



RISKS OF SEXUAL TRANSMISSION OF HIV: A REVIEW OF ADVICE IN THE UK

National AIDS Trust, February 2007

Risks of HIV transmission

Introduction

The National AIDS Trust (NAT) was a key organising partner in a major conference for people living with HIV in 2004, and one of the key messages that emerged from participants was the need for clear, comprehensive, consistent and up to date information on the risks of HIV transmission in a variety of contexts. It was noted that much of the available information on risks of HIV transmission was based on relationships between men, yet increases in heterosexual diagnoses in the UK have raised additional issues about HIV prevention information. Antiretroviral therapy can of course also affect infectiousness and consideration of risk.

Comprehensive information is needed to assist HIV positive people and their sexual partners in having safer sex, and provide those in vulnerable communities with the facts necessary to make informed choices about their sexual health in order to effectively reduce the risk of HIV transmission. NAT therefore decided to undertake a brief assessment of the sort of information and advice that is available from telephone advice lines on risks of transmission of HIV through sex.

In compiling this report, we attempted to cover the risks of transmission between heterosexuals, as well as gay and bisexual people, and to include risks related to circumcision. At the time, trials of circumcision as a means of reducing the risk of HIV transmission were gaining significant coverage in the media and people were beginning to become aware of the issue. We wanted to gauge whether advice lines were sufficiently prepared to respond to this 'new' issue.

About the 'Risks of Transmission' project

The 'Risks of Transmission' project aims to provide a snapshot of information and advice that is available through telephone help lines, and also from the internet, regarding risks of sexual transmission of HIV. This report summarises the advice that was given in response to particular issues and queries, identifies whether the advice given was accurate and consistent, and makes recommendations based on key issues that arose from the project.

This report does not claim to be a fully comprehensive review of all advice lines, or to cover all risk scenarios, but rather gives an indication of the sort of advice that is available to members of the public who may be concerned about their sexual health. In addition, the project was not designed to 'name and shame' any organisation that provided advice that proved to be unclear or inaccurate, and whilst an overall list of organisations we contacted is provided as an annex, individual organisations are not identified in this report in terms of the information they provided.

Some of the information from the help lines may sound surprising - but it should be noted that the content of the following pages is based on what the callers reported to NAT, based on what they understood they were being told by help line staff.

Methodology

NAT devised eight scenarios that cover a range of potential HIV risk situations for men and women, and NAT volunteers were provided with a list of advice line telephone numbers to call for each scenario. Some of the volunteers had been involved with other NAT projects before, some had recently applied to do some voluntary work with NAT, and others (in cases where we were seeking people from a particular background) were recommended by partner organisations and asked if they would like to be involved. The volunteers were from a range of backgrounds and had varying levels of existing knowledge about HIV and HIV-related issues, and they were asked to call anonymously rather than explain that they were working on a project for the National AIDS Trust.

The advice lines chosen by NAT included organisations with both a national and regional remit in the UK, some focussing on sexual health and others working specifically on HIV. Some offered services aimed at particular groups of people, related for instance to sexuality, gender or a specific community. They included the most-used lines, and a list is attached as an appendix to this report. The advice lines were contacted at different times of the day during the opening hours listed by their web sites or by the Department of Health.

Volunteers were given a scenario description and a list of issues that NAT hoped the advice line would cover, but were welcome to personalise the scenario to assist in making the calls, and to use their own choice of language to describe the sexual acts that the scenarios contained. For each scenario, one volunteer made all the calls and recorded the information and advice that they were offered. They asked open questions where necessary in order that the phone line adviser could provide information without being prompted excessively.

Other volunteers were given time to search the internet to see whether accurate information about the issues and concerns raised by the same eight scenarios was available and easily understood from online sources. These volunteers were intentionally not given a set list of web sites to check. Some volunteers were already aware of web sites that contained information about HIV (such as HIV organisations, although they did not use the NAT site); others chose to use internet search engines to try to find the information they needed.

The National AIDS Trust would like to thank the volunteers who participated in this project.

The risk scenarios

Men

1. You are a 31-year old man and have been in a relationship with a woman from Zimbabwe for about two years. You also occasionally meet men over the internet for sex. You had an HIV test about a year ago and it was negative but you have never discussed this with your partner and you don't think she has ever had one (you don't want to bring up the subject as she might get suspicious about you sleeping with other people). You are worried about the risk of becoming infected with HIV and/or infecting others and don't feel you know much about it.

2. You are a gay man of 28. You are on the gay scene and have a fair amount of casual sex with guys though you mainly do oral sex rather than anal sex. You try to always use condoms for anal sex - but don't always succeed.
3. You are an HIV-negative straight man of 25 and have a new girlfriend. She says she is HIV positive, but as you are circumcised she says there is nothing to worry about. You want to find out the facts.
4. You are a gay man of 36 living with HIV. You were diagnosed two years ago and have an undetectable viral load. You are in a long-term relationship and your partner is HIV negative. You also have casual sex outside your relationship. You have trouble maintaining an erection when you use a condom, even with Viagra, but you don't want to infect your sexual partners (especially your long-term boyfriend).

