the health facilities. The purpose of the restructuring of the present system is to ensure the supply of specialist physicians for the predictability of human resources management.

Government Decree 62/2015. (VI. 30.) on the Specialized Tertiary Education System for Health Care, the Grants of the Resident Support Programme and the Support of Young Specialist Physicians entered into force on 1 July 2015.

Government Decree 62/2015. (VI. 30.) on the Specialized Tertiary Education System for Health Care, the Grants of the Resident Support Programme and the Support of Young Specialist Physicians (hereafter: the Decree) covers those residents **who start their first specialized trainings after 1 July 2015.** The supported specialized training of those who started it prior to 1 July 2015 is governed by the stipulations of Government Decree 122/2009. (VI. 12.) on the Specialized Tertiary Education for Health Care. **Passing from one support system into the other is not possible. [**76**]**

As a result of the new system residents do not enter a contract of employment with health facilities; employers' rights are exercised by the HRTC in connection with them.

According to point 5.§ (4) of Government Decree 162/2015. (VI. 30.) the health facility, i.e. the primary training site, undertakes to record the certificates of residents' completion of their specialized training in the registry operated by the HRTC continuously or by the 5th working day following the reference month.

According to section 116/A. § (4) of Act CLIV of 1997 (hereafter: Health Care Act) the registry contains [77]:

a) the natural personal identification data and his/her number in the registry of active health care practitioners and professionals of the person participating in the training,

b) the specialty of the person participating in the training,

c) the name of the institution of health care higher education responsible for the theoretical training,

d) information on the completion of the practical part of the specialized training,

e) the name, address, tax identification number and bank account number of the health facility appointed by the health care government agency responsible for specialist physician training as the place of employment or -if the employer is not the health care government agency in charge of specialist physician training- the name, address, tax identification number and bank account number of the health care provider employing the person participating in the training,

f) the fact of participation in the Resident Support Programme.

To sum it up, the areas taken over by the Health Registration and Training Center (formerly: OHAAP) are the following:

- the responsibilities of the General Directorate of Health Care Human Resources Development,
- the organization of the entire specialized training and further training system, which was earlier done by the ETI and from 2011 the National Institute for Quality- and Organizational Development in Healthcare and Medicines,
- the operation of the Council of Vocational Education and Further Training for Health Care and the preparation of statistics on workforce figures and salaries/wages.

8.2.4. National Healthcare Service Center

According to the above, the responsibilities of the National Institute for Quality- and Organizational Development in Healthcare and Medicines were also divided. The institute was renamed [1]National Healthcare Service Center, and most of its duties were taken over by the HRTC and the National Institute of Pharmacy and Nutrition and the National Centre for Patients' Rights and Documentation.

The [1]National Healthcare Service Center only provides assistance with the elaboration of an economically efficient methodology related to facility management in order that the

operation of Hungarian health care can support secure medical care. The management of most of the projects in the health care sector still remains the responsibility of the Centre. Its new task is the management of the system of colleges for advanced studies.

8.3. WEB PORTALS SUPPORTING THE TRAINING OF HEALTH CARE PROFESSIONALS

The OFTEX is a web portal that continuously provides information about further trainings for physicians, dentists, clinical specialist psychologists, clinical radiation physicists, clinical microbiologists and clinical biochemists [78].

The purpose of the portal is to summarize the credits acquired by the participants of further trainings in pre-accredited courses, on-the-job trainings, accredited professional congresses, various individual trainings and during practical activities. The portal also helps with the accreditation of pre-accredited courses, post-accredited trainings and professional congresses. [79]

The SZAFTEX is an IT system concerning the obligatory further trainings of health care practitioners [80]. The portal is meant to support the continuous further training of health care practitioners. According to the registry of active health care practitioners and professionals it contains the data of the further trainings of more than 97 thousand people.

