

# HIV treatment update

Issue 210  
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**HIV treatment update**

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Each feature in *HTU* is also reviewed in advance by a readers' panel of people living with HIV. We are grateful to our panel for their knowledge, attention and enthusiasm. If you would like to be a member of the *HTU* readers' panel, please email [info@nam.org.uk](mailto:info@nam.org.uk).

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# In this issue



**Gus Cairns**  
Editor

In the world of HIV there's a lot of righting wrongs – and there's still plenty to get angry about, as you will (I trust) if you read Edwin J Bernard's update on criminalisation on page 10. Once you have, go to Sean Strub's YouTube video, where he interviews three people treated as sexual abusers for exposing their (non-infected) partners to HIV or, in one case, just for failing to disclose their status. It's heartbreaking. Such blatant stigma, shifting of all the blame for bad relationships and guilty sex on to the shoulders of people with HIV; it makes us angry, but it can also make us despair. If this is what the world thinks of us, what incentive is there for celebrating being in it?

Celebrating being in the world is exactly what *Peak experiences* (page 4) is about. Writing it felt like a gamble – comparable with *Walking back to happiness* in *HTU* 189. Such articles run the risk of sounding Pollyannaish and New-Agey – especially when people start throwing words around like 'spirituality' and 'transcendence' – so we've tried to anchor it with a touch of neuroscience and psychology. It may be speculative to link the lure of unprotected sex with the call of the mountains, but there is a respectable literature showing that, if you want people to make positive changes in their lives, there has to be a reward for doing it. Our adventurers are experts in finding their own reward – many thanks to them for sharing their experiences with us.

Being a powerful and fulfilled person with HIV is part of the subtext in our other features. Joining a patient forum or advocacy group (*Supporting patient power*, page 14) may be the first time someone has stood up and talked about having HIV. I remember someone I met at Positively UK's conference last September. White, working class, female – no member of the establishment, she. Though she kept emphasising she "didn't know anything and was here to learn", she had something more precious than knowledge – self-respect.

The article on the BHIVA guidelines (page 16) is about people power, too. Although the British HIV Association has long included patient representatives in its committees, I felt consulted and listened to to a greater extent than before, even co-writing a couple of the sections of most importance to patients. I would like to thank Ian Williams especially – who also happens to be an HIV consultant at the Bloomsbury Clinic which hosts the UK's largest patient advocacy group – for not just paying lip service to patient power but for being determined to help us make it happen.

**Correction**

There was an error in the report on immigration removal centres in the last *HIV treatment update* (issue 209). We incorrectly stated that refused asylum seekers in England who are not in detention are only entitled to free health care at the discretion of the local primary care trust.

In fact, since August 2011, refused asylum seekers who are receiving financial support from the UK Border Agency (section 4 'hard cases' support or section 95 support) are automatically entitled to free hospital health care.

For refused asylum seekers who don't get this financial support, the situation is more complex. But if a person's doctor judges the health care to be "immediately necessary" (and this is usually the case for HIV treatment), the health care must be provided, regardless of immigration status or ability to pay.

# Upfront

## Uncomfortable news on lubes for anal sex

by Gus Cairns

Commercially available sexual lubricants may increase people's susceptibility to sexually transmitted infection (STIs), US scientists reported recently. A study found that people who consistently used shop-bought 'lubes' for anal sex were three times more likely to have an STI than people who did not.

The study<sup>1</sup> confirms results announced at the 2010 International Microbicides Conference. It found that people who had consistently used commercially available lubricants while being the passive partner in anal sex over the last month (the last year if female) were three times more likely to test positive for syphilis, rectal gonorrhoea or chlamydia than people who had not.

### Details of the study

The study took a mixed population of women and gay men and asked them whether they had had receptive anal sex in the last year and month, whether they had used commercially sold lubes and, if so, what kind: were they water-based (e.g. KY), silicone-based (e.g. ID Millennium) or oil-based (e.g. Crisco). They also tested participants for rectal chlamydia and gonorrhoea with a swab and took a blood test for syphilis.

Because women tended to have anal sex only occasionally, one important distinction was that the definition of regular receptive anal sex was 'during the last month' for the men but 'during the last year' for the women.

The average age of participants was 39; 46% were women and 54% gay men. HIV status varied by age: 14% of 18 to 25 year-olds had HIV versus 37% of 26 to 35 year-olds. Over half (53%) were African-American, 18% Hispanic and 23% white.

Very few people reported one-off or casual anal intercourse: only 5% of people reported they had had a one-off sexual encounter involving anal sex during the last month (last year if a woman). In contrast, 56% reported anal sex during the last month (last year if a woman) with a main partner.

Only 12% of participants had not used commercially purchased lube at all, but only

32% of participants had used lube every time they had anal sex (the 'consistent lube users'). One important caveat is that neither the sachets of lube supplied with free condoms, nor *ad hoc* lubes like hand cream, were counted in this survey: it only concerned lubes bought over the counter.

There were differences between consistent lube users and other participants. Lube users were nearly twice as likely to have HIV if they were under 35, though not if they were older. African-Americans were less likely than average to be consistent lube users and Hispanics more so. There were no differences between lube users and non-users in the number of partners they had or how many times they had anal sex.

The survey found that 9.5% of consistent lube users had an STI versus 2.9% of inconsistent/non-users (three times more). This was statistically significant and these results were independent of people's age, race, gender, HIV status, number of partners and amount of sex.

