eHealth in the Netherlands

Policies, developments and status of cross-enterprise information exchange in Dutch healthcare

Nictiz

Better care thanks to better information
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Introduction

After years of preparation and the taking effect of the “Use of Citizen Service Number in Healthcare Act”, the go-ahead for the national implementation of the Electronic Health Record (EPD in Dutch abbreviation) in the Netherlands is expected to be given on 1 September 2008. The first nationwide information exchange to take place with the EPD involves dispensed medication information (Mg) and a patient summary for general practitioner locum tenancy services (Hwg). Other relevant information flows will be added in the coming years.

This document was drawn up by Nictiz, the national IT institute for healthcare in the Netherlands, in consultation with the Ministry of Health, Welfare and Sport (VWS) in response to requests by the House of Representatives and the so-called IT & Innovation Platform. It provides insight into the EPD and IT agendas for the coming years, including priorities and milestones. It is intended as a supplement to more detailed progress reports (in Dutch) by the Ministry of Health, Welfare and Sport submitted to the House of Representatives.
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1 National Program Results

The Dutch national healthcare system is undergoing major changes. The ageing of the population places greater demands on the healthcare system. While new medical knowledge and possibilities are being developed rapidly, care providers are collaborating more often in multidisciplinary projects and patients are becoming more and more outspoken as consumers of healthcare services. These and other changes prompt innovations. Innovations in care processes take place at the point of care and cannot be controlled top-down. It is essential to create preconditions that stimulate desirable innovations. In addition to appropriate legislation and regulations, as well as good financing options, suitable IT facilities are also often a precondition. A national program has therefore been developed for IT use in the healthcare sector. This chapter presents the results of this program to date.

1.1 Electronic Health Record

A national Electronic Health Record (EPD) and nationwide basic IT infrastructure for the healthcare sector have been developed in the Netherlands in response to the above developments.

The EPD is a collective term for IT applications to be used to support the provision of care, prevention, medical research and care logistics services. Patient information is not stored in a national database, but care providers can request relevant information from the information systems of other care providers. This is a safer option and enables care providers to continue working with their own specific information systems.

The basic infrastructure encompasses all standards, agreements and national infrastructural facilities that make this electronic health information exchange
To ensure communication safety and reliability, a trust model has also been developed for the national EPD, a system of legislation and regulations, information security, public relations and supervision. This system controls and monitors who is able and permitted to access which information and when.

To ensure that the information systems for the various care providers can exchange information, the technology and content of the information to be exchanged must be standardized. The implementation of the EPD also has an impact on healthcare policy and the organization of care processes. The Ministry of Health, Welfare and Sport, Central Information Unit on Healthcare Professions (CIBG), Nictiz and numerous other parties have worked in recent years on improving and implementing the EPD. Since this is a complex process, the EPD is being implemented in phases. The first step is obtaining the most relevant information: dispensed medication information and a patient summary for general practitioner locum tenency services. The infrastructure for this information exchange is already in place, pilot studies are being carried out in a number of regions and planning agreements for implementation have been made with 32 regions.

### 1.2 State of affairs in 2008

What is the state of affairs in 2008? The national infrastructure and standards for the dispensed medication information and the patient summary for general practitioner locum tenency services have been developed and the implementation of both has begun, on small scale as yet (Information Counter). A growing number of care providers and suppliers are qualified for connection to the national switch point (LSP) and the EPD is being developed further with other information exchanges, such as for emergency medical care, sharing laboratory test results and diabetes care. Chapters two and three cover these developments in detail.
1.3 Legislation

Two new laws affect the national implementation of the EPD: the “Use of Citizen Service Number in Healthcare Act” and the “Electronic Health Record Act”.

The use of the citizen service number (BSN, in Dutch abbreviation) in the healthcare sector is regulated by a supplementary law to the “General Provisions on Citizen Service Number Act”, a legislative proposal adopted on October 10, 2006 by the House of Representatives and on April 8, 2008 by the Senate.

The Electronic Health Record Act guarantees that all care providers can be connected to the national switch point and that their health records are available to other care providers. It also guarantees the privacy and protection of the information. This act is scheduled to be implemented in 2009.

This new legislation, together with existing legislation like the Personal Data Protection Act, Medical Treatment Contracts Act, Individual Healthcare Professions Act and Care Institutions Quality Act, largely forms the necessary framework for national electronic communication.
2 Developments

Numerous developments are taking place in the field of IT and innovation in healthcare. IT suppliers are becoming more and more adept at meeting the needs of innovative care providers. Regional collaborations often play a pioneering role when it comes to the innovation of multi-agency care processes. National developments contribute to this in two ways: the necessary standards for product innovation and cross-enterprise collaboration are under development and the necessary preconditions for a broad implementation of successful innovations is being created.

2.1 Healthcare and the IT market

There is considerable activity taking place on both the demand and supply side of the market for IT solutions in healthcare. The market constitution could be improved significantly, however. Care providers are often unable to find a product that fully meets their needs. Likewise, suppliers often struggle with selling their innovative products. A core problem is interoperability. It must be possible to easily link systems to the systems of both the same and of other care providers, but this is often not possible. For lack of a better option, less interoperable systems are often used, leaving users with a legacy problem.

Standardization on various levels with regard to process, communication and semantics can help resolve this issue. Care provider organizations must take up the matter of formulating joint requirements for IT products, so that suppliers are less confronted with individual requirements. A good example of this is the model for GP
information systems from the Dutch Association of General Practitioners (NHG, in Dutch abbreviation). On the level of “harder” technology, it is primarily up to suppliers to resolve the interoperability issue. Cooperation between suppliers within HL7 (global authority on standards) and IHE (global initiative by healthcare professionals and industry) is a good example of this. In areas where international standards already have been developed, such as in radiology, international suppliers are also active in the Dutch market. In other areas, however, it is primarily smaller niche players who are active.

The introduction of the national basic infrastructure (AORTA) and the phased introduction of the national Electronic Health Record promote standardization. More than twenty IT suppliers have already been qualified and can deliver products that are nationally interoperable for the dispensed medication overview and the general practitioner’s patient summary.