8.4. HUMAN RESOURCES REGISTRY (HENYÍR)

This is the database of the National Public Health and Medical Officer Service about the health facilities and the health care practitioners and professionals employed by them. It is the responsibility of the Office of the Chief Medical Officer to keep certified public records of health facilities and their organizational units and the health care activities and specialties they have licences for as well as the data of health care practitioners and professionals providing health care related to their activities.

The Office has created a comprehensive Excel table that contains the information of employees subject to the obligatory provision of data. It had to be submitted by the health facilities by 1st July 2014 for the first time, and it replaced the compulsory provision of data for the Office of Health Authorisation and Administrative Procedures (currently: HRTC). From that day on the Office of the Chief Medical Officer has been responsible for this task. The data are also compared to the medical registry of the National Health Insurance Fund of Hungary. The obligation of provision of data applies to every in- and outpatient specialist care facility and emergency and medical transportation service provider operating in Hungary.

8.5. The System of Standard Classification of Occupations

One of the prerequisites of the observation and examination of processes is to have systems of classification that provide a 'common language' both for collecting and processing data. The System of Standard Classification of Occupations (FEOR) was first introduced in Hungary in 1975 [81]. In its structure, organization and principles it clearly corresponds to the International Standard Classification of Occupations (ISCO-88) [82]. This nomenclature of occupations was also adopted by the EUROSTAT, and then in 2008 it was also accepted by the board of the International Labour Organization (ILO). In 2011 the ISCO-08 was introduced for all occupations. Simultaneously, the revision of FEOR-93, in force till that, took also place, which lead to the introduction of the new system of standard classification of occupations, FEOR-08, on 1 January 2011. From 2011 the Hungarian and the International systems correspond more closely than their earlier versions.

Just like in the case of every job group the elaboration of a suitable system of classification, which is greatly facilitated by the FEOR, is also very important in health care. The system has also clarified the concepts related to occupations, and has made the registries and the provision of data for human resources management, statistics and administration more standardized from the point of view of the classification of occupations. The principles of the system of the classification of occupations remained unchanged from its introduction until 1993.

Table 8/1: The FEOR numbers used in health care are the following:

2211 Medical doctors, generalist medical practitioners
2212 Medical doctors, specialist medical practitioners
2213 Dentists, specialist dentists
2214 Pharmacists, specialist pharmacists
2221 Environmental and occupational health and hygiene professionals
2222 Optometrists
2223 Dieticians and nutritionists
2224 Physiotherapists
2225 Health visitors
2226 Paramedics
2228 Alternative medicine practitioners
2229 Other human health (related associate) professionals
2231 Nurses (with higher education qualifications)
2232 Midwives (with higher education qualifications)

3311 Nurses, specialist nurses
3312 Assistant midwives
3321 General health care assistants
3321 General health care assistants
3322 Health care administrators
3323 Medical imaging and therapeutic equipment technicians
3324 Medical laboratory assistants
3325 Dental assistants
3326 Pharmaceutical assistants
3327 Alternative medicine practitioners' assistants
3331 Environmental and occupational health and hygiene professionals' assistants
3332 Physiotherapy assistants, masseurs
3333 Dental technologist
3339 Other human health professionals

9. THE ROLE OF DATABASES IN THE BUDGETS OF HEALTH CARE FACILITIES (ANTAL ZEMPLÉNYI)

9.1. THE PURPOSE AND CONTENT OF THE BUDGET

Health care facilities as budgetary institutions are obligated to make a budgetary plan every year. In the case of budgetary institutions the budget is a financial plan that contains the approved expenditure necessary for the performance of their tasks and the expected revenues to be realized during its period of validity as estimates. However, today's hospitals are complex organizations for which it is not enough to merely prepare a financial plan during annual planning, because such plans do not contain professional plans for fulfilling the facilities' primary functions and performance plans based on patient numbers and capacities.

