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**OPINION**

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## OPINION ON PROJECTED CHANGES TO THE SYSTEM OF EPIDEMIOLOGICAL SURVEILLANCE OF HIV IN FRANCE

In 1982, the French health authorities instituted an effective system for AIDS epidemiological surveillance, which has been gradually improved and modified as scientific knowledge has advanced. It has invariably protected the individual's anonymity and complied with the principles of our national regulatory controls on computer data (law of 1978 on Information Technology and Civil Liberties). In actual fact, no complaint has ever been lodged regarding an infringement of individual rights.

This system is structured around the compulsory anonymous declaration of known cases of AIDS made by practitioners to the National Public Health Centre (RNSP). This system for surveillance of known cases of AIDS, in place since March 1982, has several advantages : first, the long period over which it has been in existence, which enables changes to be monitored over the long term; second, the high quality of the data it provides : 80 % of cases are declared. It is a simple matter to verify the reliability of this source of data by means of further surveys.

This system also includes non-compulsory surveillance :

1. Measurement of levels of hospital activity and monitoring of the active hospital waiting list (DMI-2 system).
2. Measurement of screening activity made possible by the development in 1985 of the test for detecting anti-HIV antibodies. This measurement is based on :
  - blood transfusion activities (1985);
  - the results of free anonymous screening centres (1988);
  - a network of sentinel laboratories (RENAVI) in both private and public sectors;
  - a sentinel network of general practitioners, which is not specific to AIDS.
3. Epidemiological prevalence studies.

These studies are not exhaustive : the method used is that of non-correlated anonymous screening. Regional Health Observatories organize the collection of the data, including most notably the following :

- the Prévagest study of pregnant women in two regions (Paris-Ile-de-France and Provence-Alpes-Côte-d'Azur),
- the Prévadav study of patients visiting VD clinics.

Compulsory declaration of known AIDS cases has been an efficient observational tool thanks to the extensive involvement of a small number of highly motivated professional workers, and because of the highly exhaustive character of the collection of data despite the handicap of the time-lag between the date of infection and the beginning of AIDS (approximately 10 years in the absence of treatment). In 1998, compulsory declaration became less useful as an epidemiological basis for aiding the authorities' decisions on prevention policies and care programmes. This is because the significant decline in the numbers of AIDS cases since 1996 is partially due to the effectiveness of the new combined treatments, and the figures collected for actual AIDS cases are very far from reflecting new danger areas, new risks and new infections.

It is against this background that the Secretary of State for Health requested the head of the General Health Directorate to refer to the National AIDS Council the issue of the appropriateness of instituting a system of compulsory declaration of HIV infection subject to the same conditions of anonymity, strict scientific method and preservation of the rights of individuals as those governing the Compulsory AIDS Declaration system used until now and which it would replace.

At the plenary session of January 16, 1998, the National AIDS Council heard evidence from eminent experts in epidemiology and medical ethics.

Following this evidence and the ensuing discussions, **the National AIDS Council states as follows :**

1. that it is necessary to maintain and, if possible, to reinforce the epidemiological surveillance of HIV, taking into account changing knowledge and techniques. This is necessary primarily in the interests of those working in the health system and, less directly, its users ;
2. that compulsory anonymous declaration of known AIDS cases, a tool that has been of outstanding usefulness for AIDS surveillance, is no longer suited to the holistic monitoring of HIV ; however, it does provide information in terms of semiology and provides a means for evaluating the proper availability of care ;
3. that the data collected by various public health and research bodies provide good results which should be preserved and, if possible, further improved in quality, quantity and consistency, with a view to aiding the authorities' decisions on prevention and healthcare programmes ;
4. that the quality of epidemiological data collection is determined by the motivation of those working in the health and welfare systems, and by regular top-up training and empowerment of those workers – which feeds into good professional practice ;
5. that the converse of such motivation aimed at instituting effective, unified methods, is the imposition of obligations, which presuppose the existence of an automated system – an (illusory) system of penalties in the event of non-compliance with the regulations – or even amendments to the Code of Public Health Law, made even more pointless by the risk that it would bring the law into disrepute (if compliance is less than complete, which is the foreseeable outcome). Provisions laying down mandatory requirements not directly in patients' interests are invariably less effective than schemes based on individual involvement and a determination to improve practice ;
6. that the compulsory declaration of chronic medical conditions (both acquired and of genetic origin) must be envisaged with extreme care given the risk of violation of the rights of individuals.

**The National AIDS Council recommends :**

1. that the compulsory declaration of known AIDS cases should be continued in order to ensure continued monitoring of access to healthcare ;
2. that the General Health Directorate should simultaneously coordinate surveillance of new cases of infection on the basis of a unified system enabling improved evaluation of risk-taking and danger areas, along with improved assistance for sufferers to approach care facilities, where access to treatment must be constantly facilitated ;
3. that this system should be based around organizations that are already operational and charged with the task of involving medical practitioners making anonymous declarations of HIV infection on behalf of patients duly informed of this ;
4. that such declarations should not be compulsory (nor prescribed by law), but should involve French practitioners in effective and responsible participation in public health actions in the context of good clinical practice.