

**DEPARTMENT OF HEALTH CONSULTATION ON CONFIDENTIALITY
AND DISCLOSURE OF PATIENT INFORMATION: HIV AND SEXUALLY
TRANSMITTED INFECTIONS (STIs)**

EVIDENCE SUBMITTED BY THE SOCIETY FOR GENERAL MICROBIOLOGY (SGM)

Introduction

The Department of Health (DH) is undertaking a consultation to clarify policy on patient confidentiality and disclosure of information on sexually transmitted infections (STIs), including HIV. The acute trigger for this enquiry was a court case in which the Health Protection Agency (HPA), an acute hospital trust and a primary care trust were involved as claimants seeking a declaration relating to the common law on disclosure of information on STIs, including HIV. For reasons not disclosed in the consultation document, the judge decided not to make a decision. It should have been clarified that there were technical and procedural reasons for the decision (ref. 1, pages 9–10).

In the consultation document the common law of confidentiality is initially reviewed. It maintains that information given by a patient to a medical professional in confidence can lawfully only be disclosed if either the patient explicitly consents or if there is a 'public interest of sufficient force' to take precedence over the professional's duty to honour the confidentiality agreement implicit in each doctor-patient relationship.

As the principle of professional confidence itself is of considerable public interest and deeply based in and defended by law, substantial hurdles exist which have to be overcome before this principle gives way to overriding interest. There is guidance for this in the document *Confidentiality – NHS Code of Practice (2003)*. This code restricts events able to override confidentiality to the possible prevention of serious crime, and/or prevention of abuse or serious harm to others. In addition, there is special guidance about disclosure of information on STIs in the document *The NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000*. These regulations also emphasize that the trust of patients is to be certain that their detailed information given to doctors is kept in strict confidence. This has helped sexual health services in the UK, where patients feel treated without fear of moral judgement or embarrassment.

Recently (2003/4) the Crown Prosecution Service (CPS) has started to pursue a number of cases in which people were charged with reckless or intentional transmission of a STI (mostly HIV). The issues that arose during the course of these cases have often centred on the confidentiality agreement inherent in the doctor-patient relationship and where its limits would be. In this context, the present consultation exercise, including relevant questions and typical scenarios, was set up.

Response to Questions and Opinion

Having studied the document, it is clear that this is a complex and changing topic. The British HIV Association (BHIVA) document *HIV transmission, the law and the work of the clinical team* (ref. 1) was found to be very helpful in considering issues and should have been a firm appendix of this document.

Question i. 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(s) themselves?

Agree. If the patient's sexual behaviour is putting individuals at risk, a healthcare professional should consider taking steps to inform known contacts, if with reasonable persuasion, the patient does not agree to tell the individuals themselves. It should be emphasised that the patient is informed this is to happen. Justification for this course of action is that the contact could take reasonable steps to protect themselves from infection, or in the knowledge of having been exposed, seek relevant post-exposure treatment.

According to the BHIVA document (ref. 1, page 14), it must be recognised that confidentiality cannot be absolute. In the comprehensive advice given to the patient after the diagnosis of a STI has been made, in addition to receiving explanations of transmission pathways and impact of the infection on public health, they should be informed of the limits of confidentiality and of the possibility of prosecution if the patient acts recklessly (or causes harm intentionally, which is more difficult to prove). Patients should be aware that it will probably be accepted by the courts as lawful, if the health care worker (HCW), i.e. genitourinary medicine (GUM) consultant or general practitioner (GP), discloses the diagnosis to a close contact in the situation assumed above.

Question ii. 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?

If the identity of the person is known, but they are not a patient of the treatment centre, steps should be taken to identify a professional body that could transmit such information, e.g. this might include a local Health Protection Team (in Scotland) or the HPA in England and Wales. It would not be appropriate for the healthcare professional to directly approach the contact.

Although in this case there is less of a legal obligation, disclosure would probably be lawful (ref. 1, page 8) as it can be argued that the HCW also has a duty to withhold harm from a known close contact who is not under their care.

