The costs and effectiveness of surveillance of communicable disease: a case study of HIV and AIDS in England and Wales

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Abstract

Background In England and Wales, surveillance of communicable disease is carried out and co-ordinated by the Public Health Laboratory Service (PHLS). The surveillance of HIV infection and AIDS is undertaken by the PHLS AIDS Centre at the Communicable Disease Surveillance Centre (CDSC). Epidemiological data derived from surveillance are not, however, a free good: they are a resource with an associated opportunity cost and should therefore be open to economic appraisal alongside other uses of health care resources such as medical interventions. This paper assembles information on the current surveillance of HIV and AIDS in England and Wales, and explores methods for performing an economic evaluation of such activities.

Methods An examination of the cost and effectiveness of the PHLS AIDS Centre's epidemiological surveillance mechanisms for HIV and AIDS in England and Wales was undertaken. The total costs of each component of surveillance of HIV and AIDS in England and Wales were calculated. Two categories of cost were estimated: peripheral costs incurred by reporters in reporting AIDS cases or HIV infections or by laboratories in collecting samples; and central costs incurred by the PHLS AIDS Centre in processing and analysing incoming data. Using these cost data and information from a cost-effectiveness register, the additional health gains that would have to be obtained from surveillance to make the programme broadly cost-effective in comparison with other accepted uses of health service resources were then estimated.

Results In the financial year 1993–1994 the total costs of surveillance were estimated to be £1.4 million. To avoid being considered relatively cost-ineffective at least 3.5 infections per annum need to be averted. To be considered favourably cost-effective, approximately 9.5 infections per annum need to be averted.

Conclusions In 1993–1994, expenditure on surveillance of HIV and AIDS accounted for less than 1 per cent of the total allocation of resources to the National Health Service for all HIV and AIDS activities. Given these cost estimates, the number of infections which surveillance would have to contribute towards preventing in order to be considered cost-effective is low.

Keywords: surveillance; HIV–AIDS; cost; information

Introduction

Recent reforms in health care rely heavily on improving flows of information to clinicians, managers and patients. Collecting such information may require substantial resources, but good information should improve the effectiveness of health services in terms of the health outcomes of patients. Consequently, the acquisition and dissemination of information can in principle be analysed within the same framework of economic evaluation that is applied to the deployment of other health resources.

One important category of information comes from surveillance of communicable disease, which has been defined as 'the continued watchfulness over the distribution and trends of incidence through the systematic collection, consolidation, and evaluation of morbidity and mortality reports and other data... and the regular dissemination of... data to all who need to know'. In England and Wales, surveillance of communicable disease is carried out and co-ordinated by the Public Health Laboratory Service (PHLS), which undertakes diagnostic microbiology for the detection of infectious agents and epidemiological...
surveillance. The surveillance of HIV infection and AIDS is undertaken by the PHLS AIDS Centre at the Communicable Disease Surveillance Centre (CDSC) to 'describe the epidemic in time, place and person and to recognise swiftly changes in the rate or pattern of HIV transmission'.

As in other areas of public expenditure, the cost and cost-effectiveness of the PHLS have been scrutinized in recent years. The main objective of this paper is to assess the costs and cost-effectiveness of the PHLS AIDS Centre's epidemiological surveillance mechanisms for HIV and AIDS in England and Wales. Specifically, the analysis concentrates on the effectiveness of surveillance as measured by the uses to which surveillance data may be put, rather than simply the effectiveness of surveillance per se. Although there are many possible intermediate outcomes from a surveillance programme, such as the accuracy of the information collected or the population's knowledge of the epidemiology of the disease, the analysis concentrates on final health outcome as the chosen measure of effectiveness.

