HEALTH MONITORING SYSTEMS IN BELGIUM

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SUMMARY

Belgian is a federal state, which consists of 3 communities and 3 regions. The different level authorities share the responsibility of health policies. As far as health information is concerned, the federal government and the 3 communities are the key players.

Different types of data are collected at different levels. At federal level, data about the health care system is routinely collected. The federal level also support surveillance networks of general practitioners and laboratories, registration of HIV infections and drug abuse. It also organises a National Health Interview Survey every 4 to 5 years.

Community level deals with birth and death registration, infectious diseases notification. It also funds registries for various health problems (Myocardial infarction, cancer, diabetes…). Level of funding, health problems, structure in charge of the registry and procedures vary from one Community to another. The Flemish Community has developed a plan for health information system. The French Community is currently developing one. A master plan has been prepared by scientific experts. However, the implementation of the system depends on political decisions.

The main drawback is the lack of unity in the system. Various authorities and non-governmental organisations collect and treat data in their own way. The level of funding varies from one community to the other and there may be considerable delay in the treatment of data. There is no guarantee that the methods are the same in different structures. Plans for implementing a comprehensive health information system at community level and negotiation at federal level should lead to better data management, more co-ordination and a better use of the available expertise.
HEALTH MONITORING SYSTEMS IN BELGIUM

1. Preliminary note

This report reflects the findings of the researchers. It is not in any mean an official description of health monitoring systems in Belgium.

2. Introduction : Belgium as a federal state

Belgium is a federal State, which consists of 3 communities and 3 regions. As a consequence, the political system is rather complex. This complexity is also reflected in health data collection and management.

The decision-making power in Belgium is not exclusively in the hands of the Federal Government and the Federal Parliament. The management of the country is shared between different levels of power, which exercise their authorities in autonomy.

The redistribution followed two broad lines. The first concerns linguistics and, more broadly, everything relating to culture. It gave rise to the Communities, a concept, which refers to the persons that make them up and to the bound that unites them, in this case language and culture. Belgium is situated at the junction between the Latin and Germanic languages: Dutch, French and German. Thus, Belgium has three Communities today, based on language: the Flemish Community, the French Community and the German-speaking Community. These correspond to population groups.

The second main line of the State reform is historically inspired by economic concerns, expressed by Regions who wanted to have more autonomous power. This gave rise to the founding of three regions: the Flemish Region, the Brussels Capital Region and the Walloon Region. The constituent element of a region is territory.

The country is further divided into ten provinces and 589 communes.

The Federal State is in charge of social security, health care organisation and some public health matters.

The Communities are in charge of preventive health and health promotion: school medical examination, health promotion, early childhood policy, university hospitals, disabled policy.

3. Federal Structures

3.1. Inter Ministerial Conference

The federal Belgian state is a complex structure. Competencies over important matters like health are distributed between different levels of authority. In order to bring more coherence and efficiency in the system, the Inter Ministerial Conference promote dialog between various levels (federal, community and regional) of power and tend to harmonise policies. This
structure gathers the 9 ministries involved in health matters. Health information system is one of the topics that it deals with.

3.2. Federal Ministry of Social Affairs, Public Health and Environment

The federal level is responsible for social security, health insurance system and reimbursement of health care.

The Federal Ministry of Health collect data about health care and hospitals:
- For each patient, a set of clinical data is collected through the minimal clinical summary.
- There is a yearly questionnaire about hospital structures that is sent to every hospital in the country. The data are treated by the MOH and are published on paper and on the Internet.

3.2.1. Minimal Clinical Summary (RCM-MKG)

Since 1994, for each admission to hospital, every hospital has to collect data and transfer it on an electronic media to the MOH. The data collected include information on the patient (age, sex, place of residence, nationality), hospital stay (duration, ward, origin of admission...), primary and secondary diagnosis based on ICD-9, diagnostic and treatment procedures. Every 6 months, data are transmitted to the MOH.

The data are used mainly for management of the health care system and cost containment. However, it can be a valuable source of information for epidemiological studies and the Ministry of Health has published analysis of geographical variations of pathologies in Belgian hospitals.

3.2.2. Hospital statistical data

Each year, every hospital in Belgium fills a form concerning beds, equipment, type of services, management, organisation and quality control procedures. Latest year available: 2000

3.3. National Institute of Statistic (NIS)

The missions of the NIS were defined by the law of July 4th, 1962 that has been modified several times since then. The NIS mandate is to collect, treat and spread numeric data about Belgian society.

As far as health is concerned, the National Institute of Statistic provides demographic data and data about the causes of death. Each year, it publishes an analysis of the causes of death based on the latest data available at national level (presently 1997, published April 2003). Raw data are also available on electronic media. The NIS also takes part in the organisation of national Health Interview Surveys.

