

# hiv treatment update



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It's not too late to let us know what you think about HTU in our 2010 readers' survey. You can complete a paper copy, included in July's edition, and return it in the freepost envelope enclosed or do it online at [www.aidsmap.com/htu](http://www.aidsmap.com/htu) by 4 October. Thank you!



Gus Cairns

## in this issue

It's been that time of year when half NAM's staff relocate to a vast HIV conference, this time in Vienna, while the other half sit up till the small hours processing our fevered despatches. You can read some of the conference news on page 14.

To me, at least, it was a frustrating conference, mainly because of the contrast between the treatment situation for people with HIV and their social situation, which seem to drift further apart every year.

On the one hand, we had scientists talking about ever-more comfortable drug regimens and strategies for a complete cure of HIV.

On the other hand there were numerous presentations that revealed that the prejudice against people with HIV and those vulnerable to it is, if anything, intensifying.

There were a number of workshops on the increasing, worldwide criminalisation of people for passing on the virus, or even just exposing people to it. Many sessions featured my predecessor as editor of *HTU*, Edwin J Bernard, who summarises the situation on page 4.

Edwin also wrote a piece for *The Guardian* about the recent conviction of a German singer: *Nadja Benaissa's HIV trial is a distracting sideshow*. If you want to know what some of the supposedly liberal readers of *The Guardian* think of people with HIV, view the comments on the online edition. They're not pleasant reading.

Another group that still faces stigma is gay men and other men who have sex with men (MSM): not so much in the UK, but to the point of capital punishment in a number of countries worldwide. On page 18 Jack Beck of the Global Forum on MSM and HIV explains why, 30 years after gay men noticed a deadly disease in their midst and devised a community response to it, it's still necessary to have a separate MSM-specific sub-conference.

There have always been demonstrations at international AIDS conferences, but this one seemed to feature them non-stop, with disenfranchised groups – injecting drug users, sex workers, transsexuals, TB patients – screaming at the doorway as the scientists and politicians talked big money inside.

In such a situation it's easy, if you're a person with HIV, to spend your whole time imagining that every frustration of life is caused by people having it in for you. That doesn't always help when talking to people who are genuinely interested in your welfare – one of whom should be your doctor.

Storming into their consultation room waving a sheaf of internet printouts and yelling "Why didn't you tell me about this?" isn't usually the way to get the best treatment. But nor is sitting there too shy to mention the pain that's been crippling you for a month.

In the middle of all this talk about stigma and politics, on page 10 Lindsay and James from Living Well talk about how to create a dialogue between you and your doctor to get the best treatment. If you want to fight injustice, you first have to live to fight another day.



### hiv treatment update

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For more information about *HTU's* medical review panel, please visit [www.aidsmap.com/page/1445504](http://www.aidsmap.com/page/1445504)

### about NAM

NAM is a charity that exists to support the fight against HIV and AIDS with independent, accurate, up-to-date and accessible information for affected communities, and those working to support them.

For more information, and details of our other publications and services, please contact us, or visit our website, [www.aidsmap.com](http://www.aidsmap.com).

### disclaimer

The publishers have taken all such care as they consider reasonable in preparing this newsletter. But they will not be held responsible for any inaccuracies or mis-statements of fact contained herein. Inclusion in this newsletter of information on any drug or clinical trial in no way represents an endorsement of that drug or trial. This newsletter should always be used in conjunction with professional medical advice.

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## How can we afford to treat HIV?

One of the dominant themes at the recent International AIDS Conference in Vienna was how to maintain the momentum towards universal HIV treatment access in the context of a global economic slowdown.

It is estimated that the Global Fund to Fight HIV, TB and Malaria, which funds treatment for 2.5 million of the 5.2 million people on HIV treatment in the world, will need up to US\$2 billion over the next two years just to maintain the present number it supports. That figure doesn't include funding for the extra million people that will need drugs if new World Health Organization guidelines to treat at CD4 counts below 350 are to be followed, let alone expanding treatment further. It is estimated that still only a third of the people with HIV in the world who need treatment are getting it.

The Fund has committed itself to pay for programmes worth \$4-6 billion more than it has money to pay for, and given that its second-largest contributor, the European Union, actually reduced its contribution by \$600 million last year, there was a lot of nervous questioning in Vienna about whether we would see reversals in treatment access.

HIV activists have also criticised the current US President, Barack Obama, for 'flatlining' funding for the President's Executive Plan for AIDS Relief (PEPFAR) programme, which funds HIV drugs for two million people. Proposals to expand the mandate of the fund to cover maternal and child health could result in reductions in the funds available for HIV treatment.

There have certainly been reports of drug stockouts and people being forced off treatment from Uganda, from Russia and even in the USA, where 1700 people are currently on waiting lists for state-funded HIV treatment.

Ex-US president Bill Clinton, addressing the conference, had two messages, one optimistic and one sobering.

The optimistic one is that we seem to be turning the corner of the epidemic in terms of new infections. Global HIV prevalence has fallen by 17% in the last decade, partly due to better prevention, and there have been much more dramatic declines in incidence in young people in some countries – a 60% drop in young women in South Africa, for instance.

This appears to have been driven by behaviour change, but there is also evidence from some sources that HIV treatment is starting to have an impact on HIV incidence too, as the 'take the test' habit grows. Clinton said that the proportion of people in low- and middle-income countries who know their HIV status more than doubled from 15% in 2005-6 to 39% in 2007-8.

The sobering side of Clinton's message, however, was that we could not rely on the mechanisms that have led to the remarkable expansion of HIV treatment into the developing world to keep the momentum going into the next decade.

He warned that newer funding mechanisms would have to complement the Global Fund/PEPFAR state-philanthropy model. Developing countries, many of whom had the resources to do it, needed to start funding more HIV treatment for their own populations – a criticism heard at other presentations during the conference.

Whereas South Africa, for instance, has committed itself to expand its own support for HIV treatment and prevention, the populous and oil-rich country of Nigeria still relies on international donors for 80% of its HIV treatment budget and currently treats only 40% of its population in need.

Dr Michael Kayode Ogungbemi of Nigeria's National Agency for the Control of AIDS

said: "The country has enough resources to give all the people who require antiretroviral therapy access to treatment. But the priorities of government are sometimes not informed by evidence or rational decisions."

Clinton also said a massive increase was needed in private support for HIV. With the exception of a few billionaires like Bill Gates, Clinton said, the way forward was "to raise a massive amount of money in small amounts, by user-friendly means." He gave as examples the air-ticket levy started by France which now fuels the UNITAID HIV treatment fund, the main supporter of his own Clinton HIV/AIDS Initiative, and schemes like SMS fundraising where people can donate to campaigns like the Haiti earthquake and Pakistan flood appeals by sending a one-word text.

Finally, he praised task-shifting: the training of nurses, community volunteers, and people with HIV to administer HIV testing, drug distribution and education/counselling to communities instead of doctors. South Africa had saved \$300 million with its own task-shifting scheme, he said, and other countries needed to follow suit.

Clinton finished with a five-point plan to enable the continued expansion of HIV treatment: resist calls to deprioritise HIV; campaign for further drug price reductions, especially of tenofovir and second-line regimens; achieve large reductions in other treatment-associated costs; build better private donation structures; and "educate people why this is good".

**For more coverage of the conference, visit [www.aidsmap.com/vienna2010](http://www.aidsmap.com/vienna2010).**

The full news report on Clinton's speech, including a link to a webcast of the session is available at [www.aidsmap.com/page/1448242](http://www.aidsmap.com/page/1448242)

# where hiv is a crime, not just a virus

A new resource, *HIV and the criminal law*, has just been published by NAM. Its author, former *HTU* editor *Edwin J Bernard*, also presented on the issue at the recent International AIDS Conference in Vienna. Here he provides *HTU* with an update on an issue of concern to many readers.

Since 1987, when prosecutions in Germany, Sweden and the United States were first recorded,<sup>1</sup> an increasing number of countries around the world have applied existing criminal statutes or created HIV-specific criminal laws to prosecute people living with HIV who have – or are believed to have – put others at risk of acquiring HIV.

Most of the prosecutions have been for consensual sexual acts, with a minority for behaviour such as biting and spitting.

In the majority of these cases, HIV transmission did not occur; rather: someone was exposed to the risk of acquiring HIV without expressly being informed by the person living with HIV that there was a risk of HIV exposure.

In the cases where someone did test positive for HIV, proof that the defendant intended to harm them and/or was the source of the infection has often been less than satisfactory.

South Africa's openly HIV-positive Constitutional Court judge, Justice Edwin Cameron, called for a global campaign against criminalisation at the 17th International AIDS Conference in Mexico City in 2008, declaring: "HIV is a virus, not a crime."

Two years later, the discussion for people working in the HIV sector has moved on from a debate about whether such laws and prosecutions are good or

bad public policy to one on how to turn the tide and mitigate the harm of criminalisation. Most of them advocate, in the long term, for decriminalisation of all acts other than clearly intentional HIV transmission.

This, however, is a debate that many people outside the HIV sector have yet to even start.

## A global picture

For the first time we now have a good picture of what is happening globally, thanks to the Global Criminalisation Scan,<sup>2</sup> an initiative of the Global Network of People Living with HIV (GNP+). Its report on global laws and prosecutions<sup>3</sup> was published in July to coincide with the 18th International AIDS Conference in Vienna.

It found that at least 600 individuals, in more than 40 countries, have now been convicted of HIV exposure or transmission, with the greatest numbers of cases occurring in the United States and Canada. Many prosecutions have also taken place in Western Europe.

Although 63 countries now have at least one jurisdiction with HIV-specific criminal laws (including 27 in Africa and 13 in Asia), only 17 of these countries appear to have prosecuted anyone under them. The majority of prosecutions took place using general laws such as assault, sexual assault, grievous bodily harm or attempted murder.

