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Health information Systems in Europe – Structures and Processes –

Final Report

LUXEMBOURG

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Preface

Health is a broad issue including not only the physical aspects of an individual, but also his psychical and social facet. Health is tightly linked to a huge number of non-medical factors such as socio-economic, environmental, political, behavioural factors, lifestyle etc.

In future years the population of Europe will face growing challenges to health. These mostly include: an ageing population and a related increase of specific morbidity; raising levels of different chronic diseases and unknown communicable diseases, diseases provoked by environmental changes and hazards in workplace; growing number of migrants with specific health needs and problems, raising socio-economic problems, unemployment, social exclusion, inequity in health.... All these problems will have a great impact on the health of the European population and represent important challenges to our societies^{*}.

Therefore, information about Health shouldn't be restricted only to medical data (in its traditional meaning, i.e: the data which is produced and collected nearly exclusively within medical settings) but should involve, as well, all correlated data about the social, economic, educational and environmental context of the population.

To cope with those defies, a well-developed and integrated health surveillance system is intensely recommended all over the member states. International European experts have worked out a recommendation in this matter after intensive consultations along the last 2 decades^{**}.

In 1997 the European Commission adopted a framework program entitled "The European Union Health Monitoring Program" with the objective to develop a permanent health monitoring system within the members' states. Many projects have been supported, such as: Health Monitoring Program/ HMP, Health Information Exchange and Monitoring System/HIEMS, European Commission Health Indicators/ ECHI, European Health Risk Monitoring/EHRM, European Home and Leisure Accidents Surveillance System/EHLASS, European Physical Activity Surveillance System/EUPASS, the actual project HIS....etc...).

* Choices in Health Policy; An Agenda for European Union, Brian Abel-Smith et al. , European Political Economy, Office for official publications of the EC, 1995Luxembourg,

** Communication de la Commission concernant un programme d'action communautaire en matière de surveillance de la santé. Bruxelles 1995.

The project entitled “Design for a set of European Community Health Indicators / ECHI” is a key project to develop and agree on a common list of health indicators and to develop a wide network for sharing and comparing health data of good quality among members’ states.

Four categories of Health indicators have been identified by ECHI project* and HMP:

1. Health systems

- 1.1 Prevention, health protection and promotion
- 1.2 Health care resources
- 1.3 Health care utilisation
- 1.4 Health expenditure and financing
- 1.5 Health care quality / performance.

2. Health status

- 2.1 Mortality
- 2.2 Morbidity
- 2.3 Genetic health status
- 2.4 Composite health status measures

3. Demographic and socio-economic factors.

- 3.1 Population
- 3.2 Socio-economic factors

4. Determinants of health

- 4.1 Personal and biological factors
- 4.2 Health behaviours
- 4.3 Living and working conditions

The purpose of this list of health indicators is to give a global picture of the situation of health and to serve as an efficient tool to describe, evaluate and monitor the health status of a population, define its needs, evaluate the health services, orient and improve the governments’ health policies and programs by providing scientific evidences to support political decisions**.

* Design for a set of European Community Health Indicators, Final report by the ECHI project, February 15, 2001.

** Health Canada. National health Surveillance (2002), Report of the Auditor general of Canada, Chapter 2, September 2002.

Health Information System

Introduction

The fundamental principles of the Luxembourg Health system are free choice of the provider by the patient, compulsory health insurance, and compulsory provider compliance with the fixed fees-for-service set for the insurance system.

The system is split between prevention and treatment in terms of both provision and financing. For the most part, preventive services are the responsibility of the Ministry of Health; interventions are provided by a few public services and by private practitioners and non-profit associations paid from the Ministry budget. Curative treatment is a shared responsibility of the Ministry of Health and the Ministry of Social Security. The former supervises the organisation of health services and subsidises the hospital sector, while the latter is responsible for the sickness insurance system. Recent developments have led to the integration of some preventive measures in the sickness insurance scheme, thus integrating prevention into independent medical practice*.

Though, the health care system is an important contributor to improve the health of the population, but there are other issues beyond the health care system influencing the health of people, such as socio-economic, cultural, behavioural, environmental factors...etc. According to this concept of global health, the strategy of health in Luxembourg "Health for all/ Santé pour tous", published in 1994, proposed integrated and multi-sectorial actions for health. This strategy presents the main health problems and risk factors and addresses a number of priorities in the matter of health care, health promotion and diseases prevention, such as reducing cardiovascular diseases, cancer, diabetes, accidents, AIDS, ameliorate the registration of communicable diseases, protection against radiation and promotion of healthy environments ...etc. The strategy aims principally to reduce premature and avoidable deaths, to improve the health status of the population and to insure a best equity in health. A particular attention is accorded to the health of young people and of elderly. The actualisation of this document is under way and policies to tackle health inequities have been one of the first priorities. This strategy bases on an intersectorial and multidisciplinary approach, in collaboration with all the different sectors influencing health.

* Extract from "Health Care Systems in Transition" / European Observatory on Health Care Systems and "The Health System and Health Policy in Luxembourg" by Dr. D. Hansen-Koenig, Mady Roulleaux

As mentioned above, an efficient health information system should enlighten both the health care system and the health status of a population, it should identify threats and public health problems, it should be a competent tool for the prevention of disasters, the early detection of diseases and the health promotion of different population groups (children and youth, elderly, migrants, women...), and in different settings (school health, occupational health, protection of environment against radiation and pollution; safety at workplace; traffic safety; product and food safety; drug abuse...etc). Moreover, it should be able to report on correlated health factors for the purpose of development and orientation of health policies, of economical evaluation of health services and programmes and of realisation of global health strategies.

Presently, there is no central health data centre in Luxembourg that collects, processes, evaluates and analyses all the health-related data. The surveillance of different health settings, and the information on different health items are managed in the concerned health infrastructures. It is not possible to speak of one single comprehensive centralised health information system, because there are series of systems, partly linked, partly autonomous. A number of them are permanent registries, others responding, to some extent, to specific demands. While we have highly developed information systems in some health issues, such as mortality, hospital discharges, surveillance of AIDS, breast cancer, ...we have little-developed or weak systems in others domains. Some information systems function in an independent way, within the respective responsible infrastructures. The coordination mechanisms between organisms responsible for health data are either systematic or "ad hoc".

Massive efforts are made to ameliorate our overall national health information system in order to improve the intersectorial collaboration, the harmonisation of health indicators to promote synergies between responsible organizations, so as to avoid duplication or overlaps in the data management

Chapter 1. Structure

Figure 1 illustrates the organizational chart of involved Ministries and organizations, within and outside the health sector, in the process of health information.

A. Main Ministries responsible for health areas

3. Ministry of Health: (*Please see the organigram, Figure 2*)
4. Ministry of Social Security: (*Please see the organigram, Figure 3*)
 - General Inspectorate of Social Security (*Inspection Générale de la Sécurité Sociale / IGSS*).
 - Union of Sickness Funds (*Union des Caisses de Maladies / UCM*)
 - Office of Medical Control (*Office de Contrôle Médical / OCM*).

B. STATEC : National Institut of Statistics and Economic Studies / (*Service Central de la Statistique et des Etudes Economiques*).

C. Collaborating Ministries

D. Collaborating national organizations

E. Collaborating International organizations.

Roles, responsibilities and key health data:

In our attempt to give an understandable description of the health Information system in Luxembourg, we are going to emphasise the roles and areas of responsibilities of different services managing key health data.

A.1.

Ministry of Health

Public health policy decisions and priority setting are the responsibilities of the health authorities at the central level. Priority setting includes the political options of the Minister of Health or the Council of Ministers and proposal of the various departments of the Ministry of Health*

- **The Minister of Health** is responsible for defining and implementing health policy within the Government's program, for controlling the application of the laws and rules on health and health services and for the supervision of health institutions and services.
 - The health professional's registry is managed in a special service of the ministry.