Women

5. You are a straight woman of 30 living with HIV. You are single but would really like to have a relationship. You have heard all sorts of confusing information about how HIV is passed on and want to feel you know the facts.
6. You are a 19-year old woman and have just met a man you really like. He is South African and has told you he is HIV positive. You want to have sex and he's told you that as he is circumcised, you have nothing to worry about. You want to believe him, but want to check the facts.
7. You are a woman of African origin, in your 40s, and have just come out of a monogamous long-term relationship with a male partner. You have come off the pill after nearly 20 years and started dating again, and find yourself attracted to both men and women. You are really worried about the risk of becoming infected with HIV and don't really feel you understand the risks and chances of this happening.
8. You are a bisexual woman of 29 who has had a series of monogamous relationships. Your current girlfriend of four months has just found out that her ex-boyfriend has tested positive for HIV. You have used condoms or the pill with long-term boyfriends but this news has made you worry about your own sexual health.

Results of calls to telephone advice lines and internet searches

Scenario 1

You are a 31-year old man and have been in a relationship with a woman from Zimbabwe for about two years. You also occasionally meet men over the internet for sex. You had an HIV test about a year ago and it was negative but you have never discussed this with your partner and you don't think she has ever had one (you don't want to bring up the subject as she might get suspicious about you sleeping with other people). You are worried about the risk of becoming infected with HIV and/or infecting others and don't feel you know much about it.

This scenario was designed in the hope that advice lines would identify the following points:

- the higher HIV prevalence in Zimbabwe compared to the UK

- risks of HIV transmission between men having sex with men
- discussion with a partner about safer sex.

Nine advice lines were contacted in total, one of which had an answer machine during stated opening hours and the NAT volunteer had to call back. All nine recommended that the caller take an HIV test. Four talked about the counselling that would be available at the test centre, but the remainder did state that all the information the caller needed would be available at the test centre, and told him how to find one. One adviser raised the issue of the caller talking to his female partner about taking a test.

Our volunteer was advised that anal sex with men posed a high or very high risk of contracting HIV, and that anal or vaginal sex with his female partner would put her at high or very high risk. He was advised to use a condom in all cases, with one of the nine advice lines telling him to use a condom 'properly'. That same line specified that the risk from anal and vaginal sex is high 'if your partner or someone else you are having sex with is infected'.

Oral sex was covered by all nine advice lines, although only one of them initiated the subject of both giving and receiving oral sex (throughout this report, 'giving' oral sex is taken to mean performing fellatio, cunnilingus or anilingus on someone else, and 'receiving' denotes someone performing fellatio, cunnilingus or anilingus on the caller). Six advisers mentioned the risks of receiving oral sex, but in three of these cases they had to be prompted to do so by the caller. The advice was consistent: there is less chance of contracting HIV through giving oral sex than from anal or vaginal sex, but it is possible. The caller was told that the risk is increased if the person performing oral sex has a sore in their mouth, and that it would be better to use protection. Condoms (often flavoured condoms) were generally suggested.

Without being prompted, three advice lines talked about men performing oral sex on men or women, although all lines covered this issue when asked. Again the advice was generally consistent: that oral sex poses a lesser risk than penetrative sex, but it is not 100% safe and HIV can be transmitted if protection is not used. Whilst all lines recommended using condoms, three lines mentioned an increased level of risk to the caller if he had sores in his mouth.

The caller asked about any other risk factors he should be aware of, and eight of the advice lines mentioned sharing needles or sharp blades. He recorded one example of 'blood to blood contact' posing a risk of HIV transmission, and recorded being told by four advice lines that 'blood transfusions' posed a risk of HIV transmission. One line mentioned having many sexual partners as a risk, and one covered all the known risks of HIV including mother to child transmission and breast milk.

The caller noted one advice line where he thought the adviser could have been more sensitive in talking about very personal issues. In general though, he found the lines easy to get through to and the staff able to answer his questions without additional prompting.

Another volunteer searched the internet for information about the risks contained in this scenario. Through search engines he gathered information from United States-based web sites and well as a British one offering advice about the facts related to HIV transmission. He noted that a man who is having casual sex with a lot of men should be using condoms, and that he could be at high risk of contracting HIV if condoms are not used. By subsequently having sex with his long-term female

partner he is also putting her at risk. He should be retested for HIV, and if the result is positive he should talk to his partner about her taking a test too.

There were some issues that NAT thought could have been explored further by the phone advisers:

- When talking about oral sex, whilst sores in the mouth were identified as an increased risk factor for contracting HIV, the volunteer did not record any mention of sores on the genitals being discussed. None of the advice lines mentioned the potential risk or otherwise of ejaculating into the mouth or swallowing semen, and it was not always clear whether he might be at higher risk of contracting HIV through giving or receiving oral sex.
- None of the lines raised the issue of the caller's female partner potentially being HIV positive, although we acknowledge that this call did focus on a man being concerned about the risks of casual sex with other men.
- Only one advice line raised the issue of the caller talking to his female partner about taking an HIV test.

Scenario 2

You are a gay man of 28. You are on the gay scene and have a fair amount of casual sex with guys though you mainly do oral sex rather than anal sex. You try to always use condoms for anal sex - but don't always succeed.

This scenario was designed in the hope that advice lines would identify the following points:

- The relative risks of oral sex compared to anal sex
- The importance of consistent use of condoms

This volunteer was given eight telephone advice lines to call. One was closed during the week day on which he rang, another had an answering machine referring callers to another organisation and a web site, and on getting through to a third organisation he was advised to look at their web site. Of the five advice lines with which he held a conversation, all were able to offer information about the risks of HIV transmission from oral and anal sex.

