



Belgian Science Policy
AGORA Project

Preparatory study in order to supplement the health information system by means of longitudinal data

Synthesis of research

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1. Introduction

Within the framework of a better search for coordination of the socio-medical data in Belgium, the SPF Social security, in charge of the statistical coordination Group, initiated with the Federal Scientific Policy (Program AGORA) this reflexion on the contribution of longitudinal data in the existing Health Information System (SIS). This project aims to reinforce the existing SIS by paying more attention to the longitudinal follow-up of persons. Following people over the time is needed to have a better understanding of the different life events of persons that lead to good or bad health. Two strategies, complementary, exist to obtain a longitudinal vision of the health of populations: The traditional longitudinal studies and the data linkage. The cost and the complexity of the longitudinal studies and the technical and ethical questions related to data linkage require a more global approach. The literature shows that the development of a longitudinal HIS implies an integrated system where the different data producers work together. In operational term, the aims of the research were to define a conceptual framework of a longitudinal HIS in Belgium, to identify the longitudinal indicators and the ways to collect and analyse them. Within this framework, the research was based specifically on literature review and on meeting of Belgian experts as regards medical information.

2. International experiences

The scientific literature, the number of sites and conferences translate the need to reinforce the existing HIS by integrating a longitudinal approach. The international experiences present 4 types of approaches (possibly complementary): a “national” approach by the development of a plan of coordination of the data sources; the creation of independent organizations in charge of the management of the SIS and the longitudinal data of health; reinforcement of existing longitudinal follow-ups on the various levels and the development of the computerized medical files and other electronic recordings. The United Kingdom thus developed a national strategy coordinated by the Office of the National Statistics (ONS). Very interesting examples of creation of independent organizations are for example those described in Australia (Australian Institute off Health and Welfare), in Canada (Canadian Institute for Health and Information) or in Sweden (Centre of Epidemiology). Apart from these strengthening of the institutions, the other international initiatives are in the development of the longitudinal studies either by the follow-up of troops or by data linkage. Different longitudinal investigations are thus described in several contexts. In the United Kingdom, a national centre (the longitudinal U.K. centre) was created in order to supervise

the existing longitudinal studies, to support the complementarity between the studies, to facilitate the access to the data and their use and to support the linkage between data bases of studies and “official” data bases. Beyond these three principal strategies, another element to be held in account within the conceptual framework of the longitudinal HIS is the progress made in the field of electronic health records and health information network.

3. National experiences

In Belgium, there are many sources of information or relevant socio-medical and socio-economic data. There are, in a simplified way, four potential categories of sources: the sources which are managed directly by the services of the State; the sources which depend on the federal level or the Community/regional levels either under the articles or by the means of recurring financing; investigations and registers which depend on public or private subsidies; sources of information or data which do not have a structural bond with the public institutions. The study qualitatively analyzes the place and the role of various Belgian institutions on the matter and more particularly the IMA, KCE, the ISP, the SPF Social security, the SPF Public health, the INS, the INAMI, “Banque Carrefour”, as well as certain university initiatives. Since the Law Programs of December 24, 2002 which determined the legal bases of the creation of the KCE and the IMA, the possibilities of linking data bases of various public institutions as regards health and social security exist. For example, there already were projects:

- of linking data of the OA of the IMA with the data base RCM of the SPF Public health
- of linking data on the financial responsibility and health expenditure (OA)
- of linking data of drugs consumption and data from the RCM (years 2001 and 2002)
- of linking data from RCM with data from the Financial Summaries Minima (RFM) on the level of the SPF Public health.

Even if the procedures to link data together are complex (in terms of approval procedure), these studies showed the enormous benefit of the method to the community. However, the majority of these linkages don't give a truly longitudinal vision. Only the data of the IMA allow a true longitudinal follow-up.

4. Proposal of longitudinal health indicators

The characteristic of a longitudinal indicator is that it evaluates an evolution over time. The longitudinal indicators can also summarize non-consecutive periods for a particular statute like those related to the development and consequences of chronic diseases. Moreover, the longitudinal indicators can be directional. Since, by definition, they evaluate aspects over time rather than at specific times, they allow a better comprehension of the evolution of the health status of a population.

In various European studies, five types of measurements of health fill the criteria of comparability and are interesting to follow in a longitudinal way: perceived health, certain declared diseases, anthropometric measurements, certain restrictions of the daily activities and the daily tobacco consumption. Other indicators are also necessary within the framework of a prospective follow-up and we define certain operational methods of interesting indicators like the self-rating of health, self-esteem, health problems such as arthritis/rheumatism, the cardiovascular events, high blood pressure, depression and the mental health, the stress in an everyday life, the satisfaction of the patient compared to the system of health (and the evaluation of the quality of the received service), the expenditure health, the individual consumption of care, the consumption of drugs, the probability to use health services as of other longitudinal indicators including inter alia those which define "poverty".