In the past decade, the number of jurisdictions where prosecutions have – or could – take place has grown, although the exact reasoning behind new laws or a first prosecution using existing laws is often varied and complex.<sup>4</sup>

The GNP+ report finds that new HIV-specific laws continue to be enacted, notably in sub-Saharan Africa. It also notes that when HIV-specific laws have been enacted, the enthusiasm for prosecutions has increased, notably in north America, western Europe and Oceania (which includes Australia, New Zealand, and islands in the Pacific Ocean). What's especially worrying is that in many countries these laws have been framed but prosecutions have not yet taken place – as if they are lying in wait for a suitable test case.

All these laws and prosecutions seem to be motivated by the need to find someone to blame for the continued HIV epidemic.

"It is stigma, rooted in the moralism that arises from the sexual transmission of HIV, that too often provides the main impulse behind the enactment and enforcement of these laws," comments Edwin Cameron.

Concern about prosecutions was initially raised by civil society organisations, but is now shared by the Joint United Nations Programme on HIV/AIDS (UNAIDS) and the United Nations Development Programme (UNDP).<sup>5</sup>





These bodies are especially worried about the prosecution of people with HIV for exposure or transmission during otherwise consensual sex when there was no intention to harm; during assaults such as spitting and biting which carry negligible risk of transmission; and from a mother to her baby.

### Debate without data

The debate regarding the wisdom and effectiveness of legal sanctions, then, is primarily a moral and ethical one; there are few data to back up either side. Yet in order to make sound policy decisions about the use of the criminal law, understanding its impact is crucial.

The debate actually covers two distinct but interlinked issues that often get confused: public health (i.e. whether laws and prosecutions affect HIV prevention, for good or bad) and human rights (whether the rights of people living with HIV are unfairly affected by laws and prosecutions, relative to the uninfected majority's right for protection from HIV).

Considering the public health argument that a principal reason for criminal sanctions is to deter people with HIV from exposing others to their virus,<sup>6</sup> there are no studies showing that this works.<sup>7</sup> Other studies suggest that laws and prosecutions may unintentionally do more harm than good.<sup>8</sup>

In the absence of such hard data, prosecution proponents assert that the criminal law should be a reflection of society's moral code: claiming that punishing non-disclosure of known HIV-positive status when an individual exposes their partner to HIV is morally warranted.<sup>9</sup>

At present, the uninfected majority seems to agree with this – even, or sometimes especially, if they belong to the groups most affected by HIV. For instance, a majority of the 8152 gay men surveyed in the 2006 Gay Men's Sex Survey agreed with prosecution, even though few thought that prosecutions would help reduce the transmission of HIV.<sup>10</sup> It is

also clear from media coverage of proposed new HIV-specific criminal laws in sub-Saharan Africa<sup>11</sup> and continued prosecutions under existing laws in Canada<sup>12</sup> that there are lawmakers and editorial writers – as representatives of the uninfected majority – who believe that such laws and prosecutions are warranted and necessary.

Although such points of view often come from the privileged position of never having had to deal with the difficulty of disclosing one's HIV-positive status<sup>13</sup> to sexual partners, it should be noted that one-in-five gay men living with HIV in the 2006 Gay Men's Sex Survey agreed with criminal prosecutions too.<sup>14</sup>

Ultimately, the public health argument can be used by either side in the criminalisation debate, but is a side issue: prosecutions are essentially about a clash of rights and responsibilities between the accused and the complainant – one in which stigma has burdened the HIV-positive person with all the responsibilities and handed all the rights to the person initially assumed to be HIV-negative.

### Simply unjust

A satellite meeting prior to the 2010 International AIDS Conference was co-organised by NAM, GNP+ and the Canadian HIV/AIDS Legal Network.<sup>15</sup>

One thing discussed was the paucity of data on any public health impact criminal laws and prosecutions might have.

Although research continues, notably in Australia, Canada, the United Kingdom and United States, Susan Timberlake of UNAIDS said that we may never know for certain whether legal sanctions are in fact a disincentive to taking an HIV test, nor whether they deter or exacerbate HIV-related risk behaviour, increase or reduce disclosure of HIV-positive status to sexual partners, or create a false sense of security for people at risk of HIV.

Nevertheless the meeting heard a great deal of concern regarding the

enforcement of these laws, and in particular the potential for unfair treatment of people living with HIV by the criminal justice system.

"It is simply unjust," argued Yusef Azad of the National AIDS Trust (NAT) at the satellite meeting. "It is selecting a small group of people to be the scapegoats for a collective failure of action."

Although the evidence base may be anecdotal, he said, concerns about the impact on marginalised groups, about miscarriages of justice due to ignorance about HIV and about the law's potential to fuel HIV stigma ought to make lawmakers think twice before they turn people with HIV into criminals.

Such arguments are finally reaching influential ears. A recent report by Anand Grover, the United Nations Special Rapporteur on the Human Right to Health,<sup>16</sup> concluded that "the public health goals of legal sanctions are not realised by criminalisation. In fact, they are often undermined by it, as is the realisation of the right to health."

Susan Timberlake told the satellite meeting that it was now a "corporate priority" of UNAIDS to "remove punitive laws, policies, practices, stigma and discrimination that block effective responses to HIV".

Along with UNDP, UNAIDS has formed the Global Commission on HIV and the Law, which will focus on how laws and law enforcement can support, rather than block, effective HIV responses.<sup>17</sup> Part of its remit is to examine all the evidence on the impact of laws and prosecutions for HIV exposure and transmission; it is to issue a report in December 2011.

### How is the UK doing?

When a nineteenth-century law – the *Offences Against the Person Act 1861* (used in England and Wales, and potentially in Northern Ireland) – was first used in England to find Mohammed Dica guilty of reckless HIV transmission in 2003, the HIV sector was caught



unawares; the Labour government had previously recommended against prosecutions, and it was believed that the Act could not be used to prosecute HIV transmission.<sup>18</sup>

Although, to date, a total of 14 'reckless' transmission prosecutions have reached the courts in England and Wales (with eleven convictions), Lisa Power from Terrence Higgins Trust (THT) told the AIDS 2010 satellite meeting that many more individuals – possibly

hundreds – have been arrested and investigated (often with similarly rigorous investigation into the life of the complainant).

Scottish law is different. It focuses on behaviour (whereas English law focuses on the result of such behaviour), so exposing others to the risk of HIV transmission ('HIV exposure'), can, and has, also been prosecuted.<sup>19</sup> There have been four prosecutions and three convictions in Scotland.

Although prosecutions came to the United Kingdom relatively late compared with other countries in western Europe, a co-ordinated and tightly collaborative HIV sector response, led by THT and NAT (but which has included almost every HIV non-governmental organisation in the country, including NAM) has managed to provide lessons for many other countries in terms of clarifying the circumstances of prosecutions and reducing the flow of cases reaching court.

England and Wales was the first country in the world to have prosecutorial guidelines (produced by the Crown Prosecution Service in 2008<sup>20</sup>) and police guidance (produced by the Association of Chief Police Officers in 2010<sup>21</sup>), both developed with extensive consultation with the HIV sector.

Advocates in Canada – where non-disclosure before even protected sex can be considered sexual assault and non-disclosure before oral sex has been charged as attempted murder – are currently attempting to achieve something similar.<sup>22</sup>

We were also one of the first countries to highlight evidential issues around the difficulties of proving that the accused infected the complainant(s),<sup>23</sup> which has resulted in many cases being dropped and at least three individuals being acquitted; and to provide written guidance for healthcare workers,<sup>24</sup> and for individuals living with HIV.<sup>25</sup>

Nevertheless, concluded Power, “shit still happens”. She explained that, although fewer cases are reaching the courts and police investigations are taking less time to conclude than in the past, the number of allegations may actually be increasing.

