BeLHIS

BELGIAN LONGITUDINAL HEALTH INFORMATION SYSTEM

Belgian Longitudinal Health Information System

Supplement the health information system by means of longitudinal data

Summary of the research

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1. Introduction & research objective (1)

In Belgium, the production of the national health statistics is mainly based on healthcare refunds data and is coordinated by the Federal Public Service Social Security. The latter wishes to improve its understanding of the evolution of the Belgian population's health by means of indicators belonging to the longitudinal approach of health. This approach enables observing over time changes of people's health status and related –individual and environmental– determinants. A preliminary project called HIS-1 (2006-2007) carried out an international review of health information systems (HIS) that had integrated the longitudinal approach; in its final report, it presented several prerequisites and scenarios for the implementation of such a perspective in our country.

Therefore, the FPS Social Security initiated in 2008 a project called BeLHIS (for Belgian Longitudinal Health Information System) whose objective was to add a longitudinal dimension to the national HIS. In this manner, the HIS should be able to incorporate socio-medical personal data originated from different sources, to identify complementary elements and to shape a more comprehensive understanding of the population's health, thanks to indicators of the health dynamics.

Several data collection strategies enable illustrating the health dynamics: first, the usual –time and resources-consuming– prospective and retrospective studies; second, a current alternative consists in re-utilising primary (administrative) data for secondary exploitation. But this option is still hindered by technical (operational feasibility), qualitative (related to the scientific content of collected data) and ethical (related to privacy constraints) limitations that become obvious when data are linked together. Data linkage implies that data having different sources, contexts and grounds are gathered to form a meaningful set of information. Theoretically at least, any kind of data, including cross-sectional data can be useful to the longitudinal HIS, provided that they are specific to an entity (a person, an organisation...) and that they are linked to other data concerning the same entity. Third, data collected in a repeated, not to say in a systematic way within registers, each being dedicated to a particular health issue, enable also to draw population trends over the time.

The objective of the BeLHIS research was to examine the various methods of longitudinal health data supply as well as their implementation modalities in the Belgian context, while taking into account the evolution of related institutional, organisational and legal elements. Focused on the longitudinal approach of health, the research was based on a comparative analysis of international initiatives, the study of innovative projects and the analysis of specific chronic health topics. The results of the research are detailed throughout eight working papers listed hereafter. References related to each discussed issue are mentioned in the appropriate working paper.

2. Methodological framework & results

For the analysis of the longitudinal HIS and of its main components (methodologies and indicators of the longitudinal information systems, changes in the Belgian legal framework and the privacy law, management of personal data, international comparisons, etc.) as well as for the case-studies (diabetes, joint replacements and breast cancer), three complementary investigation methods have mainly been used:

A review of the scientific literature enabled us to identify several follow-up initiatives implemented abroad. It also enabled us to compare the Danish and British personal data management systems, to compare several data collection tools, to acquire a better knowledge concerning foreign agencies dealing with longitudinal health data, or even concerning Belgian updates in this field (eHealth platform, protection of the privacy, longitudinal databases, data linkage studies, national health registers, etc.).

Meanwhile, a thorough desktop research of agencies' Internet websites like Statistics Canada, the Canadian Institute of Health Information or Statistics Denmark has enriched our knowledge of the issue with organisational aspects. The theoretical (methodological) and operational frameworks proposed in this research have been strengthened through our participation to international specialised conferences.

Finally, several Belgian and international experts on the field of health information and of health data have been interviewed in order to add the most recent information on the context and its developments.

3. Management of personal data & international comparisons (2)

In Belgium, many data sources are settled within the administration or other public institutions. The secondary use of those data is less costly than specific studies would be and this advantage should be taken, for instance with exploratory studies. This opportunity has been recommended by Belgian academic experts in a 2005-report to the High Council of Statistics. According to this report, the statistic authority should have a legal access to administrative data, as long as the security of the data processing is ensured.