In terms of anal sex, three of the advice lines went into detail about the risks and advised using condoms (one of them suggested extra strong condoms) whether the caller was the insertive or receptive partner. The other two lines focussed in more detail about the risks of oral sex.

Two of the advice lines described giving and receiving oral sex as 'low risk', although one of these said it was low risk except in cases of a high viral load and gum disease and the advisor explained why the mouth isn't as receptive to HIV transmission as the anus. One line suggested using a flavoured condom when receiving oral sex, and ensuring your partner uses one when you perform oral sex on him. Two others recommended avoiding ejaculation in the mouth – one stressed that giving oral sex was riskier to the caller than receiving it and this was reiterated by the other adviser who said that the caller should not let his partner ejaculate in his mouth, and that he should be careful of brushing his teeth beforehand as the risk is heightened if you have cut gums. He also said that using condoms would help minimise the risk. One advice line said that the caller could contract herpes from an infected partner through giving oral sex.

Four of the advice lines mentioned that other sexually transmitted infections (STIs) could increase the risk of contracting HIV, particularly if the receptive partner in anal sex has an infection such as herpes or gonorrhoea. One line stressed that condoms were available for free at genito-urinary medicine (GUM) clinics, and three lines advised contacting the local GUM clinic if the caller thought he would like to take a test. The caller got the impression that the advisers generally did not consider a test necessary for someone mainly having oral sex, although one did recommend a GUM clinic check up every three to six months.

The volunteer who used the internet to research this scenario obtained similar information to the volunteer who called the advice lines, but also noted that swallowing semen from an infected partner during oral sex can increase the risk of contracting HIV. He also discovered a strong message about condom use, namely that condoms only work if used all the time and all the way through sex.

- No additional risk factors were mentioned by the advice lines, and neither the advice lines nor the volunteer searching the internet mentioned the use of water-based lubricant as a means of reducing risk during anal sex.
- The volunteer searching the internet gained clear messages about the importance of using condoms each time he has sex, but this was not highlighted to the same extent by the advice lines.
- Of the risks mentioned related to HIV transmission during oral sex, it was not completely clear whether the risk arose from ejaculating into a partner's mouth or from actually swallowing semen.

Scenario 3

You are an HIV-negative straight man of 25 and have a new girlfriend. She says she is HIV positive, but as you are circumcised she says there is nothing to worry about. You want to find out the facts.

This scenario was designed in the hope that advice lines would identify the following points:

- Risk of men contracting HIV through sex with an HIV positive woman
- Circumcision as a means of reducing the risk of HIV transmission

Nine advice lines were called - the volunteer had to call back two organisations, after being put on hold and getting a message to look on their web site. All of the advice lines addressed the issue of risks of HIV transmission for HIV negative men who are circumcised. Eight advised clearly that being circumcised does not prevent or reduce the risk of being infected by HIV, whilst one acknowledged it could have an effect on risk, but that protection (condoms) still had to be used. It should be noted that this information was gathered from phone advice lines prior to the latest announcement of results of circumcision trials in Kenya and Uganda in December 2006, but after the initial results from the South African arm of that trial had been announced.

All nine of the advice lines talked about the risk to an HIV negative man from vaginal sex with an HIV positive woman. They all advised that the risk was high or very high, with one stating that it is always a very high risk to have unprotected sex with an HIV positive woman. Three mentioned that having other sexually transmitted infections could put the caller at even higher risk of contracting HIV. Whilst all nine advice lines advised using a condom (one saying condoms should be used 'properly'), five of them stated that there would still be a risk of contracting HIV, for instance that 'using condoms is not 100% safe but it helps', and 'use a condom, but this is not a

guarantee you won't be infected'. One line mentioned abstaining from sex as 'the best' protection option, 'otherwise use a condom'.

In terms of anal sex with a woman living with HIV, all nine advice lines talked of a high risk – eight as 'very high' and four of those as 'the same as' (or 'no different to') the level of risk through vaginal sex. Condoms were again recommended as protection, with three lines reminding the caller that condoms do not offer 100% protection, and one saying he should 'always use protection if you are not sure of the person's HIV status'.

Two lines mentioned an increased risk of HIV transmission from his female partner if the caller had other sexually transmitted infections.

Oral sex was mentioned directly by three of the advice lines, but all of the remaining six discussed it after being prompted by the caller. The advice was that oral sex poses a lesser risk than vaginal or anal sex, but this was explained in varying ways. Five lines stated that there was no difference in levels of risk between giving and receiving oral sex. Another said that if there are no wounds or sores in the mouth there is less risk of infection from giving oral sex (i.e. performing cunnilingus) and that an HIV negative man performing oral sex on an HIV positive woman minimises the risk but that receiving oral sex from an HIV positive woman (i.e. the woman performing fellatio) poses the minimum risk. In total, seven recommended using condoms during oral sex for protection, and six mentioned an increased risk of transmission if there are sores in the caller's mouth, with one of those six mentioning sores on the penis also increasing the risk.

All nine of the lines recommended our caller take an HIV test, and eight gave information about where to get one. Six suggested the local GUM clinic (two of those suggested the caller could also ask his GP for a test), and two suggested 'local testing centres' and offered details. One line suggested that the risk was high that the caller had already been infected with HIV, and that he should take an HIV test. Another suggested that he should take an HIV test before having sex, and not to have sex before getting the results.

In only one case, the caller reported not being able to get enough information without significant questioning of the advisor, saying that 'without prompting, you don't get more information'.