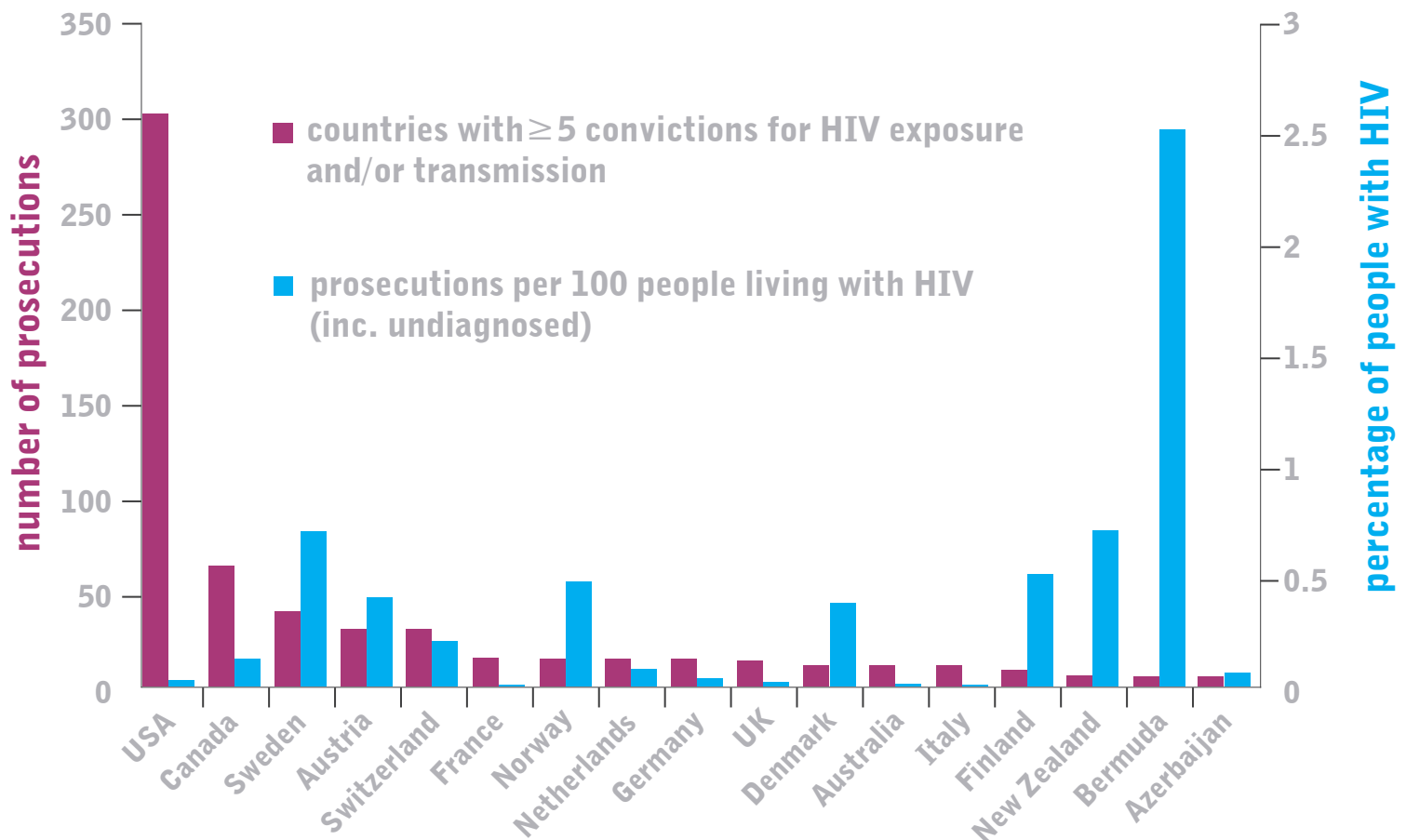
**World rankings**

The United Kingdom comes tenth in the GNP+ global criminalisation ranking according to the total number of convictions obtained by the end of 2009. Looking at it another way – based on the number of prosecutions per number of people living with HIV – the United Kingdom ranks 16th in the world.<sup>26</sup>

The data for the ‘top 15’ in terms of number of prosecutions looks rather different from the top 15 in terms of prosecutions per person living with HIV. Thus, although the 300+ convictions in the US are shocking, as a proportion of its huge HIV-positive population – the biggest in the world outside Africa and India – it only comes thirteenth.

Tiny Bermuda, on the other hand, with only an estimated 200 people with HIV, has prosecuted 2.5% of them. Apart from Bermuda, the “disproportionate prosecutors” are the Scandinavian countries, New Zealand, Austria (where the figure given is out of date and almost certain to be an underestimate) and, to a lesser extent, Canada and Switzerland.

This also doesn’t tell the whole story in terms of which countries are slackening off the prosecution of HIV, and which show a new enthusiasm for it. Prosecutions have slowed or stopped in the UK (for reasons cited above), the Netherlands and Switzerland, and have been expressly rejected by the governments of South Africa and Mauritius. Countries to watch out for are Malta (two prosecutions since 2005, representing 1% of its positive population), Poland (two since 2008), Singapore (one in 2008) and South Korea (one in 2009).





### Yes, we do – criminalisation in the US

HIV-specific laws were drafted in the United States earlier in the AIDS epidemic when life expectancy was poor. Reflecting moral panic and poor understanding of HIV transmission risks, their impact is still felt within its borders today. At AIDS 2010, I presented an analysis of criminal cases of non-disclosure, exposure or transmission in the United States during a two-year period, 2007 to 2009, and identified 82 cases of arrest or prosecution.<sup>27</sup>

Just over half of all cases occurred in eight states, all of which had an HIV-specific law: Arkansas, Florida, Illinois, Michigan, Missouri, Ohio, South Carolina and Tennessee.

Three-quarters of cases occurred in the 25 states with HIV-specific laws. Half the cases involved unprotected sex without disclosure but no alleged HIV transmission, and a quarter of all reported cases involved spitting, biting or scratching – activities which pose no risk of HIV transmission.

There is light at the end of the tunnel, however. During AIDS 2010 it was revealed<sup>28</sup> that the Obama administration's new National HIV/AIDS Strategy,<sup>29</sup> released a week earlier, included recommendations for states to review their "HIV-specific criminal statutes to ensure that they are consistent with current knowledge of HIV transmission and support public health approaches to preventing and treating HIV".

"In many instances," the Strategy report notes, "the continued existence and enforcement of these types of laws run counter to scientific evidence about routes of HIV transmission and may undermine the public health goals of promoting HIV screening and treatment."

Catherine Hanssens, Executive Director of the Center for HIV Law and Policy in New York told the *Michigan Messenger*, "It is the first truly meaningful official statement on the issue of criminalisation

and the role of civil rights in addressing the HIV epidemic, and reflects both the advocacy of HIV civil rights advocates who consistently prioritised the issue, and the willingness of ONAP (Office of National AIDS Policy) staff to respond substantively and decisively."

Hanssens and other HIV and civil rights advocates in the United States are cautiously optimistic that such recommendations will translate into further action.

She hopes the recommended state reviews will "produce findings that HIV-specific criminal laws and prosecutions contravene prioritised public health goals; subject people with HIV to irrational, exceptionalist treatment and punishment solely on the basis of their known HIV status, and also consequently represent a violation of federal anti-discrimination laws created to protect those affected by HIV."

### Exporting criminalisation to Africa

The United States doesn't just have some of the most draconian laws against HIV transmission – it also exports them.

The US has long been a global leader in creating and enforcing HIV-specific laws, including the export of laws to Africa. Until recently, its international development agency, USAID, funded the creation and widespread adoption of a 'model law' that includes definitions of 'wilful HIV transmission' that are vague and overly broad. They allow prosecutions for non-disclosure and HIV exposure – even from a mother to her infant.<sup>30</sup>

The N'Djamena model law was, ironically, conceived as human rights legislation. One of its intentions was to protect the rights of women when it came to sexual assault and rape, and many organisations for women with HIV in Africa, such as the Society for Women and AIDS in Africa – Ghana, actively lobbied for it.<sup>31</sup> However, it has been suggested that HIV-specific criminal laws may, in fact, threaten the health and human rights of women and girls, especially as such laws can place women

in a difficult situation once they learn of their HIV status.

It is ironic that, of the seven (out of a total of eleven) prosecutions in Africa where we know the gender of the accused, six were women.<sup>32</sup> At least 18 of the 27 countries in Africa that have introduced HIV-specific laws were directly influenced by this model law<sup>33</sup> and a further 8 of the 16 countries globally that are currently debating new HIV-specific criminal laws are in sub-Saharan Africa.

North America and western Europe have traditionally been the countries that jailed people who pass on HIV. We are starting to see prosecutions outside these regions, however, and it would be paradoxical if some countries started adopting prosecution as a policy just as others started to see its drawbacks.

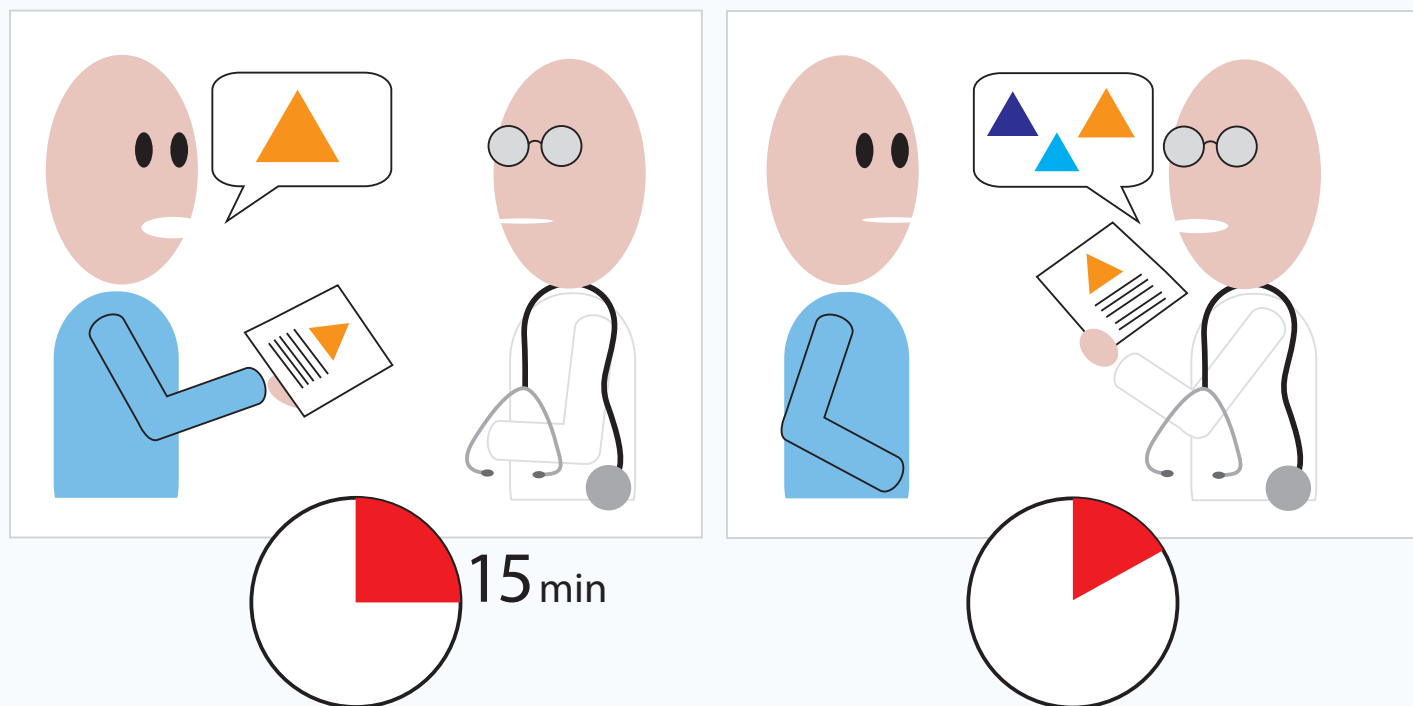
The renewed urgency with which bodies like UNAIDS and UNDP are looking into the use of the criminal law against people with HIV is to be welcomed, and comes none too soon if we are to avoid a new wave of unjust prosecutions in the world's high-prevalence countries. ■

- NAM has recently published an extensive new resource, *HIV and the criminal law*, written by Edwin J Bernard. You can read it online at [www.aidsmap.com/law](http://www.aidsmap.com/law). A print edition will also be available. Contact NAM on 020 7840 0050 or at [info@nam.org.uk](mailto:info@nam.org.uk) for more information on ordering it.