The International Longevity Centre (ILC) launched in 2003-2004 the project "Indicators of Active Ageing". The objective is to develop new measurements of health and productive engagement in order to compare various countries between them and over time.

We mention below, in the form of a synthesis, all the indicators proposed within the framework of a longitudinal follow-up. This list must be completed gradually according to the determined priorities and of the resources available. The operational methods of data collection are described more in detail in the research report.

Health status		
Well-being	Health conditions	Human function
<ul style="list-style-type: none"> - Self-rated health - Changes over time in self-rated health - Self-esteem¹ - Self-rated mental health 	<ul style="list-style-type: none"> - Adult body mass index (BMI) - Youth body mass index (BMI) - Arthritis/rheumatism - Diabetes - Asthma - High blood pressure - Pain or discomfort that affects activities - Pain or discomfort by Severity - Depression² - Injury hospitalization (CIHI) - injuries - Cardiovascular events 	<ul style="list-style-type: none"> - Functional health - Days of disability - Participation and activity limitation

Non-medical determinants of health		
Health behaviours	Living and working conditions	Personal resources
<ul style="list-style-type: none"> - Changes over time in smoking behaviour - Frequency of alcohol drinking - Leisure-time physical activity - Fruit and vegetable consumption 	<ul style="list-style-type: none"> - Average personal income - Housing affordability - Stress at work 	<ul style="list-style-type: none"> - Sense of community belonging - Social support - Life stress - Poverty

Health system performance		
Acceptability	Accessibility	Efficacy and efficiency
<ul style="list-style-type: none"> - Patient satisfaction - Probability to use health services 	<ul style="list-style-type: none"> - Consultation at the general practitioner, the specialists, the dentists, etc numbers - Evolution of the number of hospitalization per annum - Evolution of the ambulatory care per annum 	<ul style="list-style-type: none"> - Hospital Readmission - Days of hospitalization and a number of examinations prescribed diagnoses - Consumption of drugs

5. Elaboration of a conceptual framework for a longitudinal HIS

A longitudinal Health information system can be fed by various data sources:

- It can be medical indicators collected in routine and reflecting the health of an individual or a population: data of medical consumption of the OA and the INAMI for example;
- It can be also data collected over one period determined to follow an event of any nature: Health longitudinal studies.
- The data can also come from cross-sectional studies which are repeated year by year and offer the possibility to follow the health status of a population (given pseudo longitudinal data): RCM for example;
- Data resulting from Electronic Medical Record or other data bases in network;
- The data linkage also makes it possible to have a longitudinal vision of health.

Two stages are fundamental in the development of such a system:

- to set up a coordination of the principal suppliers of socio-medical data
- to support the use of a common identifier to allow the linkage between different data sources.

- **To set up a coordination of the principal suppliers of socio-medical data**

This coordination, gathered within the framework of a scientific committee, would ensure the management of all longitudinal data. This coordination would be based on the services of an institution in charge of the handling of the data bases and would allot the identifiers to allow data linkage.

- **To support the use of a common identifier**

There is a reflexion in progress on this concept of common identifier for various data sources. A common identifier proper to each person can be generated from the National Register. The development of a common identifier will have the double advantage of having a completely reliable health identifier and of eliminating any risk of unauthorized bringing together of personal data.

To set up a system integrating the aspects of identifier and the respect the private life, it is necessary to define well certain preliminary methods of which:

1. **A legal framework** which defines the role of the coordination group the missions of the organization in charge of the management of the data. This framework must also define the procedures of request and access to the longitudinal data and regulate the data protection;
2. **Organisational measurements** which will help to guarantee the independence of these authorities charged with coordinating and managing the data bases;
3. **Information/training** of the data users and all those who are brought to treat confidential statistical data on the bases and ethical principles on the matter;
4. **Methodological and technological measurements** which will help to protect confidentiality of the data.

In operational terms, five groups of measurements should be undertaken to initiate the process which will allow the development of a longitudinal HIS:

1. to develop a **global strategy**
2. **to set up at least one organisation** in charge of the coordination of all longitudinal data
3. To consider a **decentralization level** for the analysis and the dissemination of information.
4. to improve the **data collection** and the **accessibility to the users**.