The linkage of administrative data depends on an effective coordination of the various sources, as well as a univocal identification of individuals. In Belgium, the existence and the common use of the National Register identification number (which is identical to the social security number)

facilitates the information reuse, should stimulate the socio-sanitary data linkage and in the end, the development of a longitudinal perspective of health.

The eHealth project is part of the administrative reorganisation (e-government) that is led by the Belgian federal State. With regard to the health system, the reform is aimed at modernizing its healthcare services, in other words, to improve its management, its performances and the population's access to the system. By facilitating the health data flow, indeed, the eHealth platform sets itself as a better administration and management tool and as a faster access to existing services. The platform is also aimed to support the implementation of further electronic applications elaborated as part of the Belgian public health policies.

As compared to international experiences, the Danish statistical system, relying on a centralised data management, offers many advantages and could serve as a model for other European countries. Its performances are based on a proper management, the wide use of administrative data, the use of advanced statistical and informatics methods. It benefits from the existence of numerous administrative registers and of an individual identification number applied both for people and for companies. Data originated from those registers can be linked together, thereby be used to produce indicators, including with the longitudinal perspective. The Danish statistical system ensures an accurate protection of the privacy of citizens, the confidentiality of the information and the statistical secret. Effective technical and physical security measures are implemented, and confidentiality rules are published on the website of the statistical authority.

The main difference between the Danish and the British systems lies in the use of administrative data. The United Kingdom seldom uses this kind of data and should, in order to reach the Danish level of performance, reform its administrative and statistical systems. However, the British system offers certain assets: on-going reforms of the system, independence of the statistical authorities, work conforms the European declaration of quality and it benefits of a two-level decentralisation, a geographical and a "thematic" one.

Based on this comparative study some proposals for the Belgian HIS can be formulated: it is a matter of strengthening the statistics authorities' independence, to set up quality control procedures and to enhance a transparent handling of the statistical information. Finally, an increased use of administrative data, which are numerous in Belgium, requires a more efficient coordination of data sources.

4. Privacy law & changes in the Belgian legal framework (3)

On the 8th December 1992, Belgium endowed itself with a law aiming to guarantee the privacy protection during the processing of personal data. The law has evolved, notably in 1999, further to the transposition of the related European directive. The Privacy Commission, among others,

provides a support to the application of such an essential law and tries to fill in and to specify the gaps of the law.

The law pools the pieces of information related to the privacy in several categories, among which are sensitive data and health-related data. Sensitive data are personal data "that reveals the racial or ethnic origin, political opinions, religious or philosophical convictions, the union affiliation, as well as (...) the data related to the sexual life". As a rule, it is forbidden to process such data but there are exceptions, allowing that data are analysed under certain conditions well defined by the law or by executory decision.

Health-related data is all personal data that concerns past, current or future states of the physical or mental health of the person. The exceptions allowing the analysis of those data are identical to those established for sensitive data, with an additional exception related to the prevention of a real danger or to the crackdown of a determined criminal offence. The exception of general interest concerning public statistics is here substituted with the one of public health protection and promotion, including the screening. Moreover, additional guarantees are provided by the law, compelling that such data analyses are carried out under the responsibility of a health professional, that data are only provided by the involved persons themselves. A right to access and of correction of the information is granted to those involved persons, and the contact information of the person in charge of the data processing must compulsorily be communicated to them.

Most probably will the law be applicable to any longitudinal data analysis, because the longitudinal approach excludes the use of anonymous data. Indeed, researchers are working with data that they cannot identify, as data have been codified on purpose. But according to the law, codified data remain personal data and is therefore protected with the same rules. At last, several obligations impose upon the persons in charge of such processing, with regard to data security, reporting to the Privacy Commission, or in order to enable the involved persons to exert their law-granted rights.

5. Methodologies & indicators of longitudinal health information systems (7-8)

Longitudinal research mainly relies on two different methods of data collection: first, the prospective studies which follow up individuals at time intervals; second, the retrospective studies, through which life trajectories of individuals can be partially rebuilt, thanks to the data linkage.