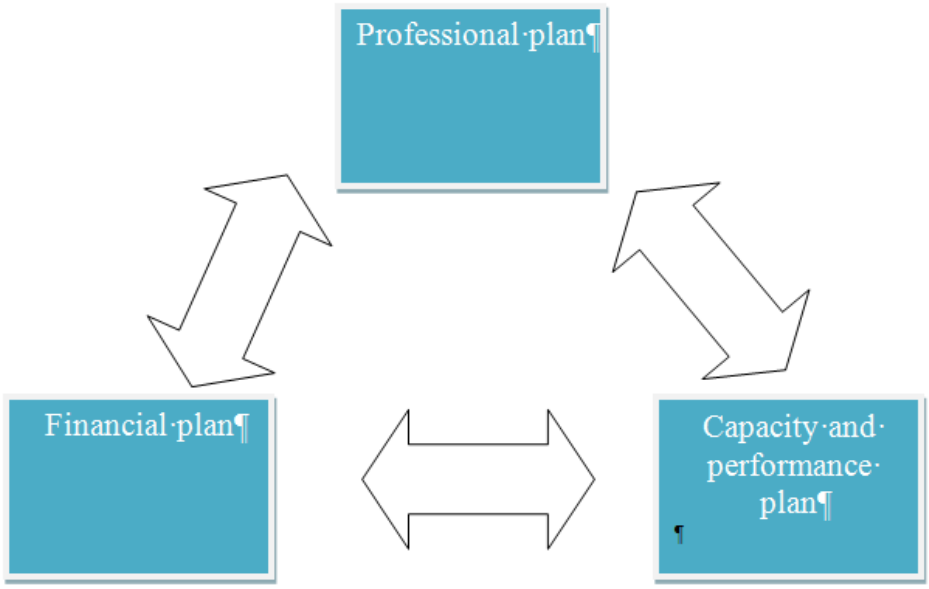

Figure 9/1: The elements of budgetary planning

Planning is to be done in a complex way on the basis of the data and forecasts available to the institution. First the annual professional plan has to be made followed by the performance plan, which ensures the optimal utilization of the capacities and the resources, and then, based on all these, the financial plan can be made taking the limitations of financing also into account. The three part plans, supporting each other, can ensure the effective management of a health care facility.

The compilation of the part plans requires serious preparations, for which a large amount of data has to be processed. This chapter briefly presents what information has to be produced during the planning process of the budget of a health care facility and what data and from what sources need to be processed for that end.

9.2. BASIC DATA FOR PLANNING

9.2.1. The professional plan

The professional plan contains the strategic goals of the health care facility and the tasks related to achieving them. Thus, the professional plan determines -among other things- the range of the health care services, the professional portfolio, the structure and the group of patients receiving care, which all influence the content of the performance and financial plans.

Consequently, for preparing a professional plan the following groups of data are needed:

a) the demographic, epidemiological and sociographical data of the population for whose care the facility is regionally responsible and their changes and trends over time,
b) the morbidity characteristics of the micro-regions within the territory the given facility is responsible for,
c) patient migration data, which show in detail in which facility the patients living in the given territory receive care and in which specialty areas the given facility provides care for patients from settlements outside the territory it is obligated to service.

The health care-related statistics in the dissemination database of the Hungarian Central Statistical Office offer suitable information for the preparation of professional plans [83]:
http://statinfo.ksh.hu/Statinfo/themeSelector.jsp?page=1&theme=FE
Patient migration data are available in the database of the National Health Insurance Fund of Hungary (OEP) [84]. The OEP publishes data concerning the movements of patients only with very limited content; detailed data for the professional public are only available upon individual request.

9.2.2. The capacity and performance plan

The capacity plan contains the working hours of the specialist physicians and the number of chronic and active beds the health facility wishes to operate, taking the goals set in the professional plan into account [85, 86]. The justified capacity of a health care facility is determined on the basis of the demand it has to satisfy in the particular specialty areas regarding the size of the population and the morbidity data and the funding framework the funder allows for that purpose [87].

For capacity planning the national and/or facility-specific capacity utilisation indicators may serve as a great starting point: e.g.