Question iii. 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?

There may be a circumstance where a healthcare professional may choose not to disclose to an individual. This may be justifiable where the individual is vulnerable and has no available support mechanism surrounding he/she. The timing of this disclosure might have to be delayed until such a support framework could be put in place. In addition, if the person at risk is a minor, further careful consideration needs to be followed to ensure support and access to appropriate suitable medical and psychological care is readily available. Of course, the HCW should always try to obtain consent for disclosure of information from the index patient.

Question iv. 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 (GMC Guidance annex 2)?

This will depend on the relevant health care professional. If it is a nurse, psychologist, or other person, they should discuss it with the appropriate doctor who might be lead doctor of the treatment centre. The appropriate doctor may also wish to discuss implications of disclosure with e.g. Medical Director, Director of Public Health or Caldicott Guardian.

However, the final responsibility in decisions on disclosure has to be with the appropriate HCW (doctor) as he/she is the partner of the patient in the confidentiality agreement.

Question v. Given the provisions 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 current safeguards preventing disclosure are as follows:

- *NHS Code of Practise* (2003)
- *European Convention on Human Rights* (1998)
- *Data Protection Act* (1998)
- *NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions* (2000)
- *Serious Communicable Diseases* (General Medical Council, 1999)
- *Confidentiality: Protecting and Providing Information* (General Medical Council, 2004)

There is a public interest in being able to disclose such sensitive information on rare occasions. The existing guidelines provide sufficient safeguards to this disclosure being frequent or inappropriate. Since the nature of the information is likely to lead to significant consequences for the individual and the patient, the current restrictions on disclosure are appropriate.

The common law and the GMC guidance on confidentiality relate to the physician-patient relationship in general, and the issues on disclosure of a STI are a special case to be subsumed under this. The grounds for confidentiality under all circumstances have also become less stringent since HIV infection, whilst remaining a chronic condition (and disease), has become eminently treatable (if not curable), and therefore the right of close and other contacts to benefit from such treatment and advice appears to have become more dominant. As said above, the HCW should always try to obtain consent for disclosure of information from the patient before considering breach of confidentiality.

Question vi. 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?

The guidance part of the BHIVA document (ref. 1, page 11) states sensibly that it is up to the patient to make reports to the police and *not* the HCW. The healthcare professional should have as their priority, the interests of the individual's health and welfare. If this is not the priority, then the risk does exist of people being deterred from using sexual health services. It would not be appropriate that the HCW should advise such a course of action as notifying the police, if the individual raises such an issue. Instead, they should be directed to the appropriate legal advice.

Question vii. [With the exception of issues relating to child protection, and apart from the case of disclosure to known sexual contacts whom a health care professional believes to be at risk, it is not clear what public health interest would be satisfied, by disclosing to others, such as other relatives, social service departments and the police.] Do you agree? 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. When answering this question please consider what the recipient of the information would be expected to do, or could do, in practice in response to receiving such information.

In addition to issues of child protection, or adults within the definition of 'Adults with Incapacity Act', it rarely may be necessary for disclosure other than to a known service or other contact. If the patient is likely to expose others to risk by blood contact, e.g. through an operation or dental treatment and will not disclose such information, despite being exhorted to do so, it would be reasonable to inform the other medical/dental practitioner. Such an individual would not have recourse to deny treatment ('Duties of a Doctor'), but could take additional steps to protect themselves and other healthcare professionals likely to be exposed.

The HCW has an obligation to answer questions when ordered by a court, as rejection would be regarded as contempt of court (guidance from ref. 1, page 12). Otherwise the HCW can supply information in the way that has been agreed by the patient. Police officers have no automatic right to see patient's records, which are either kept in hospital (then owned by the NHS Trust, disclosure procedures having to involve the Chief Executive or a specialist nominated by them) or with a GP (then owned by the Secretary of State for Health).

Question viii. 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).