2.2 Regional developments

Many forms of healthcare take place either partly or entirely on a local or regional level. This has led to innovative IT solutions. Good examples are the communication facilities between GPs and pharmacists in local so-called OZIS clusters, as well as on the OZIS standards-based local GP on-call system. In addition, GP laboratories and hospitals are able to exchange electronic messages with GPs. These communication options, where used, has resulted in considerable improvements in quality and efficiency of care.

Regional collaboration organizations have been formed at various locations to scale up these developments on a regional basis and to facilitate further innovations. These regional initiatives are primarily collaborations between care
providers, health insurers, IT companies and local governments, and feature a practical approach, innovation capability and implementation strength. A number of frontrunners among the regions have already taken the initiative to implement the national applications. Regional collaborations are also acting increasingly as sounding boards and as a “condensation core” for new national developments and as an instigator/innovator of applications that are not (yet) on the national agenda. The agendas of these regional collaborations include a wide variety of programs, not only national issues like the implementation of Mg/Hwg, referral and transfer of first, second and third line care, emergency medical care, lab access and portals, but also issues like applications for multidisciplinary care (CVA, diabetes, COPD, etc.) and telemonitoring, teleconsultation and telecardiology.

Innovative regions have demonstrated the possibility to migrate regionally applied technology to national standards in a responsible manner (i.e. without functional loss). This is necessary since the various regional facilities are not interoperable and do not meet the security requirements of the Data Protection Authority (CBP, in Dutch abbreviation). In addition, the regional initiatives together do not have national coverage and patients often have care providers in different regions. Interoperability between the regions is therefore necessary to ensure information completeness.

2.3 National programs

A governance model has been implemented for the national developments for the purposes of agenda setting, decision-making and implementation monitoring. It consists of an IT & Innovation Platform and Steering Committee. The IT & Innovation Platform is responsible for the coordination and agenda preparation for the national IT and EPD processes, and the IT & Innovation Steering Committee is responsible for the decision-making process and supervision of the national IT and EPD processes. The
Steering Committee has also commissioned Nictiz to coordinate the development of the programs.

The umbrella organizations in healthcare and other parties have put a large number of projects on the national agenda through the Platform over the past two years. Thus, programs have been initialized in addition to the medication record and GP patient observation record programs, programs that represent the priorities and interests of the field and that meet the following criteria for national programs:

- Focus on healthcare innovation: Is the focal point on care or on IT?
- Social necessity: Is there a business case?
- Commitment: Are all stakeholders involved and do they demonstrate commitment?
- National approach: Why is the sector itself unable to accomplish this? Is it a question of market/system failure?
- Time horizon: Can concrete national results be achieved within five years?

Some of the programs are already under development, whereas others are undergoing an exploration and pre-development phase. These programs are discussed in Chapter 3.

In addition to the IT & Innovation steering committee programs, there are several other national IT initiatives in healthcare in progress, which are supporting programs. This includes initiatives linking up medical and technological innovations to the healthcare sector and future healthcare needs: String of Pearls Initiative (PI), Netherlands IT Research and Innovation Authority (ICTRegie) and the Social Sectors & IT action program (M&ICT). A number of programs from the Dutch National Institute for Public Health and the Environment (RIVM) and Netherlands
Organization for Health Research and Development (ZonMW) have an affiliation with the Steering Committee programs Diabetes Sequenced Care, IT and COPD, Disease Management and Ambient Environments for Healthcare and the Diagnose Treatment Combination (DBC) Improvement Plan. Convergence with the steering committee IT & Innovation programs is actively pursued. Affiliation with the national standards as developed by Nictiz is a necessary condition for scaling up these programs.

2.4 International developments

The Netherlands is not an IT island. International developments must not only be followed but also adjusted in order to ensure optimum integration. Large-scale e-health and EPD programs are also being implemented in surrounding and other countries, a current overview of which is provided in the ERA eHealth and EHTEL reports. The approaches used in other countries differ widely, although it should be noted that, as in the Netherlands, most countries have opted for an exchange of medication data (support of the chain prescribe → check → dispense → inform) and patient summaries for the support of locum tenency services for general practitioners.

On a European scale, it is becoming increasingly important to reach agreement among the countries of the European Union regarding the manner of communication between the countries. Twelve European countries have decided to set up an international pilot to investigate the impediments to and possibilities of transnational (“cross-border”) communication of medical information. The EU supports this initiative, entitled “European Patients, Smart Open Services” (epSOS). Transnational communication is highly relevant for citizens in the border regions and also for traveling citizens.
(on vacation or business trip). The Netherlands is participating in this study into the interoperability of transnational eHealth services (particularly, again, medication information and patient summary) through Nictiz and the Ministry of Health, Welfare and Sport.

The Netherlands is also affiliated with the most important international standardization organizations and initiatives (ISO, HL7, CEN, IHE, etc.). Dutch developments in the area of, for example, HL7 and the G standards (pharmaceutical) contribute actively towards managing international standards. International standards are applied in the Dutch programs where possible. The country also actively contributes to harmonization of the various initiatives and standards.

The Netherlands recently joined the IHTSDO (International Health Terminology Standards Development Organization) for a period of five years. The IHTSDO owns the SNOMED CT (Systematized Nomenclature in Medicine – Clinical Terms) specification since 2007. This membership of IHTSDO makes it possible to determine the applicability and usefulness of SNOMED CT as a terminology standard in the Netherlands, while at the same time contributing to its further development. Dutch companies and healthcare facilities can gain experience with this terminology standard in this manner. The use of SNOMED CT in message exchanges results in a more uniform interpretation and can be used for cross-border information exchange, of particular importance in border regions.
3 Agenda

The EPD is not a monolithic and comprehensive system that can be developed and implemented all at once. The basic infrastructure and initial data exchange (Mg and Hwg) have already been completed and are ready for broad implementation. Additional applications/information exchanges are also achieved in different programs that together are referred to as the “EPD”. This chapter describes the relationship between the national programs expected to be carried out between the years of 2008 and 2013, the governance model used and the priorities and milestones within the project portfolio.

3.1 Governance model

The EPD requires both a bottom-up and top-down approach. Applications must fit well with daily care processes and utilize the opportunities for improvement identified in practice. Likewise, complex problems involving standards, for example, must be resolved using binding results for the entire sector. Due to the numerous interests involved, teamwork is not always easy. The governance model is intended to prevent “ivory tower solutions” from being imposed as well as to prevent lengthy debates from thwarting the progress. The Minister of Health, Welfare and Sport has informed the House of Representatives about this model, which is used for agenda setting, decision-making and implementation monitoring, and consists of the IT & Innovation Platform and Steering Committee.