- case number per bed or weight number,
- the ratio of potential and actual days of care (bed occupancy),
- case number or so-called 'German points' per one working hour of a specialist physician.

The data needed for the comparative analysis necessary for the preparation of the plan are made available to the public by the OEP.

http://www.oep.hu/felso_menu/szakmai_oldalak/publikus_forgalmi_adatok/gyogyito_megelozo_forgalmi_adat

On the other hand, however, capacity planning is not the sole responsibility of the health care facilities; there are statutory regulations on maintaining minimum capacity and necessary capacities may only be modified with the consent of the Office of the Chief Medical Officer (OTH) [88].

Capacity planning is done on the basis of the structure determined in the operating licence and the financed capacity, also taking the Performance Volume Limit (PVL) into account [89, 90, 91]. Concerning larger health care facilities it may be said in general that, considering their available capacities and the demand from the population, they would be capable of greater performance (care for more cases) than what the PVL allows them. This makes it necessary for the facilities to limit their performance in certain specialty areas. As a result, during capacity planning the composition of the performance needs to be analysed on the basis of data from earlier periods, which requires -among others- the following data broken down to specialties:

- performance by emergency and elective care,
- performance belonging to progressive care,

- performance by care of cases under territorial obligation and cases outside the territorial obligation,
- performance subject to financing limits or performance exempt from the PVL,
- weight number per case (CMI),
- the variable costs of care.

Performance analyses as above can be made on the basis of a database that draws on various data sources of the health care facility (e.g. medical system, controlling system, manually prepared charts).
It is the performance plan that makes the precise planning of the greatest source of revenue of any health care facility, the payments from funding by the OEP, possible and, at the same time, provides a basis for the second pillar of the financial plan: the plan of expenditures.

9.2.3. The financial plan

The budgets of health care facilities can be made according to two approaches.

- Budget-based planning: the planning of revenues and expenditures based on the estimate-management system of the health care facility.
- Finance-based planning: this means the planning of claims (receivables) and expenses by areas of responsibility and it is fundamentally based on the controlling data of the health care facility.

Due to hospitals' operational functioning, lagging financing by the OEP and hospitals' continuous indebtedness the finance-based approach to planning is more suitable for ensuring the transparency of the financial plan of a hospital and for being used as a management tool by the management of the facility.

During the planning period health care facilities create a database that shows the expected results of a period (planning period). The elaboration of a financial plan begins by creating a so-called basis, whose sources are the analytical data of an earlier accounting period. The processing of the data providing the basis of the financial plan focuses on the mapping of three large groups of data:

- costs,
- revenues,

- internal services (services performed, cost drivers).

The determining source of cost and revenue data is general ledger accounting; the transfer of data to the controlling system, which is the basis of financial planning, is done by detailed, book entry-level databases.

The costs in the controlling types of costs are **created by taking over general ledger costs.** Costs are characterized by **cost type** and **the location where they occur**. These are taken over and converted from the costs database of the closed general ledger period into the controlling system.

The majority of the revenues -the items of OEP performance-financing listed in the Social Security list- is typically not registered in the general ledger system, so the processing of these revenues is done by the health care facilities on the basis of financing analyses. In the case of every other revenue not by the OEP/Social Security the general ledger accounting is the sole source of information.

The third part of the financial planning is the collection of internal services, cost drivers and internal performance. The accounting of the internal services is necessary in order that the utilization of the resources necessary for the operation of an organizational unit can be seen realistically even if the services used (e.g. anaesthesiology, diagnostics, disinfection, medical transport, etc.) are not provided by an external service provider but by a unit within the health care facility.