Agree. Patients have a right to the added confidentiality provided by the various Regulations/Directives outlined irrespective of where the service is delivered. If adequate guarantees regarding confidentiality are not given, patients will be deterred from accessing services locally. It also stands to reason, that patients may expect additional guarantees that confidentiality will be maintained when services are delivered in the community in which they live and work. The sharing of information can be worked out in local protocols.

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

Agree. The policy on confidentiality should not prohibit the provision of non-identifying data and information for local and national surveillance. Appropriate and reliably collected epidemiological information on STIs (as well as other infectious and non-infectious diseases) is a key element of public health planning, as well as of curative and preventive measures. Additional care may be required to remove any identifiers in areas where HIV/STIs are of low prevalence, to ensure maintenance of confidentiality. However, once and if the data are appropriately anonymised, there is no good reason not to use them for surveillance information. For HIV, the time of anonymised testing *ab initio* has passed as cases identified under this procedure cannot be advised or benefit from an efficient treatment.

Scenarios

1. As a health advisor you have reason to believe that an HIV infected male patient has not told his current female sexual partner of his HIV status. You think he is not using a condom consistently and he has already infected a previous female sexual partner who is being cared for in a different clinic. His viral load is such that he is not yet on antiretroviral medication. He has had other casual partnerships as well as the current 'steady' sexual relationship.

What do you think you should do?

The health adviser should refer the patient to a doctor or GUM clinician. The patient should be made aware of the facts regarding risk of transmission and the consequences to his partners. The doctor should encourage the patient to identify all his partners, so that they can be appropriately identified, supported and treated where necessary. He can be advised there will be help available for him to carry this out if he is unable to do it by himself. If he agrees to this, the partners should be informed and asked to agree to testing, as there is an effective treatment.

The patient should be requested to wear condoms on all occasions of sexual encounters. The present viral load should be clarified, and it should be considered under the circumstances to treat the HIV infection of the patient as a matter of urgency.

If the patient resists these measures, the limits of the confidentiality agreement should be explained to him (this should already have been done at an early stage) and he should be informed that some disclosure will have to be carried out by someone else. The patient should be made aware that he could be taken to court if he continues to act irresponsibly and becomes a danger to others.

If the patient is completely irresponsible and 'reckless', the doctor should consider informing the known 'steady contact', being aware that his decision can be tested in court, but that under the circumstances his action (to inform the close contact) would probably not be considered as lawless.

2. *An HIV positive man who has sex with other men is asymptomatic but has a high viral load. He has so far refused treatment. He has told you (as the GUM clinician) that he has multiple sex partners in your small city and regards it as the duty of his sexual partners, and not his responsibility, to ask about condoms – other wise he will assume they are also HIV positive. He occasionally gets paid for sex (usually he is the receptive partner in those encounters). There is only one GUM clinic in your area.*

What do you think you should do?

The HIV-positive man should be advised that this view is wrong and that it is his responsibility to wear condoms on all occasions of sexual encounters. He should be encouraged to advise contacts to wear condoms. He should also be asked to notify all partners, if known, to attend the GUM clinic.

Treatment to bring down the high viral load should be strongly advised and should commence immediately, if the patient agrees.

He should be advised not to engage in paid or unpaid sex without appropriate precautions. This may take additional counselling and help. If the patient acts as the receptive partner in paid sex, the risk that he transmits the infection is approximately 1/20 of the risk he poses if he is the active partner. However, given the high viral load of the patient, the risk is still considerable, and advice as given above should be given correspondingly for this situation.

The limits of the confidentiality agreement should be explained to the patient if he fails to act responsibly or fails to co-operate. The patient should be made

aware that he could be taken to court if he continues to act irresponsibly and becomes a danger to others.

3. *A male attends the GUM clinic with a chancre on his penis and is diagnosed with primary syphilis. He thinks he was infected from sex with a sex worker a few weeks before. He has a long-term partner whom he had sex with one week before attending the GUM clinic. She is six months pregnant. He refuses to inform her or for the clinic staff to make contact as she will then realise he has had other partners. He is an aggressive man, knows his 'rights' and tells you that this is the GUM clinic, you are not allowed to breach his confidentiality by informing his partner without his consent. You, as the GUM physician, are very concerned because of the possibility of congenital syphilis and the need for the partner to be seen and given appropriate treatment.*

What do you think you should do?