“The advice still stands that using condoms plus silicone- or water-based lube is the best way to avoid STIs.”

### How about condom use?

Understanding condom use is problematic, because, while participants were asked about whether they had had receptive anal sex and/or used lube over the last month, they were only asked whether they had used condoms the last time they had anal sex. So we cannot say, for instance, whether people who used condoms the last time they had

sex had more or fewer partners, or had sex more or less often, than people who hadn't used condoms.

Nonetheless, in univariate analysis (i.e., not taking other factors into account), condom use at last sex was *not* significantly protective against STIs: 4.6% who reported condom use last time they had anal sex had an STI compared with 5.1% of those who did not report condom use – not a statistically significant difference. This doesn't necessarily mean that condoms don't protect against STIs. It could mean that, because condom users were more likely to use lube (44% used lube versus 24% of those who didn't use condoms), the protective effect of condoms was being eroded by a harmful effect of the lubricant used. It could mean that condom users had more anal sex, but we don't know.

### What conclusions can we draw about lubes?

The type of lube didn't make a difference. One theory<sup>2</sup> is that water-based lubes draw water out of the cells lining the rectum and damage them; silicone-based lubes might be safer, and even oil-based lubes for people not using condoms. However, in this study, although figures are small because few people exclusively used one type of lube, STIs were more common in consistent users of silicone lubes as well as of water-based ones.

The reason for these findings is unknown, but has left prevention workers at a loss as to what to say about lubes. It does not show that people should stop using lubes and at present the advice still stands that using condoms plus silicone- or water-based lube is the best way to avoid STIs. No causation has been proven: the study could not show how long participants had had STIs and so can't reliably relate them to the times lube was used. Nonetheless this study, plus another<sup>3</sup> that showed most commercially available lubes damage rectal cells to some extent, makes more research into lubricants and to how people use them in anal sex an urgent priority. [GAM](#)

# Peak exp



# HIV, adventure

It's been almost a tradition in *HTU* that January is the time to include a New Year resolution piece about exercise, diet or the benefits of healthy living. Thinking about how to put a new spin on gym regimes or a balanced diet, *Gus Cairns* started thinking of a number of people with HIV who'd done more than just try to be sensibly healthy. But what drives people to do *extraordinary* things?

Some HIV-positive people I know have pushed themselves to extremes of endurance, sought out experiences that didn't just make living bearable but added to it. Several became marathon runners; I seem to have met a lot of mountain climbers; a lot of people, post-diagnosis, caught the travel bug and have taken themselves off, sometimes despite health warnings, to remote places, some even staying there.

Even in my case, since recovering from AIDS I've climbed Kilimanjaro, done a skydive on my 50th birthday, and trekked in Laos. Standard gap-year stuff if you're

19, but with extra meaning as things I once thought I'd never live long enough to do.

We talked to a number of adventurers about why they did it.

*"It's a life-affirming thing - something I would never have done if I'd not been diagnosed with HIV. It means now death would be very inconvenient as I have so much to do!"*

**Anthony Griffiths, employment adviser, 56**

*"It gets me going. I lost my partner to HIV and have had to battle with depression but*

*I know that if I start to get stuck, I plan and execute an adventure; it's like kick-starting my life again."*

**Gareth Harries, social worker, 47**

*"The fact that I've pulled my life back round after having a CD4 count of 10 and being, I openly admit, suicidal, is mostly due to my travels (and some counselling). Just forget I'm HIV positive. I'm just a traveller, exploring the amazing world we have."*

**Nicola Brown, HIV project administrator, 45**

# Experiences

## and exploration

*"Few people understand why I climb. It's about just being in the present moment. A moment when everything is perfectly in place in the universe, and I can die right then, and it would be okay."*

**Gregory Fowler, finance officer, 53**

*"My diagnosis turned diving from something I loved to something that connected me to the universe and levelled the playing field. It didn't matter to the fish or the manta rays or the coral that I'm 'pos'."*

**Tony Carthy, diving instructor, 49**

### **Paring life down to the basics**

There were different shades of motivation in the people I talked to. For many, their adventures added richness to a mundane life. For others, especially people who already had busy lives, it was about simplicity: slimming things down to core existence.

Take Dr Jens van Roey, for instance. A wiry 58, he became HIV positive while working

for the Belgian Overseas Development Agency in the Congo in 1987. He has worked in HIV and disability projects in Africa, did a stint at UNAIDS, where he was instrumental in getting the GIPA (Greater Involvement of People with AIDS) principles on to the international agenda, and then moved over to the pharmaceutical industry. Joining what was then a small biotech company called Tibotec, he found himself in charge of developing a drug called TMC120 (dapivirine) and negotiating its licensing as a candidate microbicide to the International Partnership for Microbicides.

A high achiever: someone who says that, despite three bouts of serious illness (disseminated TB, lymphoma and an osteoporosis-related fracture), "I've never said I'm not well."

In case he's sounding superhuman, though, he also recounts a recent experience that humbled him: "It was the only time I became [desperate]... night sweats, weakness, everything dark, giving up..." It turned out to be a side-effect of an

osteoporosis drug. "It was a very valuable experience," he says. "I learned what a bad doctor I'd probably been."