3.4. National Institute for Health Insurance

The National Institute for Health Insurance provide health care insurance for more than 97% of the Belgian population. It also pays replacement income in case of illness or invalidity. It collects data about all the drugs and medical services, it pays for. The data are mainly used to manage the system and control costs. It is sometimes possible to obtain information from this Institute for scientific studies and statistical publications but there is no systematic use of those data for epidemiological purposes.
Recently, a “knowledge centre” has been created to improve the share of information between the Institute and the Ministry of Health.

### 3.5. Scientific Institute of Public Health

The Scientific Institute of Public Health has the statute of an “Institute of the State” as ruled by a Royal Decree of March 6th, 1968. It depends from the Ministry of Social Affairs, Public Health and Environment. It has "Cooperation Agreement" with the Flemish and French Communities.

The missions of the institute are: reference activities, monitoring, epidemiological surveillance, control of federal norms, quality assessment, risk evaluation, evaluation of health data, national and international representation of the Belgian federal authorities

#### 3.5.1. Main activities of the epidemiology unit

##### 3.5.1.1. Surveillance networks

Objective: To monitor health problems through sentinel networks of general practitioners or laboratories.

- **Sentinel laboratories:** The aim of this programme is to follow the evolution of different germs. This insures the surveillance of infectious diseases as well as antibiotic resistance. This registration also allows the detection of outbreaks and the estimation of infection incidence at both local and national levels.
- **Sentinel general practitioners register specific health problems on a weekly basis.** This surveillance network allows the monitoring of diseases, the measuring of their incidence and the study of their most important epidemiological characteristics.

##### 3.5.1.2. Registration systems

Objective: To monitor the incidence of specific health problems.

- **Register HIV Infections and AIDS:** This programme records new cases of AIDS and HIV infections diagnosed in Belgium.
- **Drug abuse:** Belgian Information Reitox Network (BIRN): Coordination of Belgian and European information networks united with the European Monitoring Centre for drugs and Drug Addiction (EMCDDA). (See 7.8 Illegal Drugs Abuse page 20)

##### 3.5.1.3. Health services research

Objective: To support and promote quality improvement in health services.

- Quality improvement for general practices by comparing care with existing guidelines and standards.
- **National Surveillance of Infections in the Hospitals (NSIH):** This programme aims to decrease hospital infection rates through surveillance, a confidential feedback system and self-assessment. Participating hospitals are able to monitor local infection and antibiotic resistance rates. These results can be compared with those of other hospitals in Belgium.

##### 3.5.1.4. Population surveys

Objective: To collect health data through population surveys.
A health interview survey: Using the data obtained from 10,000 individuals, the 1997 health interview survey determined the population's health, lifestyle and use of health services.

3.5.1.5. Analysis of data and development of public health indicators

Objective: To express data as useful information to be used in the decision-making process.

- The Centre of Operational Research in Public Health (CORPH) collects and processes information required in the public health decision making process.
- Environmental health risk assessment: One of the objectives is to evaluate the health risks associated with the exposure to heavy metals and to ozone.

3.5.2. Health Interview Survey

The health interview surveys took place in 1997 and 2001 and will be repeated in 2004. It is a collaboration mainly between the Scientific Institute of Public Health and the National Institute of Statistic.

Objectives:

- Identification of health problems
- Description of the health status and health needs of the population
- Estimation of prevalence and distribution of health indicators
- Analysis of social (in)equality in health and access to the health services
- Study of health consumption and its determinants
- Study of possible trends in the health status of the population

Methods:

Sample of all inhabitants of Belgium, stratified per region, province and community, and constructed on the basis of the National Register using the household as sample unit. In 1997, more than 10,000 people have been questioned by 212 interviewers recruited by the National Institute for Statistics (NIS).

There are three sorts of questionnaires:

- Oral questionnaire to be filled out by the household
- Face to face questionnaire to be filled out by each selected person (this could also be filled out by a proxy)
- Written questionnaire to be filled out by each selected person over 15 years (this could not be filled out by a proxy)

The survey dealt with the following topics:

- General health perception
- Perceived morbidity, functional status, chronic conditions
- Use of health services and consumption of care in general
- Lifestyle and health behaviour
- Social-economic characteristics

Household questionnaire:

- Constitution of the household
- Income of the household
- Expenditure for health care
- Housing
Face to face questionnaire:

- Information on the person concerned and the respondent
- Illness and chronic conditions
- Short-term functional disorders
- Long-term physical disorders
- Medical consumption (contacts with GP, dentist, specialist, primary health care, admission to hospital, drug use)
- Flu-tetanus immunisation among adults
- Dietary habit
- Physical activities
- Mother and child health (prenatal care, breast-feeding, follow up of the infant, sleeping surroundings of the infant, contraception, immunisation against rubella)
- Social-economic profile (education, employment, income)

Written questionnaire:

- Health perception
- Health complaints
- Smoking behaviour
- Alcohol use
- Knowledge of and behaviour towards HIV/AIDS
- Nutrition
- Accidents
- Mental health
- Social health
- Prevention (cardiovascular, breast cancer, cervical cancer)

3.5.3. Sentinel general practitioners

Objectives

- evaluation of public health problems and their importance within the population in general, expressed in terms of incidence and study of the most important epidemiological characteristics,
- continuous observation of certain health problems over time, such as measles, mumps, requests for HIV tests, in order to study the impact of prevention and vaccination campaigns,
- study of the management and follow-up of health problems by the general practitioners.

