

***EU PROJECT – HEALTH INFORMATION
SYSTEMS IN EUROPE***

COUNTRY REPORT

THE NETHERLANDS

Fons Blankendaal

Prismant

PO BOX 85200 AE Utrecht - Holland

Health care information in the Netherlands

***Prismant
Fons Blankendaal
Business Unit Manager Cure***

Prismant is the research and consulting agency for the Dutch health care sector. The aim is to assist in developing, implementing and evaluating policies in the health care sector for health care establishments, government bodies, sector organizations and health care insurers. The field covers all levels of the health care sector. The main topics are policy, payment, health care processes, business processes, information techniques and information products. Prismant also organizes topic-related study programmes and congresses.

Summary

Good, reliable information is extremely important in the health care sector. A national medical register (LMR) has existed in the Netherlands since 1963 for recording medical and administrative information on patients. All teaching hospitals and general hospitals participate in registration. The LMR supports hospital policy and provides specialists with an insight into their own medical actions. This is achieved by, for example, comparing data to other hospitals or firms. The LMR is also a useful source of scientific research, especially in the field of epidemiology. This has also contributed to a sharp improvement in knowledge about the health care sector and health in the Netherlands.

The LMR records all hospital admissions and day care treatment. In its present form, the register has certainly moved with the times. It has developed into a modern national database and has been expanded with other data. The LMR has links to other medical databanks and has a new appearance. Thanks to, amongst other things, developments in information and communication technology, Prismant is now working on new concepts. These are concerned with data that we no longer store physically but retrieve through a secure, electronic path from data suppliers. Put succinctly, it is a modern national register of and for the health care sector, which enables Prismant to continue to supply all the players in the field with information and analyses.

Unique registration system

Physician Dick Hoogendoorn, founder of the LMR, was one of the first to see that the health care sector could not exist without an information system that provided an insight into the effects of treatments.

| What does the LMR measure? | |
|-----------------------------------|--|
| Hospital data | establishment number, location number |
| Patient data | origin, gender, age, place of residence, referrer, method of insurance, paying authority |
| Data on hospital admission | admission number, type of health care (clinic or daytime nursing), admission date, admission time, admission department, reason for admission, urgency of admission, re-admission, origin, preventive treatment, preventive treatment provider, preventive treatment authority, preventive treatment establishment, preventive treatment type, period of responsibility, specialist with responsibility, other treatment professionals, consultants, diagnoses, treatments, treatment date, operator, co-operators, treatment establishment, treatment speciality, department, date of entering the department, time of entering the department, date of transfer / discharge / death, time of discharge, destination, destination establishment, post-mortem, follow-up care, follow-up care worker, follow-up care authority, follow-up care establishment, type of follow-up. |

Dick Hoogendoorn laid the foundations for a unique registration system. It's unique because hospitals supply data according to a fixed pattern, which Prismant then incorporates centrally into a giga databank and provides to scientists, managers and so forth, under certain conditions. Health care establishments are obliged to supply their production data to the government at the national level. This is done using this databank. There is one window where data are merged and expertise is bundled so that the correct data can be generated. This approach enables us to take a lot of work off the hands of hospitals. The construction also offers the optimum security guarantee. The privacy of patients and the reliability of establishment data are fully guaranteed. The legislation and regulations are part of the protection regime that Prismant uses.

The LMR's main objective is to provide an insight into how a hospital is operating, also in comparison with other hospitals, and to generate control information. Working in this way enables hospitals and specialists to keep up-to-date on details about deaths following operations, the results of new treatment methods and shifts in the frequency with which diseases occur in the population. There is also accountability to the community. The right information can provide an insight into the quality of the health care provided. Transparency is becoming increasingly important in the Netherlands.

Who uses the information?

All kinds of social organizations and certainly the government make thankful use of the LMR databank. The LMR plays a major role in the creation and implementation of the

Hospital Provision Act and the Health Care Charges Act. It indicates the relationship between the patient flow to a hospital, the population of a certain district and the different municipalities. This relationship is known as the 'adherent population'; this is a measure of the size of the population that a hospital serves. If the size grows, a hospital has a good market position. More people are directed towards the hospital and there is a larger patient flow. Increasing adherence provides a hospital with an argument that it has to expand. Adherence not only plays a role in planning but also in the financing system that the Health Care Charges Board (CTG) applies. Production agreements partially depend on the adherence figure. Adherence accounts for around 15% of the hospital's funding budget. It's hardly surprising therefore that hospitals still keep a close eye on the determination of the adherence figure.

