



## **CONFIDENTIALITY AND DISCLOSURE OF PATIENT INFORMATION: HIV AND STIs**

### **National AIDS Trust response to the Department of Health consultation**

The National AIDS Trust (NAT) welcomes the opportunity to comment on the Department of Health's consultation document 'Confidentiality and Disclosure of Patient Information: HIV and STIs'. In this response we address issues relating to HIV since our policy work focuses exclusively on this condition.

*Do you agree that where a health care professional believes their patient's sexual behaviour is putting individuals at risk of serious harm, and, the identity of those at risk is known, the health care professional should consider taking steps to inform known contacts, even if the patient does not consent, or consent cannot be obtained, and the patient cannot be persuaded to tell the individual themselves?*

*What might those steps be if the identity of the person at risk is known but they are not a patient of the treatment centre treating the index patient?*

NAT does agree with the general principle as set out in these questions. It should be added that partner notification is not simply to protect the contact from contracting the virus but also to provide prompt diagnosis and treatment in those instances when the contact has already been infected.

A number of important points need to be made:

The healthcare professional must have good cause to believe that the patient's sexual contact(s) is at risk of HIV infection. Having had or continuing to have sex whilst infected is not sufficient cause to believe partners are at risk. Sexual history will need to suggest significant risk taking behaviour with the identified sexual partner(s), in most cases unprotected anal or vaginal intercourse. It must also be clear that the index patient has not informed his/her sexual partner of the need to contact the clinic and has no intention of doing so. Any breach of confidentiality will need to be justified and there should never be any suggestion that someone has been considered untrustworthy simply because of their sexuality, ethnic origin, residency status or any other reason.

The process of partner notification must be rooted in the consent of the index patient. As the GMC Guidance makes clear, notification must begin with a process in which either the patient is persuaded to notify his/her sexual contact(s) or the patient agrees that the clinic can do so on his/her behalf.

Sufficient time should be allowed to complete this process. There is a danger that the recent advent of criminal prosecution for HIV transmission will improperly influence partner notification, which is fundamentally a public health intervention. It is possible the law considers someone to be 'reckless' from the moment of diagnosis if they engage in unprotected sex. But the GUM clinician or health advisor will need to assess the degree of understanding the patient has of his/her diagnosis, issues of shock, trauma and mental health, any concerns around safety and security with regard to disclosure, as well as properly advise the patient on how to disclose. This is all part of proper care of the patient and cannot be compromised by what remains a confused legal situation.

If as a last resort, the clinician decides to notify the partner without the patient's consent, the patient should be informed of this decision.

It should be noted that in cases where the doctor has clinical responsibility both for the patient and the identified partner there is probably a legal responsibility on the doctor to inform the partner without the patient's consent if the patient consistently refuses to do so or give consent for the doctor to do so.

It must be stressed, however artificial it might seem, that partner notification by the clinic need not in most circumstances involve formal identification of the index patient, even in those instances where their identity is readily inferable by the contact.

*Are there circumstances when a health care professional may choose not to disclose to a known partner even though that partner might be at risk?*

Yes there are many such circumstances. These would include where there is a risk of serious harm to the index patient, where there is a risk that the HIV diagnosis of the index patient would be maliciously communicated to others, where there is risk of abandonment, homelessness or destitution, in particular where children might be involved, and where the patient might be particularly vulnerable (for example, have learning difficulties, or be very young or be much younger than his/her sexual partner).

On the other hand, non-consented notification should perhaps be most readily considered as a last resort where the sexual contact appears vulnerable and less readily able or empowered to take responsibility for or look after their own sexual health.

It is extremely important that partner notification remain a public health based intervention rather than an expression of someone's moral assessment of responsibility for infection. To that end, the clinician will need to consider not only the health of the contact in any individual case but also the impact of non-consented notification, if regularly applied, to public trust in the confidentiality of the clinic and willingness to test ['the broader public interest in the provision of a confidential service' NHS Code of Practice on Confidentiality]. Whilst non-consented notification is an importantly available last resort, if it is routinely used with everyone unwilling to notify their sexual partner, there is a danger people will simply lie about their sexual history and current benefits of consensual partner notification will be lost.

It is vitally important that clinicians are given the discretion to make these decisions on a case by case basis, sensitive to context and circumstances, and in accordance with their ethical judgement.

*Where does final responsibility for decisions on disclosure rest? For example, does responsibility lie with the Caldicott Guardian or are such decisions the duty of only the appropriate Doctor in consultation with peers if necessary?*

NAT considers, given the sensitivity of the decision and the need to be fully aware of all clinical and social contexts, that the responsibility must remain with the appropriate Doctor. As the consultation document states, advice on an appropriately anonymised basis can be sought from colleagues, including the Caldicott Guardian.