Methods

- The participation by general practitioners is voluntary. The participants (at present about 155) are representative of the profile of physicians in Belgium, i.e. according to age, sex and homogeneous geographical distribution.
- Registration is continuous and from weekly forms. As each registration programme lasts one year, about eight different themes are included. Next to age and sex of the patient, other parameters, varying according to the theme, are recorded.
- Anonymity of the patient is always preserved.
- Retro-information is regularly distributed to participants, concerned authorities, the medical press, scientific associations and interested individuals.
Recorded health problems

- Recorded data concern problems for which the responsibility of diagnosis, treatment and follow-up rest with the medical practitioner.
- The problem has to be one for which clear and standardised definition is possible.
- It must concern an important health problem not subject to surveillance of another system, unless the network of sentinel general practitioners provides complementary information.
- The frequency of the problem should, on the one hand allow statistical analysis, but on the other hand not represent too heavy a burden on the participating physicians.
- Examples: measles, mumps and requests for HIV tests, suicide attempts, home accidents, diabetes, breast cancer, cerebro-vascular diseases…

4. Community Structures

4.1. Flemish Community

The Flemish Community through the Health and Well-being Department manages directly birth and death certificates. The department also treats compulsory declarations of infectious diseases. It also implements school health and mental health data collection. These latter activities have been limited so far. The Flemish Community also has an agreement with the federal MOH to get data of the minimal clinical summary. It also funds several groups for data collection on specific topics: cancer registries, vaccination, drug abuse. It also supports a Study Centre for Perinatal Epidemiology which data from birth certificates.

The Flemish Community publishes once every two years a presentation of Health Indicators for Flanders (Gezonheidsindicatoren) (last year available: 2000). The report gives information about births and death in Flanders, health determinants, and specific health problems.

There are also specific reports about immunisation for children between 18 and 24 months old (1999 data) and about infectious diseases (1999 data).

4.2. French Speaking Community

The French Speaking Community also manages birth and death certificates. It supports financially several organisations and initiatives of data collection.

<table>
<thead>
<tr>
<th>Data managed by the French Community</th>
<th>Data collection financed by the F.C.</th>
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<tbody>
<tr>
<td>Death and birth certificates</td>
<td>National Health Interview Survey</td>
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<tr>
<td>Breast cancer screening</td>
<td>Sentinel labs</td>
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<td>Immunisation</td>
<td>Sentinel practitioners</td>
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<td>Health promotion services</td>
<td>Myocardial infarcts registry</td>
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<td>Mandatory notification of infectious diseases</td>
<td>Cancer registry</td>
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<td>Diabetes registry</td>
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<td>New surveys and registries</td>
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It is currently reviewing its system of data collection. A master plan to structure a health information system has been submitted to the minister in February 2003. This system will include different categories of source of data. Currently, the latest data available are 1996 for health indicators and 1997 for mortality data. Data on communicable diseases had not been analysed and published since the 90’s.

The future system could be summarised by the following chart:

5. **Regional Structures**

Flanders has merged its regional and community political structures. All activities are carried out by the Flemish Community. For Wallonia, data collection is carried out by the French Community. As a bilingual region, Brussels is not covered by either the Flemish or the French Community. It has its own structures as far as health information is concerned. The Brussels Health Observatory is in charge of health information for Brussels Region. The Region has subcontracted the treatment of death and birth certificates to the Flemish Community.

6. **Other structures**

6.1. **Health Observatories**

Four out of 5 provinces in Wallonia have a health observatory. The activity of each may differ somewhat. In general, they carried out health information and health promotion activities. As they are closely in touch with local health professionals and associations, they have the opportunity to provide them with useful health data. These data are intended to guide action. Local analysis and data collection allow being more in touch with local concerns.

Health information activities consist of secondary analysis of data collected at a higher level of authority. They also collect data through local surveys for specific topics or target groups. A summary of data available at local level is published every 2 to 3 years. Specific reports are also produced.
6.2. Mutual Insurance Companies

In Belgium, the reimbursement of health care expenses by the national social security system is done through mutual insurance companies. More than 97% of the population benefit from the national health insurance scheme. Those companies have data on health care consumption and publish studies on topics of interest about drug use or health care usage. This provides information on curative and preventive health care and indirectly on health problems.