- Videos of the AIDS 2010 satellite meeting on the criminalisation of HIV exposure and transmission can be viewed online at: [www.aidsmap.com/page/1444486](http://www.aidsmap.com/page/1444486).

- Edwin's blog on Criminal HIV transmission can be seen at <http://criminalhivtransmission.blogspot.com>.

# how to talk to



You have 15 minutes and the clock is ticking. Are you saying the right thing? Does your doctor understand you? Or even take you seriously? *Lindsay Calder* and *James Miller* from *Living Well* talk to doctors and patients about that special relationship...

In the 1967 film, *Carry On Doctor*, Dr James Kilmore (Jim Dale) is examining a patient (Frankie Howerd).

**Doctor:** Just as I thought. You fell on your coccyx.

**Patient:** I did not. I fell on my back.

**Doctor:** Your coccyx is at the base of the spine.

**Patient:** Well, I've never heard it called that before.

Back in the 1960s, when matron ruled and doctor's orders were orders, patient/doctor communication was a fertile ground for comedy. Forty years on, things have changed. We're not supposed to be in awe of medical professionals any more. Now, we expect something different.

### What we want from our doctor

A 2006 survey of Mayo Clinics in the US found that patients identified seven 'ideal physician behaviours'. They wanted their doctors to be confident, empathetic, humane, personal, forthright, respectful and thorough.<sup>1</sup> All that – as well as diagnosing their problems!

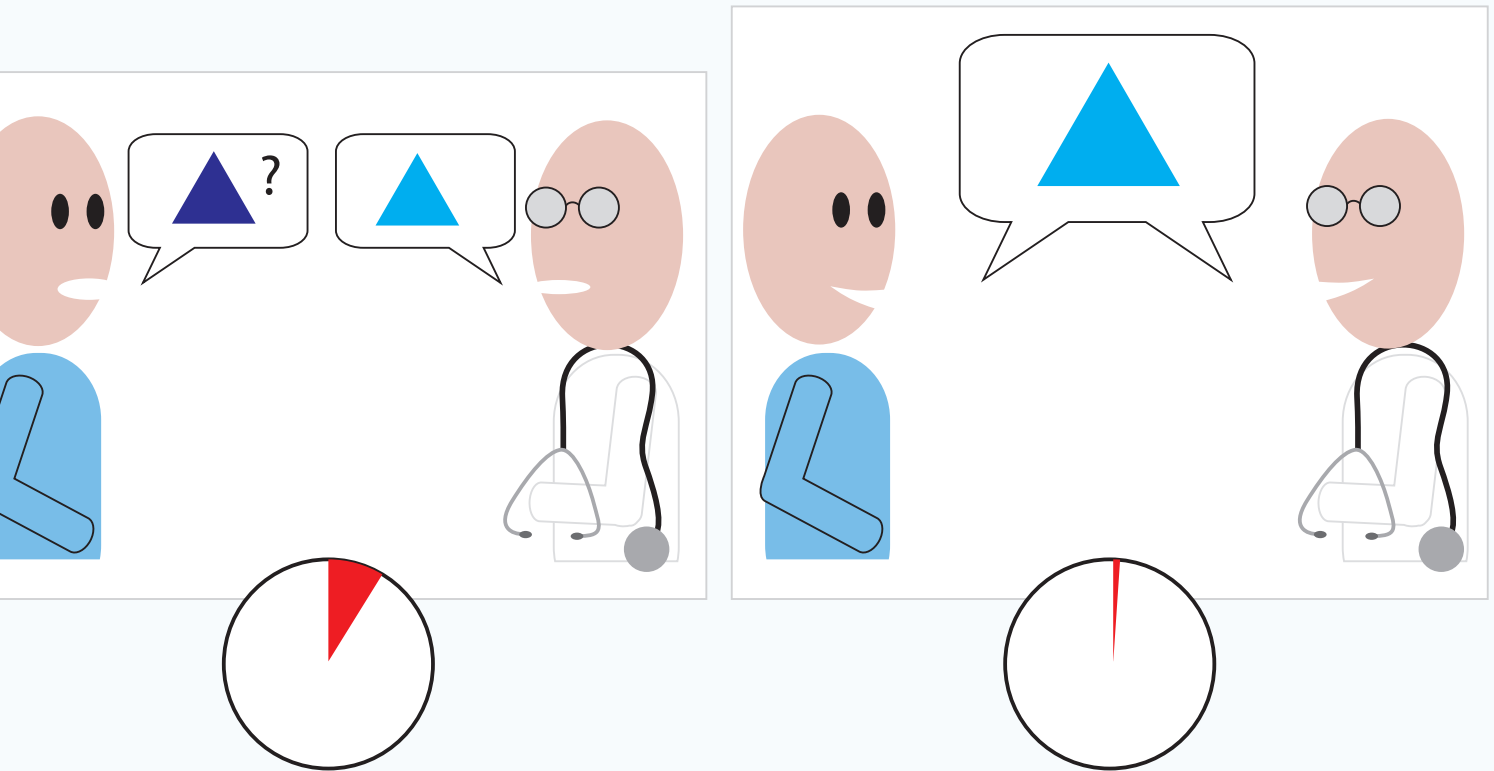
David\*, 43, was diagnosed as a teenager and has experienced HIV health care all over the world, where he has been variously made to feel like a "leper" and a "walking weapon". It was only in 2000 that he came under the care of a London clinic and finally stabilised his medication. "Half of the information the doctors can use comes from myself, so I've learnt that it's important to be honest and open," he says.

He has other medical issues not related to his HIV and sees several physicians from different disciplines and hospitals. "I put them all in touch with each other," he says. "My GP, my three consultants – they all need to know what's going on."

He is happy with his team, but he had to take control in order to get access to the right people. "My first GP was young and she had never dealt with anyone like me before. There were certain areas where she seemed unwilling to help, even though I had the backing of a consultant."

Finally, David asked to speak to someone else and saw the head of the surgery. "He was experienced and understanding

# o your doctor



and is now my GP. I have a very good rapport with him."

Alison\* is a 36-year-old mother of two from Fife. She has been living with HIV since she was 19, when she contracted the virus from a former partner. She has a good relationship with her Edinburgh consultant, who she has been with for ten years. "I see her every six weeks. I think I'm her ray of sunshine," Alison jokes. But she hasn't always experienced 'ideal physician behaviours'.

"My first baby wasn't planned. I'd only been diagnosed for two years and I didn't know as much about the condition as I do now. My GP told me it would be better to have a termination. I was frightened and could easily have taken his advice, but instead I went to the clinic where they put my mind at rest."

When Alison's second child was born, he emerged from the caesarean "a bit jittery". "They kept asking me what

recreational drugs I'd taken during my pregnancy. They made assumptions because of my diagnosis. I was so angry. Now I'm not afraid to speak my mind or say something is not relevant if I don't believe it is."

Alison now bypasses her GP's surgery and goes to the Edinburgh clinic directly. "Speaking to my GP is pointless," she says. "More often than not, because of my condition, they end up referring me to the clinic anyway. And I'm always aware the GP is under time pressure."

Dr Phillip Hay is Reader in HIV/GU Medicine at St George's, University of London, where communication skills form an important part of the curriculum. So what does he tell students about talking to patients? "One of the things I do say to my trainees, one of the arts of medicine, is to give the impression that you have limitless time with the patient in front of you, even though you don't. Show that you are giving them

100% of your attention, not looking at your computer or your notes, while they are telling you their story."

Dr Ann Sullivan, consultant physician in HIV/GU Medicine at Chelsea and Westminster Hospital, puts her stereotypical doctor's bad handwriting down to the fact she looks at patients while she is taking notes. "If I'm sitting there, spending more time looking at the computer screen, like some GPs now do, then I might miss the fact that you're rolling your eyes when I'm saying 'oh, don't worry about that headache'."

Alison says, "My consultant lets me have the time I need. Whether I'm in there for 10 or 30 minutes, I don't ever feel rushed. I always leave feeling satisfied."

Being a good listener is key but, according to one study, doctors typically give a patient 23 seconds to speak before they interrupt.<sup>2</sup> However, this doesn't necessarily mean they think

you're time-wasting or saying something of no importance. "The patient can feel they are short-changed or haven't had a chance to speak, but a lot of that is the doctor guiding the conversation to get to the bottom of a diagnosis because of the limited time," says Ann Sullivan. "I'd hate to think that a patient had left an appointment without asking what they meant to ask. Ideally, at the end of the consultation I'd like to feel that I'd given them the information they needed and that I'd found out the information I needed to deal with their issues – whether it be about their HIV or their general health."

It's a two-way process, a trading of information. So, to turn the Mayo Clinic study on its head, what are ideal patient behaviours?

### Telling it like it is

Doctors want the full picture.

Withholding relevant details because you're ashamed or embarrassed leaves your doctor in the dark and unable to give you the correct help.

"Sometimes a patient will eventually say 'I didn't want to tell you this because I knew you'd be upset'," says Ann Sullivan. "Maybe they've missed their medication. But I'm never sitting there in judgement of someone. It's supposed to be a joint relationship where you work together.