Not only hospitals, specialists and the government are grateful users of LMR data. The combination of personal details, principal and secondary diagnoses, detailed descriptions of treatments and treatment professionals mean that the LMR is also a honey pot for scientific institutions, such as universities. The Central Office for Statistics (CBS) is another enthusiastic customer. They can link databases together in a technically sophisticated way to group relevant data. The LMR can be linked to all kinds of personal factors, for example. This enables a link to be established between, for example, health and social-economic status. Subject to strict conditions, Prisma recently started working with the CBS. The Ministry of Health, Welfare and Sport also use LMR data. The information provided is on the number of treatments, production figures and data at a highly aggregated level. The Advisory Service for Traffic and Transport (AVV), affiliated to the Ministry of Transport, Public Works and Water Management, uses LMR data for checking the traffic safety policy and for increasing traffic safety through proper prevention. The National Institute of Public Health and Environmental Protection (RIVM) links the LMR to data from general practitioners and outpatient departments to obtain a better picture of the chain of health care for chronic diseases. The RIVM also produces a health atlas, which is partly based on LMR data. The Dutch Heart Foundation (NHS) uses LMR data for the research it conducts into cardiovascular diseases. The Comprehensive Cancer Centre (IKC) links data to the National Cancer Register (LKR) or to Palga, a very extensive national database with data on tissue research of the Palga foundation, the nationwide network and registry of histo- and cytopathology. International bodies such as the Organisation for Economic Co-operation and Development (OECD), the World Health Organisation (WHO) and the European Commission (EC) are pleased to be able to use the flow of information.

Privacy

The sensitivity of the data has been a controversial issue right from the start of the National Medical Register. There are various reasons for this, such as the privacy of patients, the professional secrecy of specialists and the fear that hospitals have of their dirty linen being washed in public. Information systems now have to meet the requirements of a range of legislation and regulations, such as the Personal Data Protection Act, the Medical Treatment Contracts Act, medical professional secrecy, the advisory reports of the Data Protection Board (CBP) on the protection of the registration of personal data, the Information Protection Code and, soon to be introduced, the Health Care Information Protection Standard.

The privacy dilemma will continue to play a major role in the future, although modern technology means it is no longer necessary to collect data in one large database. Hospitals will probably want to manage their own data; Prisma will have a small

database with core data. The data hospitals need as control information and for policy and research purposes will then be digitally retrieved from them directly, in an extremely selective, safe and strictly authorized manner. The data exchanges will increasingly take place using the services of a *trusted third party* (TTP) that will issue key certificates to parties that exchange data. Prismant will continue to supervise measures that assure privacy and confidentiality.

Business intelligence tools

The LMR's information supply has undergone a major transformation over the past forty years. In the early days, Prismant supplied hospitals with a set of simple statistical summaries, with figures on their own hospital, supplemented with national figures and averages. Elements were gradually introduced such as the anticipated nursing period and details of patient numbers. The expansion was a direct result of the information requirements of users. The hospital managing boards and specialists wanted to know how their hospital was operating in practice, what the hospital's adherence figure was and what the relationship was between population characteristics and hospital facilities, for example.

Developments in information technology over the last fifteen years have also led to major changes in the health care sector. The use of all kinds of applications has led to rapid growth in the possibilities that are available and there has been an enormous increase in efficiency in registration and data access. The old information infrastructure, with hospitals as peripheral measuring stations and Prismant as the central hub is becoming increasingly less important. Using data entry and processing programs, hospitals can control and manipulate their own data to produce useful packages of information. This considerably lightens the hospital's administrative workload and provides greater freedom of action.

Flexible *business intelligence tools* enable required analyses to be made immediately on the basis of new data. Prismant also provides a hospital with the possibility of passing on information about its own market and production to other hospitals. We are currently working on a new line of *web-enabled* information products under the name 'Prisma'. Prisma makes rapid data exchanges possible on the Internet via secure *portals*. Prismant also provides hospitals with text files and interactive 'information cubes', so hospitals can derive even greater and faster benefit from the information that is available.