• IT & Innovation Platform

Coordination and agenda preparation for EPD and IT processes. Participation by around 25 umbrella and sector organizations under independent chairmanship.
• **IT & Innovation Steering Committee**

Decision making and progress monitoring of current national EPD and IT processes under the chairmanship of the Ministry of Health, Welfare and Sport. Participation (second quarter of 2008) by umbrella and sector organizations: NPCF (patients), NVZ (hospitals), KNMP (pharmacists), KNMG (medical association), Orde (medical specialists), ZN (insurance companies), NFU (university medical centers), LHV (GP’s), NHG (GP’s), Nictiz (national IT institute for healthcare).

Once a program is approved, Nictiz organizes the program management and implementation. Each program is assigned a Program Advisory Committee (PAC) that acts as the sounding board for program management with regard to content. The most important stakeholders serve on this committee. In some instances, the parties are asked to explicitly confirm their commitment in an agreement or manifest.

There are five iterative phases to the programs:

• **Awareness**

Identifying needs, researching necessity, feasibility and advantages of a proposed solution and formulating a project proposal to be evaluated in the Platform.

• **Decision preparation**

Determining the scope and requirements, global concept and design, costs and risks of the proposed solution, organizing and assigning roles to parties involved and formulating a master plan for the follow-up phases.

• **Design and validation**

Design in accordance with the national architecture of the basic infrastructure and the necessary technical standards and testing and validation with suppliers and users.
• **Construction, implementation and testing**

  Implementation and testing in specific user environments and formulating implementation guides and resources for national scaling-up.

• **Implementation**

  Wide national rollout for care parties and start-up as part of regular care process.

Most of the programs have a duration of several years and feature explicit decision-making moments at the transition to a subsequent phase (such as from design to construction or from construction to implementation). The enclosure contains an overview of the program phases for the current programs.

In addition to the joint responsibility for directing and monitoring the national agenda, the parties also have specific responsibilities:

• Umbrella organizations are responsible for the professional IT use in their professional group and the necessary care standards, information standards, and guidelines.

• Healthcare insurers are responsible for implementation by referring to the appropriate care standards when contracting and financing care.

• Care providers are responsible for incorporating the standards into their working methods and care provision and purchasing only qualified systems from their suppliers.

• IT companies are responsible for implementing the national standards and incorporating the specifications into their systems, products and services.

• Nictiz is responsible for implementable specifications and providing adequate service with regard to the national information infrastructure.

• Regional collaborations are responsible for the integral implementation of or migration to systems and solutions that comply with the national standards.

• Standardization organizations are responsible for developing relevant standards that are compliant with the national infrastructure.
3.2 Composition of national program

Although it is not possible to develop an overall blueprint for the development of the EPD, the modular approach of various programs offers sufficient possibilities to safeguard coherent development. The programs can be roughly categorized as follows:

- Infrastructure and standards programs
- Basic EPD programs
- Multidisciplinary care, disease management and prevention programs

The “Patient and EPD” concept also serves as an umbrella theme that pertains to every category.
Complete interoperability between information systems connected to the national EPD requires standards for:

• Processes (procedures, guidelines)
• Communication (messages, reports, overviews, etc.)
• Language (structure, terminology, code systems)

The same standards apply in similar areas within the various programs. International standards are used where possible. Nictiz monitors the architecture of information exchange developed in the programs, thereby ensuring coherence and interoperability. Registered data such as medication information often plays a role within different care processes. This information is registered once only and can be used repeatedly. The data set required for professional summaries by GPs is approximately the same as the set needed for emergency care.

Important communication standards are defined in the basic infrastructure:

• Use of citizen service number
• Use of UZI card
  (UZI is the Dutch abbreviation for Unique Healthcare Provider Identification)
• Technology and rules for national switch point
• Requirements to the local systems to be connected to the national infrastructure

The infrastructure and standards category also includes such general standardization programs as SNOMED CT (uniformity of language) and Cliq (Classification of Medical Devices).
3.3 Priorities

The following priorities apply to the implementation of the national EPD:

1. National implementation of basic infrastructure, dispensed medication information (Mg) and GP locum tenency data (Hwg).

2. Patient and EPD

3. Expanded Basic EPD

4. Multidisciplinary care, disease management and prevention

5. Other programs

This section explains the programs carried out as part of these priorities.

3.3.1 National implementation of basic infrastructure, dispensed medication information and GP locum tenency data

The go-ahead for the national implementation of the dispensed medication information and GP locum tenency data is expected to be given on 1 September 2008. This implementation involves the use of the Citizen Service Number (BSN) and UZI card and connection to the national switch point of GP practices, locum tenency service clinics, pharmacies and hospitals. After years of preparation work, top priority is being given to national implementation. The EMD Plus program is being carried out parallel to this implementation and provides additional data exchange for reasons of medication safety. The first components (information on intolerances, contra-indications and allergies) will be available during national implementation.
EMD Plus Program

IT can be used to improve the quality and effectiveness of the processes of prescribing, dispensing and administering of medications. The EMD Plus Program aims to develop national standards to this end. The standard for dispensed medication has already been developed, making it possible for care providers to see electronically which medications have been dispensed to a patient in the past. The possibilities of this approach are being expanded as part of the EMD Plus Program. Care providers will have more relevant information at their disposal, such as on allergies and illnesses, in order to make sure they are prescribing and dispensing the right medications to patients. Another possibility is the use of a legally valid signature when prescribing medication electronically, eliminating the need to send a paper signature. Patients will also be able to request repeat dispenses from prescriptions digitally more easily and the handling of repeat prescriptions will be more efficiently organized for care providers.