"I need to make sure they know the benefits and risks of what they're doing. For example, if someone is taking unprescribed steroids to bulk up in the gym, I need to know so I can check it's not causing bad side-effects. I'm never going to condone it, but I can make sure they are doing it as safely as I can within my professional capabilities. I know some patients don't tell me things. That's why the Kobler Clinic at Chelsea and Westminster is good. The nurses and health advisers in the team can spend more time with patients who sometimes feel more able to open up to them."

Honesty is the best policy, but not always an easy one. So how do doctors deal with sensitive situations where they feel the patient is not being completely frank with them?

"If you outright accuse a patient of lying or you prove that they're lying I think that's extremely humiliating for them," says Phillip Hay. "We would try to give them the opportunity to say that they were finding it difficult to tell us something. Often patients find it hard to be forthcoming at the start of a consultation. I give them two or three opportunities as we go through the consultation to raise anything that's concerning them. I'll ask open questions like 'was there anything you particularly wanted to discuss today?' or 'is there anything troubling you?' And then, at the end, I'll ask 'is there anything else you wanted to talk about today?'"

Alison, a self-confessed chatterbox, doesn't hold anything back when she sees her consultant. "When I go to the clinic, I'm open and honest. They know how to fix things."

But not every patient is comfortable bringing up 'everything'. Rather like going to see the family GP about sexual health, it can be difficult to suddenly discuss sexual partners with a consultant you've been seeing for several years.

"When you first meet a patient, you ask if they have a regular partner, if they practise safe sex, if they disclose," says Ann Sullivan. "Then to revisit that much later on – as a physician if you don't initiate it, often the patient won't. Some patients don't find it awkward at all – they're fine about it. But quite a number do find it hard. With the growing number of heterosexuals we're seeing, people from some culture groups find it extremely difficult. As a physician, it's really down to me to make sure I mention it. But if you have 10 other things to cover in a 15-minute appointment it does tend to drop off the end."

### Working the 15-minute slot

So how do you get the most out of those 15 minutes? The organisation Living Well provides health services to help and empower people living with HIV and AIDS. Their Positive Self-Management Programme uses an acronym **Take PART** to help participants work effectively with their healthcare team (see box). One of the things they

recommend is preparing a written list of your main concerns and questions.

Mark\*, 51, has been living with HIV for 14 years and attends a London hospital. He has developed a good relationship with his consultant who he is confident 'knows everything' about him.

Mark follows this advice and keeps a health diary which he updates on his laptop, printing off the most recent record to take to his consultations.

"If you are not prepared, then you are in and out in minutes," he says. "I take the sheet of paper in with me and prioritise the most important questions. If I need to get my point across, my consultant will give me time." But do most doctors silently groan when they see a patient whipping out a list they've prepared earlier?

"I know some people say they hate it when patients bring out lists but I actually quite like it if they've got a couple of things they've specifically prepared," says Ann Sullivan.

## Take PART

**Prepare** a written list of your main concerns or questions. Also report on your symptoms, changes in your life, medications, etc., as well as the results of visits to other physicians. If you have more than two or three questions, give the whole list to your doctor, but do not expect answers to more than a couple during your visit.

**Ask** questions about your diagnosis, tests, treatments and follow up.

**Repeat** back to the doctor key points discussed during the visit, like diagnosis, prognosis, next steps, treatment actions, etc. This gives both of you an opportunity to correct any miscommunications.

**Take** action. If there are barriers to your following his or her recommendations, let the doctor know. Ask the doctor to give you written instructions, if appropriate.



Patients want different things from their consultation. Some people come in, taking the first appointment of the morning, on their way to work, with no time to spare. They might want their CD4 count and viral load and that's all they need from their doctor. Other patients might have lots of issues they want to discuss, which is when a list can be useful.

"Quite a lot of patients, even with antiretroviral therapy, still have memory problems, so for them a list is a very good aide-memoire," says Phillip Hay. "A list doesn't often lead me to making a diagnosis more easily, but clearly for the patient it's important that I see that level of detail."

A list is one thing, but should you be taking up your doctor's time with internet print-outs? The net keeps us informed about all aspects of our lives, from cinema times to last week's Lotto numbers. There, in black and white, it's fact, but consulting Doctor Google about our health can be terrifying. So, how do doctors feel about filtering our online findings?

"In the internet age we don't have an exclusive right to knowledge, so if the patient knows something you don't and they've researched it properly, then you obviously acknowledge that," says Phillip Hay. "However, there is a lot of bad information on the internet, so one thing we can do is try and encourage people to go to sites set up by appropriate organisations that have good advice rather than scare stories."

Ann Sullivan has a couple of patients who print things off the internet and bring them in. "They say 'I'm sorry to bother you, I don't like to ask but I read this'. I'd much rather they asked. Sometimes it's a bit crazy and sometimes it's something really interesting that I haven't read myself."

#### You've got mail

There is a perception that your doctor is only available to you for the allotted time of your appointment and that they are completely incommunicado until the next time. But, thanks to email, this is changing.

At St George's, where Phillip Hay is based, Trust policy is that medical professionals don't have email contact with patients because security can't yet be guaranteed. But they are in the process of drawing up guidelines for email communication that they hope will be rubber-stamped by the Trust.

"Clearly, some patients do want to use email as a means of communication. It can sometimes be much better than a phone call because you can respond quickly and at an appropriate time of day," says Phillip Hay.

GPs and consultants will vary, but it's worth asking if email communication is a possibility. Mark and his consultant often use email when Mark needs an answer to something that he feels doesn't merit a consultation. "I was going abroad and because of my condition I was concerned about the safety of having a yellow fever shot. My consultant needed to clarify the

situation, so he looked into it in more detail then he emailed me to say it was OK to have the shot."

#### The special relationship

Getting along with your health professional is crucial and, for whatever reason, if you are not satisfied you are entitled to ask for someone else – or for a second opinion.

"Patients think they'll offend you if they ask for a second opinion, but if you're a proper professional that shouldn't worry you. You've probably asked three of your colleagues about it already anyway. I would never take it personally if someone questioned what I was doing or asked for more information," says Ann Sullivan.

Phillip Hay stresses that a consultation should not just be a symptom Q&A session. "A doctor should try and find something on which the two of you can relate on a personal level, so the patient sees you as a person as well as a doctor. Find out about them and what's going on in their life other than their disease."

Alison and her consultant are both mums, so they often end up talking about their children. "That's the main reason I have to take a list in with me," she says. "Otherwise I end up chatting too much and I forget what I wanted to mention."

As a patient, you too can find common ground with your doctor, be it football, travel, dogs. But perhaps not a mutual appreciation of those 'ooh matron' Carry On films... ■

*\* some names have been changed.*

Living Well is a leading provider of health services that help and empower people to make informed decisions to improve their wellbeing and quality of life. A key focus of Living Well services is supporting people living with HIV and one of the core services is the Positive Self-Management Programme (PSMP). This is a peer-facilitated programme of six two-and-a-half hour sessions designed to provide a range of techniques and coping skills that will improve and maintain both physical and mental health.

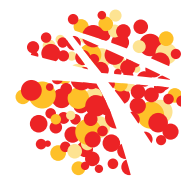
To find out more information about the Positive Self-Management Programme or any of the other services provided by Living Well, please go to: [www.livingwelluk.com](http://www.livingwelluk.com), email [clare@livingwelluk.com](mailto:clare@livingwelluk.com) or call Clare or Martha on 020 3137 3373.

To be really fully informed in discussions with your doctor, order the latest edition of NAM's *HIV Treatments Directory*.

It's free to people personally affected by HIV. (Outside of London a £12.95 postage cost applies.)

Contact us at [info@nam.org.uk](mailto:info@nam.org.uk) or call us on 020 7840 0050.

# news from vienna



**AIDS 2010**  
XVIII INTERNATIONAL AIDS CONFERENCE  
JULY 18-23 | 2010 | VIENNA AUSTRIA

## Cure

### Cure for HIV still needed

We must not lose sight of the goal of finding a cure for HIV infection, delegates were warned at the Vienna International AIDS Conference.

A report<sup>1</sup> commissioned by the AIDS Policy Project found that only 3% of the US AIDS research budget is devoted to finding a cure. This is currently dwarfed by US expenditure on HIV vaccine research.

US HIV treatment expenditure is \$20,000 million dollars a year, but the Project could only find \$60 million devoted to cure research by the US National Institutes of Health.

Sharon Lewin of Monash University in Melbourne told the conference in a keynote address that a cure for HIV infection was scientifically feasible and increasingly necessary.

Antiretroviral therapy has dramatically increased survival, but the most sensitive tests can find residual HIV in almost everyone infected, including people on effective combination therapy and elite controllers who suppress the virus naturally. "There is no such thing as an undetectable viral load," she said.

People with HIV still do not achieve normal life expectancy relative to the general population, she added. A growing body of evidence indicates that even very low-level virus contributes to a number of health problems. These problems – which range from cardiovascular and liver disease to neurocognitive impairment and bone loss – are increasingly linked to chronic immune activation and inflammation triggered by persistent virus.

Professor Steven Deeks told delegates: "There's some sort of HIV-related problem that's causing people to get sick earlier than they otherwise would have."

Deeks was speaking at a pre-conference workshop devoted to finding a cure. He said that the most promising initial direction was to use immune stimulators such as interleukin-7 or one of a class of drugs called HDAC inhibitors to 'turn on' the inactive immune system cells in which HIV is hiding.

Normally, using these drugs would be toxic and result in a huge burst of HIV replication, but if a balance can be struck between containing the newly produced HIV while allowing enough of the quiescent cells to turn into active ones, the virus could be flushed from the system.

This is because while inactive cells may have lifetimes of years, if activated they burn themselves out in days.