* Health Care System in Transition- Luxembourg. 1999, European Observatory on Health Care System.

- “Medical Chart / Carte sanitaire” is published annually, which is an inventory of all hospital data. It draws up the assessment of the hospital activities, thus illustrates the medical and scientific evolutions in the country; it allows an evaluation of the current hospital performances. The proposal of a hospital programme plan is responding to the populations’ needs.

➤ **The Directorate of Health and its specific divisions**

The Directorate of Health reports to the Minister of Health, as the executive administration for the public health in Luxembourg. It has a responsibility to study and to inform about the overall health situation in Luxembourg, to advice public authorities on public health matters, to oversee the implementation of laws and regulations on public health, to take immediate measures to protect public health in the face of any threat, to develop health prevention and promotion programs and to contribute to public health policy on the national and international level.

To fulfil these duties the Directorate of Health and its different divisions and services perform very often the process of collection, analyse, statistical and epidemiological evaluation and dissemination of health data at national and international level.

a) **Service of Health Statistics**

Missions:

- Management of the computer system and the computer net for the Ministry and the Directorate of Health
- Responsible for the collection, codification, registration and storage of the national mortality data and perinatal data.

b) **Division of Health Inspection**

Missions:

1. Surveillance of communicable diseases, with rapid intervention in case of epidemic.
2. Surveillance, research, analysis in the field of public and environmental hygiene (water, rural areas, sport, tourism, housing, alimentation...etc.)

Area of responsibility: dealing with the protection of physical, chemical, biological and social environmental hygiene, prevention of communicable diseases and nutritional security.

c) **Division of environmental medicine**

This recently created division has the mission of surveillance of environmental health.

d) **Division of Preventive Medicine**

Missions:

1. Responsible for diseases prevention and health promotion. (Monitoring and prevention of addiction, alcoholism, smoking, vaccination, AIDS, alimentation, cancer screening, accidents, surveillance of infants, schools' health promotion, iodine supplementation...)
1. Realisation of studies and surveys to evaluate the global health status of population.
2. Fight against social disasters.
3. Preparation of statistical health data on national or international request.

Area of responsibility: This division manages data related to the following areas:

- Breast cancer and other cancer screening programs.
- Health of youth and children (Health Behaviour in School Aged Children survey)
- Vaccination coverage evaluation (1998, 2001)
- Epidemiological evaluation of specific health problems (colorectal cancer, health consequences of iodine deficiency, epidemiological analysis of mortality and perinatal data.

e) **Division of Curative Medicine**

Missions:

1. Supervision of the practice of health professionals.
2. Planning and control of hospital care, surveillance and prevention of nosocomial infections by improving hospitals security, control of the medical risks
3. Quality control in laboratories

Areas of responsibility: dealing with curative health services.

f) **Division of School Medicine**

Missions:

1. Surveillance of the general health of children frequenting the primary and secondary schools
2. Management of health data from the medical school examinations

Division of School Medicine, Service of School Dental Medicine

Missions:

1. Surveillance of oral-dental health among children frequenting schools.
2. Surveillance of oral-dental anomalies.
3. Data and register about children's dental health.

Areas of responsibility: Screening of the dental health of school-aged children as well as organisation of programs of prevention and health education.

g) Division of Occupational Health

Missions:

1. Responsible for the planning and control of occupational health services.
2. Conducting of studies concerning the status of health in works' places.

Area of responsibility: planning and control of occupational health services, work security and works' accident-prevention.

h) Division of Pharmacy

Missions:

Is responsible for licensing medicines and supervising the practice of the profession of pharmacist.

i) Division of Protection against Ionising and Non- ionising Radiation

Missions: Systematic surveillance of radiological risk in different areas of the environment, such as potable water, susceptible places of work, research laboratories...etc.

Areas of responsibility: the protection of the country against ionising and non-ionising radiation, This Division provides databank about the professionals exposed to ionizing radiation, as well as the peoples whom make a demand to measure the degree of exposure to such radiation.

j) Division for Social Medicine:

Missions and area of responsibility: responsible for promoting, coordinating and supervising services dealing with handicap, mental illness, and drug addiction, home nursing services and nursing homes for elderly people. The service manages contracts with private associations working in these fields

k) Service of Orthoptics and Pleoptics.

Early detection of visual deficiencies, re -education, re-adaptation of the visual function
This service manages, analyses and evaluates the corresponding data, in particular the register of visual deficiencies in neonates.

l) Service of Audiophonology.

This service deals with the early detection, prevention, treatment and follow-up of troubles in the auditory area.

It manages, analyses and evaluates the corresponding data, in particular the register of hearing deficiencies in neonates, of hearing and language problems in infants.

➤ **The National Laboratory of Health / Laboratoire National de la Santé (LNS)**

The LNS carries out laboratory work related to health and hygiene for public authorities or private persons. It collects and analyses data in these areas, realises epidemiological studies and research within its various specialities (bacteriology, parasitology, virology, cytogenetics, clinical cytology, serology, biological chemistry, food control, pharmaceutical control, anapathology, environmental hygiene and biological surveillance, haematology, immunology, toxicology).

Some of the most important data managed by the LNS are:

- Cancer register by the national cancer registry (*Registre Morphologique des Tumeurs-RMT*).
- Neonatal screening
- Iodine surveys
- Cervical and endometrial cancer
- Hemocult lecture centre / (part of the awareness programme for early detection of colorectal cancer)
- Surveillance of the hereditary anomalies of blood (haemoglobinopathies and other components of blood).
- Immunological surveillance of measles vaccination.

A.2. The Ministry of Social Security

Is responsible to ensure the population's social protection through the sickness insurance system.

The planning, supervision and control of health services is retained centrally in the Ministry of Health. However, the responsibility of the health system in the matter of supply of curative treatment is shared with the Ministry of Social Security.

➤ **The General Inspectorate of Social Security**

The General Inspectorate of Social Security (Inspection Générale de la Sécurité Sociale / IGSS), supervises legal, regulatory, statutory, contractual and financial operations of the social protection system. Basing on data collected by the Union of Sickness Funds

(hospital discharge data), of the Ministry of Health (health professionals and services, mortality, perinatology), of the Central Service of Statistics and Economic Studies/ STATEC (demography, economics...), of the Ministry of Labour, of the Ministry of Family and of the Ministry of Economy, the IGSS analyses and evaluates, the social protection system of Luxembourg. This evaluation is done at national and international level in particular as regards health insurance, long term insurance, pensions, etc.. .

➤ **The Office of Medical Control**

The Office of Medical Control deals with the disability at work, authorisations for reimbursement, medical profiles, supervision of outpatient care and abuse of the health system.

➤ **Union of Sickness Funds / Union des Caisses de Maladie (UCM)**

Approximately 99% of the population is covered by the statutory health insurance system. The UCM is collecting and managing all health data for which the insurance system can be charged: medical and hospital services, treatment, rehabilitation, preventive care (vaccination...) and hospital discharge data.

While, the UCM can be considered as the most important databank for morbidity data in our country, nevertheless, the analyses, epidemiological evaluations and studies on morbidity are realised usually in other services, particularly in the Ministry and Directorate of Health, research institutes etc... Up to now, there is no regular analyse and evaluation of the overall morbidity data concerning the Luxembourg's population.

In case of carrying surveys, for instance in the matter of studying: the incidence of hip fractures, thyroid diagnosis, treatment and surgery, pregnancy pathology.... requests are made to the UCM for the receipt of concerned anonymous medical data, (generally according to ICD 10 codes).

