

**This study is not the final word on ICT in the care sector. ICT applications in the care sector are still in their infancy in terms of development. Numerous new issues still need to be studied, including the creation of services via the Internet and the emergence of biogenetics in relation to ICT.**

The broad target group of this study is everybody with an interest in the privacy aspects of ICT applications in the care sector. More specifically, the study is for those involved in establishing the national information infrastructure for healthcare, i.e. central government, patients' associations, care institutions, umbrella organisations, medical insurance companies and software designers.

The study has a twofold purpose: (1) to examine interrelated subjects to provide readers with an overview of the privacy aspects of the numerous ICT applications in the care sector, and (2) to set out a privacy-friendly course for developing the ICT infrastructure in the care sector.

#### **Interrelated subjects**

ICT can be used to improve the quality and effectiveness of care. By addressing five interrelated subjects, the study seeks to provide an overview of the privacy aspects of the many ICT applications that exist in the care sector.

The five subjects are:

- 1 Development of an electronic identity infrastructure;
- 2 Development of an electronic information infrastructure;
- 3 A possible stronger position for the patient via the Internet;
- 4 Changes in the organisation and financing of the care sector;
- 5 Monitoring of patients and clients.

#### *1 Electronic identity infrastructure*

The provision of good services requires the correlation of information about one and the same patient without any mix-up with information about another person. A patient number is the most commonly-used form of unique patient verification. Patient numbers are personal numbers and personal numbers are personal data. It is advisable to phase in the proposed national patient number in combination with regional and supply chain numbers in the care sector. It is further recommendable to experiment on a small scale with biometry as a way of identifying patients and care providers.

#### *2 Electronic information infrastructure*

Smart card projects were the starting point for the electronic information infrastructure. The projects triggered a growing awareness that a smart card should be a key to accessing a virtual electronic patient dossier (EPD), i.e. medical records. The ambition of national policymakers is for all authorised persons in the Netherlands to be able to view EPDs via a virtual nationwide infrastructure.

The authorisation standards for an EPD must respect professional medical confidentiality. Responsibility for processing the data will be distributed over the various actors involved in the EPD project. There are also security obligations that must be fulfilled. It is advisable to use privacy-enhancing technologies.

#### *3 Patient and the Internet*

The Internet can strengthen the position of the patient. However, the Internet is an insecure open system with privacy risks. The patient must be made aware of these risks and would be well-advised to obtain protection against them.

#### *4 Organisation and financing*

The government wants to review the system of providing healthcare with a view to bringing about competition between care providers and between medical insurers. Another intention is to introduce a funding system – ‘Diagnosis Treatment Combinations’ – based on services rendered. This will probably require the processing of detailed data on the treatment of patients. It will be important when working out and elaborating these proposals to be aware of the different roles of the medical insurer, the other parties in the healthcare sector and the constraints imposed by privacy laws and professional medical confidentiality. Lawmakers must ensure that legislation respects the standards that apply under professional medical confidentiality and for processing medical data, the European Data Protection Directive and the obligation to submit to the Dutch Data Protection Authority for an opinion all bills and draft orders in council that concern or have a bearing on the processing of personal data.

#### *5 Monitoring patients and clients*

A great need exists in the care sector to use ICT to keep track of patients/clients. This is because of such circumstances as the need to conduct scientific medical research and keep statistics, to provide managed care, to allocate care, to manage waiting-lists and to record data regionally and nationally.

Scientific medical research is usually bound by the rules embodied in professional medical confidentiality and the ‘Good Behaviour’ code of conduct currently under review in the context of the Data Protection Act.

Managed care means harmonising demand and supply in the care sector. This almost always requires a party other than the doctor and patient to be involved in information management. It is first necessary to examine whether access to medical data for managed care purposes is allowable under the rule of professional medical confidentiality. The same often applies in relation to scientific medical research and statistics. The subsequent processing of medical data must satisfy the stringent regime applicable to such processing. Moreover, the provisions concerning use of data in a way compatible with the purpose for which it was gathered must be satisfied.

Following critical comments by the Dutch Data Protection Authority, the State Secretary for Health, Welfare and Sport established a separate working group consisting of representatives of the various stakeholders to examine the privacy aspects of databases used to allocate care and manage waiting lists. Each new phase of a project is now being submitted to the Dutch Data Protection Authority for an opinion.

The Dutch Data Protection Authority needs a greater factual knowledge of national registration systems in the care sector. For that reason the Authority launched a fact-finding study in the field in autumn 2002. Care institutions and care providers would also be well-advised to obtain a greater insight into this matter, because not infrequently they can be held responsible for the data supplied to such registration systems.

#### **Privacy-friendly ICT infrastructure**

Timely and proper attention to privacy in the care sector is increasingly becoming a critical success factor. It can be concluded from the five interrelated subjects that the changes taking place in healthcare may have far-reaching consequences for the way care will be provided, managed and financed in the

near future. Economies of scale, transmuralisation (i.e. optimum co-ordination of intramural and extramural care) and market mechanisms are extremely important matters. Due consideration must be given to their privacy aspects. Privacy is hardly ever a design criterion for ICT applications at present, however. This must change.