The volunteer doing an internet search found that blood (including menstrual blood), semen and other sexual fluids (including pre-cum) could transmit HIV. He was advised that every sexual act that involves sexual fluids of some kind (but not sweat, tears or saliva) has at least some risk. Using barriers such as male or female condoms and dental dams (or using latex gloves and even plastic food wrap in place of a dental dam) is likely to reduce risk substantially.

He found that anal sex poses most risk; that vaginal intercourse would put him at risk, but that HIV is transmitted most easily from men to women; and that oral sex is risky to the person performing it, particularly if they swallow fluid. Sharing sex toys without sterilising them first also poses a risk. In terms of circumcision, the volunteer found that it is thought to help protect against HIV because cells under the foreskin are vulnerable to the virus. According to a South African study it can reduce the rate of HIV infection among heterosexual men by around 60%, however he also found advice from an HIV organisation stating that there is a danger that people who have been circumcised will feel that they are fully protected from HIV when they are not, and that circumcision can never be a substitute for condom use.

- The volunteer doing an internet search found more comprehensive information about the risks of men contracting HIV from women.
- However some of the information available on the internet about circumcision may give the impression that circumcised men are safer than they actually are.
- One phone line recommended abstinence as the best protection option, arguably overstating the risk of transmission. However none of the volunteers noted messages from phone lines about the possibility of a satisfactory sex life with an HIV positive partner.

Scenario 4

You are a gay man of 36 living with HIV. You were diagnosed two years ago and have an undetectable viral load. You are in a long-term relationship and your partner is HIV negative. You also have casual sex outside your relationship. You have trouble maintaining an erection when you use a condom, even with Viagra, but you don't want to infect your sexual partners (especially your long-term boyfriend).

This scenario was designed in the hope that advice lines would identify the following points:

- The importance of consistent condom use
- Potential effect that taking Viagra could have on anti-retroviral drugs or any other medication

This volunteer was given eight advice lines to contact, and three of them had answering machines on during listed opening hours. He was eventually able to speak to somebody at one of them, and they referred him to another advice line. On the day the volunteer called, a fourth advice line was closed – an answering machine did give the opening hours, but did not suggest any other sources of information. A fifth line, listed on their web site as offering sexual health advice, explained that they dealt only with HIV transmission and not erection problems – they did not suggest other possible contacts or sources of information, and the caller reported feeling 'very unwelcome' for having tried to get information from them.

Of the three lines that did have a discussion with the volunteer, varying advice and information was offered. One did not discuss particular risks of HIV transmission during sex, and focussed instead on the erection problem. The adviser discussed possible reasons for it occurring, including anxiety, alcohol, drugs and blood pressure. The key advice was to contact a doctor, sexual dysfunction clinic or psychosexual counsellor.

The second advice line focussed more on anal sex but the adviser was unable to give specific information apart from the importance of using condoms during sex to avoid the risk of onward transmission of HIV. She asked if the caller would like to speak to a gay male adviser, and gave a number for him to call back. The third advice line with which the volunteer had a conversation was also unable to provide much helpful information. The caller mentioned anal sex, but levels of risk or ways to protect sexual partners were not addressed during the phone call, and neither were oral sex or sexually transmitted infections. The advice line did give contact details for the local hospital and for an HIV support group in the area, but otherwise advised him to look at the organisation's web site. The caller noted that the adviser was 'not very helpful. Seemed to be flagging their web site heavily. Though I did say I had internet

access, I wonder what the response would have been if I did not have [access to] the internet?'

The volunteer who used the internet to research this scenario had more success. He found that the dose of Viagra being used might be too low, but that it would be important to consult a doctor before increasing the dose as it may react with and affect any other medication he is taking. The undetectable viral load may indicate that the level of HIV in the blood is below the threshold needed for beginning antiretroviral treatment, or that the viral load is being controlled by antiretroviral drugs. The volunteer found consistent information on the internet about the need for condom use during anal sex. He chose to use search engines with key words such as 'Viagra' and 'condoms and their use', and was subsequently directed to some sexual health web sites.

- Accessing phone lines in standard hours proved to be difficult, and the information provided on the issues raised in this scenario was limited.
- In light of recent prosecutions for HIV transmission, advice lines should be able to provide guidance for callers seeking advice about safer sex, particularly those who talk about having difficulty in using condoms.
- Whilst suggesting looking on the internet for information about safer sex may be helpful for some people, not everyone has easy access to the internet and others may not be comfortable using it to seek such information – particularly if they have already chosen to try to obtain advice over the telephone.

Scenario 5

You are a straight woman of 30, living with HIV. You are single but would really like to have a relationship. You have heard all sorts of confusing information about how HIV is passed on and want to feel you know the facts.

This scenario was designed in the hope that advice lines would identify the following points:

- Risk of HIV being transmitted from a woman to an HIV negative man
- Any risks to the woman living with HIV

The caller spoke to four advice lines. One of them referred her to another, with an assurance that they would be able to answer all her questions.

In relation to vaginal sex, all three lines advised protecting a male partner by using a condom, with one line stressing that the condom should be used correctly, and with lubricant. The caller was told by this line that as a woman she would be highly unlikely pass on HIV to her male partner this way, but that there are no guarantees. One line advised that if a condom split, the couple should go to their hospital (but further information, for example about post exposure prophylaxis, was not mentioned).

Anal sex was mentioned by two of the advice lines, and by the third when prompted by the volunteer. Again, condom use was advised, with one line explaining that the anus is more fragile than the vagina, suggesting an increased risk of transmission to the HIV negative male partner.