This might still leave a small amount of HIV in the system. For a complete cure more radical interventions would be necessary, such as the case of a German leukaemia patient who had his immune system destroyed by cancer chemotherapy and replaced by one from a person naturally immune to HIV. He is still apparently HIV-negative three years after this radical (and expensive) treatment. A cure might be possible if less dangerous alternatives to such a procedure could be found.

"This conference will not be the one where we announce a cure," said Lewin, "but it will mark the beginning of a future where we seriously prioritise a cure."

## Migration

### Immigrants risk more HIV abroad than at home

HIV-negative immigrants from countries with high rates of HIV are more than twice as likely to acquire HIV in the country they travel to rather than at home, a Dutch study presented in Vienna has found.<sup>1</sup> It also found that immigrants with HIV are very unlikely to pass it on to the general population.

The reason for both findings is that immigrants tend overwhelmingly to pick sexual partners from their own community, at least in the Netherlands. Because this involves a smaller group of people than the available pool of partners at home, HIV tends to get concentrated in this group.

Maria Xiridou of the Netherlands Institute of Public Health said that it was estimated that only one-in-47,000 heterosexual Dutch nationals acquired HIV every year but that the rate in African immigrants was one-in-1170 people. Eighty per cent of sexual encounters in African men and 77% in Caribbean men involved women of their own ethnicity.



Sharon Lewin – HIV cure keynote address

This month, *HTU* presents a digest of the most significant treatment and prevention news from this summer's eighteenth International AIDS Conference in Vienna. For more coverage visit [www.aidsmap.com/vienna2010](http://www.aidsmap.com/vienna2010)

Seventy per cent of recent Dutch HIV diagnoses were acquired in the Netherlands, figures show, but half of these are among people not born there.

Because of this, if every immigrant arriving in the Netherlands was voluntarily tested for HIV and those who were HIV-positive were given antiretrovirals, the resultant reduction in their infectiousness would reduce incidence in the heterosexual immigrant population to one case in 10,000 people a year.

Xiridou commented that her study showed that the HIV 'threat' from immigration was largely confined to immigrants themselves, and reinforced anecdotal evidence that the proportion of infections among immigrants that were acquired in their host country was increasing.

#### HIV treatment

## Nukes not necessary, studies find

For the last 15 years the nucleoside reverse transcriptase inhibitor (NRTI or 'nuke') drugs have been the backbone of HIV combination therapy. Currently these include tenofovir, FTC and 3TC, with abacavir and AZT also used, often combined with each other and with other drugs in pills such as *Truvada* (tenofovir/FTC) or *Atripla* (tenofovir/FTC/efavirenz).

However, some NRTIs (such as tenofovir and abacavir) still have question marks over long-term side-effects, while others (such as 3TC and FTC) don't work for a lot of patients due to high levels of drug resistance.

Several studies presented in Vienna evaluated the safety and efficacy of 'nuke-sparing' regimens using new drug classes. In one, a twice-daily combination of the protease inhibitor lopinavir (boosted with ritonavir in the combination pill *Kaletra*) plus the

integrase inhibitor raltegravir (*Isentress*) was found to be as effective, over one year, as a more traditional *Kaletra* plus *Truvada* regimen. After 48 weeks, 83% of people on raltegravir had viral loads under 50 copies/ml and 85% on *Truvada*.

Another study had an identical design – comparing raltegravir with NRTIs – but used a different protease inhibitor – atazanavir (*Reyataz*).<sup>1</sup> In this study 82% of people on a twice-a-day atazanavir-plus raltegravir regimen achieved a viral load under 50 copies/ml at 48 weeks, compared with 76% on a once-daily atazanavir plus NRTIs combination. The difference in this case was that in the first regimen, the atazanavir was not boosted with a small dose of the drug ritonavir, but was in the second one.

There were, however, a higher rate of side-effects – mainly a type of jaundice caused by atazanavir – in the nuke-sparing regimen, and 6% of the patients on raltegravir had to drop out due to this, versus none on *Truvada*.

A third study compared *Truvada* with a drug of another new class, the CCR5 inhibitor maraviroc (*Celsentri*).<sup>2</sup> In this study after 24 weeks 80% of people on once-daily atazanavir/maraviroc had a viral load under 50 copies/ml versus 89% on once-daily atazanavir/*Truvada*. However, CD4 gains were 20 cells/mm<sup>3</sup> higher in patients on maraviroc, an effect already seen with this drug. This study will be continued for two years.

Lastly, one disadvantage of raltegravir is that it has to be taken twice a day. A study<sup>3</sup> found that once-daily raltegravir was just as effective as twice-a-day for patients without pre-existing drug resistance who switched to it from protease inhibitors, but that there was twice the failure rate (18 vs 8%) in patients with drug resistance. Once-daily raltegravir therefore looks safe for first-line therapy, but not subsequently.<sup>4</sup>

#### HIV treatment

## Rilpivirine looks good

A new non-nucleoside reverse transcriptase inhibitor (NNRTI) drug, rilpivirine (TMC278), looks set to appear in clinics very soon after results from Vienna showed that it was as effective as efavirenz (*Sustiva*) and produced fewer side-effects.<sup>1</sup>

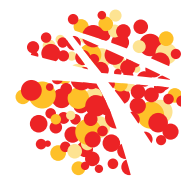
Efavirenz, both as a separate pill and in the one-pill-a-day *Atripla* combination, has been a mainstay of first-line HIV therapy since 1999 as, despite nervous-system side-effects that some patients cannot tolerate, it is consistently shown to be one of the most potent HIV drugs.

If rilpivirine is as potent but more tolerable, it may well feature heavily in first-line regimens in the next decade, and plans are underway to produce a rilpivirine/tenofovir/FTC pill similar to *Atripla*. A 'second-generation' NNRTI, etravirine (*Intence*) already exists, but this involves taking four large pills a day whereas rilpivirine comes as one small pill.

Two separate two-year studies, whose results were pooled together, showed that 84% of patients on rilpivirine-plus-NRTIs had a viral load under 50 copies/ml by the end, compared with 82% on efavirenz. This difference was not statistically significant. In one of the studies, more people on rilpivirine developed an undetectable viral load at some point during the study than on efavirenz, but there was no difference to the end result.

However discontinuations due to side-effects were significantly more common on efavirenz (7 vs 2%) and psychological side-effects such as dizziness and abnormal dreams were over twice as common (38 vs 17%).

# news from vienna



**AIDS 2010**  
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## Microbicides

### Microbicides can work

A gel containing the drug tenofovir can prevent 50% of HIV infections if applied before sex, the conference heard.<sup>1</sup> The result of the South African CAPRISA 004 study was greeted by standing ovations at the conference as it represents the first proof that a microbicide – a gel, cream or device applied locally to prevent HIV infection during sex – can work, and as such is the culmination of a 20-year research programme. “Today is the day we achieve proof of concept for microbicides,” said Gita Ramjee of the South African Medical Research Council.

The tenofovir microbicide reduced the HIV infection rate amongst 889 South African women by 39% compared to a placebo gel, and the reduction was 54% in women who used the gel at least four in every five times they had sex. An added bonus was that the gel also halved herpes infections.

Experts and politicians hailed the result as a step forward for a method of HIV prevention that can be under women’s control, unlike male condoms. Anthony Fauci, head of the US National Institute of Allergy and Infectious Diseases, said: “It fulfils an extraordinary need for a group who’ve had very little opportunity

to direct their own fate; now they will.” And South Africa’s health minister said that “young women with this technique will be able to take their health into their own hands.”

A microbicide will not be available alongside condoms in the clinic tomorrow, researchers warned. We will need confirmatory results from another study that are at least as convincing as CAPRISA before licensing a microbicide. The next study, VOICE, which will compare the performance of a tenofovir microbicide and of pre-exposure prophylaxis, is not due to produce results till mid-2012.

## Pre-exposure prophylaxis

### PrEP may work too

The conference also heard positive, though not conclusive, results from a study of pre-exposure prophylaxis (PrEP) – the idea of giving HIV medication to HIV-negative people as a prevention method.<sup>1</sup>

The CDC-4323 study enrolled 400 HIV-negative gay men in three US cities and told them to take either a daily tenofovir pill or a placebo.

This study was never designed to prove whether PrEP actually worked, but as a safety study. No differences were

observed between the two groups in any side-effect, other than more back pain in patients on tenofovir, which could be unrelated to the drug. In particular there were no indications of kidney problems, one of the most significant side-effects of tenofovir.

Another concern is that if people take pills to prevent HIV they might stop using condoms, thus cancelling out any benefit. In the study, sexual risk behaviour actually went down in men taking the pills, perhaps because a daily dose is a reminder of risk.

There were six HIV infections during the trial, and none of them were in men taking tenofovir. Because this was a small trial, this result is not statistically significant and could be a random effect. However, it is similar to the results of the only other PrEP trial to have so far been completed, one amongst women in Ghana,<sup>2</sup> which was also too small to produce a scientifically convincing result but found three times as many infections (six versus two) in women taking a placebo versus ones taking tenofovir.

We won’t have to wait as long for the results of bigger PrEP studies, as for microbicides: a trial amongst Thai injecting drug users, and one amongst gay men predominantly in Latin America, will report results by early next year.



Prof. Quarraisha Abdool Karim, Associate Scientific Director of CAPRISA, explains how to use an applicator with gel.



Director of the US National Institute of Allergy and Infectious Diseases, Anthony Fauci.

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For daily news reports and breaking stories from the international conferences visit [www.aidsmap.com/news](http://www.aidsmap.com/news)

## Hepatitis C

# Gay hepatitis epidemic may be levelling off

Cases of sexually acquired hepatitis C virus (HCV) in HIV-positive gay men in the Netherlands appear to be levelling off, a study presented at Vienna has found.<sup>1</sup>

Anouk Urbanus of the Amsterdam Public Health Service told the conference that surveys of gay men attending a large HIV/STI clinic in Amsterdam had observed no recent increase in the proportion of men testing positive for HCV, and that no recent infection had been detected since January 2008.