Transmural comprehensive health care information

There is probably no social field that will change as much as the health care sector in the coming years. The centrally directed health care system will make way for a decentral system, in which health care insurers hold the reins. Rather than supply, it will be demand and market forces that drive the sector. The patient (the customer) must be the ultimate beneficiary of this. Legislation and regulations will be made more flexible but will also set binding requirements for the quality and availability of health care. Free enterprise in health care has to be open and transparent, may be public and private, and should not be limited by the 'walls' that divided the health care sector for decades. Increasingly more widely differentiated types of health care will arise that offer transmural continuity and quality. All actors in the health care field will have to think carefully about their future position and role in this.

This upheaval presents policy makers and managers with an enormous challenge. Old, trusted policy mechanisms will prove inadequate for solving new administrative problems. Moreover, the administrative problems will involve information technology issues. Internally the issue will concern linking operational and intrinsic health care data. Externally, it will concern linking information from many sources, so that the chain of health care is possible throughout the entire health care sector. We therefore speak of solution-based, accessible and reliable information. It also makes no difference which data register is used; the focus is on solutions. By way of analogy, we could say that it's not the make of car that's important but having adequate transport from A to B. This demands a much broader outlook on the information supply in the health care sector.

Virtual information traffic controller

In the future, Prismant will no longer collect information on a large scale and physically store it in national databases. The traditional information infrastructure will make way for a virtual structure. Data registration will take place almost exclusively at the source, where health care is provided. The adage is: once-only registration for various purposes. Prismant will extract the required data for policy, control and research in a safe and fully authorized manner from the various local sources. The administrative workload for the establishments will also be kept to the minimum. The change is expected to take place over the next ten years. The pace depends on technology, the quantitative and qualitative aspects of databases, proper management and political influences.

Until recently, 'registration' and 'management' were thought of in fairly traditional terms, also at Prismant. Partly because of the effect of the Personal Data Protection Act, operations are concerned with 'processing' personal data. Prismant's task will therefore shift in the future from that of manager to that of 'data flow traffic controller': i.e. matching demand to the supply of information. Thanks to its broad experience and expertise, the availability of consultants and researchers, and built-in safety mechanisms, Prismant is pre-eminently suited for this work. In practice, 'data flow traffic controller' means that Prismant aims to become *the* organization when it comes to the national information supply in the health sector. In due course, this will require having access to all the data needed for tasks such as producing measurement and control information for policy and management, quality and efficiency improvements, scientific research and national statistics. Prismant focuses on its own information production, on generating information in co-operation with other parties, providing data and facilitating the use of data by other parties.

Besides the need for statutory anchoring, the safe extraction, dissemination and exchange of information are an absolute necessity. Here 'safe' means digital message traffic in a 'controlling' network, in which there is no doubt whatsoever about the identity of the sender and recipient, the originality of the messages is assured, there is no possibility of the message being intercepted or of this anyway being worthwhile, owing to the use of encryption technology, and in which the privacy and confidentiality of the message are assured. This safety will be covered in the organizational and technical sense by *Trusted Third Party* services and routing.

In due course, the legal and organizational separation of the public and private law tasks would seem an obvious move. Under strict supervision, some of the data will be used for the public domain. This will also be designated as Prismant's 'general utility function'. It means that (statutorily designated) data will be available via Prismant for generating relevant control information for various parties in the health care sector, such as sector

organizations, scientific associations, government bodies, advisory bodies, insurers, etc. To enable data to be used for advice and research purposes (Prismant's private function), it will be necessary to regulate the 'permeability' of the data between the public and private function in both the organizational (management) and technical sense. One of the challenges that Prismant sees itself facing over the next few years is to improve the information supply to patients. For example, how can information on hospitals be grouped so that patients are really able to make proper choices?

That information supply is currently still a lucky dip into frequently ambiguous data. Patients can draw on the following information sources. There is an Elsevier questionnaire and a study by the Consumers' Association. A daily newspaper has a waiting list site. The Association of Hospitals in the Netherlands (NVZ) displays a waiting list on the Internet. The Heart Foundation uses waiting list data and it is possible to view the annual accounts 'on line' of health care establishments at the Prismant site. Most data and manipulated data consist of data that cannot be currently accessed by the public at organizations such as Prismant, the Central Bureau for Statistics, the National Institute of Public Health and Environmental Protection (RIVM), the Netherlands Institute of Primary Health Care (NIVEL), the Association of Dutch Patients/Consumers Federation (NPCF) and at health care insurers and scientific associations. It would be wonderful if all the information patients require to make a considered choice could be made available in a conveniently grouped and accessible form. Prismant would like to play a leading role in achieving this.