Two of the lines advised that giving oral sex to her HIV negative male partner was not risky, while a third advised that her partner should wear a condom. One of the lines said there would be no risk to the male partner when he performed cunnilingus

on her, but another recommending tearing up a condom and placing it over her vulva (though not specifically referring to dental dams), and the same line that suggested her partner use a condom during fellatio said there was a theoretical risk to him through performing cunnilingus, but there no transmissions were known to have occurred.

Sexually transmitted infections were mentioned by two of the advice lines – one suggesting that the caller would be at risk and should protect herself, for instance from Hepatitis C which is far more virulent than HIV, and the other that she should protect herself from infections such as Hepatitis B and C and Chlamydia by using condoms.

The two lines that mentioned STIs also covered other risk factors, including sharing needles and syringes, mother to baby transmission, breast milk and one mentioning blood transfusions. One advice line recommended staying in touch with clinics, as they are the first places to find out about new methods of protection. In the meantime, she was told that condom use is the best method of protection available today.

As this caller had said she was HIV positive, she reported that the advice lines seemed to think she would already be aware of transmission risks. One line in particular seemed to feel that the call was a sign of underlying anxiety and paid particular attention the caller's emotional well being, for instance recommending talking to other HIV positive people, rather than giving advice about the biology of HIV transmission.

The volunteer searching the internet for this scenario found similar information, but also noted that she should use latex condoms (including female condoms) with lubricant to prevent HIV being transmitted to a negative male partner. She found that condoms, if used correctly and consistently, are highly effective at preventing HIV transmission and although there is a myth that some very small viruses can pass through latex, this is not true. Advice was also found that if she ever has sex with an HIV positive man, condoms should still be used to prevent other STIs and possible infection with a different strain of HIV. Any sexual activity that can lead to bleeding or cuts in the lining of the vagina or anus was found to be risky; that any contact with blood during sex - including menstrual blood - increases the risk of a man contracting HIV; and that her partner having any cuts or sores on his penis would increase his risk of contracting HIV. In terms of oral sex, she found that using condoms or dental dams were advised to protect her partner when giving or receiving oral sex, and that anilingus carries a theoretical risk of HIV transmission for her partner if he were exposed to any cuts or sores on her anus or if blood in her saliva came into contact with his anus or rectal lining.

- Whilst awareness of emotional well being is important, there is a concern about advice lines presuming that someone who is HIV positive will know all the facts about HIV transmission. This could be problematic if someone has been diagnosed recently, for instance, or for some reason is not fully informed of the facts they need to protect themselves or others.
- There were only limited references to female condoms or dental dams, but one line in particular arguably gave too much information (such as risks of HIV transmission through breast milk). This could potentially have a negative effect, with the caller not being able to take everything in.

Scenario 6

You are a 19-year old woman and have just met a man you really like. He is South African and has told you he is HIV positive. You want to have sex and he's told you that as he is circumcised, you have nothing to worry about. You want to believe him, but want to check the facts.

This scenario was designed in the hope that advice lines would identify the following points:

- Prevalence of HIV in South Africa compared to the UK
- Circumcision offering protection against transmitting HIV to a negative female partner

The volunteer was able to get in touch with six phone advice lines during the course of one day. One of these referred her immediately to another. Apart from waiting on hold for seven minutes to speak to an adviser on one line, it was easy to get through to the others.

Of the five lines that gave advice, two completely refuted the man's claims and said that circumcision would not offer protection from HIV to the female caller. They suggested that this man had either been misinformed or was deliberately misleading her. Both lines advised the caller to have protected sex only, with one stressing the importance of condom use and giving advice on where to obtain them for free.

The three other advice lines covered the issue of circumcision in more depth, saying that her partner's claims were 'slightly true', 'not strictly true' and that circumcision 'slightly reduces risk'. Each of them explained that unprotected sex with a circumcised man might make it more difficult to contract HIV, but that it would not act as a barrier to other sexually transmitted infections. One mentioned research in South Africa as the basis of the caller's partner's claims, and two stressed strongly that as a woman she would not be protected from HIV transmission if her partner were circumcised.

All five lines advised the caller to use protection during sex, three of them talking specifically about condom use and one of those mentioning using spermicides also. One covered the risks of STIs, HIV and pregnancy.

Four of the lines did not advise her to take an HIV test. Three of the lines suggested that she should get her partner to call the advice line for more information about HIV and its transmission, and one line suggested that she and her partner should go for HIV tests as a couple. That line, plus two others, recommended openness and communication about sexual history.

The caller reported that four of the lines were helpful and supportive, offering constructive advice. With one however, she felt as though she was being rushed off the phone, and was told to talk to her partner and 'use her instinct' whether or not to have sex with him. All of the lines focussed on the issue with which they were presented and none of them offered additional information about potential other risks of HIV transmission.

The volunteer searching the internet for information for this scenario found similar advice in relation to the importance of using condoms during sex - female condoms, latex condoms and lubricant were all noted. She found it inadvisable to use the spermicide nonoxynol-9, as this can actually increase the risk of contracting HIV. This volunteer also read that women were 30% less likely to contract HIV if their male partner is circumcised.

- It should be noted that information was gathered from these phone advice lines before the results of the circumcision trials in Kenya and Uganda were published in December 2006, but after the results had been released from the South African arm of the trial earlier that year. Evidence from even the early stage of the trial however focussed on circumcision as a means of protecting men from contracting HIV, not women.
- None of the advice lines mentioned the prevalence of HIV in South Africa.
- The advice lines and internet based research all focused on vaginal sex only.

