REPORT OF THE SURVEILLANCE SUB-COMMITTEE OF THE
NATIONAL AIDS STRATEGY COMMITTEE ON ANONYMOUS
UNLINKED ANTENATAL HIV SCREENING IN IRELAND

Results for the period 4th Quarter 1992 to 4th Quarter 2000

Introduction:

The objectives of HIV surveillance are to obtain information on the incidence and the prevalence of this infection in specific population groups in a manner that is as free as possible from bias, and to look at the determinants of the spread of the infection in those groups. HIV surveillance may be based on the monitoring of unlinked anonymous HIV screening and of linked HIV tests. Unlinked anonymous screening can limit participation bias but the effects of selection bias may remain. However, it can offer distinct advantages for public health surveillance and allow the prevalence of infections in the population screened to be more reliably estimated, particularly in situations where individuals may be unwilling to consent to a linked test. In addition serial unlinked HIV surveillance can give an indication of the incidence and of changes in the patterns of transmission. Linked HIV testing is performed with the informed consent of an individual after a pre-test discussion. While this testing can yield valuable information on the importance of specific risk activities in the transmission of HIV infection, it may also be subject to a number of biases, particularly participation bias, which may make the wider interpretation and comparison of the results difficult.

HIV surveillance is now used in most countries in Europe according to agreed guidelines as a way of monitoring the progress of the HIV/AIDS pandemic in a timely fashion. HIV case based reporting was introduced nationally in Ireland in July 2001.

European Context:

In western European countries the overall incidence of AIDS has continued to decline, with a fall of 12% to 22 cases per million population in 2000, compared to 25 per million in 1999. The incidence in 1999 was itself down on the year before. In those countries, AIDS case reporting had been used as the principal means of monitoring the HIV/AIDS pandemic. It allowed the evaluation of long-term epidemic trends, the characterisation of affected populations and, through back projection, the estimation of previous HIV incidences. In eastern Europe, on the other hand, where the pandemic was at an earlier stage, monitoring of the disease was based on the reporting of all diagnosed cases of HIV infection, including newly diagnosed AIDS cases. This strategy, often accompanied by mandatory HIV testing, allowed the spread of the disease to be followed more closely in those countries as the epidemic has progressed.

The introduction of more effective anti-retroviral therapies, which significantly delay the onset of symptoms of AIDS, and the need to continue to monitor the evolving HIV epidemic in Eastern Europe, led to the revision of the HIV surveillance strategies used throughout Europe to include the use of HIV case reporting at both European and country level.

HIV case reporting does not allow the direct measurement of HIV incidence or prevalence. However, compared to AIDS case reporting, it provides information on more recently infected cases, thus giving a more up to date picture of the HIV infected population by demographic features and by likely route of transmission. This information is essential for both the development of relevant prevention strategies and in planning and evaluating the HIV care provided and the future service needs.

In September 1997, WHO’s European Regional Office undertook a survey of 48 out of the 50 member countries in that region. 43 countries responded to the questionnaire. An analysis of the responses showed that in 1996 HIV tests were performed in 36 of the responding countries and in 31 aggregate data on these HIV tests were collected at a national level. The population groups targeted for HIV testing varied considerably between these countries. Pregnant women were screened antenatally in 23 countries and patients with sexually transmitted infections (STIs) were targeted in 36 countries. Other groups tested included prostitutes, prisoners and specific groups of foreigners.

Partner notification policies existed in 23 countries and in 10 of those countries cases identified through this activity represented more than 10% of the total HIV positive cases diagnosed. Free anonymous testing also appeared to be important, being available in 37 countries. In 1996, it represented 1.5% of all tests done in 19 of those countries, but 8.5% of the HIV positive tests. Clearly, these two strategies are important in identifying significant numbers of HIV positive individuals. However, the value of anonymous testing depends on how ‘anonymous’ is defined. By its nature, given the problems of self-selection, etc., the data collected are of limited value in monitoring the spread of the disease. The results are of most value to the individual concerned if HIV positive individuals can be informed of their status so that they can avail of treatment and make changes in their behaviour to protect their partners, etc. Enough detail must be available with the test so that duplication can be avoided if the results are to be included in national data.