Method

Costs of surveillance

All components of the surveillance of HIV and AIDS undertaken by the PHLS AIDS Centre over the period 1991–1992 to 1993–1994 were identified from relevant documentation and discussions. These components are as follows:

- voluntary confidential reporting of HIV and AIDS cases;
- voluntary HIV antibody testing (collaborative study);
- unlinked anonymous HIV antibody screening:
  - genito-urinary medicine (GUM) clinic attendees;
  - injecting drug users;
  - antenatal clinic attendees;
  - neonates (dried blood spot testing);
  - women undergoing termination of pregnancy;
  - hospital patients;
- blood donor screening programme;
- CD4 lymphocyte count study;
- monitoring of hepatitis in health care workers;
- monitoring of sexually transmitted diseases.

The foundation of surveillance of HIV and AIDS in the United Kingdom is voluntary confidential reporting of AIDS cases by clinicians, and of newly identified HIV infections by microbiologists. The clinicians and microbiologists concerned are asked to complete a special clinical report form which is sent directly to CDSC. The form is used to collect data on demographic features, behavioural and other risk factors, and the clinical details of each case. The PHLS collaborative study combines collection of information on laboratory test forms with the maintenance in each laboratory of a database of results. The study aims to collect information on all voluntary named HIV tests conducted in these laboratories. An additional source of data on HIV prevalence has been the results of blood donor screening, which can detect spread in groups not recognized as being at risk of infection.

The groups presenting for HIV testing, whether as blood donors or as patients, may well be unrepresentative of the population. Moreover, owing to the long incubation period of HIV, people may be infected for many years before infection is recognized. These factors led to the implementation of unlinked anonymous surveillance methods, in which specimens, usually taken for other purposes (such as during attendance at genito-urinary medicine clinics, or while undergoing termination of pregnancy) are 'unlinked' from personal identifiers but remain linked to epidemiological information of importance.

The surveillance mechanisms used to monitor the AIDS epidemic are continually modified and developed to recognize any changes in the rate or pattern of HIV transmission. For example, in 1993 the CD4 lymphocyte count study was introduced to estimate the prevalence of severe HIV disease not fulfilling the AIDS case definition. There are several other components of the surveillance programme, including the monitoring of hepatitis in health care workers, and the monitoring of sexually transmitted diseases, which also provide information on the epidemiology of infection.

Once all surveillance activities were identified, their costs were calculated for each of the three financial years 1991–1992, 1992–1993 and 1993–1994. There are two categories of costs of surveillance. First, there are 'peripheral' costs, for example, those incurred by clinicians in reporting HIV infections and AIDS cases or by laboratories in collecting samples for unlinked anonymous HIV antibody testing. Second, there are 'central' costs incurred by the PHLS AIDS Centre in processing and analysing incoming data. Each cost category was estimated for each component of surveillance.

For specific surveys, peripheral costs, such as clinic staff salaries, are calculated and then sent to the PHLS AIDS Centre, which is billed accordingly. Information concerning peripheral costs of reporting HIV infections and AIDS cases was obtained by interviewing two Directors of Public Health and related staff, and four
accurately as possible, some assumptions had to be made owing to the lack of relevant data. However, the estimates do provide a reasonable indication of the true costs of surveillance.

Benefits of surveillance

As an initial way of defining the range of potential benefits of surveillance data, all direct users of the information generated by the PHLS AIDS Centre, and all users of surveillance information, were identified. These are as follows:

- Chief Medical Officers – England, Wales, Scotland, Northern Ireland;
- PHLS AIDS Co-ordinating Committee;
- Communicable Disease Branch of the Health Promotion Division of the Department of Health;
- Health Education Authority;
- MRC AIDS Secretariat;
- Director MRC AIDS Directed Programme;
- Expert Advisory Group on AIDS;
- MRC Committee for Epidemiological Studies of AIDS;
- Public Health Medicine Consultants co-ordinating AIDS–HIV information in each RHA and DHA;
- Faculty of Public Health Medicine – AIDS Working Party;
- Public Health Laboratory Service Collaborating Laboratories;
- Secretariat, All Parliamentary Group on AIDS;
- European Community–World Health Organization.