The HIS-1 study recalls that "longitudinal indicators", even if they look like cross-sectional measures, describe at the individual's level, the evolution, across the time, of certain features. The European Union has already developed several longitudinal aspects in the field of health and well-

being. Especially, it is about the estimation of one's own state of health; anthropometric measures; the onset of health events (diagnosed physio-pathological states, declared episodes of disease, etc.); the assessment of the functional health; and about the statement of health behaviours and of non medical determinants.

The BeLHIS project has documented the operational aspects in Belgium of a data linkage, from a study carried out by the VUB over the social factors of health inequalities related to breast cancer mortality. The linkage involved mortality data for the years 1991-1995 and the women's socioeconomic position. Beside the education level, the research took into account different determinants of the pathology such as the mother's age at first pregnancy and the number of children. The linkage has provided a set of information at individual's level regarding the main risk factors for breast cancer mortality (survival analyses). The BeLHIS working paper presents the operational aspects of the data linkage and the constraints related to the exploitation of administrative databases in public health research.

6. Implementing a longitudinal health information system: 3 thematic case-studies

The BeLHIS project's case-studies illustrate the advantages of developing a dynamic conception of population's health, through concrete examples of longitudinal initiatives implemented beyond our borders about cancers, diabetes and joint replacements. When appropriate, the operational and evaluation features of those initiatives will inspire Belgian health professionals and decision-makers.

6.1. Diabetes (4)

There is a wide availability of data to analyse and map the socio-demographic and epidemiological extent and consequences of the "burden of diabetes" in Belgium. Still, important gaps are observed especially for longitudinal data collection.

Considerable collected longitudinal patient information is neither standardised nor centralised, which hinders its usefulness for research purposes as well as inter-institutional cooperation. Besides, the Belgian diabetes information system would benefit from the exchange of the currently available data coming from different data sources using linkage techniques, of course taking into consideration people's privacy protection.

Starting with a comparative analysis of international longitudinal data systems (the Canadian diabetes strategy, the Dutch national programme against diabetes) and the description of longitudinal studies (the cohort Epidemiological Data about insulin resistance syndrome in France

and the Prospective Diabetes Study in the United Kingdom), we provide arguments about the feasibility of the implementation, in Belgium, of a diabetes longitudinal data system, based on the currently available data. The priority "longitudinal" indicators in this issue are: (i) the glycemic control, (ii) the screening of complications, (iii) the monitoring of complications, (iv) the monitoring of cardio-vascular diseases and (v) the diabetes patients' quality of life. The calculation of those indicators could rely on existing databases such as the Belgian diabetes Register, the database of the initiative for the quality improvement and the epidemiology of diabetes, the InterMutualist Agency database, the national health interview surveys and the national mortality database. Moreover, new interesting initiatives may become additional longitudinal data sources: the global medical record and the patient's "healthcare story".

A better follow-up of this public health issue rely on a greater standardisation of the information, a better coordination of the stakeholders (and of the data sources) and the support of global politics enhancing the production of longitudinal indicators. This should also directly benefits patients, health professionals and broadly speaking, the health system itself.

6.2. Joint replacements (5)

According to the WHO, 10% of people aged 60 and over suffer clinical problems due to joint arthritis. With regard to chronic diseases and age-related illnesses, willing to improve healthcare quality implies especially that health events, their chronology, extent and consequences are followed at the individual's level.

The Canadian Joint Replacement Registry (CJRR) is an example of a public health tool based on the longitudinal approach of health. It enables to collect the essential information about hip and knee joint replacements in Canada. It is aimed at improving the clinical outcomes and at calculating, for instance, the revision rate of those interventions. Moreover, the register stimulates the healthcare quality and motivates the participants to the initiative by providing them with analyses and a feedback enabling them to situate their individual practise in relation to their field.

Three different levels benefit from the CJRR: (i) patients through an improved healthcare quality; (ii) orthopaedists who make their decisions on strong evidences and (ii) the health system, which gets better epidemiological assessments to measure performances and complications related to joint replacements in order to better control the market and the costs of this intervention.