HIV case reporting systems existed in 41 countries. Ireland was one of the two countries responding to the 1997 survey where there was no HIV case reporting. In 37 countries this case reporting system was nation-wide. In France, Italy and Spain, with the highest incidences in the region, independent regional systems co-existed. In the Netherlands, HIV cases were reported from a single area in the country.

HIV case reporting was mandatory in 7 countries and voluntary in the remainder. In 10 countries reports came from the laboratories and in 20 from both laboratories and clinicians. In the remaining 7 countries cases were reported only by clinicians. Most

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countries’ HIV case reporting systems used an identifying code for each patient when reporting, which allowed the elimination of most duplicate reports and linkage between HIV and AIDS cases. This is essential to calculate the total number of diagnosed HIV positive individuals and to get information on care patterns and on the progression to AIDS. Some countries used named case reporting but this increased the risk of breaches of confidentiality and subsequent discrimination.

In 1999, an HIV case reporting system was set up at a European level to complement the AIDS reporting system. In February of that year, the national HIV/AIDS surveillance co-ordinators in 50 countries in the Western European Region were invited to provide anonymous individual data on persons with laboratory evidence of HIV infection diagnosed at any clinical stage and reported for the first time in 1997 and 1998. Countries which could not provide individual data were asked to provide aggregate data by half-year of report. In addition, aggregate data on HIV cases reported before 1997 were collected from all countries.

Thirty-nine countries responded to this request, thirty-seven with national data and two with regional data. Ireland was one of the four EU countries, which were unable to provide data at that time. While HIV reporting data must be interpreted with caution and do not provide a direct indication of the incidence or prevalence of the infection, the reported data do provide useful information on HIV infection trends nationally, regionally within Europe and in Europe as a whole, allowing a better assessment of the extent of HIV infection in those populations. Among countries in Western Europe with available data, numbers of HIV cases reported in recent years were relatively stable overall, sexual transmission accounting for the vast majority of reported cases. However, the countries with the highest numbers of HIV infected injecting drug users were not included in the data that were collected. The report on these data concluded that the fact that most countries in the WHO European Region now have HIV reporting systems is an indication of the importance attached to this method of surveillance. It also concluded that collecting these data at a European level combined with AIDS surveillance would provide a better insight into the epidemiological situation nationally and in Europe than AIDS surveillance alone.

**Current Situation in Ireland:**

A National AIDS Strategy Committee (NASC) was established in Ireland by the Minister for Health in December 1991. Following on from that, an HIV/AIDS Surveillance Sub-Committee was set up with the following terms of reference:

“To consider the development of a sero-surveillance programme to determine as accurately as possible the spread of HIV by category of persons and by region.”

“To consider the provision of information by the National Virus Reference Laboratory at University College Dublin with a view to identifying the regional spread of the disease.”

Following a review of available information and discussions with colleagues in the United Kingdom, this Sub-Committee recommended to the National AIDS Strategy Committee that a number of unlinked anonymous screening programmes should be established. The first such programme, screening pregnant women when they attended antenatal clinics, was established in October 1992.

The principles for unlinked anonymous screening followed by this programme were:

- Only the residue of clinical specimens taken for another routine test is used;
- The original test is not compromised;
- The residue of the specimens is irreversibly unlinked from personal identifiers before HIV testing is performed;
- Data retained on the specimens are restricted so as to prevent the possibility of indirect disclosure;
- There is access to voluntary confidential HIV testing for members of the target population; and
- A valid study design is employed.

Health professionals were informed of this screening programme by the Department of Health. The public was informed by a press release and a statement from the Minister for Health.

Last year, a new national AIDS Strategy 2000 was launched which acknowledged the changing nature of HIV/AIDS in this country from a life threatening illness to a more chronic condition with the use of highly active anti-retroviral treatments. It also highlighted the changing epidemiology of the disease in the State and the need to reinforce prevention messages particularly those targeted at school children and young people, as well as the traditional risk groups. The increasing importance of heterosexual spread was noted as were the demographic changes that have occurred in Ireland over the last five to ten years and have resulted in a greater cultural and ethnic diversity in Ireland.

