

STUDY OF THE HEALTH INFORMATION HIGHWAY IN QUÉBEC: TECHNICAL, ETHICAL AND LEGAL ISSUES

Why a study of the health information highway in Québec?

For decades, our laws have provided medical information the protection it deserves. Because it is highly sensitive, very strict rules govern its transfer. The Commission d'accès à l'information receives, studies and gives opinions on different plans for the transfer of medical information.

This study falls within this mandate and is designed to help us understand a growing phenomenon of collective and individual concern in Québec, as elsewhere: the networking of computer files, making it possible to link clinical information originating from various health care organizations. The main goal pursued by the Commission in carrying out this study is to encourage a thorough public debate on the technical, ethical and legal issues raised for the protection of personal information by the clinical use of information circulating on such a highway.

Health information highway: A complex issue involving benefits and risks

The Commission is not opposed to an easier transfer of clinical data between health care organizations since it may help making timely, critical decisions. What the Commission fears is a hasty, rash development that would threaten the privacy of all Quebecers. The scope of the issues does not allow for improvisation. The challenge here – and it is a major one – is to guarantee the confidentiality of health data while giving access to caregivers and enabling them to make the most enlightened clinical decisions possible.

Content of the document

The document includes four chapters. The first looks at the broad architecture of Québec plans for a health information highway. The second brings out from these plans examples of consent and storage, technological trends, and underlying issues. The third shows the scope and limits of legal rules protecting personal information on a health network. The fourth deals with the issue of consent, its principles and application in particular clinical situations.

A methodology based on a description of Québec plans

The study is based on a description of mechanisms included in seven Québec plans for the collection, storage and access of information. These were singled out because of their high visibility and because they are, in our opinion, representative of the movement toward the establishment of a health information highway in Québec. Of these plans, some are now being implemented (Shareable Patient Record, Health Access Card and Mother-Child Network), others are in operation (Brome-Missisquoi-Perkins, SI-PRSA), or completed (Laval Health Card, Rimouski Health Card).

Findings

One fact stands out in the analysis of the Québec plans. It is the constitution of new health data warehouses on a regional (Shareable Patient Record, Mother-Child Network, SI-PRSA) or a national basis (Laval Health Card, Health Access Card). These centralized records would not replace existing records, but superpose them to allow the transfer of information between distinct health care facilities. Another study finding is the creation of a national patient index allowing, on the one hand, the pooling of clinical data scattered in different records and, on the other hand, user identification by instantly communicating his or her name, address, telephone number, health insurance number and other identifying data to health establishments and other health care facilities.

The Commission's concerns

One of the main concerns of the Commission following this study is the creation of regionally or nationally centralized clinical records. The Commission seriously questions the tendency to duplicate the content of existing clinical records and enter it in what will ultimately become mega banks. A single breach in the system could have disastrous consequences. Would clinical information not be better protected if it were accessible only where it is located, that is, locally? The centralization of clinical data also brings out the unresolved issue of the legal holder and physical keeper of such data. Who will guarantee their safety? Who will manage access? Will it be a shared responsibility? Will partitions

between the administrative and clinical uses be foolproof? As for the Provincial Patient Index, the Commission questions the need for creating a provincial register containing identifying data on the Québec population when we know that the risk of leaks increases as the number of users and the size of files grow.

Legal framework needs to be reviewed in the interest of the individual

The networking of electronic clinical records challenges the rules governing the transfer of health information. The Commission, therefore, reiterates the importance of reviewing the Québec legal framework for access to and the protection of health data in light of the new dynamic for the exchange of clinical information, in the interest of the patient.

Consent: A vital issue

The review of the legal framework will have to tackle the issue of consent. Will consent be required singly, every time a professional uses the info highway to access a clinical record? How can consent be structured in a context of networked, even centralized data bases to enable users to preserve their privacy and do away with their past, especially when it no longer serves any clinical purpose? In the context of an info highway where personal health data can more easily and readily be transferred, users will more than ever have to retain control of their information. However, as the study shows, consent may be more or less extended in time, space, and content, depending on the prevalent clinical situation.

Conclusion

Access to and protection of clinical data are complex issues on an information highway. The Québec experience shows there are different models for storing and accessing electronic clinical records. The danger is to reduce the Québec clinical reality to one of these models, which more often than not tags behind a particular plan or technology.

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