➤ **Cell for Evaluation and Orientation of dependency insurance / Cellule d'Evaluation et d'Orientation de l'assurance dependence (OEO)**

This cell covers all the disability and handicap-related data.

B. **Central Service for Statistics and Economic Studies
STATEC**

The national statistical institute of Luxembourg "STATEC", subordinated to the Ministry of Economy, is the principle organ responsible for collecting significant socio-economic information, demographic and development indicators. Its task is collecting, processing, analysing and disseminating national general statistical information, including health statistics.

The Ministry of health provides yearly mortality data, health professional data, ...etc., which are part of the data published annually by STATEC in the statistical yearbook.

C. **Other Collaborating Ministries**

Ministries other than Health and Social Security involved in health related areas are:

- A) **The Ministry of Education** as regards the training of health professionals (not university training) and health education in schools. An intense collaboration exists in the field of health promotion in schools, sexual education, healthy life styles, mental health, healthy alimentation, promotion of physical activity, etc.
- B) **The Ministry of Environment** adopted a national plan to establish a programme of durable development. In this matter, a concerted work of inter-ministerial collaboration and consultation has been developed in order to define social, economical and environmental indicators to set up this policy. The Ministry of Environment together with the National Administration of Environment and the municipalities lead the responsibility regarding the protection of the environment: air and noise pollution, water and sanitation, waste disposal. A close collaboration exists between the Division of Health Inspectorate and the Division of Environmental Medicine /Directorate of Health.
- C) **The Ministry of Family, Social solidarity and Youth** as regards homes for elderly people including nursing care, home aid services, rehabilitation and family planning clinics, services for the handicapped, and services dealing with youth health.
- D) **The Ministry of Labor**, in particular its service the **Labour Inspectorate (*Inspection du Travail et des Mines (ITM)*)** as regards to safety at work. The ITM administers, analyses and evaluates statistics on labour accidents.

- E) **The Ministry of Housing** coordinates with the Directorate of Health health inspections of states-provided housing. It is in charge for housing projects and subsidies for individual homes.
- F) **The Ministry of Transport** is responsible for legislation on transport and traffic safety. Concerted actions for traffic safety in collaboration with the Service for Road Safety and the Directorate of Health are realized.
- G) **The Ministry of Women Promotion** as regards women’s physical, mental and social health, reproductive health, gender specific violence, in particular domestic violence, equity between gender...etc.
- G) **The Ministry of Justice** as regards Drugs issues, on drug abuse between all ministries involved in the problem of addiction.
- H) **The Ministry of Agriculture** as regards the control of food security
- I) **The Ministry of Cooperation** as regards the development of programs and projects in the area of global health and durable development in developing countries

Because of wide and multidimensional collaborations with a large number of ministries, health related data are shared in order to develop common programmes, concerted reports and elaborate global health policies.

D. Collaborating Organisations

In Luxembourg many non-governmental organisations are dealing with health issues; their activities range from conducting surveys and epidemiological research, to preventive and health promotion initiatives, education and awareness projects. Many of the activities are developed between different concerned organisms in a multidisciplinary and intersectorial approach. The Ministry of Health and its respective divisions of the Directorate of Health are usual partners.

Depending on the nature of the activities and the degree of collaboration, the exchange of health data between the public health bodies responsible for health and the non-governmental organisations is either:

- Systematic and regular, (for instance with: “National Drug Observatory”; “AIDS Committee”, organisations which administer national registers in the specific domains)... or;

- “Ad hoc” for instance with: National League of Medico-social prevention and welfare, Luxembourg’s Foundation against the Cancer, Centre of Drugs and addiction prevention, Family Planning, Public’s Health Research Centre INSTEAD, ILRES, and others organisations which perform surveys and studies in different domains* .

Examples of collaborating organisations*

➤ International Networks for Studies in Technology, Environment, Alternatives and Development /Centre for Population, Poverty and Political Studies (INSTEAD) / *Centre d’Études de Populations, de Pauvreté et de Politique Socio-Économiques (CEPS)*: is a public research institution. It has the political and financial support of the Ministry of Culture, Higher Education and Research This institute has following main activities:

1. Conduction and organization of regularly cross-sectional and longitudinal studies of populations, poverty and socio-economic policy, (for example: Luxembourg Income Study (LIS), since 1983, Luxembourg Employment Study (LES), since 1993).
2. Management, analysis and evaluation of databases on a national and international level.

➤ Public’s Health Research Centre (PHRC)/ *Centre de Recherche Public -Santé (CRP-S)* :

This institute is involved in statistical and epidemiological studies, in biostatistics and health care assessment. The CRP-Santé is charged to undertake and coordinate activities of research, develop scientific progress and the technological innovation, at national and international level, in the different fields of health concerning medical sciences...etc. Most of the activities are achieved in close collaboration with concerned services.

➤ The Luxembourg Focal Point of the European Observatory of Drugs and Drug-addiction (OEDT) / *Réseau Luxembourgeois d’Information sur les Stupéfiants et les toxicomanies*– is implemented within the Division of Social Medicine of the Directorate of Health (Ministry of Health) and its logistic and administrative unit is setting up within the Public’s Health Research Centre. It represents the Luxembourg Network of information on the narcotics and drug-addiction. It constitutes an annually updated national database, provides information on the prevalence, the incidence and the evolution of the use of drugs. This database is also used as a scientific support for researches to

* Find please the abbreviation of these organizations in French and English, at the glossary, as well as list of addresses.

evaluate the new tendencies and the impact of certain interventions as regards fight against drug-addiction.

➤ ILReS Market Research / *Institut Luxembourgeois de Recherches Sociales et d'Etudes*

This institute deals with opinion poll on political, economic, social or cultural issues. It examines also questions on life styles, quality of life, socio-economic situation, health service use, degree of satisfaction concerning health care...etc.

➤ Organizations dealing with "Health Awareness and health education" perform regular inquiries on different health subjects. These data are accessible to health data seekers in different health services for statistical and epidemiological studies, evaluations and calculations of longitudinal trends. Some of these main associations are:

- Cancer awareness: the Luxembourg's Foundation against Cancer (*Fondation Luxembourgeoise contre le Cancer* (FLCC). This organisation performs regular surveys concerning tobacco consumption in Luxembourg.
- Drug awareness: the Centre for Prevention of Addiction / *Centre de Prévention des Toxicomanies* (CePT), which reports regularly on legal and illegal drug consumption.
- AIDS Committee is responsible for the surveillance of the incidence and the prevalence of AIDS and for the coordination of all the activities in this field such as awareness and education campaigns, international and national conferences, carrying out projects aimed at risk population ...
- Luxembourg League of Medico-social Prevention and Welfare
- Planning Familial
- European Youth Forum / *Conférence Générale de la Jeunesse*
- Association Iwerliewen / Leche league
- Centres médico-scolaires
- Police
- Meederchershaus: centre for women suffered from sexual or other forms of violence.
- etc.

These organisations can supply data from their specific action fields, dealing with life styles and health behaviour, alimentation, mental and social health, drug consumption, analyse of specific population groups, life and work places... They are very important providers for a lot of health determinants defined in ECHI.

The lack of a centralized health data collection centre causes a particular problem, especially for data gathered for purposes of surveys and studies, since sometimes the sources of data are not well known.

Municipalities

In Luxembourg, local authorities have legal responsibility for public health protection. The municipalities organise the medical school services of the primary schools together with local practitioners and the medico-social leagues of the region. Large towns have their own school health services and run certain projects of health education.

In practice, many municipalities tasks are mainly dealing with environmental problems, such as distribution of drinking water, sewage, waste disposal, housing and local traffic. Recently, the municipalities increase their efforts to collaborate actively in the promotion of health and the prevention of diseases.