In the new Strategy, the Surveillance Sub-Committee of the NASC recommended that: “Unlinked anonymous antenatal surveillance should continue until such time as the uptake of routine antenatal testing reaches 90% or more of the target population”.

Methods:

The screening was carried out on blood specimens routinely collected for rubella serology from pregnant women who booked into the antenatal clinics. Three laboratories, located in Dublin, Cork and Galway, were already responsible for the rubella testing for these clinics, and it was, therefore, agreed that these would be the laboratories involved in the unlinked anonymous HIV screening. Arrangements were made in each local area for all rubella samples to go to the appropriate laboratory.

Specimens in each laboratory were handled in the usual manner, and there was little alteration in the laboratory routine. The residual sera were grouped by age and by patients’ health board of residence. No other identifying information was recorded.
and, therefore, the residual sub-samples for HIV testing were both unlinked and anonymous.

Samples were screened for HIV in each of the laboratories using an Enzyme Immuno-Assay (EIA), and the Virus Reference Laboratory in Dublin performed additional EIAs and all confirmatory testing using a line assay. The small number of unconfirmed positive and indeterminate results obtained were considered to be negative as, due to the anonymous nature of the testing, repeat sampling was not possible.

Results:

The data were analysed from the last quarter of 1992 until the last quarter of 2000 inclusively, providing results for 33 consecutive quarters. A total of 464,780 tests had been carried out on blood samples from antenatal women up to the end of December 2000. Of these samples, 184 had been confirmed as HIV positive, giving a rate of 39.6/100,000 tests undertaken. Of these positive results, 126 (68.5%) were from women in the Eastern Regional Health Authority's region (formerly the Eastern Health Board) where approximately 36% of the population live and where 174,918 of the tests (37.6%) were performed.

Table 1 presents the annual figures for the numbers of blood samples examined, the numbers of positive test results and the rate for positive samples per 100,000 tests undertaken. For the purposes of presentation, data for the last quarter of 1992 have been included in the 1993 figures.

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Tests Undertaken</th>
<th>Total Negative Tests</th>
<th>Total Tests Confirmed Positive</th>
<th>Rate of Positive Results per 100,000 tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>1993 *</td>
<td>53,480</td>
<td>53,467</td>
<td>13</td>
<td>24.3</td>
</tr>
<tr>
<td>1994</td>
<td>51,118</td>
<td>51,112</td>
<td>6</td>
<td>11.7</td>
</tr>
<tr>
<td>1995</td>
<td>56,081</td>
<td>56,075</td>
<td>6</td>
<td>10.7</td>
</tr>
<tr>
<td>1996</td>
<td>62,008</td>
<td>61,996</td>
<td>12</td>
<td>19.4</td>
</tr>
<tr>
<td>1997</td>
<td>64,412</td>
<td>64,385</td>
<td>27</td>
<td>41.9</td>
</tr>
<tr>
<td>1998</td>
<td>67,124</td>
<td>67,098</td>
<td>26</td>
<td>38.7</td>
</tr>
<tr>
<td>1999</td>
<td>54,089</td>
<td>54,065</td>
<td>24</td>
<td>44.4</td>
</tr>
<tr>
<td>2000</td>
<td>56,468</td>
<td>56,398</td>
<td>70</td>
<td>124.0</td>
</tr>
<tr>
<td>Total</td>
<td>464,780</td>
<td>464,596</td>
<td>184</td>
<td>39.6</td>
</tr>
</tbody>
</table>

* Includes results of 4th Quarter of 1992

The positive results are shown in Table 2 by Health Board region of residence, comparing the Eastern Regional Health Authority's results against those from all other Health Boards combined together for the total numbers of samples examined and the rate for positive samples per 100,000 tests undertaken.
Table 2: Results of Anonymous Unlinked Antenatal HIV Screening in Ireland by Health Board Region of Residence up to December 2000.