For him, cycling is a release from a committed and busy life: last year he and his wife Bieke, an occupational therapist, took part in a cycle race for the over-55s up the 6273-foot Mont Ventoux in Provence, France (notorious as a killer stage in the Tour de France). They didn't have to, but he and Bieke cycled there all the way from Belgium too, through a week of rain.

"You close the door on your normal life," he says. "You go away with the minimum of clothes and materials." It also strengthened his faith in other human beings, especially his wife ("I think when HIV comes into a partnership it either breaks it or strengthens it; well, it's strengthened ours."), and all the villagers who went out of their way to help them.

### **The rewards of adventure**

Jens may not be your typical person with HIV, whoever that is. If there is a common denominator in our adventurers, what are

they looking for? There's probably not one single thing.

First, there's the physical benefit, the documented rush of wellbeing you get during exertion when the endorphins, the body's natural opiates, flood in.<sup>1</sup>

Some scientists have argued that so-called 'runner's high' is due to conscious involvement in the task as well as pain-masking by endorphins.<sup>2</sup> This may be the state of psychological wellbeing called 'flow'. We examined flow in *Walking back to happiness* in HTU 189. It means positive, focused attention – single-minded immersion in a task, the opposite of boredom and anxiety.

Climber extraordinaire Gregory Fowler describes it: "Climbing the steep glacier up 14,000-foot Mount Shasta, alone, in the middle of the night, just a slight breeze, the stars, and the crunching of my crampons and ice axe..."

Yet, as Greg's own account hints, our adventurers are seeking more than flow. They're after what have been called (no pun intended) 'peak experiences'.

### The peak of experience

These are experiences in which being alive acquires a special, intense meaning. In the past these might have been described in religious or transcendental terms. But the father of positive psychology, Abraham Maslow, in his 1960s book *Religions, Values and Peak Experiences*,<sup>3</sup> separated such experiences from any cultural value ascribed to them. He thought them quite common and that never having had one might indicate repression or anxiety (distorted endorphin levels are found in anxiety disorder).

Peak experiences involve a feeling of completion or wellbeing, often accompanied by joy or awe. They may feel like the discovery of something of primal importance, though it may be hard to put into words. They can be the climax of a

“Many people have a list of places to see before they die, but it's like HIV gave me permission to work through the list.”

**Nicola Brown,**  
HIV project administrator

period of fun but may also break into times of misery. They may add a sense of individual purpose but may also involve a feeling of loss of individuality, of being at one with others or one's surroundings.

And they're not fleeting; by definition, they leave a permanent positive effect on the individual.

They can be set off by meditation or prayer, exposure to beauty (of art, nature, music, whatever), perfect company, deep feelings of love... or psychedelic drugs.

A research area has sprung up in the last 20 years called neurotheology, based on the work of neurologists like Andrew Newberg<sup>4</sup> and Vilayanur Ramachandran,<sup>5</sup> who investigated whether the brain is innately prone to mystical experience. They hooked Buddhist monks up to EEG machines and put Carmelite nuns into MRI scanners to find out what bits of the brain light up during mystical experience.

What they discovered was a bit more complex than the popular press's idea that they found the so-called 'God neurons' in our brains – but they did find areas in the brain's frontal lobe that were particularly active during such experiences. Depending on your point of view, their work can be seen as either confirming the necessity of religious experience to man or debunking God as a by-product of evolution.

The scientist Antonio Damasio<sup>6</sup> suggests that, as we grow up, experience acquired after we acquire language is turned into a self-concept, arranged in time as a 'life story' by the brain's hippocampus, responsible for the formation of memory. But this leaves unfiled a whole body of earliest memories, primarily emotional, acquired before language. These will tend to consist of the most basic experiences of life: wonder at existence, attachment to others or fear of them, the first awareness of oneself as a distinct person, and so on. To Damasio, peak experiences are not revelation but recapitulation; they are memories of the



Many thanks to our adventurers for sharing their tales and their photographs with us.

wonder, bafflement and terror of being a little child.

He also maintains that a form of these experiences continue into adult life, where they form the basic unit of consciousness. The feeling of being someone at all, Damasio suggests, is caused by a constant back-and-forth switch of attention between your interior and your surroundings: you notice that what you perceive has an effect on you, and in sensing that effect you find out, from second to second, that you are a person who perceives things. This is backed up by strong evidence from studies of coma, epilepsy and 'locked-in' syndrome (where people are totally paralysed but conscious), and the differences between them. It may be why peak experiences feature a strong sense of *connection* between self and non-self.

### Addicted to transcendence

So far so good: but the mention of intense feelings of love and psychedelic drugs reminds us that the search for peak experiences may not always lead us into safe and healthy activities.

There is a body of research, for instance, that tries to find out why, despite knowing the risks, people persist in having unsafe sex. A paper by James Martin, noting how religious ecstasy has become less common and maybe less admissible as a feeling in many modern societies, wonders if, in our sexualised society, mutual orgasm has come to replace it for some people – specifically, some gay men.<sup>7</sup>

"Although the leading western religions have long suppressed their mystical traditions," comments the author, "the role of sexual experience in transcending individual selfhood...may be increasingly important in the secular West."

Then there's the thrill: as some of our adventurers attest, the meaning they get from pushing themselves to extraordinary experiences in beautiful places is *because* of the challenge or risk involved rather than

“I probably pushed the limits...doing a *Fuzeon* injection while tied to a rope team on a glacier is not very user-friendly.”