This is good news because previous reports had detected an accelerating epidemic. In the year between January 2007 and January 2008, hepatitis C prevalence among HIV-positive gay men attending the clinic had grown from 13 to 21%, and the proportion that appeared to have been infected in the previous three months had grown from 11% of all men with HCV to 38%, suggesting a rapidly worsening epidemic.

Since then, however, HCV prevalence in HIV-positive gay men attending the clinic has fallen back to 15%, and no infection detected in the first three months has been seen since January 2008. New cases are still being detected, but these are among new clinic patients who have had undetected HCV for a longer period.

There were also five cases of HCV reported amongst HIV-negative gay men, three of whom reported injecting drugs (HCV in most groups is spread via needles rather than sex).

Dr Urbanus said she could not speculate why the pattern of rapid spread appeared to have changed. Phylogenetic testing showed that hepatitis C in HIV-positive gay men tended to occur in

tightly connected groups of men who had had sex with each other, and confirmed that fisting, the use of GHB and sex toys, and group sex were the factors most strongly associated with having HCV.

## HIV services

# People living with HIV devise their own service

People living with HIV are working with leading HIV charities to develop a revolutionary online and face-to-face UK-wide support service.

Garry Brough, THT Membership and Involvement Officer, and former patient representative at the Bloomsbury Clinic, said: "The new service is expected to transform the way people with HIV manage their health, reduce isolation and empower people to become active members of the HIV community."

The programme harnesses the experience and expertise of dedicated community and clinic-based Health Trainers and innovative web services, which will respond to people's individual needs, personal circumstances and stage of diagnosis.

Funded by the Elton John AIDS Foundation, the programme is being developed by the Terrence Higgins Trust (THT) and people living with HIV in partnership with NAM and George House Trust.

You'll hear more about the launch of the service in a later issue of *HTU*. In the meantime, if you would like any more information about the programme please contact Verity Glasgow at [verity.glasgow@tht.org.uk](mailto:verity.glasgow@tht.org.uk) or on 020 7812 1600.

references to all articles [cont. on page 19]

where hiv is a crime, not just a virus [page four]

- For further details on the history of criminal prosecutions, see the *Laws* chapter of Bernard EJ, *HIV and the criminal law*. NAM, 2010.
- Available at: [www.gnpplus.net/criminalisation](http://www.gnpplus.net/criminalisation)
- GNP+, *Global Criminalisation Scan Report 2010*, Amsterdam, 2010.
- Nyambe M, Gaudet T *Slow drips and raging torrents: a global picture of criminalization of HIV transmission*, 18th International AIDS Conference, Vienna, abstract THPE1021, 2010.
- UNAIDS/UNDP *Policy brief: Criminalization of HIV transmission*. UNAIDS, 2008.
- Merminod A *The deterrence rationale in the criminalization of HIV/AIDS*. *Lex Electronica* 13 (3): 1-34, 2009.
- Burris S et al. *Do criminal laws influence HIV risk behaviour? an empirical trial*. *Arizona State Law Journal* 39: 467-517, 2007.
- For a summary of these studies, see the *Impact* chapter of Bernard EJ, *HIV and the criminal law*. NAM, 2010.
- Schuklenk U *Should we use the criminal law to punish HIV transmission? International Journal of Law in Context* 4 (3): 277-284, 2009.
- Dodds C et al. *Sexually charged. The views of gay and bisexual men on criminal prosecutions for sexual HIV transmission*. Sigma Research, London, 2009.
- BBC Online *Malawi defends plans to outlaw HIV transmission*. April 7, 2010.
- Globe editorial *AIDS and the duty to not infect*. *Globe and Mail*, July 21, 2010.
- See 'Challenges associated with disclosing one's HIV-positive status' in the *Responsibility* chapter of Bernard EJ, *HIV and the criminal law*. NAM, 2010.
- Dodds C et al. (2009), *op. cit.*
- Video presentations and discussions from the meeting can be found at: [www.aidsmap.com/page/1444486](http://www.aidsmap.com/page/1444486)
- Grover A *Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health*. United Nations Human Rights Council, Fourteenth Session (A/HRC/14/20), 27 April 2010.
- See [www.undp.org/hiv/comissiononhivandthelaw](http://www.undp.org/hiv/comissiononhivandthelaw)
- Carter M *Criminalisation of HIV transmission in the UK: how did we get here and where to now?* *Aidsmap.com*, April 7, 2006.
- Carter M *Ten-year sentence in Scottish HIV prosecution* *Aidsmap.com*, February 26, 2010.
- Crown Prosecution Service. *Guidelines on Intentional or Reckless Sexual Transmission of Infection*. CPS (England and Wales), March 2008.
- NAT/Association of Chief Police Officers (ACPO). *ACPO Investigation Guidance relating to the Criminal Transmission of HIV*. NAT, 2010.
- Mykhalovskiy E, Betteridge G and McLay D *HIV Non-Disclosure and the Criminal Law: Establishing Policy Options for Ontario*. 2010.
- Bernard EJ et al. *HIV forensics: The use of phylogenetic analysis as evidence in criminal investigation of HIV transmission*. NAM/NAT, London, 2007.
- Phillips M, Poulton M et al. *HIV transmission, the law and the work of the clinical team*. British HIV Association (BHIVA)/British Association of Sexual Health and HIV (BASHH), 2010.
- NAT/THT *Prosecutions for HIV Transmission: A guide for people living with HIV in England and Wales*. London, 2010.
- Bernard EJ *Where HIV is a crime, not just a virus: a global ranking of prosecutions for HIV non-disclosure, exposure and transmission*. 18th International AIDS Conference, Vienna, abstract THAF0201, 2010.
- Bernard EJ *Kafkaesque: a critical analysis of US HIV non-disclosure, exposure and transmission cases, 2007-2009*. 18th International AIDS Conference, Vienna, abstract THPE1016, 2010.
- Heywood T *Obama administration calls for end to HIV-specific criminal laws*. *Michigan Messenger*. July 20, 2010.
- The White House Office of National AIDS Policy *National HIV/AIDS Strategy for the United States*. July 2010.
- Pearshouse R *Legislation contagion: the spread of problematic new HIV laws in Western Africa*. *HIV/AIDS Policy & Law Review* 12 (2/3), 2007.
- See [www.swaagh.org/advo\\_programmes2.htm](http://www.swaagh.org/advo_programmes2.htm)
- Unpublished data compiled from *Global Criminalisation Scan* and [criminalhivtransmission.blogspot.com](http://criminalhivtransmission.blogspot.com)
- GNP+ (2010), *op. cit.*

# finding our global voice

*Jack Beck* of the Global Forum on MSM & HIV (MSMGF) reviews what has now become a regular event preceding the biennial International AIDS Conferences – the pre-conference meeting for men who have sex with men (MSM) and for transgender people.

## Why a pre-conference for MSM?

On 17 July, in Vienna, the Global Forum on MSM & HIV (MSMGF) held *Be Heard!* This, the fourth pre-conference on MSM, was first created in response to shared concerns that sexual minority issues were all but invisible at International AIDS Conferences. From a small inaugural meeting before the 2004 Bangkok conference, the event is now the world's largest gathering focused on the health and human rights of MSM, with over 100 speakers and 650 participants attending from more than 100 countries.

It's now time to begin asking critical questions about what this year's event achieved, what it could or should accomplish in the future, and what its existence says about the IAC and its role in the health and human rights of MSM.

The programme kicked off with speeches from a number of key global health leaders on the current state of the epidemic among MSM worldwide. Speakers included Global Fund Executive Director Michel Kazatchkine, UNAIDS Executive Director Michel Sidibé, and AIDS-Free World Co-Director Stephen Lewis.

Many speakers underscored a core set of themes – criminalisation, stigma, human rights, and access to treatment and prevention.

"We call on legislators to change outdated penal codes that contain prohibitions against same-sex activity. Getting rid of these laws is urgent," said Michel Kazatchkine in his plenary address.

Michel Sidibé concurred. "The human rights of men who have sex with men

and other sexual minorities must be fully protected and respected if universal access to HIV services is to be achieved," he said. "All people should have equal access to HIV prevention, treatment and care services in their countries regardless of sexual orientation."

Chris Beyrer of the Johns Hopkins Center for Public Health and Human Rights unveiled the results of a Johns Hopkins/World Bank survey, *Global Epidemics of HIV among MSM in 2010*. HIV prevalence rates among gay and other MSM have risen as high as 21.4% in Malawi, 13.8% in Peru, and 23% in Thailand, he said. In one of the most significant announcements of the day, he explained the survey revealed that higher levels of HIV-related services for MSM populations would result in lower rates of HIV among the general population – not just in MSM.

Topics in twenty-six small group sessions, the heart and soul of the pre-conference, ranged from recent developments in biomedical prevention, internet interventions, and effective strategies for fundraising to sessions focusing on HIV work in specific regions or with specific MSM subpopulations. The content was planned around results of a multilingual survey asking what MSM, particularly those in low- and middle-income countries, wanted to achieve.

A thought-provoking workshop entitled *Nothing about MSM and HIV without MSM Living with HIV!* addressed a key theme, discussing the importance of involving MSM living with HIV in devising and running prevention, support and treatment programmes for MSM. It included discussion on whether having

HIV automatically conferred expertise or leadership entitlement, and explored issues such as the right of people – who may have half a lifetime of symptom-free living ahead of them – to choose *not* to publicly identify as HIV-positive.

Advocacy and working with government bodies was also a theme. MSMGF staff led participants through the use of a newly developed Advocacy Toolkit that offers guidance on matters such as prioritising local advocacy issues and designing a campaign for working in hostile contexts.

Dr Mariangela Simao, Director of Brazil's National AIDS Programme, joined Hong Kong AIDS Concern Executive Director Loretta Wong and others to discuss NGO and health department collaboration in improving access to programmes for sexual minorities.

