

Response to consultation on Aids/HIV infected health care workers

Guidance on management of infected health care workers and patient information

About the Scottish Consumer Council

The Scottish Consumer Council (SCC) was set up by government in 1975. Our purpose is to promote the interests of consumers in Scotland, with particular regard to those people who experience disadvantage in society. While producers of goods and services are usually well-organised and articulate when protecting their own interests, individual consumers very often are not. The people whose interests we represent are consumers of all kinds: they may be patients, tenants, parents, solicitors' clients, public transport users, or simply shoppers in a supermarket.

Consumers benefit from efficient and effective services in the public and private sectors. Service-providers benefit from discriminating consumers. A balanced partnership between the two is essential and the SCC seeks to develop this partnership by:

- carrying out research into consumer issues and concerns;
- informing key policy and decision-makers about consumer concerns and issues;
- influencing key policy and decision-making processes;
- informing and raising awareness among consumers.

The SCC is part of the National Consumer Council (NCC) and is sponsored by the Department of Trade and Industry. The SCC's Chairman and Council members are appointed by the Secretary of State for Trade and Industry in consultation with the Secretary of State for Scotland. Future appointments will be in consultation with the First Minister. Martyn Evans, the SCC's Director, leads the staff team.

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The SCC assesses the consumer perspective in any situation by analysing the position of consumers against a set of consumer principles.

These are:

ACCESS

Can consumers actually get the goods or services they need or want?

CHOICE

Can consumers affect the way the goods and services are provided through their own choice?

INFORMATION

Do consumers have the information they need, presented in the way they want, to make informed choices?

REDRESS

If something goes wrong, can it be put right?

SAFETY

Are standards as high as they can reasonably be?

FAIRNESS

Are consumers subject to arbitrary discrimination for reasons unconnected with their characteristics as consumers?

REPRESENTATION

If consumers cannot affect what is provided through their own choices, are there other effective means for their views to be represented?

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The Scottish Consumer Council (SCC) exists to make all consumers matter. We are, amongst other things, committed to improving the understanding, communication and management of risk and uncertainty so that consumers can be confident in their use of services in both the public and private sectors.

The issue of AIDS/HIV infected health care workers is one in which consumers of health services, their carers and families have a clear interest. We therefore welcome the opportunity to respond to this consultation from NHS Scotland.

1 General

This guidance will have the effect of restricting the occasions on which it is considered necessary to notify patients that they may have been at risk of exposure to the HIV virus. This reflects the evidence which shows that in the UK there has been no recorded case of infection passing from a healthcare worker to a patient, and only two reported incidents worldwide. The NHS therefore seeks to reduce the possibility of anxiety, and the costs of unnecessary counselling and testing for the virus, in situations in which the risk of infection is considered to be very low.

Previously, all patients in the UK have been notified regardless of their level of risk. The new policy is designed to avoid unnecessary anxiety to patients and puts Britain more in line with practice in other countries. From now on the risk of HIV transmission to patients will be assessed on a case by case basis and whether patients are notified will depend on the level of risk.

The Department of Health is currently working with health professionals and patients to draw up specific guidance to quantify the level of risk associated with clinical procedures that are classified as "exposure prone". The guidance will be designed to give Directors of Public Health clear criteria to guide them when considering whether a patient notification exercise is required, and its extent. Under the new guidance, all patients who are notified will be offered pre-test discussion and an HIV antibody test.

The SCC broadly agrees with this approach, provided that the interests of patients are at all times paramount.

2 Role of the Director of Public Health

We welcome the recommendation that one person, the Director of Public Health of either the primary care trust or the NHS board, has been given the responsibility for making decisions on notification locally. Research shows that in policy areas characterised by complex organisational environments the management of risk is more likely to be effective when there is a single actor who can provide clear leadership to the agencies involved.

Our only concern is that the Director of Public Health will need to involve a wide network of specialists. In complex cases where this expanded involvement is necessary it is not made clear how this interaction will be co-ordinated, if at all. There will also be occasions when more than one Director of Public Health will be involved, for example if an infected worker has worked in different parts of the country. It is important that it is clear who has the final authority for making decisions about the need for patient notification.

From the consumer point of view the director of public health could be a clearly identifiable figure head who could also act as arbiter in any disputes which might arise about the process or aftermath of notification.

3 Patient safety and public confidence

Patient safety and public confidence have rightly been linked in the consultation document to the promotion of a climate within the health service which encourages HIV-infected or at risk employees to disclose their condition confidentially (paragraph 6.6). However the document makes no mention of how this climate will be promoted or whether there will be any monitoring system or procedures to ensure that such an atmosphere is being fostered.

