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# hiv treatment update

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Gus Cairns

## in this issue

Almost everything in this issue seems to have something to do with the workings of stigma.

Stigma, as Michael Ratsey says in his piece on page 8, is not discrimination. Discrimination is to do with how people are *treated*. It can therefore be dealt with, in a favourable climate, by equality legislation. The UK has been a leader in this field, being one of the first countries to include HIV infection (and not just HIV-related illness) in its Disability Discrimination Act.

Stigma, on the other hand, is about how people are *viewed*. Stigmatised people are viewed as if they were different and inferior, just because they have one or more characteristics not regarded as 'normal'.

Stigma is more difficult to legislate for: you can't order someone not to have prejudices. What you can do is combat the ignorance and misconceptions that cause those views. Sometimes this may simply involve giving people the facts. Press Gang, for instance, is a growing initiative of the National AIDS Trust which alerts members to stigmatising stories in the press so that they can reply with comments.

Sometimes it may require acts of extraordinary courage. HTU Readers' Panel member Annmarie Byrne says:

"I have always spoken out about living with HIV. I have had 'AIDS' graffiti painted on to my home and my son was surrounded by youths who shoved him and told him his mother was a diseased old c\*\*\*... I have been asked why I don't just keep quiet, but when it comes to trying to educate people, I feel I can't keep quiet!"

That's in the UK. In parts of the developing world there are also worrying reports of prejudice. In the last month the Zambian Health Minister suggested that people with HIV be given "sex depressants to quench their insatiable sexual appetite" and a Swazi MP suggested that people with HIV should be branded.

As our news item on page 12 discovers, there are signs of a growing culture of blame in southern Africa. And the utterly disproportionate 25-year sentence in Iowa given to a man who had sex once (with a condom, but without disclosing) with someone he didn't infect, reminds us that it is not just in Africa that people with HIV seem to be demonised for having sex at all.

But the worst aspect of stigma-based views is that they get under the targeted people's skin and they start believing them. They might keep quiet and not express themselves or, sometimes, people become hypervigilant, ready to take offence at innocent remarks.

In the case of dentists, as we discover on page 4, there are some old-fashioned views still circulating in the profession. But in researching the story it was sometimes difficult to tell what was prejudice or a candid confession of ignorance by a healthcare professional who probably knew less about HIV than their patient. If we shout 'oppressor' at everyone who comes to us with misinformation, we miss the chance to educate them.

It may be easier said than done, but sometimes the only response to stigma is to refuse to be stigmatised.



### hiv treatment update

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For more information about HTU's medical review panel, please visit <http://www.aidsmap.com/cms1281087.aspx>

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# Will the money drain out of AIDS?

by Gus Cairns

Earlier this year, on 20 February, the government of Botswana announced that, if the global recession continued, it would have to freeze the provision of treatment for its HIV-positive population.<sup>1</sup>

Botswana's treatment programme, which reaches an estimated 19 out of 20 people who need HIV drugs, is the envy of Africa. But the country is dependent for its prosperity on one key export – diamonds. After a decade during which diamond sales increased by 10% every year, Botswana will produce half as many diamonds as it did last year.<sup>2</sup>

Botswana has saved enough money for HIV treatment for the next seven years. But the head of its AIDS programme, Robson Dimbungu, has said that – after 2016 – the country would only be able to maintain on treatment those who already had HIV, not treat any more. "For those who are going to be infected after 2016, I think it is going to be very tough for them," he said.

By that time Botswana will have had a decade of HIV treatment. A decade during which, stigma apart, the one in four of its inhabitants that has HIV will have been able to function as an equal citizen. It would be devastating for Botswana's people to lose their access to lifesaving HIV treatment.

This may turn out to be politically inadmissible, but HIV advocates are concerned that at the very least, in order to sustain HIV treatment programmes, the global economic recession may mean that every other aspect of the global effort against HIV care – prevention, advocacy, social support and anti-discrimination work, for instance – will vanish in the process.

In April, the World Bank issued a gloomy report which predicted that the continuity of HIV treatment may be threatened for around 70% of people currently on treatment in sub-Saharan Africa, 50%

in Asia, and 25% in Russia and central Asia.<sup>3</sup> The economic crisis is already beginning to bite: Tanzania has already cut its AIDS budget by 25%.

Thirty-four of the 47 countries surveyed by the World Bank, representing three-quarters of the people with HIV in the world, expected prevention work to suffer in particular. The global region most expected to be starved of prevention help for groups vulnerable to HIV was on our own geographical doorstep, in Eastern Europe and central Asia.

The drive to treat the world for HIV has been an astonishing success story. Global funding for AIDS rose from \$1.6 billion in 2001 to \$13.7 billion in 2009. But financing for global HIV programmes is fragile. Eighteen of the 47 countries surveyed by the World Bank relied on grants from the Global Fund to Fight AIDS, TB and Malaria which end in 2009 or 2010. The Global Fund faces a funding shortfall of \$4 billion. In the USA, HIV campaigners have been bitterly disappointed by President Obama's decision to give just \$5 billion to the President's Emergency Plan for AIDS Relief (PEPFAR) global HIV initiative, an amount representing a 30% shortfall of Bush's funding, which Obama pledged to maintain in campaign speeches.

Overseas development assistance (ODA) – which includes all that HIV treatment money – is incredibly fragile and can suddenly vanish. At a meeting on 20 April, Robert Greener of UNAIDS pointed out to the European AIDS Treatment Group that economic growth in the form of gross national income has risen steadily in recent years, doubling between 1984 and 2007, with only mild slowdowns during economic busts such as the currency crisis of 1992 and the dot-com bubble of 2000.<sup>4</sup> In contrast, global ODA fell in real terms by 25% between 1992 and 1997. The pool of international health funding could vanish as fast today.

We are by no means proof against this in the developed world, where global recession and questions about the efficiency of HIV prevention and advocacy programmes have coincided with a third factor: the deprioritisation of HIV as a subject for funding by the pharmaceutical industry. Lisa Power of the Terrence Higgins Trust told *HTU* she does not expect to see HIV treatment programmes cut in Britain any more than Botswana. But she does expect the money for prevention and advocacy to suffer.

"So far the recession hasn't hit statutory bodies, though it has most certainly hit charities like the THT, largely because of a dramatic fall in private donations," she says. "But as we start to pay off the government's debts, primary care trusts and health boards will have less money to spend overall.

"Public health will be at the bottom of the pile when it comes to what the NHS spends money on in hard economic times and sexual health will be at the bottom of that."

As global, so local: "The time to make a difference is now; all the power of deciding how the money gets spent is now at the local level so it's important to lobby people like your local MP. Patients can have real influence this way."

Some hard questions will have to be asked. Should we be pushing harder for reductions in treatment costs in countries like the UK as well as Africa? And how do we join up services so that older people with HIV or people with co-infections get all their needs met in one place?