The municipalities are assuming increasing responsibilities in health promotion programs, considering themselves as important partners to promote a healthy environment and healthy life styles in the communities. Within the project of Healthy Communities an increasing collaboration is put in place.

E. International Collaboration

1. WHO

HFA Database

The World Health Organisation, Regional Office for Europe, developed an on-line “European Health for All Database (HFADB)”, which supports the monitoring of health trends. It provides easy and rapid access to a wide range of basic health statistics for 51 Member States, including Luxembourg. This database is a helpful tool for international comparison and for assessing the health situation in any European country in an international context. The data are collected by the Directorate of Health according to a flexible and evolutionary list of indicators, which cover various aspects of the health of a population and its determinants*.

Luxembourg is regularly participating in international WHO surveys and comparisons for different health topics, such as:

* European health for all database, HFADB, World Health Organization, Regional Office for Europe, Denmark.

- Alcohol profile
- bdine survey
- AIDS
- Reproductive Health
- Cancer
- Etc...

2) OECD

Luxembourg is a member country in the OECD group (Organisation for Economic Co-operation and Development). The work of the OECD covers economic and social issues from macroeconomics to trade, education, development and science and innovation.

The health services of Luxembourg provide the requested data for the realisation of different international publications on health, development, and health economics, health insurance.... The statistics collected by the OECD aim to meet the needs of policy makers in the field of development.

3) EU

Luxembourg participates in different projects managed by the European Community (UROSTAT) e.g: Causes of Death, Peristat, Eurocat, Cancer Atlas, Home and Leisure Accidents, cardiovascular diseases.... The aim of these projects is to harmonise the health data collected in the different Member States at a European level. By these exercises the collaboration and the cooperation between countries is reinforced, the comparability and the quality of the national and international health data is improved, the effectiveness and the overall quality of the national health information systems is ameliorated.

4) UNICEF

There is collaboration with the Unicef in the matter of children's health, mother and child's health, vaccination, reproductive health...etc.

Chapter 2. Processes

To monitor the health of a population, there is a need to develop a Health Surveillance System that integrates data on the health status of a population and its medical and non-medical determinants. Figure 3 presents the flow diagram of the Luxembourg Health Surveillance. The conceptual model is based on data **Collection**, processing of database into **Information**, then transfer of evidences into **Actions** and policy-making.

As mentioned before, there is no centralized health data centre in Luxembourg for the present time. In this report, we will confine our description to the health data that our services are most concerned with. Health data sources are:

National sources:

- Regular data
 - Registry based: registry of mortality and perinatal mortality, perinatal health, medical chart, hospitals discharges, neonatal screening, cancer registry, communicable diseases, health professionals, occupational accidents, traffic injury, AIDS registry...
 - Administrative based: general data on economics, demography, health expenditures, pollution, unemployment, education,
- Irregular data
 - Surveys and studies analysing specific health problems, such as: health behaviour in school aged children, drug and tobacco consumption, nutrition, immunisation coverage, breastfeeding, home and leisure accidents, needs and demands of women during pregnancy and delivery, socio-economic panel.
 - Action driven data: data elaborated from projects and programs, campaigns...etc.

International sources: such as

1. Health for all databases (HFDB)
2. Organization of Economic Co-operation Development (OECD)
3. Eurostat

The step of **Information** could be defined as series of interrelated processes starting from data collection, analyses and interpretation and then dissemination in form of reporting in order to provide evidences to facilitate decision-making and policy definition. In Luxembourg, the ministries of Health and Social Security, with their concerned services, are the central principal organs responsible for this process, i.e. surveillance of health statistics, whatever its sources. They analyse and propose best strategies of

action, produce health information in a form of annual reports, addressed not only to general public and health professionals but also to policy-makers.

At present, the main sources are:

1. The regular reports published by the ministries involved in health as well as the reports of activities of public and private organisations. They permit a broad description of the current picture of many health aspects of the population. For example: The Inspectorate of Health and the Directorate of Health are, respectively, responsible for the surveillance of communicable diseases and surveillance of mortality -so they have the most appropriate data in these fields.
2. The statistics published by the National Institute of statistics,
3. White documents, for instance, (health for all / *Santé pour tous*) serve as a tool of “health status” information in Luxembourg. The Medical Chart gives an idea about the health care services and medical professions. The reports of the General Inspectorate of Health and Union of Sickness Funds, and other health Insurance Funds can also be considered as a valuable data source.
4. Reports of research institutions that carry out surveys and studies. Surveys have increasingly become as an important tools for health reporting. Luxembourg has several regular and irregular surveys that have proved their efficiency and satisfactory credibility.
5. Annual activities reports from the ministries involved in health field.

Chapter 3. Policies, legislations and plans

A first law, voted in 1979, regulated the use of nominatives data by electronical ways. The "internationalisation" of data circulation and exchange across the national borders brought the EU Parliament and Council to propose the Directive 95/46/CE, which has been adopted on 24th October 1995. The objective of this directive is to harmonize the protection level of data among all member states of the EU and to regulate the free circulation of data. The law of 2^d August 2002 (edited in the Memorial A n°91, and in application since 1st December 2002) regulates the protection of persons concerning the treatment of personal data. It is the national legal expression of this European directive, concerning the public and the private sector.

This law covers the automated and non-automated treatment of data that can directly or indirectly identify a person and violate his privacy. It includes: collection, registration, organisation, storage, adaptation, modification, extraction, consultation, use, communication by transmission, diffusion or any kind of accessibility to data, inter-connexion or links as well as locking mechanisms, erasing or destruction of data.

The "*Commission Nationale pour la Protection des Données*" (CNPD - National Committee for Data Protection) is an independent and permanent control authority that insures the correct application of the actual national legal text and is the only organization that gives the authorization to create and manage a database.

Guaranties must be given by the responsible of the data treatment (physical or moral person, public authority, service or any other organism), who has to determine its aims and means.

Particular security measures must control the following aspects:

- Entry of database
- Treatment of database
- Memory of all modification of data
- Use of the treatment systems
- Access to data
- Transmission of data
- Introduction of new data
- Transport of database
- Availability of data

The regulation of all the national databases in use have to be adapted according the law mentioned at least before the 1st December 2004.

Additional information can be asked to the *Ministère de la Fonction Publique et de la Réforme Administrative* (datenschutz@mfp.etat.lu). This ministry coordinates all activities in relation with the application of this law in the public sector.

The integral text of the law is available on the website: <http://www.legilux.lu>

In Luxembourg, the legal framework includes also a range of laws and regulations for the control of communicable diseases, protection of environment against radiation, housing, safety at workplace, traffic safety, product and food safety, pharmaceuticals and medical devices, training and practice of health professions, hospital planning and funding, prevention and health promotion, such as preventive medical care during pregnancy and early childhood, school health, occupational health, restriction of publicity for tobacco and prohibition of smoking in different places, prevention of drug abuse. Legislation was largely developed following EU directives.

Chapter 4. Actual coordination mechanisms

There is a formal collaboration introduced by law between the Ministry of Health and the Ministry of Social Security for hospital planning, The Director of Health is an advisory body to both ministries for all questions related to the hospital programs, financial contributions of the state, defining priorities for health protection in industries, establishing safety standards, measuring outcome of occupational health interventions and designing information and education programs for employers and workers. Public administrative collaboration between the Directorate of Health and the Union of Sickness Funds is a contract-based to carry out prevention programs.

A mandate for collaboration is given by law to the Division of occupational health and the Inspectorate of Work depending on the Ministry of Labour to supervise the safety at the work place. Cooperation between governmental departments, public administrations and the private sector takes place within public institutions (prevention of drug abuse), national committees (AIDS) and councils (which are advisory bodies to a Minister on specific topics, e.g. hygiene, education, youth, handicap etc.) or working groups (nosocomial infections, diabetes, care during pregnancy)*. The public services and institutions depend directly and come under the administration of Ministry of Health.