3.3.2 Patient and EPD

Most IT systems in the healthcare sector are currently designed for and used by care providers. In a number of situations however, it is important that the patients have direct electronic access to the EPD. Access to the national switch point gives the patient the possibility to monitor the exchange of his or her information between care providers connected to the national switch point. Access to the relevant components of the Basic EPD and systems for disease management makes it possible for patients to take responsibility for their own self-care in a well-informed manner. Four programs contribute to supporting this priority: Information Counter, Patient Access, Patient Portal and Telecare. The Information Counter program was mentioned in section 1.2, while the other programs are described below.
Patient Access Program

The Patient Access Program makes it possible for patients to view their own medical records. Access to the Electronic Health Record allows patients to take more responsibility for their own health. Since privacy is absolutely essential, high demands are placed on the safe exchange of medical data. Access to the EPD allows patients to check which information is registered on them, which care providers can access the information and who has viewed which information and when. Patients can also object to having their information accessible to others and have their information shielded from (certain or all) care providers. In the future, patients will be able to regulate access to their information, electronically if possible, but should be well-informed by their care provider about the risks of preventing access to information. In addition, patients will be able to put together a self-care record that contains important information for care providers. A diabetes patient, for example, can submit blood sugar values to care providers electronically.

Patient Portal Program

Citizens who are sick or disabled need information on their medical history, illness and healthcare options. This knowledge and the possibility to interact with expert advisers and patient communities will enable patients to better care for themselves, also making visits to care providers more efficient. Citizens who are not sick or are disabled may be interested in obtaining advice on staying healthy. A considerable amount of healthcare knowledge, information and interaction options are already available. What is lacking, however, is an integral, comprehensive and user-friendly system of options tailored to the individual needs of citizens. The solution is an online “patient portal”. This portal will be created initially by the NPCF (Federation of Patients and Consumer Organizations in the Netherlands).
Telecare Program

Telecare opens up new possibilities for the care and quality of life of chronically ill individuals, the disabled and the elderly. It means that, more so than in the past, care can be brought to patients using IT instead of the other way around. Examples of telecare are home care using webcams and teledermatology. The integration of remote care into regular healthcare services for clients requires quality and usability criteria in order to develop, assess and select electronic care services. It also requires an accessible infrastructure across which clients can buy all necessary services, standards for remote care equipment and remote care protocols, in order to facilitate the coordination of the processes of various facilities and care providers. The Telecare Program is aimed at developing these preconditions.
3.3.3 Expansion of Basic EPD

The expanded Basic EPD entails the registration of patient information at a single location (the source), but which can be requested from elsewhere. A standard data set is defined per source/requester combination that must be available in specific situations. Mg and Hwg are examples of programs that make this information exchange possible. The figure below provides a schematic overview of the necessary information exchanges within and between “cure” and “care”, which together make up the Basic EPD.

Overview of expanded Basic EPD

Legend “Overview of progress of Basic EPD programs”

- Programs ready for national rollout
- Programs under development
- Information exchange not yet incorporated into program
- No information exchange possible within Basic EPD
A considerable number of programs must be carried out in order to develop the Basic EPD. These are Mg/EMD Plus, Hwg, e-Emergency, e-Lab, e-Pathology, e-Paramedics, Care ECD (ECD is the Dutch abbreviation for Electronic Client Record), e-Transfer, e-Radiology, e-GGZ (GGZ is the Dutch abbreviation for mental healthcare services), e-Specialist, e-Diabetes, Patient Access and Telecare. The programs on which the Basic EPD is based are detailed below, with the exception of those programs that were discussed above and the e-Diabetes Program, which is covered in the next section. A major design assumption is, that information that can be used for several processes only needs to be registered once.

**e-Emergency Program**

Approximately 900,000 visits are made to hospital emergency rooms each year in the Netherlands. Due to a lack of medical information, additional tests and treatments take place unnecessarily, the costs of which are estimated to be more than 36 million euros every year. This was the result of the “Spoed moet goed” (Quality of Emergency Care) study conducted in 2005 by the Dutch research company TNS NIPO on behalf of the Federation of Patients and Consumer Organisations in the Netherlands. The use of IT can improve the provision of information for emergency care. The e-Emergency Program aims to develop national standards to this end.

Emergency healthcare involves large numbers of care providers, including GPs, nurses, ambulance staff, emergency room physicians and emergency call center staff. The applications of the e-Emergency Program will enable care providers to quickly and efficiently inform one another about a patient in acute medical situations. The relevant patient records from the patient’s regular GP will also be available. This will allow care providers to provide better quality care and prevent duplicate testing. Moreover there will be important safety effects by the timely
knowledge of allergies, chronic conditions, recent or current illnesses. Ninety percent of care providers and patients surveyed as part of the “Spoed moet goed” study recognized the advantages of the electronic availability of basic medical information in emergency care.

**e-Lab Program**

There are around 450 medical laboratories in the Netherlands, which cover twelve different fields of study, including clinical chemistry, medical microbiology, pathology and hematology. Around three-quarters of all medical decisions are made partly based on lab results. That is why effective accessibility to lab results is so important. The use of IT can improve the availability of lab data for various forms of care. The e-Lab Program aims to develop national standards for this purpose. The program also aims to improve the process for requesting lab test results.

In the future, e-Lab applications will enable care providers, such as GPs, specialists, nursing home physicians and pharmacists, to access relevant lab data at any given time. Easy access to this information is not only important for making diagnoses, but also for medication monitoring, pathology research and infection detection. Providing access to a patient’s lab result history also prevents patients from having to undergo tests more than once unnecessarily.
e-Pathology Program

There are 65 pathology laboratories in the Netherlands, all of which are affiliated with the PALGA, Pathological Anatomy National Automated Archive, foundation. PALGA manages a national database containing all pathology results and a computer network for data exchange with all laboratories. This data exchange is aimed at direct patient care, scientific research and education, medical quality control support and for supporting information exchanges for mass screening.

The current central database provides access to summaries only. A connection to the national infrastructure will make it possible in the future to make more information from the database available and make it possible to exchange information with other disciplines electronically through the national switch point.

e-Paramedics Program

The occupational group of paramedics forms an essential part of the care chain, both preventatively and curatively. There are approximately 40,000 professionals working in the paramedical sector. After physicians and nurses, they are the third largest group of healthcare professionals and include dieticians, physical therapists and speech therapists.

