

Patient information

Patient focust information services

Summary

The organisation of information systems should focus on the patient. A proper information system is of vital importance for the effective and efficient provision of healthcare. This applies not only at the micro level to patients and care providers but equally at the meso level, where health insurers, institutions and municipalities, for instance, require information to ensure accessible and affordable good-quality care for patients, clients and residents respectively. At the meso level healthcare providers also require reflective information against which to benchmark themselves and improve their services. At the macro level the government requires information to safeguard the quality, accessibility and affordability of healthcare provided in the Netherlands. Information is additionally required for policy, implementation and research purposes.

Several problem areas currently exist. Patients lack the information to enable them to participate actively in the healthcare process. It takes patients a great deal of time and effort to gain access to their medical records, for instance. Care providers waste a lot of time in supplying – often partly the same – information for a range of registrations. Insufficient interoperability exists between healthcare information systems due to the poor level of standardisation. In addition, insufficient information is available about the outcome of care. Many of these problem areas are attributable to the fragmented, incomplete method of collecting data and the different requirements care providers must comply with for registration and reporting purposes. This is partly due to compartmentalisation in the healthcare sector and the diverging interests of the relevant parties. The Netherlands scores low on the registration and use of outcome indicators compared with other countries, such as Sweden, Singapore, Canada and United Kingdom.

In the Council's view, patients should be able to manage their own information in the form of a Personal Health Record (PHR), if they wish to.

Over 60% of all the Dutch respondents are in favour of a PHR. The majority of this group, 53%, would like a care provider to manage their PHR while 21% would prefer to manage their PHR themselves. Twenty-one percent would entrust their PHR to companies, such as Google and Microsoft. For 62% of those in favour of a PHR, privacy is a main concern.

(Source: CentERdata survey, Appendix 4).

According to the definition applied by the Federation of Patients and Consumer Organisations in the Netherlands (NPCF), the PHR is a universally accessible – anytime, anywhere – layperson comprehensible, user-friendly lifelong tool for collecting, managing and sharing relevant health information, for managing health and care, and for supporting self-management based on the standardised collection of data for the purpose of health information and integrated digital healthcare services.

The PHR does not supersede the care provider's medical records. The PHR contains (digital) copies of the existing (electronic) medical records held by care providers and information added to the file by patients themselves. This means that the PHR serves to supplement the care provider's existing medical records. A patient who has no desire to maintain a PHR will receive care on the basis of the care provider's existing medical records. The extent to which patients have a need for information and control over the care procedure can differ between patient types and the stage of the illness. In addition to the medical professional confidentiality regarding medical records, a law of 'patient confidentiality' is required for the PHR. The option to refuse access insufficiently protects the patient against commercial or non-commercial parties who could exert power to gain access to the contents of the PHR, such as the police and investigative services, life and non-life insurers, financial institutions and ICT companies. The Council is aware that it has not responded to the question of who should finance the PHR. Currently there does not seem to be a clear business model for the PHR. It must be further developed. The motto 'Information also is a care service' might be useful for a business model.

To alleviate the administrative burden on care providers, patient data should be registered once only, in a uniform and standardised manner in the care process. In many cases this will be the patient's medical record. These data can subsequently be used for several purposes. They could, for instance, be reused by other care providers and by knowledge institutes at the macro level. Patient privacy must be guaranteed. This can be ensured from the outset by incorporating privacy in information and communication systems (*Privacy by Design*) with a key role reserved for Trusted Third Parties who will ensure that the data provided for registration purposes cannot be traced back to individual patients.

In the Council's opinion all health information should be disclosed, provided it cannot be traced back to the patient on the basis of Privacy by Design.

The disclosure requirement should not only be limited to the health insurance required by law. Ensuring transparency within the system of regulated competition is so vitally important that it should apply throughout the entire healthcare sector, including supplementary insurances.

The Council furthermore recommends that good examples of patient information systems in other countries should be adopted. Reinventing the wheel should be avoided.

For research and policy purposes and to promote interoperability between PHRs and care systems, all parties must work in accordance with the same, open international standards.

The *Information Consultation* was recently launched on the initiative of the Ministry of Health, Welfare and Sport. The Council wishes to point out that the requisite changes can only be made to the provision of information in the healthcare sector if the Ministry takes charge and proceeds to take binding decisions in the Information Consultation. The Institute for Health Care Quality must take a pro-active approach in creating and implementing a coherent, internationally comparable single set of quality standards, registrations and tools for measuring the quality of healthcare.