The accounting of internal services has to be on the basis of performance that is real, measured (if possible), proportional to the costs and is in a causal relationship. That is why the recording and registering of performance, which is usually done in IT sub-systems and is regularly sorted, is of paramount importance [92]. The most important systems where data for the accounting of internal services are available are the following:

- medical system (days of care, duration of operations and the performance of diagnostic units and outpatient specialist care, etc.)
- systems substituting for the medical system or containing certain data of the medical system (e.g. funding accounting software, controlling sub-systems, which may draw on the clinical system and/or the performance reports submitted to the OEP and/or feedback),
- the local systems of service provision (e.g. catering, facility management system, transport),
- in the absence of systems tabular (electronic or even paper-based) data collection (the results of which have to be processed in databases).

10.INFORMATION PRIVACY IN HEALTH CARE (ISTVÁN ÁGOSTON)

10.1. INTRODUCTION

All through human history governments have always placed great emphasis on having up-to-date records of the citizens, which has become even more significant today especially with regard to demographic data and information related to taxation and compulsory military service. But data connected to births and deaths are important not only for states but also for individuals. However, during data collection governments also come into possession of numerous personal data that affect individuals extremely sensitively, such as medical information. This is especially true nowadays, when the development of information technology has made it possible to connect large databases which are handled separately -sometimes even at great geographical distances from one another- in an instant. This, of course, has called for the increased protection of personal data, especially sensitive ones, such as medical data.[93]

As a result, realizing the confidential nature of medical data and that due to the ubiquity of information technology these data require special protection, the Hungarian parliament passed Act XLVII of 1997 on the treatment and protection of medical and related personal data (hereafter: the Law). For understanding the stipulations of the Law it is indispensable to be familiar with Act CXII of 2011 on informational self-determination and freedom of information and Act CLIV of 1997 on health, which cannot be treated in detail here since they are outside the scope of this chapter. [94, 95, 96]

10.2. THE OBJECTIVES, VALIDITY AND PRINCIPAL STIPULATIONS OF THE LAW

The Law determines the range and treatment of special personal data about health status and the personal data related to them. It definitively sets down that personal data may only be handled in the cases and to the extent that is necessary for lawful purposes. This rule can be derived from the principle that there should be a stated purpose for all data collected. The Law identifies the persons and objects covered, according to which the stipulations of the Law apply to the system of the provision of health care as well as anyone handling medical and personal identification data. Of the definitions set down in the Law the following require special attention: medical data, personal identification data and the concepts of urgent need and medical confidentiality.[97]

The purposes of handling medical and personal identification data are listed by the Law exhaustively. Thus, without authorization by any other law these data may only be handled with the purposes of preserving, improving, maintaining health; supporting successful healing activity by health care provider; monitoring or observation of the health status of the person (individual) involved; taking measures necessary from the aspects of public health, health care or epidemiology and implementing patients' rights.

Apart from these purposes the Law also allows the handling of medical and personal identification data in cases governed by other law, but these are also listed exhaustively. These include -among others- the training of health care professionals, statistical studies, establishing ability to work, the arrangement of patient paths as well as the inspection and assessment of the performance of the health care system.

Also, the Law clearly stipulates who is authorized to handle medical data. Among these the provider of health care, who could not work effectively without medical data, the heads of healthcare institutions and employees responsible for information privacy are listed. In the case of people exposed to public health and/or epidemiological risks and any other persons who have come into contact with them the Law specifically regulates who is authorized to handle their medical data and in what way.

According to one of the most important stipulations of the Law the security of the data has to be protected from accidental or purposeful annihilation, modification and disclosure as well as from access by unauthorized persons during the handling and processing of medical and personal identification data.