Until now, paramedical professionals were only limitedly involved in the national programs for IT development. That is why the decision was made to launch a program specifically for this sector, so that paramedical professionals could also be connected to the national EPD and relevant infrastructure. This results in the development of more effective care chains in which qualitative advantages can be achieved structurally. It should be emphasized here that the kind of information of specific importance to paramedical personnel is being standardized carefully. Other patient information will not be accessible.
The participation of various paramedical professions in a single program enables the parties to benefit from one another’s knowledge and experience. As a result, the relatively small group of paramedical professionals can also participate in and be connected to the national electronic data exchange.

**e-Perinatology Program**

Obstetrics and newborn care are care components whose quality is subjected to extremely high social interest. Apart from the distress resulting from a poor start to life or perinatal death, there are also social and economic consequences involved. The need for care involved in childbirth has been leaving its mark on the nature and scope of the care provided for many years. Improving the quality of birth-related care is therefore almost immediately cost-effective and can be expressed in “quality-adjusted life years”. The prenatal screening program for Down’s Syndrome/Structural Ultrasound Screening launched on 1 January 2008 and the soon-to-be-launched national Perinatal Audit are the results of this program. The e-Perinatology Program is aimed at improving care for pregnant women and children (unborn and newborn) using an effective electronic exchange of information.

**Care ECD Program**

Organizations in the care sector (nursing homes, home care organizations, etc) aim to coordinate various forms of care from the client perspective using a virtual national Electronic Health Record database. There is currently an information exchange and infrastructure between physicians, nurses, clients and policymakers for existing services. The Care ECD Program aims to achieve an unambiguous, automated information exchange between “cure” (hospital, mental health practitioners, GPs, pharmacists) and “care” (disabled care, elderly care, long-term mental healthcare) on the one hand, and between care organizations mutually on the other hand.
e-Transfer Program

Healthcare and emergency medical care processes usually involve multiple facilities and disciplines. Physicians and nurses at different facilities use their own patient information and register it in their own systems for their own services and registration purposes.

Data registration from other institutions is not sufficiently utilized since it is often inaccessible or unusable. This is in spite of the fact that more and more facilities are involved in sequenced care services within the healthcare industry. Continuity and the coordination of patient care or services between facilities also require effective transfers. This concerns the transfer of patients or clients within professional groups, between professional groups and between departments and care organizations both within and outside of the “cure” and “care” sectors. The e-Transfer program is aimed at facilitating the process of patient transfer in order to increase the efficiency and effectiveness of the care provided. An e-Transfer message is used to transfer information on the care process (possible within a few years through the national switch point) as part of the information exchange between the “cure” and “care” sector and within the care sector itself.

e-Radiology Program

Approximately ten million radiological procedures are carried out each year in the Netherlands, primarily in hospitals. In recent years, image acquisition machines (X-ray, MRI, ultrasound, etc.) have become increasingly more digitalized and care facilities have obtained digital systems for image storage and distribution within facilities. In hospitals, this has resulted in a considerable reduction in the often complicated logistics involved with the sharing of X-ray film-files. In a number of situations, however, radiological tests (image and report) are also required in facilities other than the one in which the test was taken. This concerns situations
in which patients are referred to specialists in fields of discipline not available in the hospital concerned (such as radiotherapy, cardio surgery, neurosurgery), for requesting second opinions and for consultations. At present, prints are often made on X-ray film or, more commonly, the images are burned onto CD-ROMs. These CD-ROMS are then given to the patient to take with them or sent directly to the specialist. The receiving hospital must then attempt to read the CD-ROM files, which is often problematic. The electronic communication of digital images could put an end to such problems. The e-Radiology Program aims to develop the architecture and standards to achieve this, insofar as they do not already exist.

**e-GGZ Program**

Approximately 400,000 persons are referred to mental healthcare services (GGZ) every year, the majority of whom are referred by their GP, though other first-line care providers, such as independent psychologists, also make referrals. Mental healthcare facilities provide feedback to first-line care providers in the form of discharge certificates or, with ongoing chronic problems, annual progress reports. These forms of communication primarily take place on paper. GPs have access to GP information systems only and mental healthcare facilities use their own Electronic Health Records. Communication by paper means that information must be retyped in order to be entered into information systems. This not only results in errors, but is also highly time-consuming. The e-GGZ Program changes this situation by making electronic communication possible for referrals, discharges and progress reports. Due to the size of mental healthcare facilities, which usually cover more than one region, a national electronic communication system is a necessity.
**e-Specialist Program**

Medical specialists are turning more and more to the use of Electronic Health Records. But, as a professional group, they still lag behind GPs and pharmacists in this respect. Electronic information exchange between specialists and care providers outside of hospitals only takes place on a limited basis at present. Medical specialists are therefore still a blank page in the Basic EPD. Specialists who decide to work with Electronic Health Records often need to determine the structure of their own system. A lack of uniformity leads to limitations in the transferability of the information. Moreover, it is often difficult for the average specialist to assess whether the system purchased by the hospital complies with his or her professional requirements. e-Specialist is the working title of a program that aims to ensure a uniform electronic record structure for every specialty. The goal is to achieve standards that honor the differences between the various specialties, but combine into one framework all specialty care information, and the exchange with important other partners, such as the GP.

**Electronic Record for Child Healthcare Program**

An adequate provision of information is a necessary precondition for ensuring good integral child healthcare. An Electronic Record for Child Healthcare (Dutch abbreviation: DD JGZ) provides both care professionals and policymakers with better insight into the development and care needs of young people in the Netherlands. An Electronic Record for Child Healthcare enhances the information exchange between various facilities, thereby facilitating the identification of problems and rapid implementation of improvements in the development chain for young people. The computerization of child records allows care providers to register information on the child in accordance with the JGZ standard basic data set, making it possible to quickly and easily exchange information on the child within the child healthcare system and ensuring that safety requirements are observed and that correct,
complete and up-to-date information on the child is available. This program is being carried out under the responsibility of the Minister for Youth and Families.