6.3. Research and Information Centre of Consumer Organisations (CRIOC)

Each year, this centre organises a phone survey about tobacco use. A marketing company is commissioned by the centre to interview 2000 people in Belgium about their present tobacco consumption.
7. **Specific data collection**

7.1. **Mortality Data**

7.1.1. Overview of the flow of certificate

![Death Certification Flow Chart]

- Death
  - Pratcitioner
    - Part A-B-C are filled
  - Municipality
    - Part D is filled
    - Part A is kept
    - Parts B, C and D are transmitted
  - Community Level
    - Treatment of parts B and D
  - Provincial or Regional or Community Level
    - Collection, verification of certificates
  - Community Level
    - Coding
    - Data entry into computer system
  - Community Level
    - Statistical Analysis at Regional Level
    - Publication
  - National Institute of Statistic
    - Grouping of Data
    - Statistical Analysis at National Level

7.1.2. Death Certificate

Since 1998, a new form is used for death certification. There are 4 parts in this form. Part A, B and C are filled by the practitioner. Part C is placed in a sealed envelope. Part D is filled by a civil servant at the municipality with information provided by the person who report the death to the office.

Information on Part A:
- Identity of the deceased
- Place of death
- Medico-legal information

Information on Part B:
- Time and place of death
- Sex of the deceased

Information on Part C (Medical information):
- Causes of death

Information on Part D (socio-demographic data):
• Place of death, place of residency
• Education level, profession, social status (student, unemployed, employee, self-employed, retired…)
• Nationality, marital status (legal and actual)

7.1.3. Death Certification

A practitioner ascertains the death and filled part A, B and C.

The quality of the information provided by practitioners is dubious in many cases. Several factors play a role in the poor quality of data:

• Lack of the physician training (some emphasis should be put on death certification in the initial training of physician)
• Lack of motivation of the physician (more relevant retro-information should be provided to the physician by the analysis of deaths causes)
• The physician who fills the certificates is not always the usual physician of the deceased

This problem has been mentioned by all interviewees and is also reported in the literature. At EU level, a group is currently preparing recommendation to tackle this issue.

Part D of the certificate is filled by the civil servant of the municipality. The person who reports the death to the administration provides information. The latter can be the spouse, a child, a relative, the undertaker or an employee from the hospital or nursing home. The precision of the information recorded depends on the civil servant skill and motivation, on the knowledge of the reporting person and on the age and social status of the deceased (the older the person, the least precise is the reporting of the profession, prestigious professions are more often known than more common occupations).

In Brussels, some initiatives were taken to motivate civil servants by showing them possible uses of the data they provide. Training was also important to explain the exact meaning of each item on the form. This leads to an improvement of the quality of data.

7.1.4. Municipality level

The municipality where the death occurred keeps the part A of the death certificate. It records the death and transfers part B, C and D to the next level.

Normally, the certificates should be transferred after one month to the next level. In practice, it takes about 2 months (with a minimum of 1 month and a maximum of 13 months). At the French Community, they use several reminders: a phone call after 3 months, a letter after 5 months, a registered letter after 7 months.

7.1.5. Verification

The envelope with part C is opened combined with part B and D. The name of the deceased is not mentioned on any of these parts. The data is verified: not filled items, information is crosschecked between different items and the municipalities and/or the physician is contacted for more information. When there is judiciary inquiry, the relevant justice department can also be consulted. These operations are time consuming and the delay for an answer may be long especially from the judiciary.

These operations are carried out by different structures depending in which region the death occurred. In Flanders, the provincial health inspections are responsible for this part of the
process. In Brussels, it is the region. In Wallonia, the French Community has kept only one single “provincial inspection” in Liège that processes the certificates of the whole region.

7.1.6. Coding of the causes of death and data entry

For Wallonia, coding is done by the French Community in Liège. The Region of Brussels has committed the coding to the Flemish community. The Flemish community codes the causes of death for Flanders and Brussels.

The existence of 2 structures for coding has 2 main drawbacks:

- There may be discrepancies in the way the causes of death are coded between the French and the Flemish Communities
- The people who died outside their region of residency do not appear in the statistics of that region until all database are merge by the National Institute of Statistic much later in the process.

There is no formal mechanism to compare the way of coding in the 2 communities.

Data entry is done at Community level.

7.1.7. Analyses and publications

Each Community and the Brussels Capital Region do their own analysis. When the data from the 3 regions are available, the National Institute of Statistic merges the databases and analyses data at national level.


7.2. Mother and Child Health

7.2.1. Birth Certificates and Infant death Certificates

Birth Certificates follow a similar circuit as death certificates. In Flanders, medical data are collected on a special form. Coding and data entry is done directly by the Study Centre for Perinatal Epidemiology. This centre also carries out the analysis.

Presently, there are contradictions in the Belgian laws. The royal decree of June 17th, 1999 states that every lifeless child with a weigh of at least 500grams, or 22 weeks of pregnancy or, if no other data is available, a length of at least 25cm should be registered as stillbirth. This is in agreement with WHO recommendations. On the other hand, the communal law states that stillbirth should be registered only for pregnancies of 6 months (180 days) or more. The net result is an underreporting of stillbirth between 22 and 26-28 weeks of pregnancy.