**Gregory Fowles,**  
finance officer

in spite of it. Revelation usually happens in remote places but, for some other people, may occur in taboo places too.

A lot of gay men do talk of sex as being much more than a search for fleeting pleasure, but for some sort of transcendent experience.

In a Spanish paper that interviewed 20 gay men from Barcelona about their reasons for having unsafe sex,<sup>8</sup> one man comments: "The feeling I was hoping for [was] not to find a meaning of life and all that, but to have an experience, which I wouldn't call mystical, but a very concrete and strong experience – one which wakes you up when life sometimes seems very monotonous."

Sometimes this is explicitly related to the danger of unsafe sex or to the feeling that only unprotected sex gets close to the ecstatic union wanted. "When I have had sexual relations without a condom it has been because I have felt very connected and have unusual affection towards that person," one interviewee explained.

Martin's paper<sup>9</sup> comments that HIV prevention efforts usually treat the reasons people have unprotected sex as if they were themselves diseases or prevention 'needs' that required eradication or correction: recreational drug use, depression, low self-esteem, ignorance. This approach has to some extent been a success, with gay men making successful efforts to change sexual behaviour.

But, as UK behavioural researchers Jonathan Elford and Graham Hart entitle one paper, *If HIV prevention works, why are rates of high-risk sexual behaviour increasing among MSM?*<sup>10</sup> They find that gay men tended to see condoms as an emergency strategy to stop the spread of HIV, not a long-term solution, and hoped at some point to recover feelings of union, abandon and ecstasy.

Even one of the writers of *How to have Sex in an Epidemic*,<sup>11</sup> the book that first used the term 'safer sex' in 1983, Dr Joseph



Sonnabend, has commented to *HTU* that: "It may have been a mistake to not recognise in prevention material that condoms can be a significant impediment to a fulfilling sexual experience."

### Adventure and danger

We may seem to have strayed a long way from mountains and scuba diving. Yet pitting yourself against danger may also constitute part of what our adventurers are looking for too. This isn't just about keeping fit, it's about something bigger than physical health, and several of our adventurers have sailed close to the wind.

Gregory Fowler, for instance, started mountain climbing while he still had an AIDS-related illness, and blew what was supposed to be his last chance at therapy when, returning from ascending Kilimanjaro, he found all the *Kaletra* (lopinavir/ritonavir) capsules he'd kept back at base camp had fused into a solid mass. His viral load shot up, his CD4 cell count plummeted and his viral load is only undetectable on a combination of darunavir, *Truvada* (FTC and tenofovir), raltegravir and the now rarely used injectable fusion inhibitor T-20 (*Fuzeon*). He says, "Looking back, I probably pushed the limits of what I should have been doing." Yet you sense an incorrigible spirit of defiance when he adds that "doing a *Fuzeon* injection while tied to a rope team on a glacier at 11,000 feet is not very user-friendly".

Anthony Griffiths was diagnosed with acute HIV infection and put on a course of very early treatment. As soon as he came off the pills, he headed straight to the middle of China, partly because he wanted to go but felt he wouldn't get in carrying drugs. There he nearly drowned in a Yellow River flood, came down with pneumonia and just managed, semi-delirious, to get himself back to Bangkok "where I knew they had some experience dealing with HIV". It didn't scare him off, and since stabilising his health

“ [I have] an ongoing battle with... depression. I often feel ambivalent about life and start planning an adventure when I am trying to climb out of a pit of despair. ”

**Gareth Harries,**  
social worker

he has taken himself off to Easter Island, amongst other places.

Only Nicola Brown, of the people I interviewed, took time to emphasise the safety aspect of travel. "There are destinations I have on my 'to do' list which I've ruled out owing to the absence of nearby medical help," she says, and she always travels in small group tours to avoid unwanted male attention. Even she, though, sees her travels as opportunities to push her limits: "I had a phobia of heights and conquered that by climbing, in Tunisia, the same tower Graham Chapman climbed in Monty Python's *The Life of Brian*."

She thinks her travelling keeps her healthy – "I gave up smoking in order to go trekking in Nepal." But that's not the main reason she goes. "Many people have a list of places to see before they die, but it's like HIV gave me permission to work through the list."

Tony Carthy says almost exactly the same thing: "Being diagnosed is a form of permission to really, really live life."

It may seem far fetched to suggest that our adventurers are looking for something of the extreme experience that may lead other people to be infected with HIV in the first place. If it's true, however, it may suggest a radically different approach to groups such as gay men who may see sex as the only thing that gives their life meaning. Maybe health advisers should be advising circuit-party boys to try trekking in the Himalayas rather than counselling. The idea that an addiction can only be cured if it's replaced by something else just as meaningful to the individual is already a commonplace idea in drug rehabilitation.

### Diagnosis and transformation

Certainly one thing our adventurers unanimously mentioned was that their activities were evidence of some sort of post-diagnosis personal transformation.

"Your HIV diagnosis is like bereavement," says Anthony Griffiths. "You lose yourself in





order to gain a new self." Since his diagnosis he has not only travelled the world but, as someone who left school at 16 without even an 'O' level, he now has a BA and plans to do a PhD.

For Gareth Harries, adventures are therapy. Despite having chalked up a list of achievements including Kilimanjaro, the Inca Trail, the Exmoor Beast mountain bike race, working in a cheetah conservation project in Namibia, and cycling solo from Petra in Jordan to Mount Sinai in Egypt, he says that he has "an ongoing battle with the mental paralysis of depression. I often feel ambivalent about life [he lost a dearly loved partner to AIDS] and start planning an adventure when I am trying to climb out of a pit of despair."