The whole HIV sector is going to have to turn on a sixpence to justify its very existence, Power predicts. "If we think it's been tough in the last few years," she adds, "we ain't seen nothing yet."



# whose fear is it anyway? people with HIV and dentists

People with HIV are still failing to access good dental care, even though it's in their interest. Do they assume dentists will have issues treating them? And are they right? *Gus Cairns* reports.



A story of my own to start with. I started going to my local hospital dental clinic in the early 1990s after ringing up my dentist at the time anonymously. I said I was a patient of theirs and I had HIV; would they treat me? They said no.

Fifteen years later, however, NHS cuts meant that the dental hospital stopped sending me check-up reminders. A friend who has both HIV and hepatitis C mentioned he'd registered with a dentist nearly opposite my flat and that they had been fine with his medical status.

I duly registered and filled in a long form giving details of my medical history and current meds. When I turned up for my appointment I was met by a young dentist. I had the impression my HIV status made him a little nervous – he stumbled over the word 'antiretrovirals' – but he gave me a check-up and a good clean, warned I might be prone to gum disease because of my modest CD4 count (350), and told me my dental hygiene was pretty good. On the whole I was satisfied.

I include this personal experience because it's still far too untypical of what a large number of people in the HIV-positive community have experienced. A survey aired at this spring's British HIV Association Conference<sup>1</sup> showed that people with HIV were much less likely to have seen a dentist recently than those HIV-negative people attending the same genito-urinary medicine (GUM) clinic.

Why was this? Were dentists refusing to see patients or were patients afraid to access dental treatment, assuming dentists would refuse to see them?

### HIV and the mouth

What is clear is that people with HIV should see a dentist regularly. This is borne out by another statistic from the survey: in one in eight patients with HIV, the last time they saw a dentist was because it was an emergency.

In pre-HAART days, oral HIV symptoms were one of the most characteristic first signs of AIDS – and of course still are in people diagnosed late. You can almost predict a person's CD4 count by what is happening in their mouth, according to one study.<sup>2</sup> At CD4 counts below 150, oral thrush (candidiasis) and the similar-looking viral infection oral hairy leukoplakia (OHL) appear. Below 100,

patients can develop Kaposi's sarcoma lesions and persistent mouth ulcers. Below 50, and they start getting gum disease so severe the gums die back and teeth fall out. Happily in the HIV treatment era, these manifestations of AIDS are rarer.

Some conditions that are more common in people with HIV have not got rarer, though. Last month we looked at human papilloma virus (HPV), for instance, and its role in cervical cancer. But oral HPV infections are also a lot more common in people with HIV.<sup>3</sup>

Oral HPV-related warts may just feel like bumps inside the mouth, especially on the inner surface of the lips. But they may become obstructive and distressing, need repeated surgical removal, and become cancerous: HPV causes 20 to 25% of cases of oral cancer. Oddly, oral warts have become more than twice as common in people with HIV since the introduction of antiretroviral drugs (ARVs) and people on ARVs are much more likely to have them than people who aren't, for reasons that aren't clear.<sup>4</sup> A visit to the dentist, clearly, could result in a cancer, or cancer risk, being spotted that could be missed by your regular doctor.

Oral cancer is rare. But tooth decay isn't and gum disease even less so. Neither is likely to kill you; but failing to visit the dentist can result in a lot of pain, loss of teeth, and, as much as a risk to health, become a risk to your self-esteem and social acceptability. Who wants to have bad breath or be scared to smile?

Tooth decay is more common in people with HIV, though not hugely so: a five-year-long study found that it developed 20% faster in women with HIV.<sup>5</sup> What is a lot more common, is a condition called xerostomia, which simply means a dry mouth; the salivary glands produce less saliva than they should. This is nearly three times as common in people with HIV: 4% of HIV-negative people have xerostomia but nearly 11% of positive people do.<sup>6</sup> It's 2.5 times more common in people with low CD4 counts versus those with high CD4s, but it's also 2.5 times more common in people taking HIV therapy, and has been associated with drugs ranging from ddI in 1992<sup>7</sup> to protease inhibitors in 2009.<sup>8</sup>

This condition is really important because saliva has natural antibacterial

agents in it – that's why animals lick their wounds. It also contains substances that help remineralise the teeth. And the flow of saliva washes food particles and associated bacteria away from crevices – people with xerostomia experience an often dramatic increase in tooth decay.

One major cause of xerostomia is 'speedy' recreational drugs such as methamphetamine, cocaine and ecstasy. Damage to teeth and gums – 'meth mouth' – is worsened by the fact that these drugs can cause clenching of the jaw and teeth-grinding. Carrying a bottle of water with you and use of sugar-free gum can help.

Whatever the cause, you can help with gum disease and tooth decay by regular and attentive teeth cleaning using a high fluoride toothpaste, and flossing too. And where you can't, it's the job of the dentist and their indispensable assistant, the hygienist, to do it for you. Dentistry is as much about preventing gum disease and tooth decay as it is about treating it.

### A positive dentist advises

'Dr Steve', a dentist from the home counties, thinks that patients and dentists should stop seeing HIV as a big issue that prevents proper dental treatment.

He should know. Steve is HIV-positive himself (hence the pseudonym).

"The principal dental problem in HIV-positive and -negative people alike is gum disease," he says. "And the main cause of that is plaque." Wiggling his fingers as if I was his patient and he was lecturing me in the chair, he shows how plaque – the soup of bacteria inside the mouth – gets into the crevice between tooth and gum. If it's not cleaned off properly, two things happen.

Firstly, it starts eroding the gums. They recede – leaving teeth vulnerable to loosening and exposing softer parts of the tooth to decay. Erosion can also happen out of sight, in 'periodontal pockets' between the inside of the gum and the tooth root.

If that happens, these pockets can become infected and turn into abscesses. Even if they don't, the bacteria inside can attack the tooth root, killing off the living nerve inside, and erode the bones of the jaw itself. "And that bone loss can't be reversed," says Dr Steve. "Without supporting bone,

your teeth are like buildings without foundations and will fall out."

If people cleaned and flossed properly, he says, they would rarely have to see dentists. "But you need to do it regularly and be shown how to do it properly, not just with a toothbrush but with floss and an interdental brush" (a tiny one that cleans between teeth). "I have four hygienists in my practice. In fact the first question you should ask of any private or NHS practice is: do you employ a hygienist? They're the most important people."

"As you state, recreational drug use can be particularly damaging. It's not a bad idea for patients to discuss this in absolute confidence with their dentist and hygienist so that they are able to make a clear differential diagnosis as to the causes of their damaged dental health."

Diet, of course, is important, and we all know we should avoid eating sweets. "But the hidden sugar in items like ketchup is just as important," Steve adds.