7.2.2. Birth Defects

Belgium has two registries within the framework of EUROCAT (European Registration of Congenital Anomalies and Twins): one in Wallonia (Hainaut and Namur Province) since 1980 and one in Flanders (Antwerp Province). The latest years available are 1999 for the Hainaut-Namur register and 2001 for the Antwerp register.
Congenital anomalies are recorded according to the EUROCAT guidelines. Any congenital anomaly is recorded when detected at the time of abortions, stillbirths or live births or in children until 1 year old, in foetuses born after 20 weeks of pregnancy or in abortion induced because of a congenital anomaly. Data comes from maternity wards, obstetricians, paediatricians, and cytogenetic labs.

7.2.3. Mother and child health follow-up

Each community has an official institution in charge of mother and child health ("Office de la Naissance et de l'Enfance" in the French Community, “Kind en Gezin” in the Flemish Community and “Kind und Familie” in the German-speaking Community). They provide antenatal care and preventive consultation for children between 0 and 5 years.

Each body collects data about its activities and data are managed independently by each institution.

7.2.3.1. French Community

The Office de la Naissance et de l'Enfance (ONE) collects data about all its activities: antenatal care, medical consultation for 0-to-5-year children, immunisation, home visits by medico-social workers. Data are stored in a “Medico-social DataBase”. The ONE publishes the data in an annual report and also publishes studies on specific topics.

7.2.3.1.1 Medico-Social DataBase (BDMS)

The medico-social database gathers data about prenatal care and 0-1-year-old childcare provided by the Office. Data are collected on 4 opportunities: prenatal care, at birth, first home visit, 0-1 year synthesis.

Prenatal data are obtained when the ONE follows up a pregnant woman. No data is collected for women who go to a private practitioner. In 1999, 27% of pregnancies were followed up at the ONE; the data are available for 19% of the pregnancies. Data includes general information (age, nationality, civil status, place of residence), medical data (gestity, parity, known risk factors, smoking habits) and follow-up data if available.

For each delivery in a maternity where ONE has full access, a socio-medical worker sees the mother and the baby and fills a form. In 1999, this form was filled and available for the database in 91% of births. Data includes general information, medical data about mother and child, data about delivery and perinatal data (breast feeding, smoking habits).

At the first home visit, the medico-social worker takes note of general information, type of baby feeding, type of follow-up (ONE or private). In 1999, the first home visit took place for 86% of births; data were available for 82%.

The 0-1 year summary deals with baby feeding and weaning, congenital anomalies, screenings and immunisations. In 1999, 81% of the 0-1 year children were seen at least once at ONE consultations, but 0-1 year summary is only available for 40% of the children.

Data are published in an annual report. The 2001 report includes some data for the year 2000. Beside that report, the ONE also publishes an activity report about the care and services provided.
7.2.3.2. Flemish Community

Kind en Gezin manages 2 databases:
- One for the immunisation (see 7.7 Immunisation page 20)
- One for the activities of the socio-medical workers

7.3. Cardio-vascular diseases

Both the French and Flemish Communities finance myocardial registration following the WHO MONICA methodology. Registries exist for Gent in Flanders and Charleroi in Wallonia. Other temporary registries also existed in the province of Luxembourg and in the region of La Louvière in Wallonia.

7.4. Cancer Registries

7.4.1. Federal level

At the national (federal) level, there is the National Registry of Cancer. It is managed by a non-profit organisation (Œuvre Belge du Cancer), which receives subsidies from the federal government and the communities.

Data are collected for the whole of the country and all type of cancers. Since 1983, data comes from mutual insurance companies. When a case of cancer is diagnosed, the mutual insurance company receives a request for financial intervention and the case is registered. The companies anonymise data and transfer it to the registry. During the anonymisation process, a code is attributed to the patient so that the case is only taken into account once even if several physicians declare it at different phases of treatment and follow-up. It is estimated that the underreporting amounts to around 20%.

7.4.2. Other Registries

There are other, more local or more specific registries. All of them are in the Flemish Region:
- LIKAR is a provincial register of cancer in Limburg province (since 1996)
- AKR in Antwerp province
- Bronchial carcinoma register for the Flemish region (1990-1998)
- Melanoma registry in East-Flanders province (since 1996)
Each registry has its own characteristics. The LIKAR registry collect data about all kind of cancer from pathology labs and through active pursue. AKR is hospital based and collect data about all types of cancers. Data for bronchial carcinoma came from pneumologists and pathologists. It was managed by a non-governmental organisation, the VRGT (Vlaamse Vereniging voor Respiratoire Gezondheidszorg en Tuberculosebestrijding). It collected detail clinical information. The melanoma registry collects data from pathology labs.