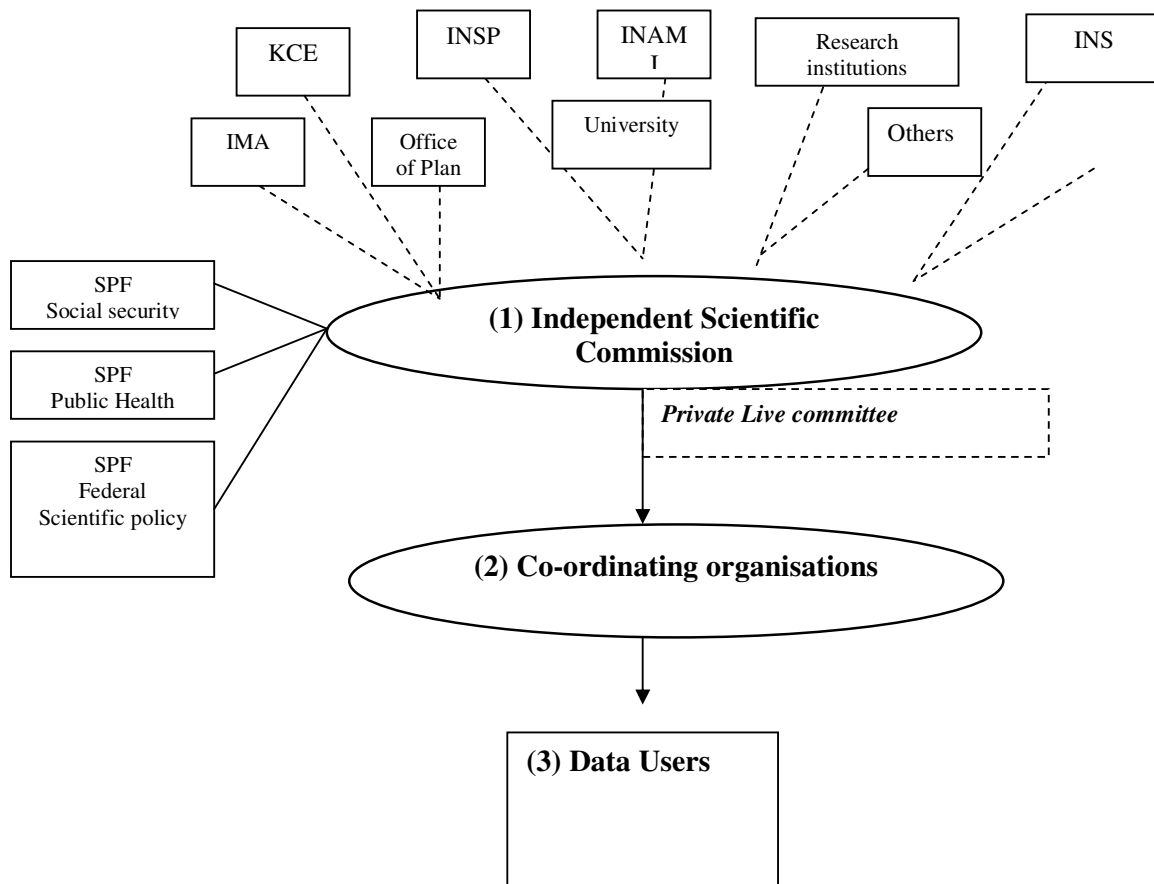
- to establish a **synergy** between the federal level, the communities and the regions within the framework of the national HIS.

We mention below the different measurements to be implemented within the framework of the development of longitudinal HIS:

1. To develop a global strategy

The integration of data within the framework of longitudinal HIS shouldn't be centralized. Most important is that the institutions which would like to link data of different sources will be able to do it with simple and fast procedures. Therefore, a co-ordinating organization, such as "Banque Carrefour", could link different data bases, ensure the management of the requests and provide the data to the users, in compliance with the legal and deontological rules related to this type of data. This organization should be independent (not a data supplier or user) and could be under the direction of a scientific Commission made up of the representatives of the principal data suppliers and users: KCE, the ISP, the SPF Public health, the SPF Social security, the INAMI, the IMA, the Office of the Plan and any other institution of research which would justify its integration. The diagram hereafter has the structures suggested to manage the principal functions of the system and their relations.

Figure: Presentation of institutional framework of a longitudinal SIS



The scientific Commission would propose various interesting couplings in public health and should be legally made up as within the framework for example of the details of implementation of the permanent sample. A legal framework would define the procedures of coupling of the data bases which would support “flexible” procedures, accessible to the principal interested institutions and in respect from the rules of confidentiality determined by the law. Therefore the need for the scientific independence of the commission and institution of coordination, and also, consequently, the existence of a legal and institutional framework suitable to guarantee this independence. This scientific Commission could be integrated in the creation of the Higher Council of Health at the federal level. Indeed, this type of authority is currently missing on this level. Another proposal is that stays under the supervision of the SPF Federal Scientific policy (in bond itself with the SPF Public health and the SPF Social security) which has in its attributions to coordinate scientific research and to facilitate the access to the data to the research teams.