3.3.4 Multidisciplinary care, disease management and prevention

Some new forms of care are not possible without IT. Examples are multidisciplinary care and sequenced healthcare. It is precisely these new forms of care that are often urgently needed from a viewpoint of quality, safety and efficiency. The standardized IT support for diabetes care can serve as a model for other future applications in this area, such as CVA (Cerebro-Vascular Accident) care and chronic conditions like COPD (Chronic Obstructive Pulmonary Disease) and CHF (chronic heart failure).

e-Diabetes Program

Diabetes is a serious chronic illness. According to the figures of the National Institute of Public Health and the Environment from 2007, there are approximately 850,000 diabetes patients in the Netherlands. Around 600,000 people have been diagnosed with diabetes and an estimated 250,000 people have not yet been officially diagnosed, but suffer from the illness all the same. The number of diabetes patients is expected to increase over the next 20 years by 35 to 60 percent. A prerequisite for good diabetes care is that the care providers involved, such as the GP, internist and diabetes nurse practitioners and, first and foremost, the patient can have access to up-to-date and comprehensive information during their treatment that is relevant to their own role and responsibility in the care process. A good supply of information can also
contribute to effective policy and research. The use of IT makes this possible. The e-Diabetes Program aims to develop national standards to this end.

3.3.5 Other programs

In addition to programs carried out directly as part of achieving the various healthcare priorities, other programs are also being carried out to create the necessary preconditions for these activities.

Reference Architecture Program for hospitals

Hospitals are information-intense organizations and benefit considerably from good IT facilities. This is clear from the large investments being made, among other things. Nonetheless, less is invested in IT in the hospital sector than in many other industries. As a result and due to the lack of standards and norms for hospital IT systems, suppliers are reluctant to develop new products. The Dutch market is simply too small and precarious. For many years, hospitals have suffered from the “not invented here syndrome”, as a result of which every hospital has developed its own IT system. In the meantime, it has become clear that it is only by consolidating requirements, developments and interests that affordable and practical modern IT solutions can be developed for these facilities. The Reference Architecture Program is aimed at developing practical standards that improve the transparency and the structure of the hospital IT market.

SNOMED CT (Clinical Terminology) Program

For the safe and proper functioning of electronic communication, it is essential that all care providers and, in the future, also computer systems, register and interpret care information in a uniform manner. Currently, medical information on patients is still primarily registered in normal written or spoken language. The disadvantage to this is that it can lead to medical errors since care information
can be misinterpreted. Moreover, classification systems like ICD9 and ICD10, ICF, ICPC and LOINC that are used in healthcare are not primarily designed for direct patient care, but for statistics, claim forms and invoicing. They are not suitable for registering daily medical activities and lack the coherence required for safe information exchange in chains of direct care.

SNOMED CT (Systematized Nomenclature of Medicine-Clinical Terms) is a terminology database that can make an important contribution to the uniform registration and unambiguous interpretation of care information. It is the largest and most complete terminology system in the healthcare sector and is generally considered to be the leading candidate for becoming the global standard for medical terminology. The SNOMED CT Program is aimed at determining the best possible introduction of SNOMED CT in the Netherlands.

**Cliq Program: quality improvement of medical devices**

Millions of people with functioning limitations, such as the disabled and elderly, require the use of medical devices every year in the Netherlands – at an annual cost of billions of euros. But the devices provided are far from adequate and are not always practical. Cliq (Classification of Medical Devices) makes it possible to effectively match the possibilities and desires of a person with regard to his or her function and the assistance offered by a medical device. Cliq classification is an expansion of the international classification of medical devices for people with functioning limitations based on the intended use. This expansion is in response to patients’ “function-oriented entitlement” to a “function-facilitating device”, giving care providers and insurers more options to provide tailor-made care and giving users more freedom of choice.
3.4 Milestones

Every program being carried out to achieve the EPD priorities has its own milestones, which are described in the relevant program plans. The progress of the programs is monitored by the IT & Innovation Steering Committee under the chairmanship of the Ministry of Health, Welfare and Sport. This document does not include all milestones. Instead, it lists the three overall milestones for achieving the national EPD:

Milestone 2010: Mg/Hwg implemented in full
• 100% connection of GP practices and after-hours clinics, hospitals and pharmacists.
• National accessibility of medication information and GP patient observation records.
• 100% of the Dutch have access to their own access logging, referral and authorization data in the national switch point and medication and observation records.
• Information on intolerances, contra-indications and allergies are available for medication monitoring.

Milestone 2013: Basic EPD implemented in full
• Professional summaries are in place for transfer, referral and feedback between GPs, specialists, pharmacies, ambulance, paramedical professionals, nurses and emergency medical services.
• National availability of results of diagnostic testing (pathology, clinical chemistry, medical microbiology, radiology, nuclear medicine).
• Care sector connected to medication and observation records.
• Extensive patient access to Basic EPD.
• Perinatal chain: communication between obstetricians and physicians in first, second and third lines; link to The Netherlands Perinatal Registry (PRN) and prenatal screenings.
Milestone 2014: Disease management and prevention with EPD

- Entire medication chain (electronic prescriptions, medication monitoring, discharge medication, repeat prescriptions) has been established.
- Diabetes care chain: communication between diabetes care providers takes place in accordance with NDF (Dutch Diabetes Federation) standard; standardized quality reports.
- Diabetes patient can access self-care records.
# Appendix A: Glossary