With the support of the Flemish Community, those registries have been integrated in a registry network. The network is co-ordinated by the National Registry of Cancer. Moreover, 18 pathology labs and 3 university hospitals contribute to the network. All the registries may exchange data through a single patient code number. This has increased the quality and the exhaustivity of the data for Flanders. Nowadays, underreporting is more a problem in Wallonia and Brussels than in Flanders.

7.5. Diabetes Registry

The registry was set up in 1989.

7.5.1. Objectives

- Register new cases of type 1 diabetes occurring before the age of 40 and measure the incidence of type 1 diabetes in Antwerp district. Since 1994, other type of diabetes (type2, pregnancy diabetes) can also be recorded.
- Collect biological and clinical data about the diabetic patient and its family in order to
  - Better understand the relation between genetic and environmental factors in the appearance of the disease
  - Find new markers for the disease in order to detect individuals at high-risk for the disease or its complications
- Study prevention strategies to avoid or lessen complications
- Improve knowledge of the disease and possibilities of diagnosis, treatment and prevention among professionals, patients and general audience.

7.5.2. Methods

New cases of diabetes are collected by more than 100 diabetologists from 7 university hospitals and more than 65 non-university hospitals around the country. A questionnaire is filled by the doctor with the authorisation of the patient. Data are anonymised and entered in the database. A blood sample is also taken and kept for future scientific studies. First degree relatives of the patient can also be registered and followed as high-risk persons.

In Antwerp district, new cases are also registered with the participation of paediatricians, endocrinologists, general practitioners. The completeness of the registration is assessed by the capture-recapture method. The first source of information are paediatricians and endocrinologists. The second source are general practitioners, nurses, patients associations and patients taking part in the “Early Diagnosis and Prevention of Diabetes Project”. These studies are part of European studies EURODIAB and IDA. It is estimated that approximately 90% of the patients are registered by that method in Antwerp district. From the period 1989-94 to 1995-2000, the reporting of type 1 diabetes improve from 36 to 67% in Belgium (Flanders 42 to 74%, Brussels 55 to 81%, Wallonia 20 to 51%).

7.6. Communicable Diseases

Health information on communicable diseases comes from statutory notification by physicians and laboratories. There is a known underestimation of incidence due to incomplete notification.
Notifications are sent to the Flemish or French Communities or the Brussels Capital Region depending on the place where the case is detected. The 3 entities have different systems for collecting data and different requirements on the diseases that must be declared. Analysis and publication are done separately by the 3 entities.

### 7.6.1. Flemish community

Statutory notification is ruled by a decree of 1995. Infectious diseases that are to be declared are grouped in 3 categories. Special forms were defined.

- **Category A**: every practitioner and every laboratory has to declare the case within 24 hours by phone or fax.
- **Category B**: every practitioner and every laboratory has to declare the case within 48 hours by phone or fax.
- **Category C**: every practitioner has to declare the case within 48 hours by phone or fax.

The next table gives the list of diseases per category.

<table>
<thead>
<tr>
<th>Category A</th>
<th>Category B</th>
<th>Category C</th>
</tr>
</thead>
<tbody>
<tr>
<td>Botulism</td>
<td>Brucellosis</td>
<td>Gonorrhoea</td>
</tr>
<tr>
<td>Borreliosis</td>
<td>Salmonellosis</td>
<td>Hepatitis A, B or C</td>
</tr>
<tr>
<td>Rabies</td>
<td>Cholera</td>
<td>Whooping cough</td>
</tr>
<tr>
<td>Malaria</td>
<td>Diphtheria</td>
<td>Listeriosis</td>
</tr>
<tr>
<td>Plague</td>
<td>Yellow fever</td>
<td>Anthrax</td>
</tr>
<tr>
<td>Poliomyelitis</td>
<td>Hantaviruses</td>
<td>CNS Infections by protozoa</td>
</tr>
<tr>
<td>Haemorrhagic fevers</td>
<td>Meningitis due to Haemophilbia influenzae type B</td>
<td>Q-fever</td>
</tr>
<tr>
<td>Typhus</td>
<td>Legionellosis</td>
<td>Scabies</td>
</tr>
<tr>
<td>Any transmissible disease</td>
<td>Leptospirosis</td>
<td>Syphilis</td>
</tr>
<tr>
<td>taking epidemic proportion</td>
<td>Meningitis due to Neisseria meningitidis</td>
<td>Tetanus</td>
</tr>
<tr>
<td></td>
<td>Psittacosis</td>
<td>Gastro-enteritis with more than 3 cases within one week</td>
</tr>
<tr>
<td></td>
<td>Trichinosis</td>
<td>in the same community</td>
</tr>
<tr>
<td></td>
<td>Tuberculosis</td>
<td></td>
</tr>
</tbody>
</table>

The provincial level collects the notification forms, performs controls of the data and epidemiological enquiry if required. It codes the following data and performs data entry:

- **Patient identity**: sex, age, nationality, profession
- **Disease**: type; duration, diagnosis
• Source of infection
• Spread of the disease
• Measures taken to control the disease.

