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**OPINION**

**1992 APRIL 9TH**

**CONFIDENTIALITY**

**OPINION ON A PERSONAL HEALTH RECORD BOOK  
PROJECT**

**EN**

Following discussion of the issue in plenary session, the National AIDS Council now issues a negative Opinion regarding the personal health record book project, referred to it on January 13, 1992 by its vice-chairman, Professor Alain Sobel.

This project appears to the Council to suffer, both in terms of its design and the results that can be expected from it, from major drawbacks far exceeding hoped-for advantages.

The health record book project was launched by the drug company Pfizer as part of their public image policy. The task of designing the book's content was entrusted to a committee of doctors and the graphic layout to the advertising agency Paragraphe ; at the same time, an advisory committee of doctors was set up. The project's instigators submitted it to various official bodies, among them the National AIDS Council. The announced aim of the personal health record book was to improve communications between all the professionals involved, while it would remain the patient's property, for whom it could be a source of reassurance.

The Council bases its negative opinion on two categories of drawback:

## **DRAWBACKS IN THE APPROACH ADOPTED**

The project committee has produced a projected record book without first evaluating demand or defining patients' needs.

Such an approach fails to help determine what the patients involved think of this kind of project, and is based on purely medical reasoning, in itself contrary to the announced intentions of the project's instigators, who maintain that they wish patients to feel a sense of ownership of this personal health record. Moreover, it has the additional defect of making impossible any ex post assessment of patients' needs, since such a procedure, based on a finalized design, would inevitably produce biased responses.

## **FUNDAMENTAL DRAWBACKS**

These drawbacks fall into three categories:

- ethical : The projected personal health record book, by enabling patients to add the names of individuals to be contacted, entails the risk that privacy and confidentiality, which are indispensable, may be compromised.
- psychological : Given that only the reasoning of the project's instigators was taken into account in its execution, advantages possibly beneficial to patients are absent. On the contrary, many patients endeavour to avoid thinking about their HIV-positive status, and a document of this kind, which would in fact be more aptly described as a personal record of bad health, continuously reminds them of it.
- practical : This project's usefulness must be questioned. First, it is not a response to a desire expressed by patients, since they were not consulted. Second, it is yet another document, with all the associated risks of overload and duplication. Finally, a personal record of this kind will only be beneficial if it is used by certain categories of patient seeking healthcare very sporadically. However, these are precisely the individuals who will very probably not make use of it.