I ask if therefore adventure is a form of escape. "No," he says, "because I know what I'm doing. I'm not trying to ignore my low self-esteem; I am trying to boost it with a sense of achievement."

For others, their HIV diagnosis may lead to a renewed interest in helping others. Tony Carthy was captivated by scuba diving in 1992, moved to the Philippines (where there is currently an explosive HIV epidemic in young gay men) and qualified as an instructor in 2001. When diagnosed with HIV in 2008, he says that "My first thought was that I'd lose diving", but instead he started working at a project for young gay men: "I am taking these newly diagnosed lads diving: it makes them feel 'normal' again."

Nicola Brown has discovered value as a travel companion: "I always seem to end up being the 'mother figure' others confide in on these tours."

### Adventure and spirituality

But for all of them, there remains some deeper mystery to be searched for. There is a body of research about HIV diagnosis and spirituality but a lot of it is buried in theological journals or coloured by 'born-

again' religiosity, often of the American kind.

Paul Clift, HIV patient representative at King's College Hospital in south London, cautions on making too bold links between religion and personal change after diagnosis. He says: "Experiences like these have beneficial potential to the person who has them and makes sense of them, but we need research into how European and indeed African people apply their spiritual models to interpret them."

But one study by respected US behaviourists<sup>12</sup> questioned 147 people with HIV, including 13 who did in-depth qualitative interviews, about spiritual feelings. They found that 80 out of the 147 (54%) described themselves as having undergone a significantly positive 'spiritual transformation' since their diagnosis.

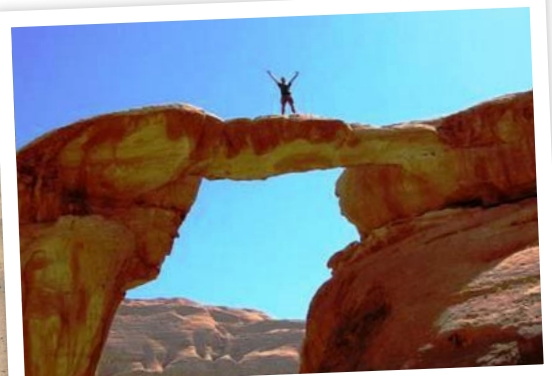
This was *not*, in general, a conversion to organised religion. Few were deeply involved in organised churches but many said they prayed or meditated. They tended to follow a journey from what subjects called an "empty life", through depression - not necessarily tied to HIV diagnosis - through a period of intense self-reconstruction, and finally to a renewed, altruistic, interest in others.

One gay man said: "I came to a God of my own understanding. No one has a monopoly on God."

Others might not call it God, but they know it when they experience it. I listen spellbound to an account by Anthony Griffiths of a night on Easter Island: "[We took] a long drive through the pitch black and once we got there we could see the great Moai statues as silhouettes against the starry sky - every star you could ever wish to see was picked out in white fire - and we were blundering around trying to see by the light of our mobile phones - and suddenly there were all these green eyes around us - they were wild horses..." his voice trails off. I can feel the wonder of it. *That's why people go on adventures.* [nam](#)

## Advice

- If you want to go on adventures, start by reading ➔ [www.aidsmap.com/Travel/cat/1688/](http://www.aidsmap.com/Travel/cat/1688/)
- To find out about entry restrictions for people with HIV, visit ➔ <http://hivtravel.org>.
- Talk to your HIV clinic or your GP about where you want to go and what preparation is necessary, particularly if you're going away somewhere unusual or for a long time. Vaccinations are sometimes needed, so make sure you think about these in plenty of time.
- Get kit appropriate for your trip; you can't climb Kilimanjaro in trainers. A good backpack may save you a lifetime's backache. Remember the travellers' rule: "Take half the clothes you think you'll need and twice the money".
- Talk to your doctor about how to pack and keep your HIV medications safe, and if you should take any other medications, such as antimalarials. Pack rehydration salts and *Imodium* in case of diarrhoea, sunscreen, plasters, painkillers and, if necessary, insect repellent and mozzie-bite soother and antibiotics.
- Do take condoms; they can be hard to come by in the wild.
- Several insurance companies in the UK offer HIV-specific travel insurance, including ➔ [www.insureandgo.com](http://www.insureandgo.com), ➔ [www.world-first.co.uk](http://www.world-first.co.uk), ➔ [www.hivtravelinsurance.com](http://www.hivtravelinsurance.com) and ➔ [www.freedominsure.co.uk](http://www.freedominsure.co.uk). They will ask you medical screening questions and you may have to pay a higher premium, especially if you have a low CD4 count, but don't be tempted to scrimp with 'normal' travel insurance: it won't pay out. Even they won't insure everyone and you may have to pay through the nose if you're not on treatment or have had a recent hospital admission.



# Getting tough on criminalisation



"Nothing short of barbaric." This was the comment of a BBC presenter, confronted with the number and sheer arbitrary injustice of criminal convictions of people accused of transmitting HIV or exposing other people to it. In some cases, people have been jailed for failing to disclose HIV in situations where they couldn't possibly have transmitted it.

And yet, says *Edwin J Bernard*, there have been some encouraging international policy developments in the fight against the unjust persecution of people with HIV.