<table>
<thead>
<tr>
<th>Health Board of Residence</th>
<th>Total Tests Undertaken</th>
<th>Total Negative Tests</th>
<th>Total Tests Confirmed Positive</th>
<th>Rate of Positive Results per 100,000 tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern Regional Health Authority (formerly the Eastern Health Board)</td>
<td>174,918</td>
<td>174,792</td>
<td>126 (68.5%)</td>
<td>72.0</td>
</tr>
<tr>
<td>All other Health Boards</td>
<td>289,862</td>
<td>289,804</td>
<td>58 (31.5%)</td>
<td>20.0</td>
</tr>
<tr>
<td>Total</td>
<td>464,780</td>
<td>464,596</td>
<td>184 (100%)</td>
<td>39.6</td>
</tr>
</tbody>
</table>

A breakdown by age group for all the tests undertaken together with the positive results is given in Table 3.

Table 3: Breakdown of Anonymous Unlinked Antenatal HIV Screening by Age Group.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Total Tests</th>
<th>Total Negative Results</th>
<th>Total Confirmed Positive Samples</th>
<th>Rate of Positive Results per 100,000 tests</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 20</td>
<td>35,572</td>
<td>35,566</td>
<td>6</td>
<td>16.9</td>
</tr>
<tr>
<td>20-24</td>
<td>73,180</td>
<td>73,146</td>
<td>34</td>
<td>46.5</td>
</tr>
<tr>
<td>25-29</td>
<td>121,820</td>
<td>121,755</td>
<td>65</td>
<td>53.4</td>
</tr>
<tr>
<td>30-34</td>
<td>131,797</td>
<td>131,744</td>
<td>53</td>
<td>40.2</td>
</tr>
<tr>
<td>35-39</td>
<td>63,178</td>
<td>63,161</td>
<td>17</td>
<td>26.9</td>
</tr>
<tr>
<td>40+</td>
<td>15,640</td>
<td>15,635</td>
<td>5</td>
<td>32.0</td>
</tr>
<tr>
<td>Not Stated</td>
<td>23,593</td>
<td>23,589</td>
<td>4</td>
<td>17.0</td>
</tr>
<tr>
<td>Total</td>
<td>464,780</td>
<td>464,596</td>
<td>184</td>
<td>39.6</td>
</tr>
</tbody>
</table>

Discussion

The total number of tests undertaken in 1999 was significantly less than the year before at 54,089 compared to the 67,124 undertaken in 1998. There is no obvious explanation for this as the number of births in the State in both these years was very similar, 53,551 in 1998 compared to 53,354 in 1999. The following year the number of tests did increase again to 56,468 while the number of births increased by a smaller amount to 54,239.

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Following the marked increase in the total number of anonymous unlinked blood samples from antenatal women testing positive for HIV in each of the previous three years in Ireland, 1998 had seen a levelling off in the number of positives confirmed, which continued into 1999. The total number of HIV positive samples detected was in fact slightly lower in 1999 at 24. However, because of the smaller number of samples taken, that meant that the national rate of positives per 100,000 tests had actually risen from 38.7 in 1998 to 44.4 in 1999.

The significantly higher sero-prevalence seen amongst women presenting for antenatal care in the Eastern Regional Health Authority's antenatal clinics compared to women attending the other Health Boards’ clinics had persisted. In 1999, there were 19 positive tests in the ERHA's region out of the 23,533 tests undertaken, giving a rate of 80.7 per 100,000 tests, compared to the 5 positive results in all the other Health Boards taken together out of the 30,556 tests undertaken, a rate of 16.4 per 100,000 tests. This meant that the rate for the ERHA had increased between 1998 and 1999, while that in the rest of Ireland had fallen slightly.

In 2000, the total number of HIV positive samples confirmed nationally increased almost threefold to 70, while the number of tests undertaken increased only slightly to 56,468. That meant that the national rate for positive samples per 100,000 tests had risen significantly to 124.0. Three quarters of the positive tests (52) in 2000 were in the Eastern Region, giving a regional rate of 197.0 per 100,000 tests. The rate had also risen significantly in the rest of the country, but only to 59.9 per 100,000 tests, maintaining the differential rates between the Eastern Region and the rest of the country.