The list shows that the direct users include decision-making bodies, those responsible for treatment and care, those responsible for prevention and education, and those involved in research. It confirms that surveillance may have only a limited direct effect on health outcome, but a major impact via various interventions initiated or modified as a result of surveillance information. For example, surveillance can lead to the detection, investigation and control of an outbreak of acute infectious disease such as salmonellosis, and in this case it is possible to estimate the benefits in terms of the medical and other costs which have been averted. Similarly, epidemiological information gained through surveillance may affect the subjective assessment of risks facing individuals and thus influence their behaviour, and this could be used as a measure of effectiveness. For example, there is survey evidence that 19·5 per cent of men of all ages and 14·2 per cent of women of all ages adopted less risky behaviour after the onset of the AIDS epidemic. Those at greater risk of infection were more likely to have taken measures to avoid HIV infection. These behavioural changes are likely to have resulted at least in part from health education and promotion...
campaigned, which in turn were based in part on surveillance data. Other instances of such behaviour changes have been discussed in this context: for example, the demonstration that knowledge of HIV prevalence affected the decision to use a condom in random heterosexual encounters.\textsuperscript{11}

Some commentators have argued that a major barrier to a successful comprehensive surveillance system is the lack of appreciation of such uses of high-quality surveillance data.\textsuperscript{12} However, it is often difficult to accurately measure the benefits of surveillance. A review of the literature performed as part of this study identified very little research in the area, which may reflect these difficulties. Ideally, benefits could be measured by identifying the costs that would be incurred without any surveillance in place, but the opportunities of doing so in any experimental setting are highly constrained. With HIV infection, these difficulties are compounded by the long period over which the impact of the infection on morbidity and mortality occurs.

In addition to the potential benefits of surveillance data in altering health outcomes, it is possible that the economic efficiency with which available resources are used could be enhanced by such data. For example, surveillance information is used in the allocation of funds to Regional Health Authorities to combat the AIDS epidemic. Funds for direct treatment and care have been allocated according to a formula that uses data on the number of people with AIDS who are still alive categorized by the Region where they were first reported and by their Region of residence. The formula also includes the number of people who are HIV positive categorized by the Region where they were first reported.\textsuperscript{17-20} Surveillance data provided by the PHLS AIDS Centre enable the Department of Health to use these formulae, and therefore play an important role in policy formulation and resource allocation. If the surveillance data were unavailable or less accurate, a substantial mismatch could occur between the funds distributed for HIV- and AIDS-related activities and the health care requirements generated in different regions by the epidemic, resulting in an overall loss of welfare. However, as with the public health and health education interventions discussed above, the actual benefits of surveillance data are difficult to quantify, not least because it is so hard to estimate what the outcome would have been with no surveillance.

Rather than measure the benefits of surveillance directly, the method adopted in this study was to calculate the costs of the programme as accurately as possible, and then estimate the additional health gains that would have to be obtained from surveillance to make the programme broadly cost-effective in comparison with other accepted uses of health service resources. Equipped with such information, decision-makers can then decide if the additional health gains required to achieve cost-effectiveness seem plausible.

**Results**

**Costs of surveillance**

Table 1 lists the main components of HIV and AIDS surveillance undertaken by the PHLS AIDS Centre and