*Given the provision of the common law of confidence and the NHS Code on Confidentiality, what additional safeguards do the current Regulations/Directions on STIs provide in practice? Are these additional safeguards necessary? Are they too restrictive?*

The consultation document explains some of the interpretative confusion surrounding the Regulations and Directions. This would suggest there is a benefit in legislation to remove the confusion. But great care must be taken not to undermine the current level of confidentiality routinely enjoyed by people living with HIV in GUM settings. And NAT would only support clarification which accorded with the principles outlined in this consultation response. The fact is the confidentiality experienced in GUM settings does appear to be greater than that experienced elsewhere in the NHS, including in relation to communication between health professionals.

*If you consider that disclosure to the known sexual partner is appropriate in any circumstances, do you consider it to be appropriate for the healthcare professional to inform the partner directly that they can report their partner to the police for reckless transmission of HIV or other serious STI? Would this be likely to deter people from using sexual health services?*

NAT does not believe healthcare professionals should inform patients or partners of the possibility of approaching the police about criminal prosecution. This is to confuse their public health responsibility with that of the criminal justice system, and to venture into an area where they do not have adequate training or competence. If asked about the possibility of legal action, the patient should be referred to an HIV support organisation for professional advice.

In most cases the clinician will not be in a position to know with any degree of certainty who is responsible for an instance of HIV infection and whether the infection was the result of behaviour the courts would deem to be 'reckless'. The only equitable course of action would be to advise everyone diagnosed with any STI of the possibility of legal action – this would be burdensome and cause untold anguish and confusion.

Were it to become known that clinicians were advising patients or sexual partners of the possibility of prosecution, trust in GUM services would be fatally undermined.

*Other than for child protection, in what circumstances might a health care professional need to consider disclosure to someone other than a known sexual contact?*

NAT agrees with the consultation document that there is no clear benefit from disclosure to third parties apart from the contexts of partner notification or child protection.

The consultation question does not state exactly what disclosure is envisaged. But recent prosecutions have raised the possibility of reporting to the police someone known to be engaging repeatedly in risk taking behaviours without disclosure of HIV status on the basis that a 'serious crime' [i.e. reckless transmission] could well be occurring which requires intervention. NAT would strongly oppose such actions as a breach of confidentiality likely to undermine trust in the confidentiality of sexual health services.

As the consultation document implies, it is hard in any event to see what benefit would result from such an approach to the police. With regard to identified contacts,

the GUM clinician or health advisor can as a last resort inform the contacts of the need to attend the clinic. They are the only people in any event who would be able to approach the police as complainants, should they prove to be infected 'recklessly'. There is no offence of 'attempted' reckless transmission.

*Do you agree that the added confidentiality provided by the Regulations/Directions applies wherever STI services are provided? (i.e it is not limited to GUM services)? This may require sharing of information, in line with locally agreed protocols in settings providing integrated STI and contraceptive services in order to provide a seamless service to patients (e.g avoid duplication of questions)?*

NAT strongly supports the ambition of the national strategy and *Choosing Health* to make STI services (including, for example, HIV testing) more available in primary care settings. But recent research such as that of Professor Jonathan Elford from City University identifies primary healthcare workers as a significant source of HIV-related stigma and discrimination experienced by people living with HIV. It is particularly important, therefore, if primary care is to become an accessible provider of sexual health services, that it enjoys the same level of trust as that currently enjoyed by GUM clinics. NAT therefore agrees that the principle of enhanced confidentiality for sexual health services needs to be applied wherever the services are provided.

*Do you agree that policy on confidentiality should not prohibit the provision of non-identifying data and information for local and national surveillance?*

Yes. Surveillance is extremely important and has to date not as far we know caused any real difficulties for patient confidentiality.

#### *Scenarios*

NAT will not comment in detail on the scenarios, other than to acknowledge that they are examples of the situations frequently encountered in GUM clinics. The principles outlined in the responses above would assist GUM clinicians or health advisers in these circumstances but cannot provide ready-made answers to complex problems.

There can also be something misleading in presenting such scenarios when discussing policy. The choice of scenario inevitably determines the 'problem' to be addressed. There is no scenario here, for example, in which someone living with HIV is deterred from getting a test because s/he understands the clinic will inform her/his sexual partners of a positive result.

There is a danger that GUM clinicians and health advisers feel pressurised into thinking that in every instance 'something must be done'. They do not have a responsibility to police the spread of infectious disease. They have a responsibility to treat the healthcare needs of the patient before them. Such treatment is also a public health opportunity, and consensual partner notification is without doubt an important intervention. There are also certain occasions, described above, where breach of confidentiality might be justified – but these are very limited and must remain the exception rather than the rule if trust in sexual health services is to be maintained.

**National AIDS Trust  
October 2006**