Generally, the intersectoral cooperation is a basic principle of the “Health for All” (HFA) strategy of the Ministry of Health for its activities.

* The Health System and Health Policy in Luxembourg, 1998, Dr D.Hansen-Koenig, Mady Roulleaux.

Chapter 5. Future development

Better information for better health

An efficient “Health Information System “ should respond to the following criteria:

- Report on the status of health of the population and of the health care system
- Identify health priorities and health threats
- Develop and coordinate health databases and registries
- Measure and evaluate interventions in the fields of health promotion, prevention, curative, rehabilitative or palliative care

The urgent need to collect a wide range of data and to set up a competent health information system is essential in order to monitor the outcome and the progress of the “Health for all strategy “. It is a tremendous challenge, based on a multidisciplinary and intersectorial approach. This work needs a good coordination between all the providers of data.

A national intersectorial working group, consisting of the most important health data providers, managers and users has been created recently with following main objectives:

- Establish an inventory of the data sources and existing statistics and their respective persons in charge;
- Promote the development of national health indicators, according to international agreed definitions (ECHI, ICD 10...).
- Coordinate and promote the development and the maintenance of national health standards for collecting, processing and sharing health information.

In consequence, the group of work starts the coordination to settle down the building-stone of a future development of a central health information system in Luxembourg. The nucleus of this group comes up from representatives of Ministry of Health and the Ministry of Social Security. The projects’ plan is to create a national structure responsible to assemble all the health data, a “National Health Information Database” which receives regularly the health data from different sources, in order to be processed, analyzed, and evaluated to define the priorities and, to disseminate defined data perhaps in a form of reports, publication, on-line...etc. (Please see figure.4).

In addition, there are specific partners from other ministries and organizations involved in health areas such as (Ministry of education, family, labour, interior, environment,

economy...etc) as well as STATEC, medical control services and health insurance agencies and others.

The available Health information database offered by the partners cover the following key areas:

- Health services;
- Health human resources; and
- Health care expenditures.
- Health data, such as: Mortality, morbidity, health status, life style, mental health...etc.

Chapter 6. Conclusion

Some aspects of the Luxembourg's Health system are centralised, (Sickness insurance, hospital discharge data, mortality registry...etc), though others are decentralised and widespread. The mortality surveillance, cancer surveillance, notable communicable diseases surveillance system, the evaluation of medical costs have a rather good standard, however the information in other health areas is quite poor.

At the moment a comprehensive and integrated health information system is not developed so far. Weak points in our system :

- Dispersed sources of health data and statistics
- Lack of coordination between the different providers of health data in terms of collection and management of data, way of presentation, description of available data and its quality.
- Scattering of the suppliers of national data to the international organisations (wasting of time, of resources, gaps and overlaps, etc...)
- Non-standardisation in the definition of certain health indicators between concerned organisations.
- Health professionals, whether from public or private sector, are sometimes insufficiently aware of the importance of a regular and high quality health reporting
- Incomplete health information for a number of significant public health priorities (cardiovascular diseases, alcohol related diseases, mental illness, socio-economic related health issues....), as well as lack of information about the health status specific population groups.
- Difficulties in the accessibility of health data and insufficient diffusion of existing health information.

On the other hand, there are strong points too, such as:

- highly developed information systems as regards the mortality, hospital discharge, AIDS surveillance, breast cancer surveillance...
- good data concerning the health services and health expenditures, exist in the General Inspectorate of Social Security. In addition, the realisation of the health behaviours school Aged Children (HBSC) in Luxembourg. The results of this survey are considered as rich sources of data about the young people's health states.

- strong will of the managers and the persons in charge to ameliorate the health information system. Thus, massive efforts are made to improve the intersectorial collaboration, the harmonisation of health indicators, to promote synergies between responsible organizations, so as to avoid duplication or overlaps in the data management.

It is an urgent challenge to develop a high performing national health information system, responding to the increasing national and international demands for good quality health data, that:

- respect agreed definitions,
- guarantee the comparability in time and space.
- is easily accessible and comprehensible.

Against this background, our first priorities for the present time are to concentrate the efforts of different actors in health monitoring to strengthen the health information system. For this purpose we need to:

- coordinate and promote the development of the centralization of national health information in terms of collecting, processing and sharing health data;
- identify and respond to health information needs and priorities; by analyzing current information, conducting community-based studies, and supporting health system researches.
- establish a national health surveillance network able to coordinate the flux of data from its sources, to process, analyze, interpret, and finally disseminate the information.

This project remains in process that reacts to suggestions. As in most other European countries, work on the development and perfection of the National Health Information System should be never being declared complete.



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- 11) Santé pour tous, 1994, Ministry of Health, Luxembourg.

Glossary

- M H : Ministry of Health / MS: Ministère de la Santé
- MSS: Ministry of Social Security / MSS : Ministère de la Sécurité Sociale
- GISS : Inspection General of Social Security / IGSS: Inspection Générale de la Sécurité Sociale.
- USF: Union of Sickness Funds / UCM: Union des Caisses Maladies
- AF: Accidents Funds / AAI: Association d'Assurance contre les Accidents
- OMC: Office of Medical Control / ACMSS: Administration du Contrôle Médical de la Sécurité Sociale.
- CEO : Cell for evaluation and orientation of dependency insurance / (OEO) Cellule d'évaluation et d'orientation de l'assurance dépendance.
- NLH: National Laboratory of Health / LNS Laboratoire National de la Santé
- PHRC : Public's Health Research Centre / (CRP-Santé) Centre de Recherche Public-Santé
- NCR : National cancer registry / (RMT) : Registre Morphologique des Tumeurs.
- INSTEAD: International Networks for Studies in Technology, Environment, Alternatives and Development. / CEPS: Centre d'Etudes de Populations, de Pauvreté et de Politiques Socio-économique.
- STATEC: Central Service for Statistics and Economic Studies.
- ILReS Market Research / Institut Luxembourgeois de Recherches Sociales et d'Etudes
- OEDT : The Luxembourg focal Point of the European Observatory of drugs and drug-addiction / R.E.L.I.S : Réseau Luxembourgeois d'Information sur les Stupéfiants et les toxicomanies.
- Centre of prevention against addiction / (CePT) : Centre de Prévention des toxicomanies.
- Luxembourg's League of Medico-social Prevention and Welfare/ (LLPAMS): Ligue Luxembourgeoise de Prévention et d'Action Médico-sociale.
- FP : Family Planning / (PF) : Planning Familial
- European Youth Forum, Network of Youth Organizations / Conférence Générale de la Jeunesse
- Medical School Centres / (CMS) : Centres médico-scolaires

Appendix

Figure 1: organizational chart of different involved Ministries and organizations within and outside the health sector in the process of health information. (Adapted from Organizational chart of the health care system in Luxembourg, Health cares system in transition, 1999)