### Access and prejudice

So what about the issue of access to dentists? Are patients mistaken in thinking they'll be turned away?

The General Dental Council guidelines<sup>9</sup> say: "The spread of HIV infection has served to highlight the precautions which a dentist *should already have been taking* [our italics]... It is unethical for a dentist to refuse to treat a patient solely on the grounds that the person has a blood-borne virus or any other transmissible disease."

Despite this, people with HIV are still reluctant to see dentists.<sup>10</sup> Silvia Petretti of Positively Women says: "I have been training dentists on HIV awareness as part of an 'Access to Mainstream Services' project commissioned by Hammersmith and Fulham PCT [primary care trust]. Only 65% of positive people in the PCT were registered with a dentist, only 45% would tell their dentists about their HIV status, and 55% perceived their HIV status as preventing them accessing services."

### Patients' experiences

We asked a sample of HTU readers about recent experiences with dentists.

Outright refusal of treatment was rare, but it did happen:

## It is unethical for a dentist to refuse to treat a patient solely on the grounds that the person has a blood-borne virus. General Dental Council

"When I moved to Devon I disclosed my HIV status. The dentist said 'I am very sorry but we wouldn't be able to treat you here because we don't have the facilities.' I asked if she'd mind ringing the PCT to find out what someone in my position should do. A few hours later she got her secretary to ring back and say that she was now willing to treat me."

More often, there was a suspicion that the dentist was avoiding taking the patient:

"I work for an HIV organisation in the north of England, rang a dentist on behalf of a service user and was told that, yes, they were accepting new NHS patients. Less than half an hour later, after I had notified them that the service user was HIV-positive, I was told that they were not accepting any new patients at present."

Some dentists refuse on cost, rather than directly on safety grounds:

"I signed on as a private patient to a practice in London. The dentist said 'It will cost you more because of the extra infection control equipment'. I thought,

*you're talking rubbish, what you already do should be enough. So I went to another practice and they couldn't have been nicer. The receptionist was charming and the dentist offered to do as much as he could on the NHS.*"

In other cases people are perfectly happy and open with their dentists but still have an uneasy feeling that they are being treated differently:

"I disclosed my status to the dentist I already had on diagnosis. He is a very good dentist, supportive, interested and helpful...but...he still sees me only as the last patient of the day. I haven't challenged him about it – I don't want to lose him! But there is no reason I'm aware of that he needs to do this."

In the patients HTU talked to, only ever being seen as the last patient of the day was the most frequent complaint, and the most common reason patients gave for feeling, rightly or wrongly, that they were seen as a 'problem'.

### What do the dentists really think?

Do dentists really worry about taking on HIV-positive patients? Or are patients too ready to regard as discrimination normal practice and precautions?

One of the few studies that asked dentists what they really thought of patients with HIV was conducted in north-west England six years ago. It may therefore not be representative of views now, but it might explain some reactions.<sup>11</sup>

The researcher asked 15 dentists for detailed interviews, out of a group of 330 who had been part of a larger survey<sup>12</sup> on the same subject. Two-thirds of the dentists in the larger 330-subject survey had agreed with the statement that they had "an ethical responsibility to provide dental care to HIV-positive patients".

However when the 15 practitioners were quizzed more closely, only seven of the 15 said that they would accept HIV-positive patients 'without hesitation'. Of the others, five would 'accept with some hesitation' HIV-positive patients while three would refer them elsewhere.

Some practitioners had no reservations:

"If a person needs dental care and you're able to provide treatment, then you are

*responsible to provide it, providing it doesn't put you at risk, and I don't see that HIV does that."*

Others were much more hesitant, however. Several stressed the "disproportionate time involvement" and this centred round the belief that they needed to take extra precautions. Some expressed rather contradictory attitudes towards infection control:

*"Yes, routine infection control procedures should be sufficient but I would say extra precautions are needed such as double-gloving."*

A lot of the dentists mentioned the presumed extra expense:

*"Any patient that takes longer, and the same applies to a nervous patient, it means the patients are unprofitable to see."*

Some practitioners said they were concerned about the reactions of their staff:

*"Even if you explain everything – HIV has such a psychological aura about it – if they genuinely do go home and have sleepless nights... you could potentially have tribunal concerns on your hands."*

Finally, one had been on an HIV awareness course which seemed to have a counterproductive effect:

*"It changed my attitudes quite a lot, but if you had a needlestick injury, the drug regime you had to go on was horrendous – that scared me."*

### How to get a dentist

Faced with attitudes such as these in both patients and practitioners, not to mention the general shortage of dentists willing to provide NHS care, one option is to contact your local Community Dental Service: clinics in which dentists who are receiving an NHS salary provide first-line services.

In Lothian, for instance, Dr Chris Cunningham, co-author of the BHIVA study,<sup>13</sup> works for the Salaried Primary Care Dental Service (the equivalent of a Community Dental Service).

"We do still have a specialist care team for people with HIV. Edinburgh has always been different in that we've had

quite a large population of people with HIV and also injecting drug users.

"Only a small minority of our patients have had problems getting a dentist specifically because they have HIV. A larger number can't find an NHS dentist for the same reasons as anyone else – there aren't enough of them. A proportion of patients want to disclose their HIV status to us and not to a high street dentist. And, finally, some think we will offer a better service.

"For a while we have only been accepting new referrals for people with CD4 counts less than 200 or with specific oral problems but as a result of our study we are reconsidering whether we should accept asymptomatic HIV-positive individuals. We'll offer a course of treatment, get you dentally fit, and our advice is then to go and find a regular NHS dentist. If you get refused because of HIV you can take them to the General Dental Council."

Dr Steve adds: "If they reject you because of HIV, or if the dentist insists on conditions such as double-gloving (such rubbish!) or your having to have the last appointment of the day, you have the winning hand, not the losing one: the General Dental Council Good Practice Standards are quite explicit and they could face a charge of professional misconduct. I hope, armed with this knowledge, HIV-positive dental patients who are feeling a little intimidated about going to the dentist may feel just that little bit more empowered."

In other parts of the UK, however these services are seeing fewer patients with HIV as their reason for referral. A spokesman for the Lambeth, Southwark and Lewisham Community Dental Service, for instance, told *HTU* that "In contrast to the early 1990s, when I saw lots of people with HIV at the PCT dental clinic, now to get referred you'd need to have additional needs other than HIV: maybe a low CD4 count, complex dental problems, or issues such as mental health [problems]. Having said that, our criteria also include 'people who may not otherwise seek or receive dental care'".

One option if you have difficulty in getting a dentist is not to disclose your HIV, of course. There is no legal obligation to do so, you're unlikely to have HIV-specific

complications with a reasonable CD4 count, and relatively few drugs used in dentistry have interactions with HIV medications (ones that do include sedatives for patients who have dental phobia and some antibiotics). However drug interactions do exist and you're withholding medical information that might help your dentist make a diagnosis.