Scenario 7

You are a woman of African origin, in your 40s, and have just come out of a monogamous long-term relationship with a male partner. You have come off the pill after nearly 20 years and started dating again, and find yourself attracted to both men and women. You are really worried about the risk of becoming infected with HIV and don't really feel you understand the risks and chances of this happening.

This scenario was designed in the hope that advice lines would identify the following points:

- Having been in a very long-term relationship, the caller may not have been receptive to HIV advice that was widely publicised in the 1980s
- Risks of contracting HIV from men and from women
- Increased prevalence of HIV amongst the African community in the UK

This caller was able to make contact with five advice lines, one of which referred her to another as it dealt more specifically with pregnancy rather than HIV. Of the four lines that she spoke to, one gave a general overview of HIV and how it can be transmitted before focussing on the particular risks of sexual transmission.

In relation to vaginal sex between women and men, all four lines recommended using condoms and two specifically mentioned female condoms as well as male ones. One advice line explained that HIV is not necessarily passed on during each sexual encounter but that it can be, and that it is always best to use protection.

Two of the advice lines mentioned anal sex, and it was raised by the volunteer in a third call. It was explained that as the membrane in the rectum is very thin and does not have much lubrication, anal sex poses a high risk and the caller was advised by all three lines to use condoms, and by one of them to use lubricant with condoms.

The risk of passing on HIV through oral sex was described as 'very little', 'minimal' and 'not high'. One line advised the caller that not many people have been infected with HIV through oral sex and she would be at risk only if she came into contact with infected body fluids. Good mouth hygiene was stressed, and she was advised to ensure she had no throat infections or sores, cuts or bleeding in her mouth. Two lines recommended using a dental dam when giving or receiving oral sex, or a flavoured condom – one told the caller where to get dental dams, and another advised about cutting up a condom and using it to cover her tongue as an alternative.

In response to the caller saying she found herself attracted to women, she reported one advice line saying that 'HIV is not really transmitted from woman to woman, so it should not concern' her. The three other lines advised that coming into contact with vaginal fluid from an HIV positive woman would be a risk, and one advised of a small risk from blood coming into contact with infected blood if there are any cuts in the

body. Both other lines recommended avoiding sharing any sex toys if possible, or cleaning any shared toys before use and using a condom over them where possible.

Two of the lines mentioned that having STIs such as herpes, Chlamydia and gonorrhoea would increase the risk of contracting HIV and that the caller should use condoms to protect herself.

Information about how to get an HIV test was given by one of the help lines, but they did not advise the caller to take one. One line did not mention HIV testing at all, and the other two another advised her to go and take a test, also mentioning the counselling that would be offered to her.

More additional information was offered to this volunteer than to any other – perhaps because she stated that until recently she had been in a monogamous relationship for over 20 years. It was explained to her that she has the right to say no to sex, that some men do not like to use condoms, that she should not necessarily listen to people who just tell her that they are healthy, and that if you have multiple partners and subject yourself to HIV, there are various strains and some of these can fail to respond to medication. This caller welcomed the reassurance she was offered, for instance that she would not necessarily automatically contract HIV if a condom broke when having sex with an HIV positive man, that she should have her own supply of condoms and not be embarrassed to buy them. A comment from one line was highlighted by the volunteer – namely that ‘it is hard to get HIV and gay people are more at risk’.

She did mention that with one line, only brief answers were given and she was not asked if the information that was provided was sufficient, but on a positive note another line offered the opportunity of speaking to an adviser in a different language if she wished, and recommended an African-specific information source that might be able to advise on cultural issues.

The volunteer searching the internet also found extensive information on this scenario. The advice she found was generally consistent with the advice given over the telephone, but she also found out about some of the ways that HIV cannot be transmitted. The message of 'ABC' - abstinence, being faithful and using condoms - was noted. She also noted that she should not douche as it removes some of the body's natural protection, and that most birth control methods do not offer protection against HIV transmission.

- This caller was given extensive advice, specifically related to HIV transmission but also on a practical level. Whilst it is true that men who have sex with men in the UK are most affected by HIV, in recent years the number of new HIV diagnoses acquired heterosexually has been higher. The majority of heterosexual infections are thought to have been acquired abroad, particularly in sub-Saharan Africa, but none of the advice lines mentioned the increased prevalence of HIV among the African community in the UK.

Scenario 8

You are a bisexual woman of 29 who has had a series of monogamous relationships. Your current girlfriend of 4 months has just found out that her ex-boyfriend has tested positive for HIV. You have used condoms or the pill with long-term boyfriends but this news has made you worry about your own sexual health.

This scenario was designed in the hope that advice lines would identify the following points:

- Risk of HIV transmission between bisexual women
- That only barrier methods of contraception can offer protection from HIV

This caller tried to contact six organisations, and was able to speak to three of them. Two were constantly engaged at various times of day on the different days they were called, and neither of them had recorded messages or answering machines. A third line had an answering machine on during stated opening hours.

In response to this scenario, advisers from two organisations gave an overview of how HIV is transmitted - through blood, semen, pre-cum and vaginal fluid - and one of those emphasised that HIV needs a route to move from one person's body to another. It was stressed that the caller would be unlikely to have contracted HIV from her girlfriend even if she was HIV positive, and that the girlfriend may not even necessarily be HIV positive in spite of her ex-boyfriend's new diagnosis.