In Belgium as in other countries, specialists in joint replacements notice a great variability of implants' survival, of hospital length of stay, of operative and post-operative practices. A detailed analysis of the implants performances should thus be based on their cost-effectiveness ratios taking into account the implant's characteristics, the surgical technique used as well as the particularities of the patient and of the facility where the surgery took place. Facing the multiple limits of cross-sectional studies, the experts agree to say that a joint replacements register is one

of the best tools which orthopedists can have to estimate the quality of implants and of medical practices. The major asset of a register is to establish an early alarm system thanks to which the defective implants can be quickly detected and withdrawn from the market. Whenever necessary, it enables to effectively contact the patients bearing those unreliable edvices.

Beyond the surveillance of the material, the register can give rise to extensive researches on the clinical, biological factors influencing the success or the failure of a replacement; it emphasises the improvement of the surgical techniques.

In 2007, the Belgian orthopaedists asked for the assistance of the INAMI to set up a joint replacement register, ORTHOpride®. Following the example of other international initiatives, the data of this register should be coupled with other databases, in particular, the hospital morbidity and mortality databases. The interesting indicators of the longitudinal perspective concern the implant's survival and the surgery functional outcomes, because they bring to healthcare professionals, to the healthcare system administrators as well as to the patients, a useful information on the efficiency of the care and on the quality of the services.

6.3. Breast cancer (6)

Breast cancer is a real public health problem, given its incidence and its mortality but also because it generates important human, technical and financial costs. In 2006, a law provided a legal framework to the collection in Belgium of cancer-related data. The law authorises the Cancer Registry Foundation to use the social security number as univocal patients' identifier. Besides the epidemiological data exhaustiveness, the Foundation also carries on an objective of healthcare quality improvement.

Other data recording systems are dedicated to cancers in Belgium: a program of breast cancer screening began in 2001, at first in Flanders, and one year later in Brussels and in Wallonia. Additionally since 2008, Belgium benefits from several national Plans against cancers.

The working paper dedicated to this issue presents the French and Canadian experiences on the evolution of the data collection concerning cancers. In France, the national estimations of cancers incidence and mortality are produced by Francim, a network of cancers registers, by the department of biostatistics of the civil Hospital of Lyon and the by the Institut de Veille Sanitaire (InVS). The latter is also in charge of the coordination. This partnership was widened in 2008 to the national Institute of the cancer.

In Canada, the incidence data of cancers diagnosed since 1992 are collected within provincial and territorial registers. They are then centralised in the Canadian Register of the Cancer (CRC), sheltered by the Division of Health Statistics of Statistics Canada. The first advantage of this register is that it supplies longitudinal data for every person affected by a cancer because the CRC is patient-oriented. A second advantage is that it facilitates the linkage of the collected data.

7. Conclusions and perspectives

The implementation of the longitudinal health approach requires the development of a comprehensive and coherent system of health data coordination. In this system, data providers and users work together at establishing the health profile of the population, defining the efficiency of the healthcare system and at elaborating sound health policies. The BeLHIS project wanted to inform public and private agencies about the added-value of such an approach. It tried to foster the participation of the largest number of actors of the sector in this new perspective.

The advantages of data linkage, in particular within the framework of epidemiological or socio-sanitary studies, is not any more to be demonstrated. Indeed, it enables not only to reach a more complete, multidisciplinary and time information but also to a life-long approach. This strategy gives a better understanding of the dynamics of health and thus constitutes a tool for the decision-making and the planning processes.

Belgian university experts consider that the quality of the statistics widely depends on the budget which is dedicated to it. They particularly emphasised that resources dedicated to the national statistical system were too limited. More resources should be attributed to it, in order to supplement it with a longitudinal analysis capability and to meet the European requirements. This improved statistical system should be more efficient and capable of organising the necessary quality controls.

Among the Belgian institutions called upon within the framework of the BeLHIS research, we can quote FPS Social Security, the INAMI-RIZIV, the InterMutualist Agency, the KCE and the e-Health platform. These various interlocutors' participation in the analysis of propositions made during the project can possibly become a reality later, at the invitation of FPS Social Security, backer of the BeLHIS project.

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