A session on internet interventions provided international examples of online communities seeding in-person peer support. Yves Yomb from Alternatives-Cameroun explained how – where homosexuality is penalised, funding is limited and harassment and blackmail are common – peer educators

**Michel Kazatchkine,**  
Executive Director of  
the Global Fund.



befriend and inform men using sexual networking sites. In eastern Europe, Tudor Kovacs of PSI Romania described how he conducted an internet search of MSM contact sites for Romanian MSM who disclosed HIV-positive status, who came to form the core of a support and social group.

In Asia, Nada Chaiyakit and Christopher Walsh of MPlus in Chiang Mai, Thailand, described how they use short, downloadable, animated videos to inform and contact subpopulations such as immigrant male sex workers. Working on a much larger scale, Stuart Koe of the large Singapore-based MSM website [www.fridae.com](http://www.fridae.com), described launching the world's second-largest MSM sex survey and an HIV test reminder service.

Soon after the event concluded, conversations began springing up in meeting rooms, online discussion forums and magazine articles about where the event succeeded and what could have been done better. But first, what is the event trying to achieve?

Some ask whether an MSM pre-conference is necessary. Maybe it was needed before – but hasn't there been progress in MSM representation at the IAC?

The MSMGF Secretariat did an analysis of the MSM content at this year's main conference. The results were shocking. Only 2% of all conference sessions, excluding posters, specifically and exclusively concerned MSM. Plenty more mentioned us – but, as we've found, lip service is not enough. This population, in low- and middle-income countries, is on average 19 times more likely to be infected with HIV than the general population.

"When I can spend three hours in the poster hall most days having great discussions with people whose abstracts (on MSM issues) have not made it into the main programme... but where I am sitting in oral sessions whose quality is poor, then I know that something is very wrong," said Mike Kennedy, Executive Director of the Victorian AIDS Council/Gay Men's Health Centre in Melbourne, Australia.

"The quality of the oral sessions was very patchy. The quality of the MSM-related posters – most of which could have been orals, but did not make the cut – were excellent."

Greg Gray, Key Populations Campaign Co-ordinator for the World AIDS Campaign, agreed. "The pre-conference was far more valuable in bringing the issues of MSM to the table; the IAS has failed to give adequate recognition of the importance of MSM issues in the main conference agenda, particularly issues for positive MSM," he said.

The MSM pre-conference has been integral to making the International AIDS Conference useful for those working with MSM. How can such an event maximise its benefits for those it is meant to serve from now on?

*Xtra! Canada's Gay and Lesbian News Service* ran a thought-provoking article suggesting too much time was spent on new data; the opportunity would be better used for organising action at the main conference to make demands on key leaders.

Others wanted more data – citing the utility of hard numbers when advocating for MSM issues with funders and political leaders.

As evaluation results begin to come in, the MSMGF and partner organisations will continue these debates in efforts to improve future initiatives.

In the lead up to AIDS 2012 in Washington, DC, the MSMGF encourages all who have a stake in the health and human rights of sexual minorities to get involved early on. Connect directly with other advocates around the world by registering at [www.msmsgf.org](http://www.msmsgf.org) and have your opinions heard on the direction of the next MSM pre-conference. The earlier we co-ordinate, the better chance we have to move AIDS 2012 in the right direction. ■

Jack Beck is Communications Associate at the Global Forum on MSM & HIV (MSMGF). Learn more about the MSMGF at [www.msmsgf.org](http://www.msmsgf.org).

## references to articles [from page 17]

### how to talk to your doctor [page ten]

- 1 Bendapudi N et al. *Patients' Perspectives on Ideal Physician Behaviors*, Mayo Clinic Proceedings. vol. 81 no. 3 338-344, March 2006
- 2 Marvel MK et al. *Soliciting the patient's agenda: have we improved?* JAMA 281(3):283-287, 1999.

### news in brief [page fourteen]

All news references unless otherwise indicated are from the eighteenth International AIDS Conference, Vienna, 2010.

#### Cure for HIV still needed

- 1 AIDS Policy Project: *AIDS Cure Research for Everyone*. July 2010. Available online at: [www.aidspolicyproject.org](http://www.aidspolicyproject.org)

#### Immigrants risk more HIV abroad than at home

- 1 Xiridou M et al. *Changes in patterns of migration barely influence the heterosexual HIV epidemic in Europe*. Abstract WEAC0104.

#### Microbicides can work

- 1 Abdool Karim Q *Effectiveness of 1% Tenofovir Vaginal Microbicide Gel in South African Women: Results of the CAPRISA 004 Trial*. Abstract TUSS0502.

#### PrEP may work too

- 1 Grohskopf L et al. *Preliminary analysis of biomedical data from the phase II clinical safety trial of tenofovir disoproxil fumarate (TDF) for HIV-1 pre-exposure prophylaxis (PrEP) among U.S. men who have sex with men (MSM)*. Abstract FRLBC102.
- 2 Peterson L et al. *Findings from a double-blind, randomized, placebo-controlled trial of tenofovir disoproxil fumarate (TDF) for prevention of HIV infection in women*. 16th International AIDS Conference, Toronto, abstract ThLb0103, 2006.

#### Nukes not necessary, studies found

- 1 Kozal M et al. *The SPARTAN study: a pilot study to assess the safety and efficacy of an investigational NRTI- and RTV-sparing regimen of atazanavir (ATV) experimental dose of 300mg BID plus raltegravir (RAL) 400mg BID (ATV+RAL) in treatment-naïve HIV-infected subjects*. Abstract THLBB204.
- 2 Mills A et al. *Safety and immunovirological activity of once daily maraviroc (MVC) in combination with ritonavir-boosted atazanavir (ATV/r) compared to emtricitabine 200mg/tenofovir 300mg QD (TDF/FTC) + ATV/r in treatment-naïve patients infected with CCR5-tropic HIV-1 (Study A4001078): A week 24 planned interim analysis*. Abstract THLBB203.
- 3 Vispo E et al. *Simplification from protease inhibitors to once or twice daily raltegravir: the ODIS trial*. Abstract MOAB0102.
- 4 Reynes J et al. *Lopinavir/ritonavir combined with raltegravir demonstrated similar antiviral efficacy and safety as lopinavir/ritonavir combined with tenofovir disoproxil fumarate/emtricitabine in treatment-naïve HIV-1 infected subjects*. Abstract MOAB0010.

#### Gay hepatitis may be levelling off

- 1 Urbanus AT *Continuing increase in hepatitis C virus infections among HIV-infected men who have sex with men (MSM)?* Abstract WEPDC104.

#### Rilpivirine looks good

- 1 Cohen C et al. *Pooled week 48 efficacy and safety results from ECHO and THRIVE, two double-blind, randomised phase III trials comparing TMC278 versus efavirenz in treatment-naïve HIV-1-infected patients*. Abstract THLBB206.



# Craig sets off!

By the time you read this I will be well into my expedition to cycle across Europe from London to Vienna to raise money for NAM.

After setting off on 27th August my 2200 mile route will take me through six different countries and through the Pyrenees, French Alps, Dolomites and Austrian Alps to end up in Vienna on 16th September...fingers crossed!

I am feeling positive and looking forward to the ride with equal measures of fear and excitement.

I'm hoping to reach my target of £1500 for NAM and would be so grateful for any support. I believe NAM is a vital resource in the fight against HIV and AIDS for affected communities and those working to support them. Needless to say, a very worthy cause and one I'm proud to be supporting.

If the rivers, lakes, mountains and my own personal ambition fail me for inspiration, the thought of your generosity will surely see me through. That and a lot of pasta, wiener schnitzel and quiche.



You can make a donation and follow my progress here:  
[www.justgiving.com/vienna](http://www.justgiving.com/vienna)



Wish me luck!

## thanks to our funders

NAM's treatments information for people living with HIV is provided free thanks to the generosity of:

Abbott Laboratories Ltd; Abbott Fund; Allan & Nesta Ferguson Charitable Trust; Avexa Ltd; Boehringer Ingelheim Ltd; Bristol-Myers Squibb Pharmaceuticals Ltd; Cavid AB; Delphic Diagnostics Ltd; Derek Butler Trust; Government of the United Kingdom, Department of Health; Government of the United Kingdom, Department for International Development; Diana, Princess of Wales Memorial Fund; Elton John AIDS Foundation; Estate of Sidney Klieff; F. Hoffmann-La Roche Ltd; Gilead Sciences Ltd; GlaxoSmithKline PLC; GlaxoSmithKline's Positive Action; Hugh Fraser Foundation; Lloyds TSB Foundation for Northern Ireland; Manchester City Council; Merck & Co., Inc; Merck Sharp & Dohme Ltd; Merck Sharp & Dohme Romania SRL; Miss Agnes Hunter's Charitable Trust; NHS Ashton, Leigh & Wigan; NHS Birmingham East and North; NHS Bolton; NHS Brighton & Hove; NHS Manchester; NHS Norfolk; NHS Pan-London HIV Prevention Programme; NHS Salford; NHS South East Essex; NHS South West Essex; NHS West Sussex; NHS Worcestershire Health Services; Pfizer Ltd; Plumptions Ltd; Roche Molecular Systems, Inc.; Roche Products Ltd; Sanofi Pasteur MSD; Schering-Plough Corporation; Tibotec (a division of Janssen-Cilag) Ltd; UNAIDS; World Health Organization.

NAM would also like to acknowledge the generous support of its individual donors.

## donate to nam

Every year NAM provides information resources, like *hiv treatment update*, to thousands of people living with HIV, completely free of charge. To do this we really do rely on the generosity of people like you to help us continue our vital work. You can make a difference today. Please make a donation by visiting [www.aidsmap.com/donate](http://www.aidsmap.com/donate) or by ringing us on 020 7840 0050.

## 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](http://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