The same two advice lines addressed risks of transmission between men and women, emphasising the importance of condom use. They both focussed on vaginal sex, though when prompted one addressed the risk of HIV transmission through anal sex, and recommended condoms and lubricant. Both advisers said that HIV is not always passed on automatically through unprotected sex, and one deemed it 'unlikely' that HIV would be transmitted through one act of sex, although 'the odds increase the more times you have unprotected sex'. One also advised of the importance of avoiding sexually transmitted infections as they can increase the likelihood of HIV transmission, and advised going to a clinic to be tested. One of the advisers mentioned oral sex, saying that the risk of contracting HIV through oral sex was not high, but recommended using flavoured condoms and dental dams for women giving and receiving oral sex.

All three lines addressed the risks of HIV transmission between women. One said that HIV is transmitted through 'blood on blood contact' and stated that it was 'impossible' for the caller to have contracted HIV from her girlfriend if indeed the girlfriend was positive. Another line stressed that infected vaginal fluid would have to have a route into the other person's body, which could be caused by a cut or tear which may be caused through rough sex or by a vibrator, for instance. The advisor also highlighted that there is more vaginal fluid at the top of the vagina, near the cervix, which makes it hard to reach and consequently more difficult for infection to occur, and that the HIV virus does not survive for long outside of the body. She stated that only five cases of female-to-female HIV transmission had been recorded. That advisor mentioned that vibrators could pose a 'small risk', and the other organisation advised against sharing sex toys, because if one partner has a cut on or in her body and blood mixes with infected blood, HIV could be transmitted.

All three of the lines advised that the caller's partner should be tested for HIV. All advisers asked if the caller knew where to get one done, and two of them offered to find the nearest one if given the first part of the postcode. One line gave information about clinics that provided test results on the same day or within an hour, and another line said that results usually take around a week.

Of the three organisations the caller spoke to, two picked up on the fact the caller had just found out about her partner's ex-boyfriend's new diagnosis, and gave extensive information. One seemed particularly concerned with reassuring her in light of the new diagnosis, and focussed more on the likelihood of her being infected in this circumstance rather than discussing HIV transmission or sexual health more

generally, as well as offering reassurance and saying she should call back if she had additional questions. One line however was very quick, with the adviser simply recommending that the partner 'needs to get tested ASAP' and that it would be 'impossible' for the caller to have contracted HIV. The caller recorded feeling 'very rushed, with little opportunity to discuss my concerns' and felt that the advisor 'wanted to end the call as soon as he'd said I wouldn't have got HIV and my partner should get tested. I would have appreciated him checking if there was anything else I'd like to ask'. The caller also noted that she was sceptical of his advice about it being 'impossible' to contract HIV, having previously been given details by another organisation about HIV transmissions between women having occurred, even though she acknowledged that it was rare.

- Information about timelines for HIV testing varied significantly between different advice lines.
- Whilst advice lines might, in an attempt to reassure the caller, play down the risks of HIV transmission between women by saying it cannot happen, this could have a negative effect if the caller is told by other advisers that such transmission is possible and has in fact occasionally occurred.

Conclusion

As NAT would have expected, advice lines were consistent in their promotion of condom use to prevent the transmission of HIV. However this project identified a number of areas on which advisers gave varying advice or callers were unclear about the likely risk of HIV being transmitted, amongst other issues:

- The main area of inconsistent advice related to oral sex. Some advice lines described oral sex as 'not risky', whereas others advised using condoms or dental dams and said it would be possible for HIV to be transmitted this way.
- In addition the risk of contracting or transmitting HIV was not always explicitly clarified, depending on the sort of oral sex activity the caller talked about. Having sores on the mouth or genitals was frequently mentioned as an increased risk, but it was not always clear exactly which partner this referred to - whether this would be to the person performing oral sex, or having it performed on him or her. The risks of ejaculating in a into partner's mouth compared to the partner actually swallowing semen was also not made clear.
- NAT recognises that in some cases, trained advisors may judge it appropriate to concentrate on reassuring their caller - for instance with one line we contacted telling a bisexual woman that it would be 'impossible' for her to contract HIV from her female partner, or another asking an HIV positive woman 'when have you heard of HIV being transmitted through oral sex?' Whilst such support has its place, NAT's caller found it better to be informed openly that transmission had occurred this way on rare occasions, but then be reassured that it would be very difficult for this to happen.
- Anal sex was mentioned consistently in relation to queries about men having sex with men, but not as frequently in relation to men and women. The women callers often had to prompt the advice lines to cover this issue, and not all callers may be comfortable doing so.
- Only one advice line consistently mentioned 'proper' use of condoms, whereas internet sites tended to refer more frequently to 'correct and consistent use'. Use of a condom during sex is of course important, but using them correctly does ensure they have a greater chance of preventing HIV transmission. There were only occasional references to the use of condoms with water-based lubricant, and female condoms were rarely mentioned.