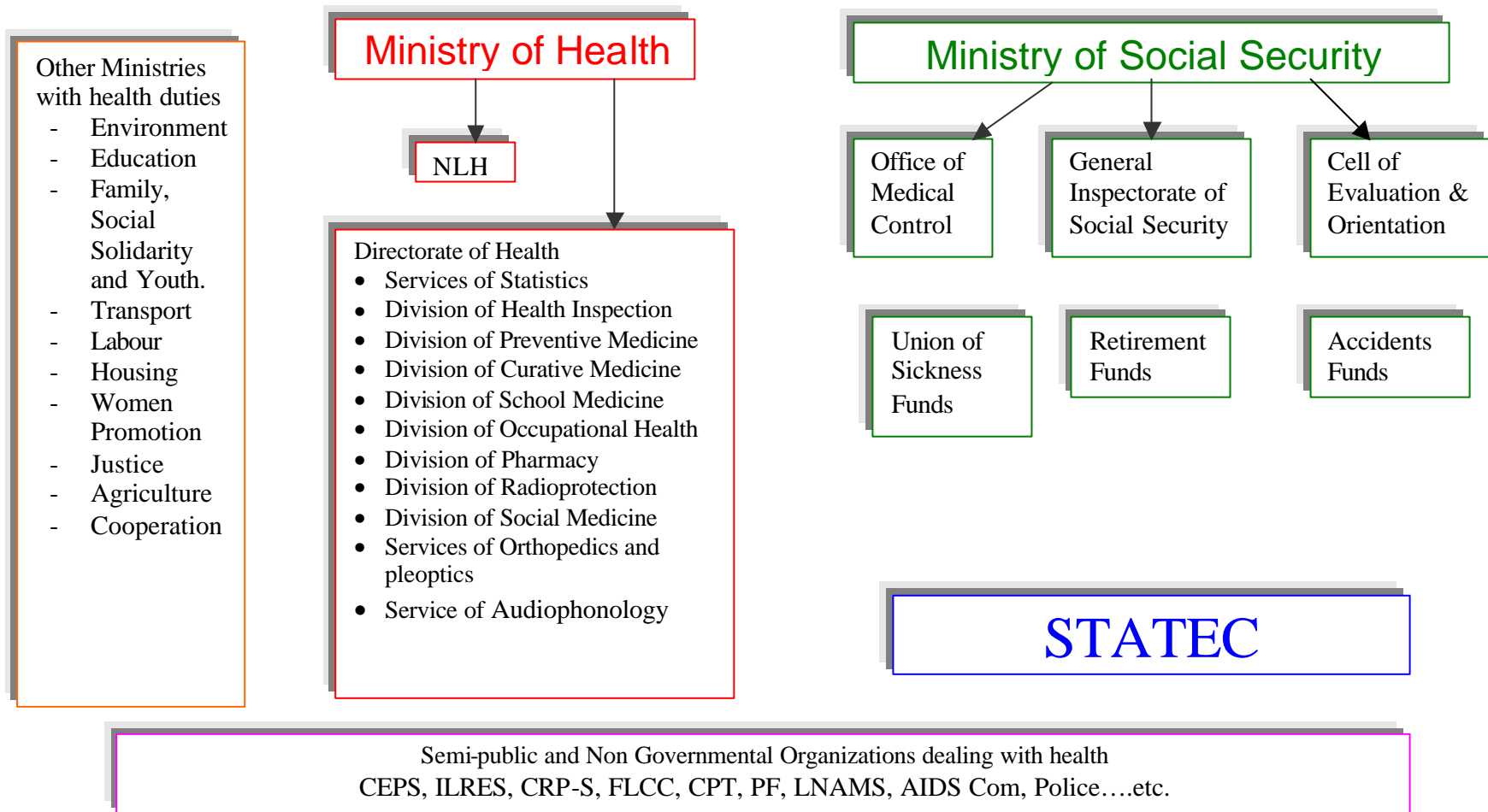


Figure 2. Organigram of Ministry of Health

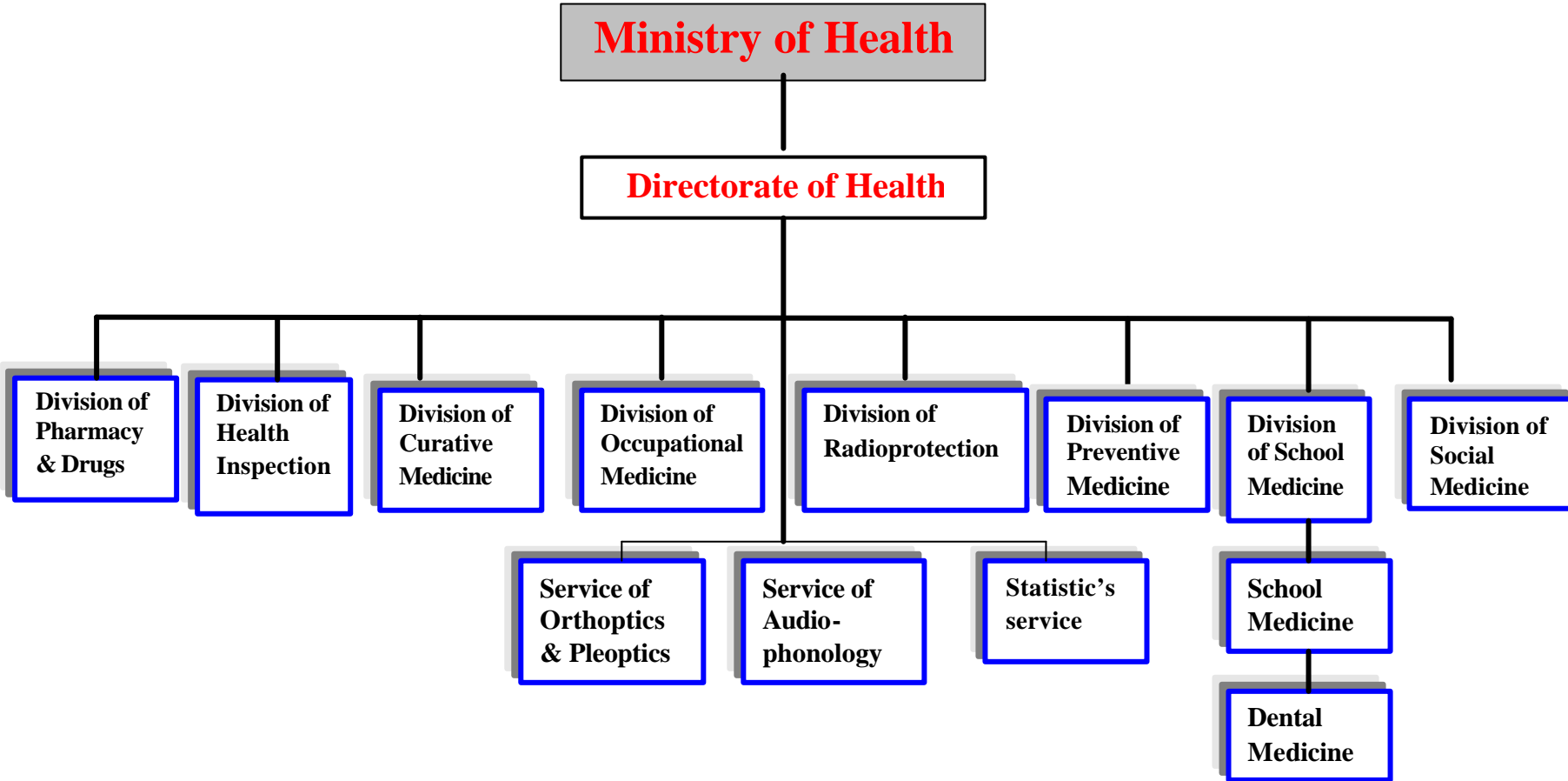


Figure 3. The organigram of Ministry of Social Security