10.3. THE HANDLING OF DATA WITHIN THE HEALTH CARE SYSTEM

The most important purpose of data handling is the handling of data for the purpose of medical treatment, which takes place within the health care system mainly. During data handling the persons responsible have to maintain medical confidentiality, which is also prescribed by the health act for health care workers broadly defined. According to this, every worker in health care is bound by an obligation of confidentiality without any time limit concerning any data and other fact in connection with patients' health conditions or the medical or health care provided for them, regardless of where or how they learned about them. Health care workers may become exempt from the obligations of confidentiality only by the patient's or their legal representatives' written consent or authorization by law. It is part of patients' rights that patients are entitled to receive information about their data related to their treatments and the handling thereof and to view their medical documentation, of which they may make copies at their own expense. The

right of access to medical documentation may be practised by persons authorized by the patient in writing during the period of their medical treatment in a private document that provides conclusive evidence after ending their treatments. In the case of a patient's death his/her legal representative, close relative or heir may have access to the medical documentation that is connected or may be connected to the cause of death, upon request. [98]

The Law also stipulates that within the health care system medical and personal identification data may be transferred and may also be linked for taking medical, public health, health care and epidemiological measures, to the extent and for the time necessary. For the purpose of the preservation, improvement and maintenance of the patient's health any medical data related to his/her disease may be transferred, except if the patient has prohibited that in writing, about the possibility of which he/she has to be informed in advance. Except for the data needed for receiving medical care by the patient, all medical data are provided by the patient voluntarily. If the patient receives health/medical services voluntarily, his/her consent to handling his/her medical data is taken for granted, except he/she makes a declaration otherwise.

In the case of urgent need, however, medical and personal identification data related to a patient's medical care may be transferred without his/her consent. The condition of urgent need, similarly to the rules applied in the case of the right of self-determination, also involves differences in the handling of medical data compared to the general regulations. Consequently, in the case of urgent need and/or in the case of the lack of the patient's ability of understanding his/her voluntary consent to the handling of data is taken for granted. The Law stipulates the patient's obligation to provide data in the case of certain communicable diseases, acute poisoning, screening and aptitude tests, diseases of occupational origin, for the purposes of crime prevention and crime control as well as state security. [99]

It is the patient's right to allow during his/her examination and/or medical treatment the presence of exclusively those persons who perform or are needed for the performance of his/her medical treatment and those whose presence he/she has consented to. In the case of no consent by the patient, in certain cases official members of the police force and/or correctional services may be present, and in the case of treating several patients simultaneously the health care workers treating the other patient(s) as well. For the purpose of the education of health care professionals medical students and or students and teachers participating in the training of health care professionals may only be present during the patient's examination and treatment with the patient's consent. The patient's consent is not

required if the institution is regarded as an institution of education for health care professionals, such as university clinics and teaching hospitals.

The health care provider is allowed to handle the patient's medical and personal identification data:

- It may forward them to the state administration bodies responsible for health care if the patient suffers or is believed to be suffering from one of the communicable diseases listed in the annex of the Law, with the exception of the cases of anonymous screening tests (HIV, AIDS).
- In the case of diseases threatening food chain safety it is necessary to inform the Food Chain Safety Office.
- For public health reasons, for purposes and with contents specified by the Law data may be transferred to the National Registry of Congenital Disorders, the registries of cancers, the Registry of Paediatric Oncology and the National Registry of Myocardial Infarction.
- Data handling for statistical purposes and scientific research comprise a separate category. This also includes transferring particular personal data for statistical purposes to the Hungarian Central Statistical Office, which deletes them immediately after statistical processing.
- In the case of scientific research authorization by the head of the institution or occasionally by the person in charge of information privacy is required for accessing personal data, which, however may not be included in scientific publications.

Any accessing of the data has to be recorded and the records have to be kept for 10 years.

10.4. TRANSFERRING DATA OUTSIDE THE HEALTH CARE SYSTEM

Upon written request and in the cases determined by the Law the health care system forwards patients' medical data and personal data necessary for identification to organizations with competence and authority, e.g. in criminal cases to the investigation authority, the prosecution office and the court of law or in the case of disciplinary proceedings against a health care worker to the responsible body of the chamber responsible for the process. Immediate action is required upon requests by the investigation authority marked 'for action without delay' and in the case of information necessary for the examination of a dead body in an urgent investigation or in the procedures of the authorities related to extraordinary deaths.