Based on the views stated above, the Council has formulated the following recommendations:

1. With a view to the future, a PHR should be made available to patients on a voluntary basis and with freedom of choice.
2. In addition to the medical professional confidentiality of medical records, a law of 'patient confidentiality' should be instituted for the PHR to protect patients against improper pressure from parties, such as the police and investigative services, the Ministry of Security and Justice, life and non-life insurers, financial institutions and ICT companies.
3. Ensure that the patient's privacy is guaranteed in the technical and organisational design of all healthcare information systems (Privacy by Design). Trusted Third Parties (TTPs) must ensure that the patient's privacy is guaranteed.
4. All care providers should register their data, once only, in a uniform and standardised manner at the source, from where data can be reused multiple times for healthcare purposes. Non-identifiable health data must be transparent for public purposes, such as policy, implementation and research purposes.
5. Ensure that the information system is properly set up from the outset on the impending decentralisation of healthcare tasks to the municipalities. Stipulate conditions for the measurement tools to be deployed and for the secure management of client data. Ensure that the provision of information can still be facilitated beyond the limits of the Health Insurance Act (Zvw), the Social Support Act (Wmo) and the Exception Medical Expenses Act (AWBZ, which will be superseded by the Long-Term Care Act (WLZ) effective 1 January 2015) to, for instance, monitor substitution in healthcare. Apply international open standards. Be mindful of care avoiders who could fall through the cracks due to the decentralisation of healthcare tasks. The decentralisation of healthcare tasks to the municipalities could pose additional privacy risks which can largely be removed through Privacy by Design.

6. The Institute for Health Care Quality must act proactively by determining which (international) measurement tools should be incorporated in the healthcare standards and quality registrations on the recommendation of scientific and patient organisations. The registration data should be derived directly from reporting on the primary process. Healthcare professionals must be compelled to cooperate with the current registrations in their discipline approved by the Institute for Health Care Quality. Health insurers should include this in their conditions of purchase based on the motto: 'information also is a care service'.

7. The requisite changes can only be made to the provision of information in the healthcare sector if the Ministry takes charge and the Information Consultation proceeds to take binding decisions.

Essence of the recommendation

This recommendation advocates as a future perspective that the patient/citizen/insured person (hereinafter referred to as the patient) should have disposal of all of his or her health data if he or she wishes and has the ability to manage it; in the first instance via the Internet with a mouse click on the button of a website (by analogy with *Blue Button*, a US government initiative), ultimately in the form of a lifelong personal health record (PHR). The PHR contains (digital) copies of the existing (electronic) medical records held by care providers and information added to the file by patients themselves.

For the benefit of the patient, in addition to the medical confidentiality which care providers are required to observe, 'patient confidentiality' must be instituted to protect patients against improper influence from the police and investigative services, life and non-life insurers, financial institutions, ICT companies and other commercial or non-commercial parties who could exert power to gain access to the contents of the PHR.

To improve quality and reduce the administrative burden, data must be recorded by care providers once only, in a uniform and standardised manner so that it is suitable for re-use. The Ministry of Health, Welfare and Sport should fulfill its systemic responsibility by taking charge to effect the requisite changes in patient information systems. Not only is this in the patient's interest but it is also in the interests of healthcare provision, governance, policy, implementation, research and supervision, underpinned as far as possible by 'registration at the source'.

This recommendation furthermore advocates that non-identifiable health data must be transparent for public purposes, such as policy, implementation and research. Patient privacy should take centre stage in the design of systems facilitating the above (Privacy by design) to ensure that privacy is guaranteed.

What problems does this recommendation resolve?

The Council for Public Health and Health Care has currently identified the following problems:

- patients do not have an overview of their own data held by care providers;
- the care provider does not have a complete overview of the patient's data;
- insufficient data are available for public purposes in the healthcare sector, such as policy, implementation and research;
- up until now privacy too often seems to be a stumbling block in making available individually untraceable health data for public purposes in the healthcare sector;
- when information is transferred between care providers, often duplicated information is provided;
- insufficient interoperability exists between healthcare information systems and there is a reluctance to share information that is available.

What are the consequences for citizens?

The PHR makes available personal health data to citizens anytime anywhere, as a consequence of which they take on the role of a partner in their healthcare/treatment and the quality and affordability of the care they are provided is enhanced due to the improved provision of information. Their options increase as does awareness of their health.

What are the consequences for care providers?

Once-only, uniform, standardised registration at the source and multiple reuse will ultimately help to reduce the administrative burden. The quality of clinical registrations will improve. Due to the PHR the information available to the care provider – with the patient's consent – will be of better quality which will, in turn, enhance the quality of healthcare provision. Better information will also be available to care providers on patients who do not have a PHR as a result of 'registration at the source'. Moreover the PHR supports the partnership between the patient and the care provider. The transfer of information between care providers will improve.

What are the consequences for health insurers?

Having better quality information will enable health insurers to procure better care.

What are the consequences for the government?

At the meso and macro levels better management information – that cannot be traced back to the individual – will be available to the government. As part of its systemic responsibility, the government (i.e. the Ministry of Health, Welfare and Sport) must take charge to accomplish the above. The Institute for Health Care Quality must act proactively in respect of the pace, contents and creation of professional healthcare quality standards, measurement tools and registrations. The decentralisation of healthcare tasks offers municipalities the opportunity to build up information concerning the patient from the outset.