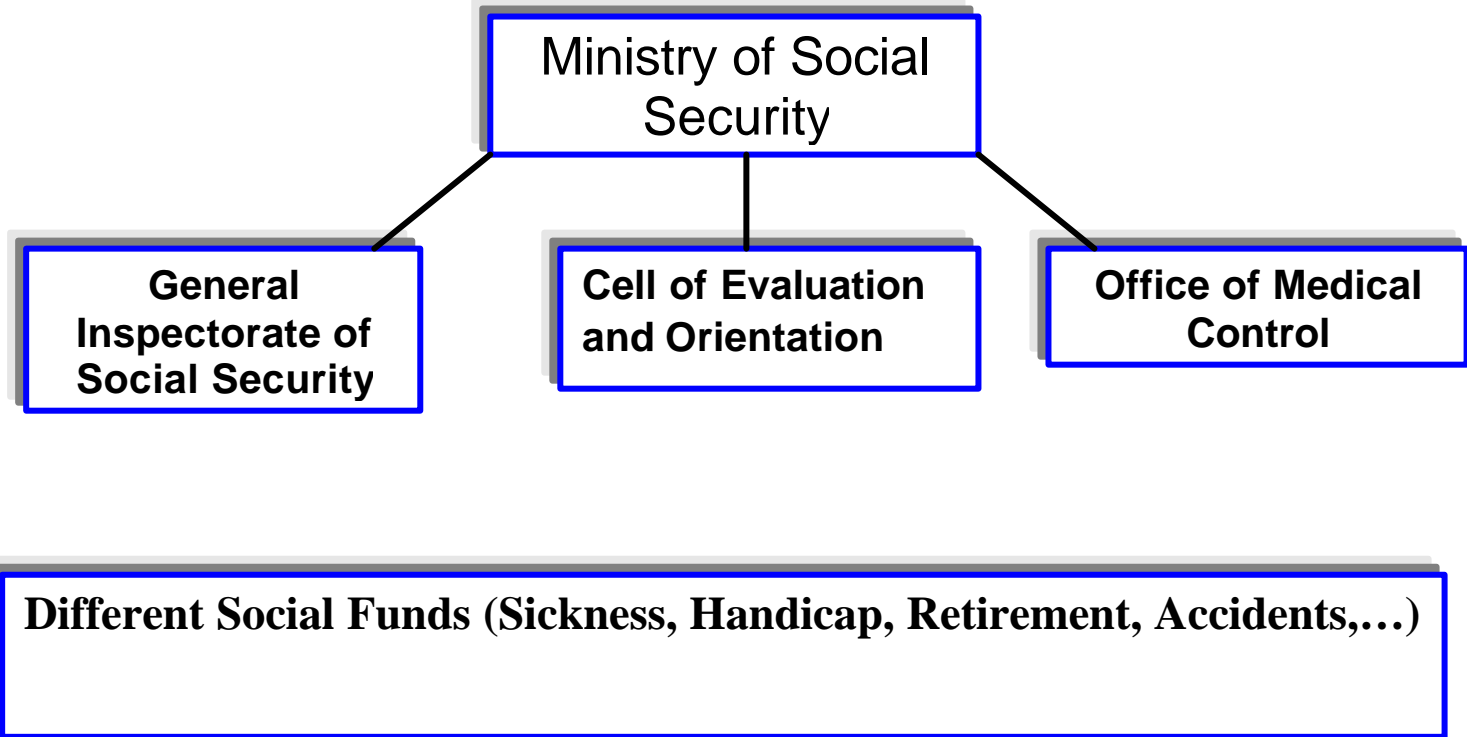


Figure 4 Flow-Diagram of Luxembourg's Health Monitoring

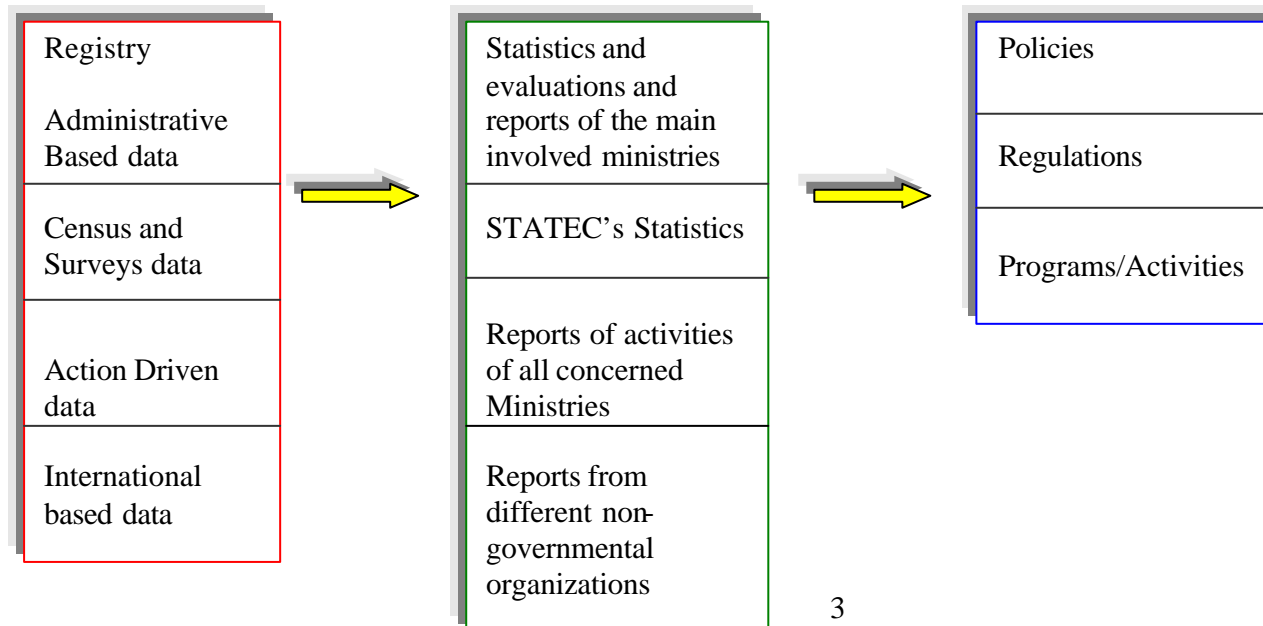
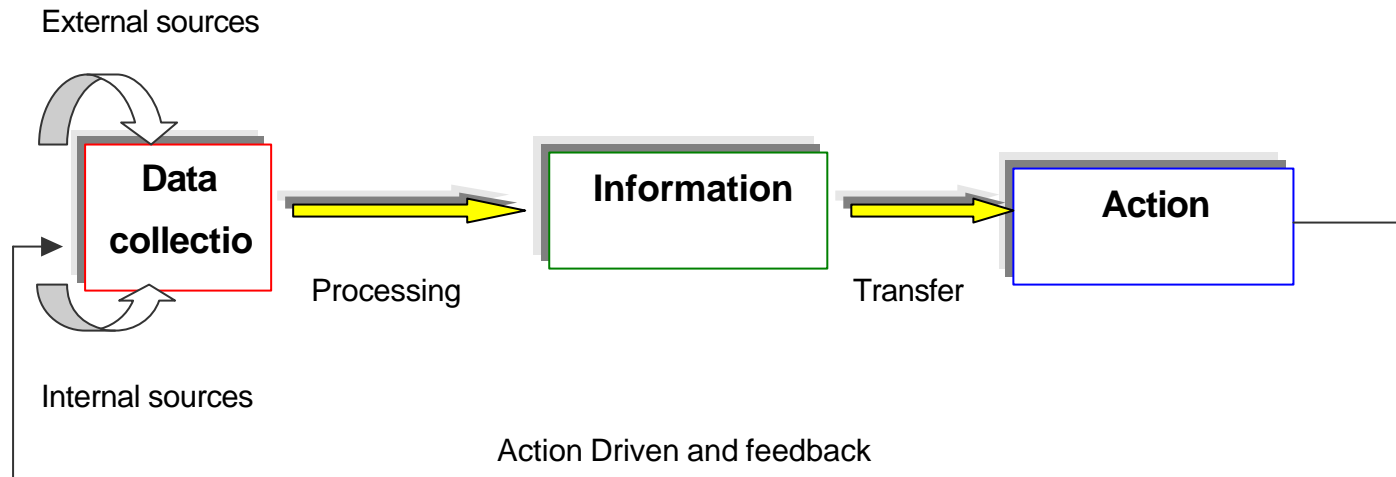
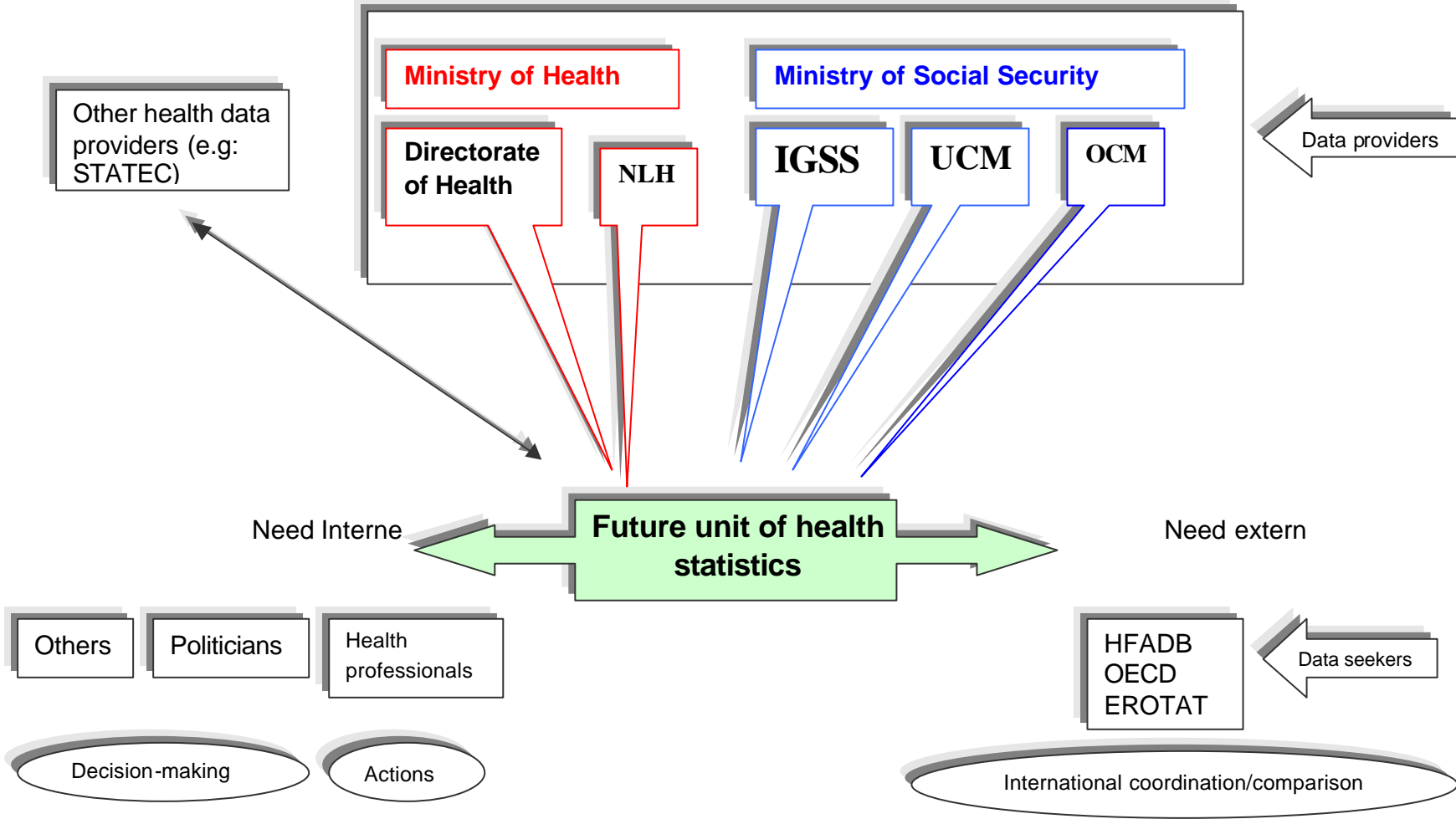