Data are then included in weekly, monthly and annual tables. The information is then disseminated in various publications. Data of tuberculosis cases are put in a special register.

7.6.2. French Community and Brussels Capital Region

Data also come from practitioners and laboratories. Mandatory notification is still based on the federal legislation of 1976. No recent figures have been published for Wallonia.

This is the list of diseases to be notified: Ancylostomiasis, anthrax, any transmissible disease taking epidemic proportion, bacterial intoxication, borreliosis, botulism, brucellosis, cholera, cns infections by toxoplasma gondii, dengue fever, diphtheria, epidemic diarrhoea of newborns, gonorrhoea, group a streptococcal infection, haemorrhagic fevers, hepatitis a, b or c, legionellosis, lepra, leptospirosis, listeriosis, liver flukes, malaria, malleomyces mallei, meningitis due to haemophilia influenzae type b or to neisseria meningitidis, plague, poliomyelitis, psittacosis, q-fever, rabies, salmonellosis, scabies, syphilis, tetanus, trichinosis, tuberculosis, tularemia, typhus, viral encephalitis, whooping cough, yellow fever.

Tuberculosis has its own register that is managed by a non-governmental organisation, FARES (Fondation contre les Affections Respiratoires et pour l'Éducation à la Santé) supported by the French Community. It records all cases of tuberculosis in Wallonia and Brussels. Latest figures available: 2001.

7.6.3. Sentinel Laboratories

There is network of sentinel laboratories that notify some infectious diseases to the Scientific Institute of Public Health.

This is the list of germs they notify:

Adenovirus, Bordetella pertussis, Borrelia burgdorferi, Brucella, Campylobacter sp., Chlamidia pneumoniae, Chlamidia psittaci, Chlamidia trachomatis, Clostridium botulinum, Corynebacterium diphtheriae, Cryptococcus neoformans, Cryptosporodium, Cyclospora, E. coli (VTEC and EHEC), Entamoeba histolitica, Giardia, Haemophilia influenzae type b, Hantavirus, Hepatitis A, Influenza A, Influenza B, Legionella pneumophila, Leptospira, Listeria, Mycoplasma pneumoniae, Neisseria gonorrhoea, Neisseria meningitidis, Parainfluenza, Plasmodium, RSV, Shigella Streptococcus pneumoniae, Streptococcus pyogenes, Vibrio cholerae, Vibrio parahaemolyticus, Yersinia enterocolitica, Yersinia pseudotuberculosis, any transmissible disease with epidemic potential.
7.6.4. Acute Respiratory Infections and Influenza

The surveillance is co-ordinated by the Scientific Institute of Public Health. It is based on different data sources:

- a network of sentinel practitioners who record cases and provide weekly reports
- a network of sentinel practitioners who collects nasal and throat samples from patients who are thought to have the flu
- virological data obtained from sentinel laboratories
- monitoring of weekly sales of medication by a wholesaler and by a computer-linked network of pharmacies,
- percentage of workers at the Belgian National Railways Company (SNCB/NMBS) who are absent for less than thirty days
- daily mortality rate from all causes from the National Register.

The service publishes a weekly report of the cases of Acute Respiratory Infections (ARI) and flu-like illnesses.

7.7. Immunisation

In the French Speaking part, PROVAC is a interuniversity body supported by the French Community. Its objectives are to measure the immunisation rate among children and to analyse the roles of different health structures in immunisation. It collects data through school health centres for all children. Every 5 years, a survey of all infants (less than 24 months) is organised. The next one will start this year. Selection is done by random cluster sampling.

Data collected:

- Sex
- Date of birth
- Immunisation status before school health examination
- Immunisation after a reminder from the school doctor
- Immunisation at the school health centre
- Parental refusal
- Immunisation card shown at the school health centre

Annual reports available since 1989 plus five-year survey report.

7.8. Illegal Drugs Abuse

The Scientific Institute of Public Health is in charge of the drug-monitoring program at the federal level. It acts as Focal point for the European Network for Drugs and Drug Addiction (Réseau Européen d'Information sur les Drogues et les Toxicomanies - REITOX). There are also four sub-focal points respectively for the Flemish Community, the French Community, Brussels and the German-speaking Community. For the French Community, this task is also carried out by the Scientific Institute of Public Health. For the Flemish Community, this role is played by the VAD (Vereniging voor Alcohol- en andere Drugproblemen). Concertation Toxicomanies Bruxelles - Overleg Druggebruik Brussel (CTB/ODB) is the sub-focal point of the Brussels-Capital Region. The German-speaking Community has set up a study group for this problem.

7.8.1. Objectives

With the purpose of painting an accurate and exact image of the extensiveness of the drug phenomenon, objective and reliable information is necessary. The aim is to provide
politicians, professionals and citizens the information needed in order to campaign in an appropriate way against drugs.