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<tr>
<td>Core HIV–AIDS surveillance</td>
<td>512 (40)</td>
<td>495 (36)</td>
<td>491 (35)</td>
</tr>
<tr>
<td>PHLS collaborative study</td>
<td>67 (5)</td>
<td>64 (5)</td>
<td>64 (5)</td>
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<tr>
<td>Unlinked anonymous screening:</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Antenatal clinics</td>
<td>325 (26)</td>
<td>162 (12)</td>
<td>70 (5)</td>
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<tr>
<td>GUM clinics</td>
<td>162 (13)</td>
<td>334 (25)</td>
<td>268 (19)</td>
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<tr>
<td>IDU–saliva*</td>
<td>95 (7)</td>
<td>103 (8)</td>
<td>114 (8)</td>
</tr>
<tr>
<td>Hospital patients</td>
<td>98 (8)</td>
<td>65 (5)</td>
<td>94 (7)</td>
</tr>
<tr>
<td>Terminations</td>
<td>14 (1)</td>
<td>19 (1)</td>
<td>11 (1)</td>
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<tr>
<td>DBS testing</td>
<td>–</td>
<td>110 (8)</td>
<td>160 (11)</td>
</tr>
<tr>
<td>Shared</td>
<td>–</td>
<td>–</td>
<td>98 (7)</td>
</tr>
<tr>
<td>CD4 lymphocyte count study</td>
<td>–</td>
<td>–</td>
<td>27 (2)</td>
</tr>
<tr>
<td>Total</td>
<td>1273 (100)</td>
<td>1352 (100)</td>
<td>1397 (100)</td>
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<td>Annual per cent change</td>
<td>–</td>
<td>+6.2</td>
<td>+3.3</td>
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* Includes pilot survey of HIV in London prisons.
The preceding discussion has emphasized the range of costs and benefits associated with surveillance activities. The peripheral costs of time taken by clinicians and microbiologists to fill in the AIDS case and HIV infection report forms were then passed on to the PHLS AIDS Centre, estimated to be very low and consequently were not included. Other non-negligible peripheral costs such as clinic staff salaries were included with the costs of specific unlinked anonymous surveys.

It should be noted that not all components of surveillance have been in place since 1991: HIV antibody testing of neonatal dried blood spots was introduced in 1992, and CD4 lymphocyte count monitoring began in 1993.

Some aspects of surveillance incur no costs to the PHLS AIDS Centre. Blood donor screening is undertaken by the National Blood Transfusion Authority, and data from the monitoring of hepatitis in health care workers and the monitoring of sexually transmitted diseases (STDs) in selected GUM clinics are utilized in HIV-AIDS surveillance in England and Wales but are part of normal surveillance of the diseases. These costs were therefore excluded from the analysis.

As the table indicates, the total cost of all HIV and AIDS surveillance activities undertaken by the PHLS AIDS Centre was £1.27 million in 1991–1992, and rose in real terms by 6.2 per cent in 1992–1993, and by a further 3.3 per cent in 1993–1994 to just under £1.4 million. The main components of surveillance were core surveillance (i.e. HIV infection and AIDS case reporting), and unlinked anonymous HIV serosurveillance in GUM clinics, which together accounted for approximately 54 per cent of all expenditure in 1993–1994. Over the period studied, the share of total expenditure taken by core surveillance fell from 40 per cent to 35 per cent, and by the ante-natal clinic unlinked anonymous screening programme from 26 per cent of expenditure to 5 per cent. However, neonatal dried blood spot testing, established in 1992, was responsible for 11 per cent of all expenditure by 1993–1994.

Expenditure on surveillance can also be compared with the total allocation of resources to the National Health Service (NHS) for all HIV and AIDS activities. This allocation came to £137 million in 1991–1992, £179 million in 1992–1993 and £196 million in 1993–1994 (Communicable Disease Branch of the Health Promotion Division of the Department of Health, personal communication, 1994), so that surveillance expenditure was equivalent to 0.86 per cent, 0.74 per cent and 0.71 per cent, respectively, of this allocation.

Cost-effectiveness of surveillance

The preceding discussion has emphasized the range of uses to which surveillance data may be put. These may be summarized as: (1) monitoring the effect of HIV and AIDS on morbidity and mortality; (2) providing the basis for predicting the future course and impact of the epidemic; (3) providing a basis for assessing the need for various interventions; (4) aiding policy formulation and resource allocation; (5) guiding research into the patterns of transmission and the evaluation of preventive programmes; (6) aiding the clinical care of patients via the appropriate allocation of limited resources.