Figure 5: Proposition for a future organigram of Health Information System in Luxembourg:



List of main important addresses

Ministry for Health

Allée Marconi / Villa Louvigny
L-2120 Luxembourg
Tel.: 478-5505
Fax : 46 79 63
Email : ministere-sante@ms.etat.lu
www.etat.lu/MS/

Direction de la Santé

Allée Marconi / Villa Louvigny
L-2120 Luxembourg
Tel : 478-1
Fax: 467962
Mail: direction-sante@ms.etat.lu

Division of Medicine preventive

Allée Marconi / Villa Louvigny
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Mail: yolande.wagener@ms.etat.lu

Ministry of Social Security

26, rue Zithe
L-2936 Luxembourg
Tel: 478-1
Fax: 478-6328
Mail : Romain.Fehr@mss.etat.lu
<http://www.etat.lu/MSS/>

General Inspectorate of Social Security (IGSS)

P.O. Box 1308
L-1013 Luxembourg
Tel.. 478-6363
Fax 478-6225
Email : igss@igss.etat.lu
www.etat.lu/MSS/admini/igss.htm

Ministry of National Education / Ministère de l'Education Nationale de la Formation Professionnelle et des Sports (M.E.N.F.P.S.)

29, rue Aldringen
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Tel: 478 51 51
Télécopie: 478 51 13

Ministry for Agriculture, Service of Economy Rural

115, street of Hollerich
L-1741 Luxembourg
Tel. 478-2551
Fax 49 16 19

Ministry for the Interior

19, rue Beaumont
L-1219 Luxembourg
Tel.. 478-1
Fax : 241846 (Affaires générales)

Ministry of the environment / Ministère de l'environnement

18, Montée de la Pétrusse
L-2918 Luxembourg
Tel: 478-6824
Faxr: 400410
Télex: 2536
Mail address: Officille.boite@mev.etat.lu
www.etat.lu/MEV

Ministry of Women Promotion / Ministère de la Promotion féminine

12-14, avenue Emile Reuter
L - 2921 Luxembourg
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Fax : 241886
Contact email : promotionfeminine@mpf.etat.lu
Tél: 478-5814
Fax: 24 18 86

Ministry of Labour / Ministère de Travail et Emploi

26, rue Sainte-Zithe
L-2939 Luxembourg
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Fax: 478-6325
<http://www.etat.lu/MT/>

Ministry of Family, Social Solidarity and Youth / Ministère de la Famille, Solidarité Sociale et Jeunesse.

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STATEC (Central service of the statistics and the economic surveys)

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Fédération Internationale pour **la Planification Familial** mouvement luxembourgeois
pour le planning familial et l'éducation sexuelle asbl
L-1630 Luxembourg, 18-20 rue Glesener
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fax : 40 02 14
<http://www.planning-familial.org.lu/>

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MEEDERCHERSHAUS / Femmes en détresse a.s.b.l.

B.P. 1024
L-1010 Luxembourg
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Fax: 48 86 27

Iwerliewen fir bedreete Volleker / Cercle de Coopération Les ONGD au Luxembourg

9, rue Bertholet
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Tél. : 26258687
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280, route de Longwy
L-1940 Luxembourg
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Commission Médico-Psycho-Pédagogique Nationale (CMPP)

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20, rue de commerce / place de Strasbourg
Tel : 47962948

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Boîte Postale 78
L-8005 Bertrange

Administration Communale de Bertrange
Service Enseignement
Boîte Postale 28

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Focal Point Luxembourg

Location of the national focal point

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For further information, please consult the web-site: www.resolux.lu

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