Worldwide, arrests, prosecutions and their associated media reports continue to have a devastating impact on the people accused of exposing or transmitting HIV, as well as adding further to the stigma of living with HIV.

Yet since *HTU* last covered the issue of HIV and the criminal law (*HTU* 199, September 2010), there have been some remarkably encouraging national and international policy developments.

### **"Nothing short of barbaric"**

For the past 18 months, the Global Commission on HIV and the Law, led by the United Nations Development Programme (UNDP) on behalf of the Joint United Nations Programme on HIV/AIDS (UNAIDS), has been gathering evidence from all over the world about the impact of the law on HIV. The Commission has been examining issues much broader than the criminalisation of HIV non-disclosure, exposure and transmission. These include the criminalisation of sex between men, sex work and drug use; the impact of the law on women and children; and the impact of intellectual property law and trade agreements on the availability of generic antiretrovirals.

However, some of the world's leading experts on the criminalisation of HIV non-disclosure, exposure and transmission are part of the Commission's Technical Advisory Group, including the UK's Professor Matthew Weait. And the Commission's report (due soon) is expected to censure countries that continue to treat people with HIV as potential - and actual - criminals and where HIV-related stigma is trumping evidence-informed laws and policies.<sup>1</sup>

At the Commissions' High Income Countries Dialogue held in Oakland, California, in September 2011, the issue of criminal prosecutions for HIV non-disclosure, exposure or transmission was very much at the heart of the meeting. The often emotional testimony was skilfully moderated by BBC presenter Nisha Pillai, herself moved to tears by the end of the meeting, overwhelmed by the stories of legal injustices perpetrated against people with HIV.

"The Western world's treatment of many people with HIV is nothing short of barbaric," Pillai wrote in a blog entry a few days later. "The distressing testimony I witnessed from people living in the world's richest countries - the US, Canada, the UK, Denmark, Germany, and elsewhere in Europe - left me profoundly shocked... The reason is simple - criminalisation... In some states of America you can kill someone in a car accident and

“The Western world's treatment of many people with HIV is nothing short of barbaric. The distressing testimony I witnessed...left me profoundly shocked.”

**Nisha Pillai,**  
international moderator

get a lighter sentence than *if you fail to pass on HIV* to a sexual partner. Passing on herpes or hepatitis C isn't prosecuted, but not passing on HIV is. The injustice is staggering. Seldom in my many years as a BBC journalist, and now as an international moderator, have I felt so outraged."<sup>2</sup>

The meeting was hosted by the sole US member of the Commission, Oakland Congresswoman Barbara Lee. Congresswoman Lee recently unveiled the *Repeal HIV Discrimination Act* which creates financial incentives and support for states to review and reform HIV-specific laws that are not consistent with good public health or HIV science.<sup>3</sup>

"Laws that place an additional burden on HIV-positive individuals because of their HIV status lag far behind the medical advances and scientific discoveries in the fight against the epidemic," said Congresswoman Lee. "Instead of progress against the disease and protection for people living with HIV/AIDS, criminalisation laws breed fear, discrimination, distrust, and hatred. Although our country has made notable advances in the global fight against HIV/AIDS, we have a long way to go. The decriminalisation of HIV/AIDS is one way we can reduce stigma in our communities, while fighting the epidemic in a rational, holistic, and truly rights-based fashion."<sup>4</sup>

Although it is unknown whether the bill will pass when introduced to the US House of Representatives, at the very least it will create awareness and debate amongst US lawmakers about the issue.

Since 2008, when they produced their policy brief on the issue,<sup>5</sup> UNAIDS and UNDP have been actively trying to persuade governments and policymakers to repeal HIV-specific criminal laws and to limit the application of general criminal law to actual cases of intentional transmission, where a person:

- knows his or her HIV-positive status;
- acts with the intention to transmit HIV;
- and does in fact transmit it.

At the heart of this position is the need to establish a threshold for criminal liability that would serve justice in truly blameworthy cases - where the intention to harm can be clearly established - while avoiding overly broad application of the criminal law which risks jeopardising public health and human rights.

### **Basing legal decisions on good science**

Three years before the 'Swiss statement'<sup>6</sup> on the impact of antiretroviral therapy on infectiousness, the Netherlands' highest court decided that one act of insertive

unprotected anal sex when the accused was on treatment was not significant enough to be considered a risk of serious harm. The result is that, consistent with UNAIDS' recommendations, only maliciously intentional exposure or transmission remains a criminal offence.<sup>7</sup> The impact of the Swiss statement was not only felt in Geneva, where HIV exposure charges were dropped because the risks were considered to be purely "hypothetical",<sup>8</sup> but also in Austria,<sup>9</sup> Canada<sup>10</sup> and the US military.<sup>11</sup>

In August 2011, UNAIDS convened an expert meeting in Geneva on the scientific, medical, legal and human rights aspects of the criminalisation of HIV non-disclosure, exposure and transmission. This was the first part a project funded by the Government of Norway to expand on its 2008 policy brief in order to provide more detailed guidance and inform law and policy internationally.<sup>12</sup>

The meeting presented a unique opportunity to explore the latest developments in HIV science – such as the impact of treatment on transmission risk and life expectancy. It was also a chance to provide the UNAIDS Secretariat and other stakeholders with recommendations that would promote an application of criminal law to HIV non-disclosure, exposure and transmission, if any, that serves justice, without jeopardising public health objectives and fundamental human rights. The meeting reached expert consensus on issues such as HIV-related risk and harm; clarifying criminal intent and acceptable defences; and highlighting limitations of scientific evidence in proving transmission.<sup>13</sup>

The second part of the project – a high level policy consultation – will take place in February 2012 in Oslo. It is hoped that the Oslo meeting will lead to a greater understanding of the current issues around HIV non-disclosure, exposure and transmission and assist countries to reform their HIV-related criminal laws, policies and practices.