According to mathematicians, 'most people use statistics the way a drunk uses a lamp-post, more for support than enlightenment'. Prismant will avoid making the same mistake. It knows every nook and cranny of the health care sector. It can clarify and provide an insight into problems; thanks to its prominent role as the main health care information centre, it provides practical solutions for various parties. The information link, the concept of comprehensive health care information, will enable the health care sector to see what the actual situation is, so that policymakers and managers will be able to tackle new developments and challenges dynamically. The right information makes it possible to offer an insight into the quality of health care, a subject that is becoming increasingly important in the Netherlands.

Health Information Management

Fons Blankendaal
Netherlands



Prismant

- Health research, consultancy and information
- More than 50 registrations
- Most well known is the Dutch Medical Registrations
 - Hospital admissions
 - Since 1963



Organization

- 250 people
- 80 people for registrations
- 15 people for all hospital registrations (DMR, waiting lists; ambulatory care; FONA)
 - Medical doctor
 - Classification specialists
 - Registration workers
 - Information/DWH specialists
- 'Raad van Toezicht' / 'privacy commissie' / 'handvestcommissie'
 -



Partners

- Ministry: legal basis on part of all data
 - user
- NVZ/VAZ: organizations of hospitals
 - User
 - Sometimes also contractpartner/responsible
- Hospitals:
 - User
 - 'owner of data'
- Medical doctors
 - User
 - 'owner of data'
- Statistical office
 - User (law on statistics)
- Control agency (CBP)
 - Law on privacy protection
- A lot of other users (science, prevention, EU, WHO)



Legislations

Law on privacy protection
Law on hospitals
Law on statistics

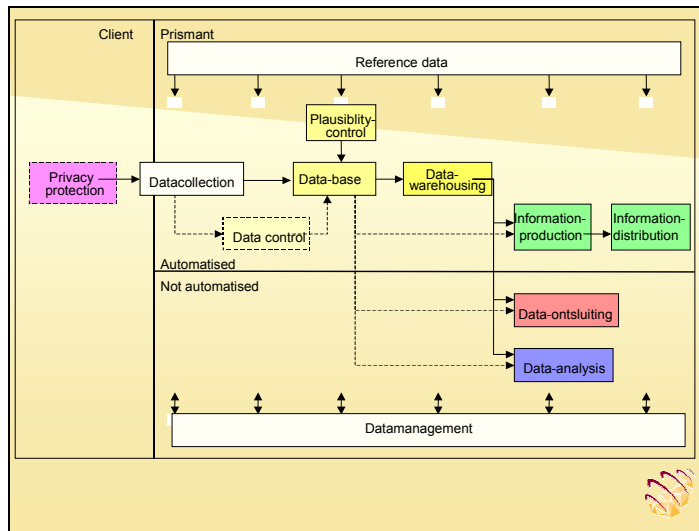
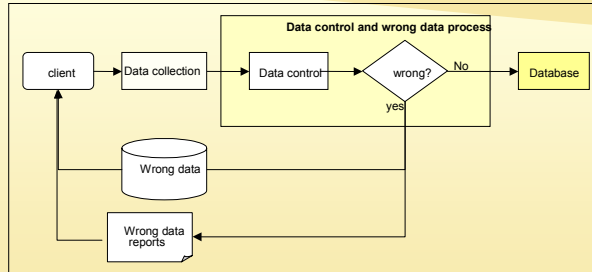


Finance

- Hospitals pay per record
- No money from government



Collection process



Quality

- classification/registration courses
- Service desk
- News letters
- Regional and national working groups
- Continuous update of reference data
- Extensive automatised control program
- Local application with all control loops
- Automized control mechanisms on information products
- ITIL procedures (change and incident management)
- ISO



SWOT

Strength

- International comparable
- Great quality of data
- Independent
- Reliable
- Linking data
- CBS-RIVM-Prismant

Weaknesses

- Only diagnosis data for admissions and daycare
- Quality procedures may be improved
- Differences between registrations



SWOT

Opportunities

- DBC: case mix system

Threats

- DBC: case mix system



This report was produced by a contractor for Health & Consumer Protection Directorate General and represents the views of the contractor or author. These views have not been adopted or in any way approved by the Commission and do not necessarily represent the view of the Commission or the Directorate General for Health and Consumer Protection. The European Commission does not guarantee the accuracy of the data included in this study, nor does it accept responsibility for any use made thereof.