<table>
<thead>
<tr>
<th>(Dutch) abbreviation</th>
<th>English meaning</th>
<th>Website</th>
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<tbody>
<tr>
<td>AORTA</td>
<td>National basic infrastructure for healthcare</td>
<td></td>
</tr>
<tr>
<td>BSN</td>
<td>Citizen Service Number</td>
<td></td>
</tr>
<tr>
<td>CEN</td>
<td>European Committee for Standardization</td>
<td><a href="http://www.cen.eu">www.cen.eu</a></td>
</tr>
<tr>
<td>Cliq</td>
<td>Classification of Medical Devices</td>
<td><a href="http://www.cliq.nl">www.cliq.nl</a></td>
</tr>
<tr>
<td>CBP</td>
<td>Data Protection Authority</td>
<td><a href="http://www.cbpweb.nl">www.cbpweb.nl</a></td>
</tr>
<tr>
<td>CIBG</td>
<td>Central Information Unit on Healthcare Professions</td>
<td><a href="http://www.cibg.nl">www.cibg.nl</a> (only in Dutch)</td>
</tr>
<tr>
<td>CHF</td>
<td>Chronic Heart Failure</td>
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<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
<td></td>
</tr>
<tr>
<td>CVA</td>
<td>Cerebro-Vascular Accident</td>
<td></td>
</tr>
<tr>
<td>DBC</td>
<td>Diagnose Treatment Combination</td>
<td><a href="http://www.dbconderhoud.nl">www.dbconderhoud.nl</a></td>
</tr>
<tr>
<td>DD JGZ</td>
<td>Electronic Record for Child Healthcare</td>
<td></td>
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<tr>
<td>ECD</td>
<td>Electronic Client Record</td>
<td></td>
</tr>
<tr>
<td>eHealth ERA</td>
<td>eHealth coordination service to the European member states</td>
<td><a href="http://www.ehealth-era.org">www.ehealth-era.org</a></td>
</tr>
<tr>
<td>ETHEL</td>
<td>European Health Telematics Association</td>
<td><a href="http://www.ethel.org">www.ethel.org</a></td>
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<tr>
<td>EPD</td>
<td>Electronic Health Record</td>
<td></td>
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<tr>
<td>epSOS</td>
<td>European Patients, Smart Open Services, European eHealth project</td>
<td><a href="http://www.epsos.eu">www.epsos.eu</a></td>
</tr>
<tr>
<td>GGZ</td>
<td>Mental healthcare services</td>
<td></td>
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<tr>
<td>HL7</td>
<td>Health Level Seven, global authority on standards for interoperability of health information technology</td>
<td><a href="http://www.hl7.org">www.hl7.org</a></td>
</tr>
<tr>
<td>Hwg</td>
<td>Patient summary for general practitioner locum tenency services</td>
<td></td>
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<tr>
<td>ICD</td>
<td>International Classification of Diseases</td>
<td></td>
</tr>
<tr>
<td>ICTRegie</td>
<td>Netherlands IT Research and Innovation Authority</td>
<td><a href="http://www.ictregie.nl">www.ictregie.nl</a></td>
</tr>
<tr>
<td>(Dutch) abbreviation</td>
<td>English meaning</td>
<td>Website</td>
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</tr>
<tr>
<td>IHE</td>
<td>Integrating the Healthcare Enterprise, global initiative by healthcare professionals and industry to improve the way computer systems in healthcare share information</td>
<td><a href="http://www.ihe.net">www.ihe.net</a></td>
</tr>
<tr>
<td>IHTSDO</td>
<td>International Terminology Standardization Organization</td>
<td><a href="http://www.ihtsdo.org">www.ihtsdo.org</a></td>
</tr>
<tr>
<td>ISO</td>
<td>International Standardization Organization</td>
<td><a href="http://www.iso.org">www.iso.org</a></td>
</tr>
<tr>
<td>JGZ</td>
<td>Child Healthcare</td>
<td></td>
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<tr>
<td>KNMG</td>
<td>Royal Dutch Medical Association</td>
<td><a href="http://www.knmg.nl">www.knmg.nl</a></td>
</tr>
<tr>
<td>KNMP</td>
<td>Royal Dutch Pharmacy Association</td>
<td><a href="http://www.knmp.nl">www.knmp.nl</a></td>
</tr>
<tr>
<td>LSP</td>
<td>National Switch Point, core of the IT infrastructure for the Dutch healthcare sector that enables and ensures the secure nationwide electronic exchange of patient information</td>
<td></td>
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<tr>
<td>LOINC</td>
<td>Logical Observation Identifiers Names and Codes</td>
<td>loinc.org</td>
</tr>
<tr>
<td>Mg</td>
<td>Dispensed medication information</td>
<td></td>
</tr>
<tr>
<td>NDF</td>
<td>Dutch Diabetes Federation</td>
<td><a href="http://www.diabetesfederatie.nl">www.diabetesfederatie.nl</a> (only in Dutch)</td>
</tr>
<tr>
<td>NHG</td>
<td>Dutch GP Society</td>
<td>nhg.artsennet.nl (only in Dutch)</td>
</tr>
<tr>
<td>Nictiz</td>
<td>National IT Institute for Healthcare in the Netherlands</td>
<td><a href="http://www.nictiz.nl">www.nictiz.nl</a></td>
</tr>
<tr>
<td>NPCF</td>
<td>Federation of Patients and Consumer Organizations in the Netherlands</td>
<td><a href="http://www.npcf.nl">www.npcf.nl</a></td>
</tr>
<tr>
<td>NVZ</td>
<td>NVZ Dutch Hospitals Association, the organization of the Dutch hospital sector</td>
<td><a href="http://www.nvz.nl">www.nvz.nl</a></td>
</tr>
<tr>
<td>(Dutch) abbreviation</td>
<td>English meaning</td>
<td>Website</td>
</tr>
<tr>
<td>----------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>OZIS</td>
<td>Initiative by Dutch IT companies to determine standards for communication between health professionals</td>
<td><a href="http://www.ozis.nl">www.ozis.nl</a> (only in Dutch)</td>
</tr>
<tr>
<td>PAC</td>
<td>Program Advisory Committee</td>
<td></td>
</tr>
<tr>
<td>PALGA</td>
<td>Pathologisch-Anatomisch Landelijk Geautomatiseerd Archief - The nationwide network and registry of histology and cytopathology in the Netherlands</td>
<td><a href="http://www.palga.nl">www.palga.nl</a></td>
</tr>
<tr>
<td>PI</td>
<td>String of Pearls Initiative, cooperation between the eight Dutch University Medical Centers to collect clinical information and biomaterials</td>
<td><a href="http://www.parelsnoer.org">www.parelsnoer.org</a></td>
</tr>
<tr>
<td>PRN</td>
<td>The Netherlands Perinatal Registry</td>
<td><a href="http://www.perinatreg.nl">www.perinatreg.nl</a></td>
</tr>
<tr>
<td>RIVM</td>
<td>Dutch National Institute for Public Health and the Environment</td>
<td><a href="http://www.rivm.nl">www.rivm.nl</a></td>
</tr>
<tr>
<td>SNOMED CT</td>
<td>Systemized Nomenclature in Medicine – Clinical Terms</td>
<td><a href="http://www.snomed.nl">www.snomed.nl</a></td>
</tr>
<tr>
<td>UZI</td>
<td>Unique Healthcare Provider Identification</td>
<td><a href="http://www.uzi-register.nl">www.uzi-register.nl</a></td>
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<tr>
<td>VWS</td>
<td>Ministry of Health, Welfare and Sport</td>
<td><a href="http://www.minvws.nl">www.minvws.nl</a></td>
</tr>
<tr>
<td>ZonMW</td>
<td>Netherlands Organization for Health Research and Development</td>
<td><a href="http://www.zonmw.nl">www.zonmw.nl</a></td>
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</tbody>
</table>
## Appendix B: Priorities and Programs