Unlinked testing of antenatal women has in the past provided useful statistics for comparison purposes between countries in a population that is largely accessible during their attendances at antenatal clinics when blood is routinely taken from all women for rubella serology. It is also an indicator generally of the rate of heterosexual spread in a population, though women who may have been infected by other routes such as injecting drug use will also be identified as HIV positive. While this antenatal population cannot be taken to be representative of the population as a whole, the unlinked HIV antenatal testing data makes it clear that heterosexual transmission has become more important as a mode of spread of HIV infection in Ireland. This is supported by the HIV/AIDS data for 2000 recently published by the National Disease Surveillance Centre (NDSC) which showed a significant increase in the numbers of HIV positive individuals identified overall, but particularly in those thought to be due to heterosexual transmission. Initial reports based on linked HIV testing data from the main clinics indicate that a significant proportion of those with heterosexually acquired HIV infection are non-nationals. This is in keeping with data from Europe. In countries where sufficiently detailed data are available, 58% of those infected heterosexually originated from a country where the HIV epidemic is generalised.

5 National Disease Surveillance Centre. HIV and AIDS Statistics 2000
1999/2000 saw a change in the system for antenatal testing for HIV with the introduction nationally of linked testing in antenatal clinics. The maternity hospital where this had already happened had not experienced any difficulty in terms of significant numbers of women being unwilling to submit to linked HIV testing after a pre-test discussion. Only a small number of women had actually refused initially, and some of those had subsequently agreed to be tested after further discussion/counselling.

At one level, the establishment nationally of linked antenatal HIV testing will reduce the potential for the duplication of results of tests from the same antenatal women being included in the results, improving the accuracy of this monitoring. It will, however, be necessary to continue unlinked testing until linked testing is available all over the country and a good level of compliance of greater than 90% is seen, so that the HIV infection rate in this population can continue to be monitored effectively in the interim.

At another level, the establishment of nation-wide routine linked antenatal HIV testing was seen as ethically important as it had been clearly shown that perinatal transmission can be dramatically reduced or prevented by antenatal treatment of HIV positive women with anti-retroviral drugs and by careful management of the delivery. Mother to child transmission can be further reduced by advising mothers who are known to be HIV positive against breast-feeding their child. In Ireland, when the positive HIV status of the mother is known antenatally, the perinatal transmission rate has so far been less than one per cent.

Conclusions

1) The national prevalence of HIV infection in antenatal women rose by more than 10% in 1999, supporting the view that the heterosexual transmission of HIV infection was continuing to increase in importance as a mode of HIV transmission in Ireland. However, there was an even more dramatic increase in prevalence in the year 2000 when the rate almost tripled from 44 to 124 positive samples per 100,000 tests, further emphasising the importance of heterosexual transmission and the need to promote safer sex amongst the heterosexual population, particularly amongst the younger generation before they become sexually active.

2) This increase in the importance of heterosexual transmission in Ireland was confirmed by the HIV figures from the main laboratories for 2000, which showed a marked increase overall, but particularly in infections thought to be due to heterosexual transmission. Data on the ethnicity of individuals being tested for HIV has not been routinely collected in Ireland, but initial reports based on linked data from the main clinics indicate that a significant proportion of those with heterosexually acquired HIV infection are non-nationals.

3) A national linked antenatal HIV testing system was initiated in 1999/2000. In view of the availability and proven value of antenatal anti-retroviral therapy in reducing perinatal transmission of HIV, universal linked antenatal HIV testing should continue to be promoted. A review of the implementation of this programme has shown that there are still gaps in achieving adequate coverage nation-wide. It is
imperative that a coverage of greater than 90% is achieved throughout the State before the unlinked antenatal HIV monitoring is discontinued.

4) Based on the experience of implementing a linked antenatal HIV testing programme, and with the increasing numbers of women from other countries delivering in Irish maternity hospitals, it would seem reasonable to initiate a programme of universal antenatal hepatitis B screening, as it is also possible to prevent mother to child transmission of the infection.

5) In July 2001, a national system of HIV case-based reporting was initiated, bringing Ireland in line with most of the rest of Europe and allowing for the use of more recent epidemiological data to track the spread of HIV infection in Ireland. The significantly increased incidence of HIV infection in this country and the changing pattern of transmission with increasing heterosexual spread, make this development all the more important.

6) A unique patient identifier is still not available in Ireland but would clearly be an important part of a strategy to avoid duplication of the results included in the national data and to assist in linking records for individuals who test positive for HIV on different occasions or in different locations in any HIV screening programme, including one for linked antenatal testing.

30 November, 2001