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REPORT EQUIVALENT TO AN OPINION

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CONFIDENTIALITY

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REPORT EQUIVALENT TO AN OPINION ON THE INCLUSION OF HIV SEROLOGY DATA IN THE SESI ANNUAL STATISTICAL SURVEY OF DRUG ADDICTS ADMITTED TO HOSPITAL FACILITIES

At the invitation of the Commission nationale de l'informatique et des libertés (CNIL) [National Commission on Information Technology and Civil Liberties]. (correspondence dated April 27, 1992 – GJ/SVT/VJ/92-718), the National AIDS Council agreed to address on its own initiative the issue thus submitted to it, that of the inclusion in the survey of a heading relating to HIV serology, said inclusion having made following the issuance by the CNIL, in October 1998, of a favourable opinion on the survey's implementation.

The head of the statistical department at the Ministry of Health advised the CNIL in correspondence dated February 28, 1992, of his regret that this addition had not been previously submitted to the CNIL for its opinion and that he would comply with any final view taken by the latter on this question. He explained that this addition had been made with a view firstly to improving knowledge using the information obtained with each individual's consent and without duress of any kind or compulsory screening, and secondly to providing a possibility of early treatment (cf. CNIL document : Memorandum for the attention of Mr. Jaquet, dated April 7, 1992).

SESI's regular survey covers 10,000 individuals, and is conducted over a single month in each year. Additional selective surveys cover 123 and 157 drug addicts under the responsibility of Doctor Ingold, as well as 479 individuals in post-treatment facilities, these individuals being under the responsibility of Unit 302 of the INSERM.

Specific questions regarding HIV serology were included in order to improve the quality of the information collected and to evaluate screening in this population segment.

According to SESI, the question as put – serology test not performed / serology test performed (followed by the various results or possible further stages) – necessarily invalidates any hypothesis that screening is compulsory. Furthermore, the person responsible for the survey emphasizes that the care provided is based on a moral contract, a relationship of trust between addict and physician, ruling out any unauthorized or forced screening, which would destroy what is a delicately balanced relationship.

After inquiry, analysis and discussion, the National AIDS Council has reached the view that, insofar as there is no imposed screening, but rather the putting of a straightforward question, similar in principle to questions as to drug addiction or homosexuality, the objective of which is to increase knowledge regarding the specific links between drug addiction and HIV-positive status, it sees no ethical reason to oppose it.

On the other hand, the National AIDS Council notes that there are two surveys of this kind presently on the market : the SESI one-month annual survey, and the monthly survey of facilities receiving drug addicts conducted by the public welfare department.

In both cases, the Council points out that the difficulty of completing what is a quite complex questionnaire (cf. the SESI and public welfare questionnaires), the failure to seek information on issues of great current concern, such as the sharp increase in intravenous cocaine abuse, the scope specific to each of the surveys and disparities in the data collected, combine to make such surveys invalid in epidemiological terms, given the absence of a representative sample or harmonization of the data collected, and further that they cannot therefore provide reliable information likely to assist in defining new policies.

Thus, from the technical and the ethical points of view, but somewhat aside from the issue initially laid before it, the National AIDS Council has doubts regarding not only the usefulness of the systematic use of such questionnaires, but also in principle, from the ethical point of view, on the use of biased data in the context of public health and prevention policies.