### The problem with HIV-specific laws

However, for every sign of progress – such as the February 2011 suspension of Denmark's HIV-specific criminal law<sup>14</sup> or Guyana's rejection of a new HIV-specific criminal law in September 2011<sup>15</sup> – there have been at least as many problematic developments, such as Romania's new HIV-specific criminal statute, implemented in October 2011<sup>16</sup>, or South Africa's opposition leader Helen Zille's recent speech calling for men who don't use condoms to be prosecuted for attempted murder.<sup>17</sup>

In addition, many jurisdictions, notably high-income countries in Australasia, western Europe and North America,

“Criminalisation laws breed fear, discrimination, distrust, and hatred.”

Congresswoman Barbara Lee

continue to prosecute people living with HIV inappropriately for non-disclosure, alleged exposure and non-intentional transmission.<sup>18</sup> Last year also saw prosecutions in Belgium<sup>19</sup> and in the Congo<sup>20</sup> for the first time, both using anti-poisoning laws. The vast majority do not meet criteria for "deliberate" transmission, despite the frequent use of this word in the media.

HIV-specific laws are found all over the world – notably in Africa, central Asia, eastern Europe and Latin America.<sup>21</sup> At least 32 states of the United States also have such laws, and in the US there are arrests on an almost daily basis.<sup>22</sup>

Rather than criminalising HIV transmission, most US laws criminalise behaviour that may or may not (and in some cases *definitely does not*) risk HIV transmission. Some outlaw practices that are not significantly risky or harmful (for example, sharing sex toys, spitting, performing oral sex); and others criminalise non-disclosure of known HIV-positive status, regardless of whether or not a condom or other risk-reduction methods is relied upon.<sup>23</sup> Consequently, states with HIV-specific laws that make disclosure compulsory, that do not require proof of intent and/or that do not require proof of significant harm or transmission have generally had much higher prosecution rates than those without.<sup>24</sup>

For example, Louisiana's HIV-specific criminal law, first enacted in 1987 and revised in 1993,<sup>25</sup> specifies that it is "unlawful for any person to intentionally expose another to HIV through sexual contact or through any means or contact (including spitting, biting, stabbing with an HIV contaminated object, or throwing of blood or other bodily substances) without the knowing and lawful consent of the victim." The maximum prison sentence is ten years. A 1993 appeal<sup>26</sup> found that the statute was neither too vague nor too broad and it has not been challenged since.

In recent years, several people with HIV in Louisiana have been arrested for

behaviour that carries a very low risk of HIV transmission, including a man for having oral sex with his wife,<sup>27</sup> a male sex worker for suggesting to an undercover policeman, but not actually having, unprotected sex,<sup>28</sup> and an injured man receiving medical attention for throwing a "blood-covered identification card into the face" of, and "trying to spit" on, a healthcare worker.<sup>29</sup> The outcome of these cases is unknown.

### Criminalisation confusion

In the rest of the world, most prosecutions are taking place under general criminal laws, such as physical or sexual assault statutes. Their relevance to HIV non-disclosure, exposure or transmission is often based on legal precedents informed by one or more cases taken to appeal early in the HIV epidemic that were commonly informed by HIV-related stigma and/or incomplete understanding of HIV science. In an attempt to fit non-disclosure, exposure or transmission into a wide variety of legal definitions, many jurisdictions appear to have inappropriately characterised the risks and/or harms of these acts. When the law is unclear – as it often is when it evolves based on case law – this also creates uncertainty over what behaviour is criminal and what is not, leading to conflicting standards of HIV-related risk and the conflation of non-disclosure with a malicious intent to deceive or harm.

This is the case in Canada, the country with the second highest number of prosecutions – at least 130<sup>30</sup> – after the United States. That's about one prosecution for every 550 people with HIV – considerably higher *per capita* than in the US where there have been well over 300 prosecutions but whose larger HIV-positive population means that about one person per 3300 has been prosecuted. Prosecutions intensified following a 1998 Supreme Court ruling which established that a person who knows they are living with HIV has a duty to disclose their HIV status before engaging in conduct that poses a "significant risk" of exposing another person to the virus. Non-disclosure (regardless of whether it is active deceit or as a result of not discussing HIV risk) is treated as fraud that invalidates consent to sex and which results in this sexual contact being classified as an assault.

