CONFIDENTIALITY AND ACCESSIBILITY OF ELECTRONIC PATIENTS' RECORDS: A BALLANCING ACT

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The right of patients to confidentiality of their medical records is firmly embedded in Dutch health legislation (Data Protection Act, Act on Patients' rights, Act on Professionals in individual health care). It implies that – in the absence of a legal duty to give information – a health care professional needs consent of the patient to give information to others. In case of sharing information with colleagues that are also involved in the care for the patient, implied consent is sufficient. Explicit consent is required in all other cases of sharing information.

Presently the Netherlands are in the process of facilitating the electronic linking of patients' records in order to make them available to all health care providers allowed into the national system. This enhanced accessibility of (subsections of) patients' records can have many advantages in the field of avoiding mistakes and quality of care. But serious questions have been raised about the compatibility of the proposed system - that will grant access to patients' records to all registered health care providers - with the duty to maintain confidentiality. What safeguards are necessary to avoid breaches of confidentiality and how can they be implemented in the system? Will precautions in order to guarantee confidentiality stand in the way of reaping the benefits of a system of electronic linking of patients' records?

The Royal Dutch Medical Association has conducted a survey on the opinion of doctors on these issues and the Federation of Patients and Consumers has conducted a survey on the opinion of the general public and patients' groups. Generally speaking doctors in the Netherlands are rather reluctant to participate in a system that implies giving up control over which colleagues can obtain access to their patients' records. The general public and patients' groups expect the benefits of enhanced access to their medical records to outweigh the risks to their privacy. Both doctors and patients agreed on patients' consent to be the basic requirement for this form of accessibility of patients' records. They also expect adequate guarantees on only health care providers actually involved in the treatment and care of the patient being able to gain access to his/her medical records. Both aspects need further analysis in order find proper ways of implementing them into the system. How can patients be properly informed about the extent and consequences of enhanced availability of their medical records? Will general information suffice or is individual information necessary? Will it suffice to obtain consent just once or will consent have to be renewed every once in a while or in case of specified events? How will the legitimacy of access in individual cases be checked? Will it be possible to build a system based on a more detailed specification of who has access, to which records, under which circumstances? And if this is not possible: will it be feasible to check legitimacy 'after the fact' and which sanctions will be applied in case of misuse?