Although it is extremely difficult to quantify the health impact of such data, it is possible to estimate the impact such data would need to have to be cost-effective, where the benefits of surveillance are measured in terms of final health outcomes. Using results from a detailed costing exercise, we have shown that the cost of HIV and AIDS surveillance in 1993–1994 was £1.4 million per annum. The most comprehensive costing study conducted to date in the United Kingdom, covering approximately 10 per cent of the national case-load, established that the annual health care costs by stage of disease progression (indexed to 1993–1994 prices) are approximately £1079 per person who is HIV infected but asymptomatic, £4001 per person who is symptomatic but without AIDS, and £17 683 per person with AIDS. Additionally, a recent study examining the cost and utilization of community services for people with HIV and AIDS estimated average total annual costs of providing community based care by stage of disease progression (indexed to 1993–1994 prices) to be £21 344 per person who is HIV infected but asymptomatic, £2819 per person who is symptomatic but without AIDS, and £4134 per person with AIDS. Therefore, total annual health care costs, by stage of disease progression, are £3213 per person who is HIV infected but asymptomatic, £6820 per person who is symptomatic but without AIDS, and £21 817 per person with AIDS. If we assume that the length of time an individual is likely to spend at each stage of disease progression is 10 years HIV infected but asymptomatic, 1 year symptomatic but without AIDS and 21 months with AIDS, then the total health care costs incurred by an individual progressing through these stages would be £77 130; discounted to present values at an annual rate of 6 per cent this would be approximately £51 200.

Therefore, for the benefits of surveillance to exceed the costs, the information gained must directly produce sufficient marginal changes in individual behaviour, or indirectly create sufficient marginal improvements in prevention campaigns, clinical decisions and resource allocation, to prevent an additional 27 individuals from becoming infected each year. Benefits as defined in this
illustration exclude indirect costs such as lost earnings, and intangible costs such as pain and suffering, all of which would have to be incorporated in any formal cost–benefit analysis. Including these would substantially reduce the cases of infection that would have to be averted to ensure that benefits outweighed costs.

An alternative framework for evaluation which avoids the many difficulties of attaching monetary costs to such indirect and intangible items is cost-effectiveness analysis, in which costs are expressed as a ratio of an appropriate outcome measurable in terms of natural units, such as deaths averted, life-years gained, or, in the case of cost–utility analyses, some measure embodying a valuation of the utility derived from a health gain, such as quality-adjusted life years (QALYs) gained. Estimates of cost-effectiveness are increasingly available for a range of interventions currently provided by the NHS, and these provide an opportunity to assess how many life-years or quality-adjusted life years would have to be gained by HIV and AIDS surveillance to make the programme cost-effective in comparison with other funded interventions.

Using information from a recently published register of cost-effectiveness studies, all reported costs per QALY in UK studies performed since 1980 were extracted. In total, 116 such ratios were identified, and when indexed to 1994 prices the mean cost per QALY was £14,721 (SD £32,987). The data were highly skewed, and the median cost per QALY was £4,213, with an inter-quartile range of £1,621–£11,567. There is no currently accepted way of assessing what might be regarded as acceptable level of cost-effectiveness, but for the present purposes let us suppose that the critical cost-effectiveness range is between the median value of £4,213 and the upper quartile of £11,567 per QALY. That is, any intervention with a cost-per-QALY of less than £4,200 can be classed as comparatively cost-effective, and anything with a cost-per-QALY greater than £11,600 will be classed as relatively cost-ineffective. It follows that HIV–AIDS surveillance, with an annual cost of £1.4 million, must yield at least 121 QALYs each year to avoid being classed as relatively cost-ineffective. It could be classified as comparatively cost-effective if it yielded 332 QALYs each year.

Pursuing this line of reasoning further, let us suppose that the average male with AIDS dies at the age of 40 (an estimate made from the age distribution of AIDS cases), and would otherwise live for another 35 years, so that one case averted yields an average of 35 life years. If we assume that these life years are in fact QALYs then for surveillance to avoid being classified as relatively cost-ineffective it must lead to an additional 3.5 cases per annum being averted. To be considered comparatively cost-effective, approximately 9.5 additional cases of infection per annum need to be averted.