Another answer is to go private, but even Dr Steve (who only does private work) recommends that if you haven't had dental care for a long time, it may be a good idea to seek out an NHS dentist first. If you've not been able to find a dentist in your immediate local area you could search for one at the NHS website [www.nhs.uk](http://www.nhs.uk) or contact NHS Direct on 0845 4647. Working with an NHS dentist should restore you to basic dental health and save you money. In Scotland, basic check-ups are free. Unless you are on certain benefits such as Income Support, in which case you get free treatment, NHS dentists in England and Wales will charge you one of three fees:

- £16.50 for a basic checkup, X-rays and cleaning
- £45.60 for drilling and anything up to 20 fillings
- £198.00 for crowns, inlays or anything outsourced such as dental lab work.

If you go private you may get a quicker service, or one that is closer to where you live, but it is likely to cost you a lot of money. Steve gives as typical private charges for an out-of-London clinic – London practices may cost a lot more:

- £80 for an initial consultation
- £150 for a complete check-up and comprehensive clean
- At least £460 for a crown

Another reason for going private or contacting your Community Dental Service might be dental phobia.

Even if you don't have an extreme fear of people putting sharp metal objects in your mouth, Steve says, "It's very important to establish a rapport. It's a very intimate procedure. You might simply not like the dentists. Well, if you don't, move on." ■

# stigma begins



The stigma attached to having HIV is one of the most all-pervasive aspects of living with the virus. *HTU* plans a series of articles addressing this complex subject. In the first, guest writer *Michael Ratsey* discovers that some of the people who most strongly condemn or shun people with HIV are members of the communities most affected by it. This also has implications for HIV prevention, he finds.



# ins at home

Stigma is more subtle in these post-HAART days and may therefore be even more difficult to tackle – based less on the fear of the illness and more on the disapproval of the type of person who is seen to have HIV. We might expect stigmatising attitudes and behaviour to come entirely from the sections of society that are mostly untouched by the virus, where ignorance could be an attributing factor. Or does stigma also exist within the communities where HIV information is widely available and HIV is an integral part of life? The answer, sadly, is yes.

## Stigma and risk within the gay community

In response to an online video on stigma made by Cass Mann, the founder of holistic gay men's HIV charity Positively Healthy UK, one viewer commented:<sup>1</sup>

*“I, as an HIV-positive gay man, have experienced more HIV stigma and discrimination from other gay men than from any other members of human society. These HIV-negative gay men treat me as if I was a piranha in their goldfish bowl and a ghost at their banquet...”*

Some of the findings of a 2009 Sigma Research paper on criminalisation of HIV transmission make for very disturbing reading.<sup>2</sup> Couched within the responses is an unexpected stigmatisation by gay men towards HIV-positive gay men.

Overall, 57% of gay men supported the imprisonment of people with HIV who had infected a sexual partner with the virus. One of the factors involved in the support for criminalisation seemed to be

**We have to look from within, deal with our own demons, be comfortable in our skins, ask ourselves what we are afraid of, learn not to be apologetic for getting on with our lives and...remain productive members of society and equal citizens.**  
Winnie Ssanyu-Sseruma

an outdated view of the inevitably lethal nature of HIV, with little appreciation of the effectiveness of HIV treatment. Some individuals equated the transmission of HIV with murder. One of the components of stigma is ignorance – ignorance often clung to because it justifies stigmatising views.

“These responses reveal the perception that there is little capacity for living well or longevity among people with diagnosed HIV”, write the researchers, “getting HIV is regarded as utterly disastrous.”

The researchers believe that the findings of the report have important implications for HIV health promotion. They note that “the perception that HIV equals certain death helps to maintain the stigma related to HIV, which in turn, negatively impacts on the environment in which prevention interventions occur.”

Because HIV-positive gay men often fear reaction from disclosure, they may seek out sexual situations where they are not obliged to disclose. Another Sigma Research survey, for instance,<sup>3,4</sup> found that many men used saunas, not just because sex was readily available, but also because they rationalised that almost all other sauna users were HIV-positive. Some men tried to avoid disclosure but maintain their sense of moral integrity by suggesting to sexual partners that it would be a good idea to use a condom, but even this was fraught with the risk of rejection; for instance, one man described how this suggestion prompted one sexual partner to ask directly whether he had HIV. When he said yes, the man became angry and left.

UK Community Advisory Board member Robert James, who is not gay but does have HIV, sees it this way: "I suspect that reduced risk of rejection versus the hard task of disclosure and the likelihood of rejection makes going to saunas feel like a rationally made choice. The fear of being prosecuted may also increase the preference for anonymous venues."

Understandably, but unfortunately for its impact on HIV prevention, gay men with HIV feel that it is much harder to disclose in sexual situations than in social situations. Gay men recently interviewed for GMFA's *FS Magazine* emphasised how difficult this was.<sup>5</sup>

James, a 29-year-old recruitment consultant, said he talked with friends about HIV "almost every day, because a lot of my friends have HIV." But when asked if he spoke about HIV before having sex, he said: "Never, I just wouldn't. It's bad enough trying to get someone to put a condom on, let alone talking about HIV."

Andy, a 22-year-old art dealer, said he thought that gay men had trouble talking about HIV because "there's a real stigma attached to being HIV-positive and gay. But," he acknowledged, "the less people talk about it, the more stigma there is, so not talking about HIV creates a vicious circle."

Even in the relatively anonymous environment of internet cruising sites, few men explicitly advertise their HIV status on their profile, though more may mention it during private instant messaging. HIV-positive men often report looking for clues in other profiles.

I conducted an ad-hoc survey in late March of the profiles of 200 UK men using the 'HIV cruising room' on Gaydar. Presumably the majority of men using this chat room were looking for an HIV-positive partner and were probably HIV-positive themselves. But nearly 60% gave no clue at all of their HIV status, and only 14% stated it. The remaining quarter couched a possible HIV-positive diagnosis under the sexual preference categories of 'rather not say' or by ticking the 'safer sex needs discussion' box. The few who did disclose directly in their profiles often took an aggressive slant in a follow-up sentence:

**There's a real stigma attached to being HIV-positive and gay. But the less people talk about it, the more stigma there is, so not talking about HIV creates a vicious circle.**  
**Andy, 22-year-old gay man**

"I'm HIV-positive – and if you can't cope with it then look elsewhere!"