2. Creation of one or more structures in charge of the coordination of the longitudinal health data (global or thematic)

We propose three scenarios to ensure this coordination:

- either the creation of an independent organization
- either entitle Belgian public institutions responsible for specific sets of themes
- either to work exclusively on the missing data and the existing system

Scenario 1. Creation of an independent organization:

In accordance with the proposal mentioned in figure 7, the data bases of longitudinal indicators could be under the responsibility/coordination of an organization such as the “Banque Carrefour”. The latter is only in charge of socio-economic data and develops various collaborations like that with KCE concerning the data on health care.

Operationally:

Either this coordination is integrated in an existing institution such as for example:

- the current “Banque Carrefour” if it is possible to widen its competences
- a public institution like the SPS Social security and/or the SPF Public health.
- either it is necessary to consider the creation of a new institution which would treat socio-medical data (in close collaboration with “Banque Carrefour”).

Scenario 2. Entitle Belgian public institutions responsible for specific sets of themes:

The development of a longitudinal HIS could be integrated in the existing institutions in charge of data collection or via the creation of a statistical coordination Group in Belgium (according to the experiment currently undertaken by the SPF Social security).

In Belgium, one can thus identify 3 institutions which cover specific and complementary socio-medical fields within the framework of a global HIS:

- The National Institute of Statistics; This institution is responsible for the centralisation of the data, for the coordination and their diffusion (with the SPF Public health).
- KCE is an institution mainly directed towards the economic analysis of health (economic effectiveness economic of the medical system) and the health care quality.
- The ISP has the specificity to work on public health indicators through the National health Survey.

Scenario 3. To work exclusively on the missing data and the existing system

This scenario is thus based on the use of the existing system, the more spontaneous collaboration between institutions and the need for better links between the data sources available and the existing tools (e.g. Register of population and data of mortality).

3. To consider a level of decentralization for the analysis and the dissemination of information

The development of a decentralization level for the analysis and the dissemination of the information will require exchanges with the various data producers in order to lead to proposals aiming at modifying the system and adopting new data and/or new data collection methods. These indicators must then be disseminated to the potential users.

4. To improve the data collection and accessibility to the users

The system must be integrated in the existing links between institutions. The political responsibility of the system must also be assumed.

5. To establish a synergy between the federal level, the communities and the regions within the framework of national HIS

The suggested system will only have sense if it is integrated in an overall vision on a country scale which takes into account the federal, Community and regional responsibilities.

6. Conclusions and prospects

6.1. Relations between the different federate entities

One of the priorities of The Second Federal Sustainable Development Plan 2004-2008, is "... to improve communication and to support the access to healthcare" which implies involving and coordinating a wide range of government departments. The objective is not only limited to identify the determinants of health but also to evaluate the influence of information, prevention and care on health. The new European Directives for health and safety at work could be the catalyst of this installation of a better coordination. Indeed, this directive will impose certain obligations on the Member States and is an opportunity to create a statistical coordination group.

6.2. Development of a longitudinal HIS

Following the realization of this preliminary study, to bring a longitudinal HIS in operation will have to take into account of various elements cited in this report including:

- a coherent choice of variables on health care and their consumption, and variables currently not available: labour forces, data on private expenditure on health, ambulatory data, long term care, care to old people, social care, data living conditions
- the need for identifying the missing data, for defining the methods to produce this kind of statistics and the need for integrating other institutions in direct or indirect bonds with these data (ex: Ministry for Employment and Work);
- the need for setting up longitudinal health studies for developing of a true longitudinal follow-up of population recruited within the framework of current investigations;
- a better analysis of the legal, technical and financial obstacles;
- the most operational identification of the co-ordinating institutions
- the need for basing on the international experiments

- the development coordination strategies between institutions and to have a better view of the “similar sphere of activities of certain institutions”;
- the need for proposing a system which facilitates the initiatives of data linkage between public institutions and research;
- the conceptual framework of the proposed longitudinal indicators and which take account of the different dimensions of health.
- to support a reflexion based on the exchanges of good practices between institutions.

6.3. Follow-up of the research and the bringing the suggested system in operation

The present study will be followed by a second project whose principal objective is to develop in practise a coherent and powerful longitudinal HIS. The question is to choose an approach which would take into account the health system as a whole (which potentially integrates all services (public and private), all actors (formal and abstract), all policies, etc and would emphasise the longitudinal prospect. This second phase will validate the conceptual framework and the proposed theoretical approach and set up a coordination of the principal suppliers of socio-medical data.