As noted above, surveillance information may have a direct effect on behaviour and hence on health, but it is more likely to have an indirect effect by influencing prevention campaigns, clinical decisions and resource allocation. Of these, the most straightforward to quantify is prevention. For the year 1994–1995 (the year in which 1993–1994 surveillance data would be likely to be used), the total regional allocation of funds for prevention within the overall HIV and AIDS allocation was £47.6 million. Total NHS expenditure on surveillance and prevention therefore totalled £49 million. For this combined programme to avoid being classified as relatively cost-ineffective it must lead to at least an additional 121 cases each year being averted. To be considered comparatively cost-effective, at least an additional 333 new cases of infection each year need to be averted.

To place these figures in context, 2,514 newly diagnosed (though not necessarily incident) HIV infections were reported during the financial year 1993–1994, so the marginal annual number of infections that the existing surveillance programme would have to prevent to be considered comparatively cost-effective would be equivalent to 0.4 per cent of the actual number of new infections reported. Similarly, the surveillance and prevention programmes taken together would be comparatively cost-effective if the annual number of infections they prevented was equivalent to 13 per cent of the actual number of new cases reported.

**Discussion**

Communicable disease surveillance has many potential uses, some of which may be of great importance. For example, the former Chief Medical Officer Sir Donald Acheson has argued that only from the results of surveillance was it recognized that there was a long latent period between HIV infection and the onset of symptoms during which the infected person might be infectious; without surveillance and the epidemiological data that it provides, very little would be known about the relative importance of various modes of transmission of the disease and geographical variations in the UK epidemic. Furthermore, surveillance underpins NHS resource allocation and provides the basis from which projections of the spread of the epidemic can be made. Surveillance shows where infection occurs and allows effective direction of resources to high prevalence areas. Without such direction, resource allocation
may be inefficient and hence may adversely affect patient care.

Despite these arguments, it is extremely difficult to quantify the benefits of surveillance data, and information on costs may be absent or inadequate. This paper has reported on a detailed costing analysis and a framework for considering the cost-effectiveness of surveillance. It has established that the total costs of surveillance of HIV and AIDS in England and Wales carried out by the Public Health Laboratory Service were £1.397 million in the financial year 1993–1994, having grown in real terms in each of the previous two years. This expenditure is equivalent to 0.71 per cent of the total allocation of £196 million in 1993–1994 to the NHS for all HIV and AIDS activities.

Given these cost estimates, and using information on the cost-effectiveness of a range of other interventions offered by the NHS, we have calculated that the number of infections which surveillance would have to contribute towards preventing to be considered as comparatively cost-effective compared with other health interventions in the UK is approximately 9.5 cases per annum, and to avoid being considered comparatively cost-ineffective, around 3.5 additional cases of infection per annum need to be averted. Adding in all NHS expenditure on HIV and AIDS prevention, these figures rise to 333 and 121 cases, respectively. Within this framework, decision-makers can at least consider whether these required levels of effectiveness are plausible.

Others measures of outcome could be considered. For example, it has been argued that an important role of information in the reformed NHS is to enable managers prospectively to gain maximum health gain from their purchasing decisions and to improve decisions about the allocation of resources at their disposal.29 If the surveillance data on HIV and AIDS are used to improve decisions about the allocation of NHS expenditure on HIV and AIDS, which totalled £196 million in 1993–1994, then the costs of surveillance would be recouped by an efficiency gain in the allocation of these resources of just 0.7 per cent.

A noticeable feature of this study has been the apparent lack of previous work on the effectiveness of surveillance mechanisms. This may be attributable in part to the difficulties encountered when valuing epidemiological information and measuring benefits. Health promotion interventions have also generally lacked rigorous evaluation, and the design of evaluation in this area needs to be improved if reliable evidence on effectiveness is to be generated.30

Although evaluation of surveillance information poses many problems, it is becoming increasingly difficult to avoid. This paper has attempted to initiate discussion on an evaluative framework and to provide the cost data relevant to such an evaluation.

Acknowledgement

We would like to thank Dr Noel Gill for his helpful comments.

References


Accepted on 1 May 1996