HIV is not the only infection that can stigmatise gay men. An increasing number of HIV-positive men are also becoming infected with hepatitis C (see *HTU* 185, April 2009). In a small survey of six co-infected men, all said they felt stigmatised by their own community. Furthermore, a hepatitis C diagnosis can lead to greater feelings of shame, guilt, and 'dirtiness' as it is not 'owned' by the gay community in the way HIV used to be, and is therefore even more marginalised and stigmatised.<sup>6</sup>

### **Stigma within the African and Caribbean communities**

Winnie Ssanyu-Sseruma, former chair of the African HIV Policy Network (AHPN), who now combines working for Christian Aid in the UK with running a 'breakfast club' for HIV-positive schoolchildren in Uganda, says that many Africans in the UK have multiple lives, maintaining a life in the UK and a life 'back home' where their families and often children still reside. People don't necessarily want to be open in all arenas.

A 2007 study found that although African people account for the greatest number of new HIV diagnoses in the UK, many African people still do not come forward for testing or to access health services.<sup>7</sup> About 60% of Africans in the UK have never tested for HIV and therefore do not know their status.<sup>8</sup> A 2008 study<sup>9</sup> found black, heterosexual HIV-positive men and women were the group least likely to tell others about their status, including new partners. A third of HIV-positive African men and 40% of African women had a sexual partner who did not know their HIV status.

What is holding people back from disclosure? Part of the reason may be perceived stigma from within their own communities, rooted in fear of HIV, and at times exacerbated by religion and family culture. Much of the work AHPN does relates to social exclusion, and the organisation reports that in the UK, Africans with HIV are stigmatised not only by the wider UK community, but also within local African communities in the UK. This can lead to low self-esteem,

social marginalisation and breakdown of relationships.

The HIV crisis in black African Britain was visible as far back as 1995 but, Winnie comments, the reaction of the government was at best one of inaction or sweeping it under the carpet. At worst, she told *The Guardian* in 2005, the government left it to Pentecostal churches and lay pastors to deal with the problem.<sup>10</sup>

The African community is not the only UK black community that may suffer from actual or perceived stigma. A 2008 study<sup>11</sup> found that HIV-positive people of Caribbean descent were keenly aware of HIV-related stigma in their communities. Respondents in the survey often expected to be treated like lepers, and had experiences of enacted stigma such as excessive cleansing of household objects and family exclusion. Similar situations were recorded by the same researchers within the African community a few years earlier:

*“My wife started calling me names. She took the phone, she rang [names an African country], she rang my mom, she rang her parents and she said that she cannot stay with somebody that is AIDS”* HIV-positive African man living in the UK.<sup>12</sup>

*“Even now it is very hard to tell somebody I am sick, because like our community they take it as a curse, or like you misbehaved or went out with somebody, like they take you as a prostitute, it is an attitude which is very bad...”* HIV-positive African woman living in the UK.<sup>13</sup>

In the study, HIV was also associated with sexual behaviour regarded as immoral, including promiscuity, prostitution and above all, homosexuality. Religion had a strong influence on the perception that ‘sinners’ contracted HIV as a form of punishment.

### What can we do about it?

While a lot of in-community stigma is deeply psychological and hard to eradicate, a lot is simply founded in ignorance.

Various campaigns have attempted to address both the ignorance and the

underlying attitudes. The ‘Changing Perspectives’ campaign, for instance, was launched by AHPN<sup>14</sup> to encourage faith communities, the media and the government to address HIV-related stigma and discrimination. A media watchdog group, Press Gang, has also been set up by the National AIDS Trust (NAT),<sup>15</sup> encouraging people with HIV to report and reply to overt or covert stigmatisation in media pieces on HIV. NAT also worked with the National Union of Journalists to produce guidelines on reporting HIV to help journalists ensure the articles they write are not misleading and do not encourage negative perceptions about HIV.<sup>16</sup> Journalists need to be encouraged to report on the human stories behind living positively with HIV rather than always perpetuating the misinformation and myths that exist around it.

An important factor in dealing with stigma is coming to terms with what HIV means to us as individuals. As Winnie Ssanyu-Sseruma wisely says, “as individuals we have to look from within, deal with our own demons, be comfortable in our skins, ask ourselves what we are afraid of, learn not to be apologetic for getting on with our lives and as far as possible remain productive members of society and equal citizens.”

For some, a further step will be disclosure. Being positive about being positive is an attractive characteristic and the fear of stigma is often worse than the reality of disclosure. UK African HIV organisations have consistently taken this line in recent years and in campaigns such as Changing Perspectives, have trained people with HIV to be community spokespeople, realising that there is nothing that better neutralises stigma than the presence of an authoritative and confident HIV-positive person talking about their status. There’s even a study which shows that disclosure is an independent predictor of higher CD4 counts.<sup>17</sup>

It is human nature to seek out support and empathy and being able to be open with friends, family and partners can be an important part of this. But whether or not someone is open about their HIV in their personal life, the support of other people with HIV – through self-help groups composed of kindred spirits –

can be valuable. HIV-positive people often gain strength from other HIV-positive people and there are various ways of making contact with people – from websites like HIVmatch.co.uk and plus-friends.com to local HIV community organisations. Support also begins at home. ■

● *HTU* intends to cover other aspects of stigma and discrimination, including stigma within health care, anti-discrimination legislation, how we measure stigma, and its effects on mental health, in future issues. If you have been affected by stigma or want to write about it, contact the Editor.

● NAM produces a booklet called *HIV & Stigma*, which is available on [aidsmap.com](http://aidsmap.com). Alternatively contact us for a copy by calling 020 7840 0050 or emailing [info@nam.org.uk](mailto:info@nam.org.uk).



# news in brief



## Africa

### How religious leaders use science to discredit condoms

Religious leaders in Africa are using scientific studies of condom efficacy to portray them as dangerous and likely to increase HIV prevalence – the opposite message to that intended, a Canadian social scientist has found.

Researcher Nicole Rigillo<sup>1</sup> talked to Pentecostal religious leaders in Namibia and found that, in arguing against condoms, they had shifted “from faith-based arguments that promoted abstinence and fidelity as expressions of religious morality ... to abstinence and fidelity as ‘healthy’ choices as compared to ‘unsafe’ condom use.”

Studies of condom effectiveness in preventing pregnancies under ideal-use conditions have suggested failure rates as low as 2%.<sup>2</sup> However, large meta-analyses of their efficacy in preventing sexually transmitted infections in populations that attempt 100% condom use point towards an efficacy of 80 to 85% in preventing HIV.<sup>3</sup>

Traditional HIV prevention messages, Rigillo contends, which rely on the use of scientific fact to correct misconceptions, are ill-equipped to combat anti-condom messages that use the same facts as evidence against their use.

Such arguments are often accompanied by conspiracy theories that condom promotion is even intended to *increase* HIV prevalence. Rigillo points out that in Namibia before 1990 the apartheid government authorised forceful injection of Depo-Provera contraceptives in a bid to curb increases in the black population, and cultural memories are long.