The patient should be treated immediately and asked to identify the sex worker so that she can be investigated and treated as necessary.

There is a duty to inform his long-term partner, so she can get appropriate care for herself and her unborn child and, as such, the patient should be counselled with regard to his responsibility to them, particularly as the infection is eminently treatable. He should be advised that his partner and their child have the same right as him to treatment.

Having had the full facts explained and their likely significance, if the male does not agree to do this, the limits of the confidentiality agreement should be explained to him. Then the GUM physician may have to disclose the information to the patient's partner's obstetrician. The doctor's decision to inform the partner so that she can be treated (and thus the child be protected from serious harm) is likely to stand in court, and the doctor should not give in to the patient's aggressiveness which borders on bullying.

The patient should be made aware that he could be taken to court if he continues to act irresponsibly with regard to his long-term partner and their child. Their right to be treated is to be regarded as in competition with his right for confidentiality, and on balance the latter will have to give in.

4. *An HIV positive man has infected two women. The first woman was his long-term partner and tested positive shortly after his HIV diagnosis. The second woman he infected was someone he had a brief relationship with two years after he was diagnosed and she is now also a patient of yours. The second woman asks you (as her GUM clinician) when this ex-partner knew he was HIV positive as he had not told her about his diagnosis. You can see from his notes that you asked him to inform his new sexual partner (the second woman) when their relationship began two years previously (which he said he had done but in retrospect clearly had not).*

Do you tell her the information she requests? Do you tell her that she can report the matter to the police? Do you say that if she brings a case to court the evidence can be subpoenaed but you are not able to disclose to her otherwise because the information is confidential?

The GUM clinician can inform the second woman that it is standard practise to advise every patient that any sexual partners should be informed of the risks and advised to seek treatment or help, and that every patient is advised, as a matter of routine, the necessary precautions to prevent transmission of infection under any circumstances.

She should be advised if she wishes to know the position regarding reporting to the police and should she ask for a legal opinion, she should seek advice from the Citizens Advice Bureau.

Under *subpoena* the evidence can be given. Molecular techniques are sensitive enough these days to confirm or not confirm that the second woman was infected by the male patient.

5. *A male, who is a well-known regular attender at the GUM clinic (usually comes for treatment of his gonorrhoea) attends this time and is not at all well. He has lost some weight and has oral candidiasis. You suspect he may be HIV positive, but he refuses to have a test. You know he has a long-term regular partner and also many casual partners. You also know from his history that he says he never uses condoms. You ask him to inform his partner of your suspicion that he may be HIV positive. He refuses.*

As you suspect he is probably HIV positive, do you have a duty to inform his regular partner that she might be at risk? Do you think she could bring a legal case against you as the doctor, for not informing her of the potential HIV risk? You suspected her partner to be positive and this is documented in his notes.

One possibility would be to have a further conversation with the patient in the presence of another HCW, as a witness and supporter of your views. If the male patient continues to refuse to be tested then this is his decision. However, every attempt should be made to encourage him with the benefits such knowledge might bring, e.g. antiretroviral therapy, access to preventative measures, psychological support, etc. The patient should also be told that he will get worse without appropriate diagnosis and treatment, and that he may be a real danger to others, in particular if he never uses condoms.

If the male patient continues, despite being made fully aware of the risks to others of transmission of infection, then consideration should be given to informing his regular partner. He should be informed of such intentions.

The question of doctor's legal responsibility in this case is controversial (ref. 1, page 8). However, it can be argued that the HCW also has a duty to withhold harm from a known close contact who is not under their care. It is correct to assume the partner may pursue a legal case against the doctor for failure to inform her. Whether the fact that there is not a definite HIV diagnosis might alter such a case is not sure, but if it is documented that there is a high index of suspicion and she does become infected with HIV, she may have a case.