The SCC considers that one way of promoting such an atmosphere would be to produce guidance for staff and employers about how disclosure should be handled. This should stress the importance of disclosure, as well as making assurances about the way in which the confidentiality of the employee will be protected. It should describe who any disclosure should be made to, and how the disclosure will be handled by the employer. The guidance should outline the steps which will be taken following disclosure, both in relation to the health of employees and in relation to the impact this will have on the work which they can do.

This is particularly important in the light of evidence from a survey of junior doctors at Guy's and St Thomas's Hospitals which suggests a low level of knowledge about occupational exposure to HIV among junior doctors. Two thirds of doctors surveyed did not know the names of drugs which could protect them against possible infection.

To promote a climate which encourages disclosure, and in an NHS which increasingly recruits staff from overseas, where the risk of having acquired HIV may be higher, it may be useful to make efforts to increase the level of knowledge and awareness of the risk of HIV infection generally in different health care settings.

Similarly, the SCC welcomes the duty which is placed on health care workers to inform employers if they know that an HIV infected worker may be practising in a way which puts patients at risk (para 4.17). This is not an easy thing for fellow employees to do, and again it is important that a climate is encouraged in which it is made as easy as possible for an employee to inform employers of their concerns. The suggestion that wherever possible the health care worker should be informed before information is passed to an employer or regulatory body may constitute a real barrier to an employee giving voice to their concerns.

4 Patient notification (section 8)

It could be argued that all patients have a right to know if they are being treated by a health care worker who is infected with HIV or AIDS, particularly in relation to informed consent. If a patient has to give consent to a particular course of treatment, are they entitled to know the full facts about that treatment, who will be treating them and what risks might be involved?

However, as discussed above, the medical evidence is that the risk of transmission of HIV/AIDS from a health care worker is extremely low, and can be virtually prevented if, but

only if, good practice in relation to disclosure and risk management is followed. It is critical that Directors of Public Health are able to demonstrate that good practice is being followed in each of these areas. The existence of guidance of the type described above, in relation to patient safety and public confidence, will be an important element in indicating that good practice is being followed. It may be that NHS Quality Improvement Scotland should have a role in monitoring the extent to which good practice is being followed.

In addition, infected healthcare workers have a right to confidentiality in relation to something which is unlikely to have an impact on their work.

The SCC accepts the principle that patients should only be notified if they are judged to have been exposed to a sufficient level of risk, provided that the risk assessment procedures in place are effective in determining the degree of risk involved. However, we would recommend that in cases where the risk assessment does not produce clear results regarding whether or not to pursue notification, the health service should err on the side of notification. In paragraph 8.16, the guidance suggests that if a decision cannot be made about the need for a patient notification exercise, then the UK Advisory Panel for Health Care Workers Infected with blood borne viruses (UKAP) should be consulted. We would recommend that where doubt exists, the precautionary principle should be followed, and patients should be notified.

Studies of patients who have been notified of low level risks show that, despite the considerable anxiety which notification brings, on average over 90% of these patients accepted the notification programme as necessary. Patients thought that they should always be informed following exposure to an infectious health care worker¹. This was the case even where the risk was considered to be small.

5 Guidance on notifying patients (section 11)

The SCC agrees that, wherever possible, patients should be notified before any public announcement is made (para 11.2 and 11.10). We agree with the guidance that the most appropriate way of contacting the patient should be used. The SCC believes that, wherever feasible, this should be done in person, in some cases through the GP. Paragraph 11.13 "suggests" that when patients are informed by letter, local GPs should be written to at the same time. We suggest that GPs should always be written to in these circumstances, and the guidance should be stronger on this point.

Where there is no alternative to notifying patients in writing, it is important that this is done in a way that can be understood by all patients. It should not contain jargon, but be written in plain English, pitched at the average reading age of the Scottish population. In addition, to ensure that it is accessible to most patients, it would be useful to print any letters in a minimum font size of 14, to comply with the Scottish Accessible Information Forum's accessibility standards. All such letters should contain a phone number for seeking advice.

In addition, the needs of disabled patients must be borne in mind, particularly those with a visual or hearing impairment, as well as those with learning disabilities. It will be important to ensure that carers get the notification when the patient is unable to understand the content of the letter or other communication.

¹ Blatchford O, O'Brien SJ, Blatchford M, Taylor A, "Infectious health care workers: should patients be told?", *Journal of Medical Ethics* 2000 Feb; 26(1): 27-33

McCordle, King, Newman, Murphy, Corey, Poon, Freedom, "What do families know about blood product exposure during pediatric cardiac surgery and the risk of HIV infection?", *Pediatr AIDS HIV Infect.* 1994 Oct;5(5): 317