A pastor told her: “Since it’s a scientific fact that 15 to 20% of condoms are not safe ... and condoms in Africa are being

sponsored by the United Nations, the question comes then if they are not purposely trying to eliminate the populations of Africa.”

Others, while not indulging in conspiracy theories, maintain that condom-based HIV prevention methods offer a misleading illusion of safety. Eve Seobi of Doctors for Life (DFL) South Africa told Rigillo: “The rate of infection goes up. That, to me, means one of two things: either people don’t know how to use the condom, or people use the condom with an understanding that the condoms are going to protect them, and they don’t.”

Arguments that campaigns to promote abstinence haven’t worked do not impress DFL, she says. The result is an almost ‘violent’ degree of blame against people who do acquire HIV. In an ‘educational’ video for schools, DFL Chief Executive Dr Albu van Eeden says that “the innocent are largely left to suffer for the immoral actions of HIV infected people”.

Rigillo finishes her paper by saying that “the results of this research point to a worrying challenge to the promotion of condoms for HIV prevention in epidemic contexts across Africa.”

## Herpes and HIV

### Herpes drug does not reduce HIV transmission

A large study that gave the herpes drug aciclovir, or a placebo, to the HIV-positive partner in 3400 serodiscordant couples has found it made no difference to HIV transmission rates.<sup>1</sup>

Giving anti-herpes medication to reduce HIV transmission has a plausible rationale behind it. People infected with the genital herpes virus HSV-2 appear to have a two- to three-fold higher susceptibility to HIV and people with active herpes infections have higher HIV viral loads.

A large study last year<sup>1</sup> found that there was no difference in the rate of new HIV infections amongst HSV-2-positive, HIV-negative men and women given aciclovir, but it was still hoped that the drug might reduce the infectiousness of people with HSV-2 and HIV.

However the seven-country ‘Partners in Prevention’ study found that aciclovir made no difference to the risk of HIV transmission. There were 41 new HIV infections in the aciclovir arm, compared to 43 in the placebo arm. Aciclovir treatment did, however, lead to a 73% reduction in genital ulcers and was also associated with a 40% drop in HIV viral load.

Despite being disappointed by the study’s main finding, the investigators said it had provided important information for the future. “We have demonstrated that interventions must achieve a bigger reduction in HIV levels to reduce HIV transmission”, said lead investigator Dr Connie Celum.

## Europe

### New ‘treatment as prevention’ statements

The French National AIDS Council and the largest German HIV voluntary organisation, Deutsch AIDS-Hilfe, have both recently issued statements endorsing the use of antiretrovirals (ARVs) as a valid method of HIV prevention.

The French and German statements do not go as far as the statement by the Swiss Federal AIDS Commission in January 2008, which said that people who have had consistently undetectable viral loads on treatment for six months, are adherent to ARVs and have no sexually transmitted infections (STIs) “do not” transmit HIV.

The German statement<sup>1</sup> just says that in these circumstances, the risk of transmission is “improbable”. It adds



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that having sex with a partner with an undetectable viral load needs considerably more disclosure and discussion than using condoms and does not protect against other STIs.

It acknowledges that although there is little evidence on the effect of viral load on infections in gay men who have anal sex – a major criticism of the Swiss statement – it is reasonable to assume that gay men with undetectable viral loads are dramatically less infectious than those not on treatment.

The French document<sup>2</sup> avoids stating whether 'undetectable equals uninfected', saying that "study results will not... identify a specific plasma viral load threshold below which the risk of transmission would be null".

It does say that reducing HIV viral load on a population level could have a significant impact on HIV incidence and implies a "paradigm shift" in HIV prevention messages. It cites the British Columbia mathematical model presented in June 2008<sup>3</sup> finding that if more than 50% of the HIV-positive population was kept virally suppressed, a slow decline in HIV prevalence would result. However it points

out that even in France, where there are high rates of diagnosis, treatment and viral suppression, only 46% of people with HIV have an undetectable viral load.

It therefore recommends campaigns to raise awareness of the benefits of early testing and treatment; regular voluntary HIV screening for high-risk populations; and changing outdated and negative messages about the toxicity of HIV drugs.

### Drug interactions

## Ginkgo may reduce efavirenz levels

Extracts from the *Ginkgo biloba* tree may have significant interactions with the HIV drug efavirenz, a case study from the Netherlands suggests.

Efavirenz can cause side-effects such as poor concentration and depression, and Ginkgo is a widely used herbal remedy that is thought to have beneficial effects on these. It appears to improve blood flow to the brain, and users are already warned not to combine it with anticoagulants like aspirin and warfarin.

The current case involved a 47-year-old man with HIV. He was fully adherent to his antiretroviral therapy. His treatment consisted of efavirenz combined with FTC and tenofovir.

The patient started therapy in 2005 and, in late 2007, experienced virological failure. He turned out to have drug resistance to both efavirenz and FTC. The only non-prescription product he had been taking was *Ginkgo biloba*.

Using stored samples, the investigators checked concentrations of efavirenz in the patient's blood. Concentrations declined from a peak of 1.26mg/l (well within the drug's therapeutic range) in late 2006, when the patient's viral load was undetectable, to a non-therapeutic 0.48mg/l in February 2008. By this time the patient's viral load was 1780 copies/ml. It is thought that Ginkgo may induce higher levels of the drug-processing liver enzyme CYP450, resulting in faster elimination of efavirenz.

"We conclude", write the investigators, "that an intake of *Ginkgo* can decrease human plasma efavirenz levels, may result in virological failure and should be discouraged."

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# love is a danger

American researchers have reported that gay men in the US are more likely to contract HIV from their main sexual partner than from casual sex. What are the implications for HIV prevention messages there? ask *Gus Cairns* and *Michael Carter*.

In a country where sex between men and women is the main transmission route for HIV, the biggest increase in a woman's risk of getting HIV happens when she gets married. That's one reason why sexual abstinence campaigns don't work: most women with HIV were abstinent – till their wedding night.

But in countries where most transmission is between gay men, there has been an underlying assumption that it's all fuelled by casual sex. This idea was recently challenged by a US study<sup>1</sup> which calculated that two-thirds of gay men who acquire HIV do so from their regular partner.

The study didn't look at actual HIV transmission episodes in a group of men. Instead, it analysed data from the National HIV Behavioral Surveillance System (NHBS), a study of 3652 HIV-negative and positive gay men in five US cities between 2003 and 2005.<sup>2</sup> This looked at: the number of sexual partners men had in a year, both main and casual; the perceived HIV status of their partners; the proportion having anal sex who didn't use a condom last time they had sex; and whether they were insertive ('top') or receptive ('bottom'). The NHBS study also took anonymous saliva samples for HIV screening from half of the men they studied. It could therefore tell whether gay men's knowledge of their HIV status was accurate.