General points

As a general point, and with particular significance for HIV infection, so-called opt-out testing should be considered (ref. 2). This means that the procedure of testing only with informed consent and after extensive counselling be changed to a procedure under which all patients entering a hospital or a clinic will be tested, except when they explicitly object. The rate of testing will significantly increase, more people will know their HIV status and can be treated appropriately, and preventive measures can be more widely advised upon. Experience in countries where opt-out testing has been introduced has shown that only few patients have declined to be tested, and early diagnosis and treatment have decreased spread and improved the prognosis at a population level.

A wide range of individuals and professional bodies are being consulted (see Appendix 5, page 18 of the consultation document). As most of the topics under discussion relate to difficult clinical management problems, the highest weight should be given to the opinions of people (HCWs) who are faced with these questions on a day-by-day basis and to experts in common and penal law. (Among the latter it may also be advisable to consult judges of family courts and partners in law firms who are involved in these matters on the medico-legal side and are up to date with current legislation and its application). The microbiological questions are of relatively minor importance in the context, as the facts are relatively clear and uncontroversial.

The document of the BHIVA (ref. 1) is an excellent contribution to the DH consultation process, and the conclusions emanating from the BHIVA's enquiry should be of particular importance for the DH's deliberations on policy.

References

1. British HIV Association (BHIVA). *HIV transmission, the law and the work of the clinical team*. Confidential draft, March 2006, for consultation (concluded July 2006), result to be published.
2. Editorial. *AIDS tests, everywhere*. International Herald Tribune, page 4. October 14-15, 2006.

Sources

This evidence has been prepared on behalf of SGM by Professor Judith Breuer, Barts & The London Queen Mary's School of Medicine & Dentistry, Dr Sheila Burns, Royal Infirmary of Edinburgh and Dr Ulrich Desselberger, SGM General Secretary.

About the SGM

The Society for General Microbiology, founded in 1945, is an independent professional scientific body dedicated to promoting the 'art and science' of microbiology. It has now established itself as one of the two major societies in the world in its field, with some 5,500 members in the UK and abroad.

Society membership is largely from universities, research institutions, health and veterinary services, government bodies and industry. The Society has a strong international following, with 25% of membership coming from outside the UK from some 60 countries.

The Society is a 'broad church'; its members are active in a wide range of aspects of microbiology, including medical and veterinary fields, environmental, agricultural and plant microbiology, food, water and industrial microbiology. Many members have specialized expertise in fields allied to microbiology, including biochemistry, molecular biology and genetics. The Society's membership includes distinguished, internationally-recognised experts in almost all fields of microbiology.

Among its activities the Society publishes four high quality, widely-read research journals (*Microbiology*, *Journal of Medical Microbiology*, *Journal of General Virology* and *International Journal of Systematic and Evolutionary Microbiology*). It also publishes a highly respected quarterly magazine, *Microbiology Today*, of considerable general educational value. Each year the Society holds two major scientific meetings attended by up to 1500 microbiologists and covering a wide range of aspects of microbiology and virology research.

The governing Council of the SGM has a strong commitment to improving awareness of the critically important role of microbiology in many aspects of human health, wealth and welfare. It has in this connection recently initiated a 'Microbiology Awareness Campaign' aimed at providing information to the government, decision makers, education authorities, media and the public of the major contribution of microbiology to society.

An issue of major concern to the Society is the national shortage of experienced microbiologists, particularly in the field of clinical microbiology and in industry. To attempt to improve this situation long-term, the Society runs an active educational programme focused on encouraging the teaching of microbiology in university and college courses and in the school curriculum, including primary schools. Some 400 schools are corporate members of SGM.

Society for General Microbiology
Marlborough House
Basingstoke Road
Spencers Wood
Reading RG7 1AG, UK

Telephone: 0118 988 1812
Fax: 0118 988 5656
Web: www.sgm.ac.uk

Contact: Dr R S S Fraser, Executive Secretary (e-mail: r.fraser@sgm.ac.uk)