In certain cases the transfer of information does not even require the consent of the patient involved, e.g. when the patient has suffered injuries that do not heal within eight days and it is assumed that they resulted from a criminal act. In such cases it is necessary to report the case to the police, or in the case of injuries to a minor or if a minor's illness is the result of neglect or if the physician treating the patient is informed of such a case, he/she must report it to the child welfare service. In the course of administrative proceedings medical data may only be transferred if they are absolutely necessary for implementing the rights or obligations of the person involved. [100]

10.5. REGISTERS OF MEDICAL AND PERSONAL IDENTIFICATION INFORMATION

It is stipulated by the Law that the medical and personal identification information recorded about the patient and any transfer thereof have to be registered with a specified data content. The register includes the records that the doctor treating the patient has to make about the medical data he/she or somebody else has recorded and his/her own activities. Institutions providing health care have to register people affected by the illnesses listed in the Annex of the Law, the people obligated to receive vaccination, people using illegal drugs and those consuming drugs in pathological amounts; in this case, however, they have to store the medical and the personal data separated from each other. [101]
As part of health care documentation images produced by diagnostic procedures have to be kept for 10 years, evidence from the images for 30 years and discharge summaries for 50 years. After the prescribed period of storage these data have to be deleted, except if the case has a scientific significance, in which case they have to be given to the Semmelweis Museum, Library and Archives of the History of Medicine. Patients have a right to access the health care documentation made about them and if they find mistakes or misspellings in them, they may request their correction. Correction is to be done in a way that leaves the original data discernible.

Within a healthcare institution the head of the institution handling the information is responsible for the protection of medical and personal data and the storage of the registers. If an institution employs more than twenty persons who handle information in each unit, a person in charge of information privacy has to be appointed for each organizational unit. Only specialist physicians, lawyers with at least 2 years of legal experience or people with higher education and at least 2 years of experience in handling health care information may be put in charge of information privacy.

Institutions outside the health care system may only handle medical data to the extent it is necessary for the performance of their duties, always complying with the relevant stipulations of the Law. In these institutions only persons charged with handling data by the head of the institution and/or persons exercising public authority are allowed to handle information; health care information may be recorded by members of the pedagogical service of public education and drafting physicians of the conscription agency to the extent necessary for their tasks.

10.6. THE LEGAL PRACTICE OF THE INFORMATION AND PRIVACY COMMISSIONER

The information and privacy commissioner has passed several resolutions on the privacy of personal data, two of which are presented below to highlight the challenges and interesting features of the practical side of medical data handling. [102]

A typical example of the problems of data handling within the health care system is the transfer of patients' records in connection with the succession of general practitioners' practices. In several cases when a patient changes his/her GP, the old GP withholds and dos not send on the medical data of the patient to the new GP. In his resolution 31/A/2005 the information and privacy commissioner pointed out that it is always the provider of general medical care who is entitled to handle the health care documentation of patients; the former GP must not create a situation in which the practice might 'become empty' by withholding the patients' records. In the absence of agreement the court of law has to force the transfer of information.

The following interesting case of medical data handling related to requests from outside the health care system is meant to illustrate that with seemingly well-founded justification and in the course of administrative proceedings even an administrative authority might make requests addressed to health care institutions that are beyond the range of data necessary to bring the proceedings to a close. Consequently, it has no right to handle the medical information and the personal identification data of the persons involved.

According to the plea a GP, who regularly visited his patients in his car, objected that the competent directorate of the Tax and Financial Audit Office did not accept his mileage log during an investigation in 2003 with the justification that the doctor had not provided them the names of the patients visited. On the one hand, the doctor claimed mileage reimbursement for the use of his own vehicle, which required the keeping of a mileage log. On the other hand, he pointed out that in his opinion the tax authority did not have a right

to know data suitable for personal identification that are subject to medical confidentiality. In his resolution 891/K/2003 the information and privacy commissioner stated that no law grants the tax authority the right to know and handle the data of the patients' treated by the doctor.

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