Because the NHBS only collected data about the last sexual episode, one missing piece of information was how many times men had actually had sex during the year with main and casual partners. They therefore added in data from a previous study, the Vaccine Preparedness Study, which recruited 3617 gay men in six US cities between 1995 and 1997.



With all these data, the researchers were able to work out what proportion of HIV infections must have come from regular partners, and the answer was around two-thirds – 68%. Even when they tested their model to destruction by putting in the minimum possible estimated rate of unsafe sex with main partners and the maximum possible for casual partners, still more than half of HIV infections came from main partners.

There were several reasons for this. Firstly, men had more actual occasions of sex with their main partner. In raw numbers there were about 195,000 occasions of sex between main partners and about 173,000 episodes of casual sex. So gay men don't exactly behave like blushing brides, but they still have more sex (about 80 times a year on average) with their regular partner than with casual partners.

Secondly, they were more likely to have anal sex with main, rather than casual

partners and were more likely to be the receptive partner too. Forty per cent had been anally receptive last time they had sex with their boyfriend (though they might have been active too) but only a quarter of them the last time they had casual sex.

Thirdly, they were considerably less likely to use condoms with main than casual partners. Men used condoms for anal sex (in either role) 72% of the time with casual partners but only 43% of the time with main partners. Add all these together and you get a lot more instances of unsafe sex with main partners per year than with casual partners.

HIV prevalence was around 25% in both casual and main partners. Men were pretty bad at either knowing or guessing their own or their partners' HIV status. When the researchers looked at actual HIV transmissions, they worked out that only 16% of men who caught HIV had known their partner had HIV.

In contrast, 46% of men who acquired HIV caught it from someone they had believed to be HIV-negative, and 55% of transmissions from main partners came from men who believed themselves to be negative. In casual sex, 63% of transmissions happened in situations where the partner's status had been unknown.

Men with diagnosed HIV infection were therefore the group *least* likely to be responsible for HIV transmission. This was because, when one partner was known to have HIV, couples were no less likely to use condoms with their main partner than during casual sex.

There were a couple of other standout findings from the study. Firstly, although being the receptive partner (the 'bottom') accounted for nearly 70% of infections, 28% of infections were acquired by the insertive partner (the 'top'). This is more than predicted from previous studies, though some HIV campaigners did comment that some men might have lied about being a 'bottom' as it is still stigmatised. Note also that the study found that 2 to 3% of infections came from oral sex – a figure that backs up earlier studies.

Secondly, the annual HIV incidence – the proportion of this group that acquires HIV every year – was calculated to be 2.2%. Given that this is ten times the observed mortality rate among gay men in the Vaccine Preparedness Study,<sup>3</sup> the number of gay men in the USA with HIV will continue to grow, at least until significant numbers start dying of old age, unless HIV incidence is cut drastically.

This study obviously has huge implications for HIV prevention messages. It's well known that people use condoms much less with their main partner and for many couples this is because condoms are seen as a sign of distrust. Trying to get regular partners who don't use condoms already to use them can be a challenge.

Encouraging couples to test, or re-test, for HIV the moment they get involved with someone emotionally has several benefits. If one partner does test positive for HIV it not only means they are in a much better position to look after their own health, but successful treatment will also reduce their infectiousness. And

regardless of test results, testing for HIV is a powerful prevention tool, bringing people into contact with sexual health services and, most importantly, opening up a discussion between partners about sexual health and safer sex.

Exactly which prevention message is most appropriate, however, depends on one question not asked by the survey. In the words of Roger Tatoud, Senior Programme Manager for the International HIV Clinical Trials Research Office at Imperial College in London: "If most people get HIV from their main partner, where did he get it from?" This is also a dilemma faced by researchers into heterosexual transmission. There are two theories:

The 'serial monogamy' theory is based on the idea that committed relationships among gay men and especially young gay men might not last very long, and this is borne out by the finding that the men averaged 1.4 'main partners' a year. If the average interval between HIV tests or, for those who've never tested, between first sex and the most recent, is longer than or near the average length of committed relationships, then there are going to be a lot of men entering new relationships who don't know they have HIV. Message: test as soon as you get involved.

The 'concurrency' theory, on the other hand, assumes there is far more sex going on outside a lot of main relationships than the researchers captured, both because respondents didn't tell them about it (we know people lie about sex to even the most confidential survey) or because the researchers made assumptions about what 'main relationships' mean to gay men, for instance that emotional commitment means monogamy, and so didn't ask clearly enough about it. Message: have an agreement to maintain safer sex outside your main relationship.

Whichever theory is right, this study challenges assumptions that offering gay men marriage and the chance to settle down with the dog and Radio 4 might mean less HIV transmission, and will cause some rethinking in the world of HIV prevention. ■

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## where to find out more about hiv

- **Find out more about HIV treatment:**  
NAM's factsheets, booklets, directories and website keep you up to date about key topics, and are designed to help you make your healthcare and HIV treatment decisions. Contact NAM to find out more and order your copies.
- **www.aidsmap.com**  
Visit our website for the latest news about HIV & AIDS, a fully searchable treatments database and a complete list of sexual health clinics in the UK.
- **THT Direct**  
Offers information and advice to anyone infected, affected or concerned about issues relating to HIV and sexual health.  
**0845 1221 200**  
Mon-Fri, 10am-10pm Sat-Sun, 12pm-6pm
- **i-Base Treatment Phonenumber**  
An HIV treatment phonenumber, where you can discuss your issues with a treatment advocate.  
**0808 8006 013**  
Mon-Wed, 12pm-4pm





www.aidsmap.com

# hiv treatment update

## 2009 readers' survey



If you would prefer to complete the survey online, you can access it from our website [www.aidsmap.com/htu](http://www.aidsmap.com/htu)



## About getting HIV Treatment Update

### 1. Where do you currently get your copy of HIV Treatment Update (HTU)? Tick all that apply.

- I receive the print edition at home
- I see the print edition at work
- I read the print edition at my clinic or HIV centre
- I subscribe to the email edition
- I read it online
- I read someone else's copy
- Other

### 2. If you get your own copy, roughly how many people other than you read your copy of HIV Treatment Update?

- One other person
- 2-4 people
- 5+ people

### Do you recommend it to other people?

- Yes
- No

### If so, who?

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### Is there anyone you would not recommend it to? Why not?

.....

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.....

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### 3. Where did you find out about HTU?

- Not sure/don't remember
- From my HIV doctor
- From other HIV clinic staff
- From THT's HIV Health Support Service
- I picked it up at my clinic
- From a support group
- From a friend or family member
- From seeing it on www.aidsmap.com
- From reading about it in another NAM publication
- From reading about it in a non-NAM publication or website
- From another source

Please specify from which NAM, non-NAM or other source you found out about HTU.

.....

