

EXECUTIVE SUMMARY

On 15 April 1999, the Advisory Council on Health Research received a request for advice from the Minister of Health, Welfare and Sport with regard to HIV surveillance in the Netherlands. The Minister wished to know whether, taking into account recent medical and social developments, the system of HIV surveillance currently in place should be modified in order to ensure the ongoing accuracy of information concerning HIV epidemiology in the Netherlands. To provide the requested advice, the Council appointed a committee comprising a number of Council members and external experts.

The number of people infected with HIV in the Netherlands is estimated to be between twelve and eighteen thousand. The current system of HIV surveillance intends to identify relevant changes in the prevalence of HIV infection within the known high-risk groups, as well as any spread of HIV infection into the general population. In addition to reporting individual cases to the Health Care Inspectorate, the 'official' surveillance system, as financed by the Ministry of Health, Welfare and Sport, involves monitoring the prevalence of HIV infection among those presenting at STD clinics in Amsterdam and Rotterdam, among pregnant women seen at four locations (two hospitals, a midwife practice and an abortion clinic in Amsterdam) and among intravenous drugs users in various Dutch cities.

During the 1980s, it proved possible by means of effective information and education campaigns to reduce drastically the rate at which HIV infection spread in the Netherlands. However, the past decade has seen no reduction in the number of new HIV infections reported each year, although the introduction of two new categories of HIV inhibitors in 1995/6 has led to a clear reduction in the number of AIDS-related deaths. Because there are now more new cases of HIV than there are deaths caused by its effects, the prevalence of HIV in the general population is likely to have increased significantly in recent years. Moreover, there are indications that the nature of the HIV epidemic in the Netherlands has itself changed. The original idea of distinct high-risk groups is becoming less clear, with the proportion of people acquiring the virus through heterosexual contact having risen substantially during the 1990s. Unsafe sexual behaviour and the 'import' of HIV are significant factors in this regard.

Recent recommendations by UNAIDS/WHO with regard to *second generation* HIV surveillance have been used as a guideline in evaluating current HIV surveillance practices, leading to the conclusions of the Council as set out below.

- HIV surveillance among visitors to the STD clinics run by the Amsterdam Municipal Health Service (GG&GD) and by the department of dermatovenerology of Dijkzigt university hospital in Rotterdam, provides a good general overview of the prevalence of HIV among the specific high-risk groups studied. Such monitoring also provides information concerning specific risk factors involved. It is therefore recommended that this form of monitoring be continued.

- HIV surveillance among intravenous drugs users in various parts of the Netherlands (the so-called 'circus') is conducted by the National Institute of Public Health and the Environment (RIVM) in close cooperation with Municipal Health Services. Through their efforts, it has proven possible to gain a clear picture of the incidence of HIV among drugs users in various regions. Since the prevalence of HIV among drugs users has remained reasonably stable for some time, and since the relevant group is itself decreasing in size (thus reducing the extent of the problem), the Council is of the opinion that it is no longer essential to carry out the monitoring activities in Amsterdam, Rotterdam, Arnhem and Heerlen/Maastricht every two years, as was previously the case. Unless there are indications that the situation is changing, the Council recommends that the frequency of monitoring should be reduced to once in every five years. In other regions, incidental monitoring may be undertaken as and when the necessity arises.

- Among various other recognized high-risk groups, especially bisexual men, prostitutes and their clients, and immigrants from regions with generalized HIV epidemics, there is currently little or no targeted HIV surveillance. Partly because these high-risk groups can act as a 'bridge' in terms of the spread of HIV into the general population, the Council recommends research into both current HIV infection rates ('sero-surveillance') and sexual conduct among these groups.

- The HIV surveillance among pregnant women at three Amsterdam locations indicates that the prevalence of HIV among those tested has increased in recent years. However, it is not yet clear whether there has indeed been a real increase in the prevalence of HIV among pregnant women in Amsterdam. In view of the greatly improved opportunities for preventing vertical transmission, it is extremely important that HIV infection in pregnant women should be recognized at an early stage. The high proportion (13-25%) of women refusing the offer of an HIV test gives cause for concern. The Amsterdam Municipal Health Service is to start a new research project in the spring of 2001, whereupon for the coming three years *all* pregnant women in the

city are to be offered an HIV test. The existing system of selective HIV surveillance among pregnant women in Amsterdam will therefore be discontinued. An analysis of the results of general HIV screening among pregnant women should become an integral component of any future reports on HIV surveillance in the Netherlands.

- Statistical data concerning the number of HIV tests (both positive and negative) conducted in the Netherlands should be collected and analysed on a regular basis. Developments in HIV testing technology should be followed closely. In addition, incidental research into testing behavior among various sub-populations will be necessary. These sub-populations have yet to be defined. An analysis of the results of blood donor screening, those of general STD surveillance in the Netherlands and those of HIV surveillance activities which fall outside the 'official' sphere should form integral components of the annual HIV surveillance report.

- Since the introduction of more effective HIV inhibitors in 1995/6, the number of AIDS cases reported to the Health Care Inspectorate has dropped significantly. However, it is clear that this decrease does not reflect a lower incidence of HIV infection in the past, as might have been concluded prior to 1996. The number of AIDS cases reported can therefore no longer be used as a basis for estimates of the prevalence and incidence of HIV in Dutch population. As a consequence HIV surveillance in the Netherlands has lost its main foundation, and there is therefore a risk of losing sight of the development of HIV infection in the country. Given recent developments in the extent and nature of the HIV epidemic in the Netherlands, and given the fact that despite improved treatment and prospects, HIV infection remains an extremely serious condition which is likely to require complex and lifelong treatment, and in the light of recommendations made by various international organizations, the Council believes that it is necessary to expand current HIV surveillance activities with a system of national HIV registration.

Partly due to the fact that hospital care (including treatment) for those with HIV in the Netherlands is heavily concentrated in treatment centres and allied institutions, opportunities for setting up a national HIV registration system are good. Registration of the data of those infected with HIV can take place during the initial visits to one of the relevant institutions. It is intended that the data of all HIV-infected patients who attend an AIDS treatment centre or a similar institution on a more or less regular basis should be recorded, including data of patients who are not (yet) being treated with HIV inhibitors. Of course, the data

relating to the five thousand HIV patients currently receiving treatment and the data of HIV-infected children should also be included.

It is considered essential that personal information should be encoded. This advice includes a list of the essential information to be recorded, and presents a number of conditions which, in the opinion of the Council, the register must fulfil.

The Council further considers it essential for the registration to be independent with clear responsibility for the collection, collation and management of information. Provided that the privacy of all involved can be guaranteed, and provided registration will be conducted on a voluntary basis, there is likely to be a broad level of support among patients and medical practitioners for such a national HIV register.

- The information collected by the care institutions for the purposes of registration must be processed and analysed. It is also essential to establish the relationship between the results of the various HIV surveillance activities by means of regular collation and comparison. The Council therefore believes that these and other tasks (as described in the advice) might best be undertaken by a 'Surveillance Unit' to be created for this very purpose. Among the responsibilities of this Surveillance Unit would be the production of an annual report presenting a picture as complete as possible of the current status of the HIV epidemic in the Netherlands. This report can be used to adapt ongoing HIV surveillance activities if necessary.

To ensure optimum performance, the Council considers it absolutely essential that the new Surveillance Unit should have a neutral, coordinating role with regard to all other parties and should be set up in close consultation.