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<tr>
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<th>Awareness</th>
<th>Decision Preparation</th>
<th>Solution Design &amp; Testing</th>
<th>Construction, Testing, Implementation</th>
<th>National Rollout</th>
</tr>
</thead>
</table>

**Priority 1: National implementation of basic infrastructure and Mg/Hwg**

| Mg |                        |                        |                          |                        | >>>>>>>>>> |
| Hwg |                        |                        |                          |                        | >>>>>>>>>> |
| EMD Plus |                        |                        |                          |                        | >>>>>>>>>> |

**Priority 2: Patient and EPD**

| Information counter |                        |                        |                          |                        | >>>>>>>>>> |
| Patient access |                        |                        |                          |                        | >>>>>>>> |
| Telecare |                        |                        |                          |                        | >>> |
| Patient portal |                        |                        |                          |                        | >>> |

**Priority 3: Expanded Basic EPD**

| e-Emergency |                        | >>> |                        |                        | >>> |
| e-Lab |                        | >>> |                        |                        | >>> |
| e-Pathology |                        | >>> |                        |                        | >>>>>>>>>> |
| e-Paramedics |                        | >>> |                        |                        | >>> |
| e-Perinatology |                        | >>> |                        |                        | >>> |
| Care ECD |                        | > |                        |                        | >>> |
| e-Transfer |                        | >>> |                        |                        | >>> |
| e-Radiology |                        | >>>> |                        |                        | >>> |
| e-GGZ |                        | > |                        |                        | >>> |
| e-Specialist |                        | >>> |                        |                        | >>> |
| DD JGZ |                        | >>> |                        |                        | >>> |

**Priority 4: Multidisciplinary care, disease management and prevention**

| e-Diabetes |                        | >>> |                        |                        | >>> |

**Other programs and projects**

| SNOMED CT |                        | >>> |                        |                        | >>> |
| Cliq |                        | >>> |                        |                        | >>> |
| Ref. Architecture |                        | >>>> |                        |                        | >>> >>> |

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**Application Awareness Decision Preparation Solution Design & Testing Construction, Testing, Implementation National Rollout**

**Priority 1: National implementation of basic infrastructure and Mg/Hwg**

| Mg |                        |                        |                          |                        | >>>>>>>>>> |
| Hwg |                        |                        |                          |                        | >>>>>>>>>> |
| EMD Plus |                        |                        |                          |                        | >>>>>>>>>> |

**Priority 2: Patient and EPD**

| Information counter |                        |                        |                          |                        | >>>>>>>>>> |
| Patient access |                        |                        |                          |                        | >>>>>>>> |
| Telecare |                        |                        |                          |                        | >>> |
| Patient portal |                        |                        |                          |                        | >>> |

**Priority 3: Expanded Basic EPD**

| e-Emergency |                        | >>> |                        |                        | >>> |
| e-Lab |                        | >>> |                        |                        | >>> |
| e-Pathology |                        | >>> |                        |                        | >>>>>>>>>> |
| e-Paramedics |                        | >>> |                        |                        | >>> |
| e-Perinatology |                        | >>> |                        |                        | >>> |
| Care ECD |                        | > |                        |                        | >>> |
| e-Transfer |                        | >>> |                        |                        | >>> |
| e-Radiology |                        | >>>> |                        |                        | >>> |
| e-GGZ |                        | > |                        |                        | >>> |
| e-Specialist |                        | >>> |                        |                        | >>> |
| DD JGZ |                        | >>> |                        |                        | >>> |

**Priority 4: Multidisciplinary care, disease management and prevention**

| e-Diabetes |                        | >>> |                        |                        | >>> |

**Other programs and projects**

| SNOMED CT |                        | >>> |                        |                        | >>> |
| Cliq |                        | >>> |                        |                        | >>> |
| Ref. Architecture |                        | >>>> |                        |                        | >>> >>> |
Appendix C: List of Reference Works


Kenl (with the cooperation of the Ministries of Health, Welfare and Sport (VWS), Economic Affairs (EZ), SenterNovem, Education, Culture and Science (OCW), Agriculture, Nature and Food Quality (LNV)) and the Innovation Platform


EHTTEL Briefing Paper *Sustainable Telemedicine: paradigms for future-proof healthcare* (www.ethel.org)

E-Health ERA Roadmap Country Reports (www.ehealth-era.org)

Ministry of Health, Welfare and Sport, Information and Communication Technology (IT) in Healthcare; Minister’s brief on current state of affairs regarding information on the implementation of Citizen Service Number (BSN) in healthcare, March 2008, 27529, no. 36

Ministry of Health, Welfare and Sport, Information and Communication Technology (IT) in Healthcare; Minister’s brief presented as part of the sixth progress report on the implementation of EMD/WH and BSN (June to November 2007), December 2007, 27539, no. 35

Technical progress report on the implementation of EMD/WH and BSN, June-November 2007 (appendix to 27529, nr. 35), December 2007, 27529, no. 35, Appendix

HARM study (Hospital Admissions Related to Medication), 2006, University of Utrecht carried out on behalf of NVZA and Orde van Medisch Specialisten

*Spoed moet Goed*, 2005, TNS-Nipo on behalf of the NPCF
Better care thanks to better information

Nictiz - the National IT Institute for Healthcare in the Netherlands - is the national coordination point and knowledge centre for IT and innovation in the healthcare sector.

The national switch point forms the core of electronic communications in the sector, which is managed by Nictiz. Any authorized healthcare practitioner can be connected to the switch point so that he or she can obtain the latest and most relevant information about a patient at any time, from anywhere in the Netherlands and in a simple, secure and reliable way.

In consultation with and at the request of the healthcare sector, Nictiz is continuously developing and refining national standards for electronic communications in healthcare. Furthermore, Nictiz supports the sector in developing functional IT solutions that can be used nationwide, and contributes to policy making on IT issues as they relate to healthcare on a national and international level.