### Do you keep copies of HTU to refer back to?

- Yes
- No

### If yes, roughly how often might you do that?

- At least once a month
- Every few months
- A couple of times a year
- Less often than that

## About reading HIV Treatment Update

### 4. Why do you read HTU? Tick all that apply.

- I'm HIV-positive
- I work in the HIV field, in healthcare
- I work in the HIV field, elsewhere
- I'm a partner/relative/friend of someone with HIV
- Other (please specify)

.....

### 5. How long have you been reading HIV Treatment Update?

- Less than a year
- 1-2 years
- 3-5 years
- 6-9 years
- 10+ years

### 6. Which sections of HIV Treatment Update do you read?

	Regularly	Often	Sometimes	If topic interests me	Never
Editorial and content	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Upfront	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Main articles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
News in brief	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I read it from cover to cover	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### 7. How do you decide what to read?

- I read it from start to finish
- I go straight to my favourite pages
- I use the contents listing
- I flick through it
- I look at the illustrations first

### 8. How do you find reading HTU? Tick all that apply.

- It's easy to understand
- The language is too simple
- It's not technical enough
- Its technical level is about right
- It's too technical
- The language is too complicated
- It's hard to understand
- There's too much text
- There's too little text

Please add any comments in your own words.

.....

.....

### 9. Is there anything you would like to see to make the content of HTU easier to understand or more accessible to you?

.....

.....

**10. Is English your first language?**

- Yes  No

If not, what is it?

.....

**About content in HIV Treatment Update**

**11. Which subjects would you like to see covered in future issues of HTU? Tick all that apply.**

- New/future treatments and science
- Current HIV treatments and HIV-related conditions
- Co-infections and other medical conditions
- Prevention and sexual and reproductive health
- Healthcare services and the NHS
- Social and psychological issues
- Political, policy and legal issues
- Personal stories

Please tell us about any topic you'd specifically like HTU to cover.

.....

.....

.....

Is there any type of topic you'd like to see less of (or none) in HTU?

- Yes  No

If so, what?

.....

**About learning from HIV Treatment Update**

**12. As a result of reading HTU have you learnt anything about HIV, health and treatment?**

- I have learnt nothing new
- I have learnt something but it's not particularly useful to me
- I have learnt something that is useful to me
- I have learnt something that seems vitally important to me

Please give some examples in your own words of what you have learnt.

.....

.....

As a result of reading HIV Treatment Update are you now more likely to:

Discuss your health and treatment with your healthcare team

- Agree  Disagree

Feel more confident talking to your healthcare team

- Agree  Disagree

Feel better equipped to take decisions regarding your treatment and care

- Agree  Disagree

Have you made any changes to your treatment or care, or taken decisions, based on something you have read in HTU?

- Yes  No

Please give us an example of what you discussed and/or what these changes or decisions were.

.....

.....

.....

**13. With whom do you discuss the information you read in HTU? Tick all that apply.**

- HIV healthcare worker (doctor, clinic nurse, etc.)
- Non-HIV healthcare worker (GP, practice nurse, etc.)
- HIV support worker (housing/social worker, etc.)
- People on HIV helplines
- Online forums, chatrooms and email lists
- Other people with HIV or HIV support groups
- Partner, friends and/or family
- Colleagues at work
- Other (please specify)

.....

**About the design of HIV Treatment Update**

**14. Regarding the design of HTU, what do you think of the use of:**

	About right	Would like to see more	Would like to see less	Doesn't make a difference
Photography	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Illustration (drawings)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Graphs and diagrams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Does HTU's design help your understanding of the articles and information in the newsletter?

- Yes  No  Don't notice

Please add any comments you have on HTU's design.

.....

.....

.....

.....

## About you

### 15. Are you:

- Male       Female       Transgender

### 16. How old are you?

- Under 20       20-29       30-39  
 40-49       50-59       60-69       70 or over

### 17. How would you describe your sexuality?

- Gay man       Lesbian  
 Bisexual       Heterosexual (straight)  
 Other       Prefer not to say

### 18. How would you describe your ethnic background?

- White British       White other (please specify below)  
 Black African       Black Caribbean       Black other  
 Asian       Mixed race (please specify below)  
 Any other group (please specify):

What is your country of birth?

### 19. What is your highest educational level?

- No qualifications       GCSE or equivalent (year eleven)  
 A-level or equivalent (year thirteen)  
 Vocational qualification or diploma  
 University degree       Postgraduate (masters or doctorate)

### 20. What's your employment status?

- In full-time work       In part-time work  
 Self-employed       Voluntary work  
 Student       Retired  
 Unemployed and seeking work  
 Unemployed and not seeking work

### 21. Where do you live?

- In London  
 In the UK, outside London  
 Outside the UK

If you live in the UK, please give the first half of your postcode

How far away is your nearest HIV clinic?

- A mile or less       2-5 miles       5-20 miles  
 More than 20 miles       Don't know

### 22. What is your HIV status?

- I'm HIV-positive  
 I'm HIV-negative (go to question 37)  
 My HIV status is unknown (go to question 37)

### 23. If you are HIV-positive, how do you think you got HIV?

- Sex between men       Sex between men and women  
 Injecting drugs       Blood or blood products  
 Mother to child       Don't know  
 I'd rather not say       Other (please specify)

### 24. If you are HIV-positive, are you:

- Asymptomatic (no illnesses), not on HIV treatment  
 Asymptomatic (no illnesses), on HIV treatment  
 Symptomatic, not on HIV treatment  
 Symptomatic, on HIV treatment

Do you receive any HIV-specific medical care?

- Yes       No

If you are HIV-positive, were you diagnosed:

- In the last year       1-2 years ago  
 3-5 years ago       6-9 years ago  
 10-15 years ago       16-20 years ago  
 More than 20 years ago ?

## About NAM's information materials

### 25. Which of NAM's other publications do you receive/subscribe to?

	Regularly	Often	Occasionally	Never
HIV Weekly (email bulletin)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HIV Treatments Directory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HIV Reference Manual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Criminal HIV Transmission	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Others (please specify)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

### 26. Which of NAM's publications do you read?

	Regularly	Often	Occasionally	Never
HIV Treatment Update	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HIV Weekly (email bulletin)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
www.aidsmap.com	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
www.namlife.org	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HIV Treatments Directory	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HIV Reference Manual	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Criminal HIV Transmission	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Others (please specify)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please return this survey in the envelope provided or to:  
**HTU Readers' Survey, NAM, Freepost LON17995 London, SW9 6BR**

**Thank you for your time!**

NAM welcomes feedback from all users of our materials and uses it to make our information appealing and relevant.

If you would like to give us more feedback on HTU or any other NAM materials, or to find out more about the materials we produce, please contact us on 020 7840 0050 or at [info@nam.org.uk](mailto:info@nam.org.uk).