The "Drugs" programme of the Scientific Institute of Public Health, has to fulfil a number of obligations:

- on the national level, as described in the "Political note of the Federal Government related to the Drug issue" of 19 January 2001 under the headings of the "Belgian Monitoring Centre for Drugs and Drug Addiction" and the "Early Warning System";
- on the international level within the framework of the missions of the European Monitoring Centre for Drugs and Drug Addictions (EMCDDA; regulation EEC n° 302/93 of the European Council on 8th February 1993, which fits into the general framework of the Treaty of Maastricht), because it carries out the role of Belgian Focal Point of the European Network for Drugs and Drug Addiction (Réseau Européen d'Information sur les Drogues et les Toxicomanies - REITOX).

7.8.2. Methods

The data are collected through a network of organisations concerned with drug issues. Efforts have been made to develop a structured co-operation with the partners, to foster synergy and complementarity and to avoid double use. Data are analysed and synthesised to provide information about prevalence and incidence of drug use and drug related health problems. An Early Warning System is being developed. The activities are carried out in connection with the European network EMCDDA. The data collected at regional, national and European level are disseminated through the partners of the network.

7.8.3. Implementation

Estimation the prevalence and incidence of drug use in the population:

Data concerning the frequency of use of cannabis and ecstasy/amphetamines in the general population have been collected during the national health interview survey conducted in 2001. The statistical processing of these data has been carried out in 2002.

In 2001, a study protocol was drawn up with regard to consumption patterns, health risks and demands for health care of heroin users. A questionnaire based on existing European studies was designed. The field survey, based on the "snowball sampling" method has been realised in 2002. It is a collaborative study bringing together the "Drugs" programme of the Scientific Institute of Public Health, 'Free Clinic' and 'Modus Vivendi'.

A feasibility study on the use of the "capture-recapture" method has been undertaken, in order to estimate the prevalence of problem drug use in the city of Charleroi in 2002.

In 2002, the several phases of the course of life of a problematic drug user were the issue of a mathematical modelling of the drug phenomenon. The application of this model on the data should enable to predict the probable evolution of the incidence of problem drug use for the coming 20 years.

Treatment Demand Indicator

The organisation of the Treatment Demand data collection process is being managed by the four Sub-Focal Points. Each of them has its own registration system.

Drug-related health problems
Information about the prevalence of HIV as well as hepatitis B and C among intravenous drug users are collected. The field survey carried out in 2002 also provided information on this subject.

Mortality data collected from NIS (National Institute of Statistics) have been analysed according to the new guidelines of the EMCDDA for the period 1991-1996.

Development of an Early Warning System

A system for collecting and exchanging information has been developed and the links with existing networks, telephone helplines and toxicologists have been strengthened. Within this context two laboratory networks have been set up: one for analyses of clinical samples; the other one for analyses of psychoactive substances.

7.8.4. Publications

The program publishes an annual report and several articles appeared in scientific journals.

8. Conclusions

There are many sources of health information in Belgium. The quality of the data may vary from one source to another. The institutional complexity of the country hampers a global approach of the management of health data. The Flemish Community is making a big effort to build a health information system that integrate the various sources of information and combine available data. The French Community is currently considering the development of such a system. Contact at the Inter Ministerial Conference provide an opportunity for a health information system.

At the other end of the system, loco-regional structures like health observatories provide opportunities for local analyses meaningful for local health professionals and people involved in health promotion. They can also diffuse the information to a larger audience.

<table>
<thead>
<tr>
<th>Strength</th>
<th>Weakness</th>
<th>Opportunities</th>
<th>Threat</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public health expertise available in universities and public health schools</td>
<td>The institutional complexity of the Belgian state which spreads the responsibility of health information system on several levels of authority</td>
<td>Working group of the Inter Ministerial Conference in charge of developing a national Health Information System</td>
<td>Underfunding of the public health sector</td>
</tr>
<tr>
<td>Nation-wide Health Interview surveys regularly performed</td>
<td>No institution is explicitly in charge of health information system at the French Community level</td>
<td>Master plan in preparation at French Community level</td>
<td>Health information system does not seem to be a really high priority in the political agenda</td>
</tr>
<tr>
<td>Knowledge Centre established by the Ministry of Health</td>
<td>Limited amount of publication</td>
<td>Development of breast screening program increase the need for data collection</td>
<td>Data collection relies partially on non governmental organisations which is a problem for sustainability</td>
</tr>
<tr>
<td>Several initiatives for data collection and analysis</td>
<td>Limited amount of synthesis of data at Federal level.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Office mandated for Health Information System in connection with health priorities at the Flemish Community level</td>
<td>Delay in treatment and publication of basic indicators</td>
<td></td>
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</tr>
</tbody>
</table>
10. Bibliography


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Web site of the Vereniging voor Alcohol- en andere Drugproblemen (several pages); www.vad.be; May 2003

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