- NAT was surprised that throughout this project, only one help line advised one caller to go to hospital if a condom broke whilst having sex in a couple where one partner is HIV positive, the other HIV negative. With post exposure prophylaxis (PEP) now being available on the NHS following potential sexual exposure to HIV, we had expected this to be mentioned more extensively.
- Blood on blood contact is a recognised route for HIV to be transmitted. Several callers noted being told by advice lines that blood transfusions posed a risk. Whilst this is theoretically possible, it should be clarified that blood donated in the UK is screened for HIV before being given to patients. Also in relation to blood, advice about the risk posed by contact with menstrual blood from a women living with HIV tended to be available on web sites, but was generally not mentioned by advice lines.
- Use of water-based lubricant was mentioned by only a minority of advice lines, and spermicide by even fewer. NAT was however pleased to note that one line advised that spermicide containing nonoxynol 9 (or 'N9') should be avoided as a means of preventing HIV transmission, in line with advice from the World Health Organisation.
- There was little discussion of a satisfactory sexual relationships that can exist between people living with HIV and their HIV-negative partner.
- More detailed information could have been given by some advice lines, but others could arguably have tailored their information to the query with which they were presented, rather than giving out information from what seemed to be a standard list of all possible routes of HIV transmission.

Recommendations

On the whole, NAT found that the UK's telephone advice lines are an important resource, offering a valuable service to members of the public seeking information and advice. Some advice lines may wish to consider the following recommendations that arose from NAT's review:

- Where advice lines have an out of hours answering machine service, they should include alternative sources of information in case callers require immediate advice, rather than simply listing their own opening times.
- All information about risks of HIV transmission given by advice lines should be up to date, and advisors should be aware of current issues related to HIV, such as trials for new methods of HIV prevention like circumcision.
- Information about HIV testing should also be up to date and take account of geographic variations. Some advisers stated HIV test results take one week, whereas others gave information about one hour or same day testing - although we acknowledge that in some areas only certain tests are available.
- People may interpret words in different ways, or understand them to mean something different to what the adviser is intending to describe. Advice lines should take steps to ensure that what they are explaining is being fully understood by the caller, and also check that they are happy with the information they have been given before ending a call.
- NAT acknowledges that advice lines cannot cover all issues in one call, and it is understandable to focus on the question being asked directly - but where

appropriate, advice lines should take the opportunity to provide additional appropriate information that could help protect the caller's sexual health.

- It should be noted, however, that too much information could have a negative effect. Advice lines should tailor information to particular callers and not necessarily list every possible way that HIV can be transmitted, as there is a risk a caller may not take in everything they are told.
- Several advice lines suggested looking at the internet for more information. Whilst the internet can be a valuable resource, it should be noted that not everyone has easy access to it, or is comfortable or confident in using it for such purposes.
- Providing emotional support is important, but advice lines should not assume that a caller already has all the facts about HIV transmission, even if they are HIV positive.
- Advice lines should be clear and consistent about whether anal sex has the same level or risk or more risk of transmitting HIV than vaginal sex.
- Anal sex between two male partners was mentioned in many instances, but not often in relation to men and women. Advice lines should raise the issue of anal sex when talking to heterosexual people.
- In relation to oral sex, advice lines could offer more clarity about who is at risk and how. Many volunteers recorded being told that sores in the mouth could increase the risk of HIV transmission, but the direction of infection was not always fully understood. Furthermore, few advice lines covered the issue of whether swallowing semen posed a particular risk.
- Advice lines should make people aware that other STIs have the potential to increase the risk of HIV transmission. It was not mentioned consistently by all the advice lines.
- Condom use was mentioned many times, but only one advice line talked consistently about 'proper' use of condoms. Advice lines should reiterate the importance of correct and consistent use of male and female condoms, and be prepared to advise on any potential problems to be aware of.
- Advice on use of lubricants and spermicide should also be available to callers.
- Offering information about where the local GUM clinic is situated, or how to find one, is useful.
- Where appropriate, advice lines should be prepared to offer information about accessing post-exposure prophylaxis (PEP).
- Whilst blood transfusions pose a theoretical risk of transmitting HIV, advice lines should reassure callers that blood donated in the UK is screened extensively before being used for other patients.

About the National AIDS Trust

The National AIDS Trust is the UK's leading independent policy and campaigning voice on HIV and AIDS. A registered charity, NAT develops policies and campaigns to halt the spread of HIV and improve the quality of life for people affected by HIV, both in the UK and internationally.

All the National AIDS Trust's work is focussed on achieving four strategic goals:

- effective HIV prevention
- early diagnosis of HIV through ethical, accessible and appropriate testing
- equitable access to treatment, care and support for people living with HIV
- eradication of HIV-related stigma and discrimination.

For further information e-mail info@nat.org.uk

National AIDS Trust, February 2007

Appendix:

The advice lines that were contacted for this project were:

African AIDS Helpline
Body Positive North West
Brighton Lesbian and Gay Switchboard
British Association of Sexual Health and HIV
George House Trust
Healthy Gay Scotland
HIV Scotland
Marie Stopes International
Men's Health Matters
NUS Sexwise
Positive Line
Positively Women
Scottish National Public HIV/AIDS Information Centre
Sexual Health Direct
Sexual Health Line
Sexual Health Wales
THT Direct

Web sites that volunteers used to gather information about the scenarios included:

www.aidsmap.com

www.aidsnet.au

www.aproposinc.com/hap/catch.htm

www.avert.org

www.bbc.co.uk/news

www.cdc.gov

www.circinfo.org

www.circumstitions.com

www.cirp.org

www.coolnurse.com

www.dhiverse.org.uk

www.genderandaids.org

www.google.co.uk

www.iasusa.org

www.labtestonline.org

www.niaid.nih.gov

www.sfgate.com

www.teenwire.com

www.thebody.com

www.thewellproject.org

www.yahoo.com