The problem is that "significant risk" has not been clearly or consistently defined and prosecutions for non-disclosure prior to oral sex<sup>31</sup> and sex with condoms<sup>32</sup> have taken place. As a result, substantial confusion amongst people living with HIV, healthcare workers and legal practitioners exists regarding when the duty to disclose arises.<sup>33</sup>

Next month, in a case that will have

far-reaching implications for people living with HIV in Canada, its Supreme Court will revisit two cases, allowing a re-examining of the 1998 ruling in the light of inconsistent lower court decisions. In particular, it will examine what constitutes a “significant risk” of HIV transmission in the context of recent scientific developments. Although both sides agree that the “significant risk” test is unfair and should be reassessed, the representatives of the Crown are arguing that the only way to make the law work fairly is to obligate disclosure (and, therefore, criminalise non-disclosure) before any kind of sexual activity, regardless of the risk involved. Advocates working to assist the defence are hoping that the Court will recognise advances in HIV science and rule that when a person with HIV uses a condom and/or has an undetectable viral load due to effective antiretroviral therapy the criminal law will not apply.<sup>34</sup>

### When disclosure is no defence

Although the current situation in Canada seems harsh, some countries in Europe have an even more draconian approach. In Austria, Finland, Norway, Switzerland and Sweden, people with HIV can be prosecuted for having consensual unprotected sex even when there was prior disclosure of HIV-positive status and agreement of the risk by the HIV-negative partner.<sup>35</sup>

Fortunately, most of these countries are in the process of examining such laws and policies. Norway has set up a special committee to examine whether its current law should be rewritten or abolished: its recommendations are due in May.<sup>36</sup> Switzerland is currently revising its *Law on Epidemics*, to be enacted later this year, and the latest version appears to be mostly consistent with UNAIDS’ recommendations. And a recent conference attended by police, prosecutors and politicians that highlighted the many human rights concerns over its current laws and policies, may result in a review of the Swedish *Communicable Diseases Act*, as well as a change in the application of legislation and regulations for people with HIV in Sweden by the end of the year.<sup>38</sup>

### England and Wales: a ‘best practice’ example...

The expert meeting heard how a partnership between the HIV sector and the criminal justice system in England and Wales led to the creation of prosecutorial<sup>39</sup> and police guidelines,<sup>40</sup> which have helped to clarify the circumstances regarding when prosecutions might be warranted and reduced the flow of cases reaching court. Attempts to replicate this pragmatic response are now going

“Not one person has been found guilty in England and Wales [who] pleaded not guilty from the start and got decent representation.”

**Lisa Power, policy director,  
Terrence Higgins Trust**

on in Scotland,<sup>41</sup> the Canadian provinces of Ontario and Quebec, on a federal level in Canada<sup>42</sup> and in the Australian state of Victoria.<sup>43</sup>


The Crown Prosecution Service prosecutorial guidelines were recently updated to highlight how tests for recent infection are unreliable for legal purposes,<sup>44</sup> and to clarify that the reduced transmission risks of having an undetectable viral load on treatment could be seen as an “appropriate safeguard” alongside condoms and thus be used as an affirmative defence in ‘reckless’ transmission cases.<sup>45</sup>

### ...but guidelines aren’t always followed

However, there continue to be inappropriate investigations, arrests and prosecutions with remarkably different outcomes often solely depending on whether the accused obtained timely access to good legal advice. “What’s weighing on my mind,” Lisa Power, policy director at Terrence Higgins Trust (THT) tells *HTU*, “probably because of these latest cases, is how often the police are still not following their own guidelines and what a huge difference it makes if someone gets a decent, experienced lawyer early on. It’s important to remember that so far not one person has been found guilty in England and Wales [who] pleaded not guilty from the start and got decent representation.”

This suggests that not only should anyone living with HIV contact THT Direct for referral to a lawyer and/or other support the moment they are involved in a criminal case – as a defendant or a complainant – but also that any healthcare worker should do the same, mindful, of course, of patient confidentiality issues. The benefit of the latter is that THT is then aware of an ongoing case and the healthcare worker may receive

some good advice about how to best support the prospective complainant or defendant.

“I think a healthcare worker should ring THT Direct if they have doubts as to their own practice,” Yusef Azad, NAT’s director of policy and campaigns tells *HTU*, “and also, when it is published, look to the [updated] BHIVA/BASHH guidance [on the management of the sexual and reproductive health of people living with HIV] – but they, of course, should not disclose any identifiers of a patient without that patient’s consent.” 

### For more information

For NAM’s book on HIV and the criminal law and the latest news on the subject, visit: ➔ [www.aidsmap.com/law](http://www.aidsmap.com/law)

For information if you are personally affected, see: ➔ [www.myhiv.org.uk/Telling-people/Law](http://www.myhiv.org.uk/Telling-people/Law). If you are being investigated, or you think that someone may make a complaint against you, it’s important you get good advice from an HIV organisation and find an experienced lawyer prior to making any statement. THT Direct, can help you find both these; you can speak to them in confidence on 0808 802 1221. You may also want to speak to THT Direct if you are thinking of making a complaint. You can find HIV organisations near where you are using NAM’s online e-atlas at ➔ [www.aidsmap.com/e-atlas](http://www.aidsmap.com/e-atlas).

Edwin’s own blog, which gathers together news and developments on the subject from around the world, is at ➔ <http://criminalhivtransmission.blogspot.com> and you can follow him on Twitter @edwinjbernard.

POZ magazine founder Sean Strub has made a trailer for what he hopes will be a full-length documentary featuring people unjustly criminalised for HIV non-disclosure, exposure or non-intentional transmission. See ➔ [www.youtube.com/watch?v=iB-6b1Jbjc](http://www.youtube.com/watch?v=iB-6b1Jbjc).



# SUPPORTING PATIENT POWER

## The role of patient advocates and advocacy groups

Chris Sanford is sitting in his office at the Bloomsbury Clinic, one of the UK's busiest HIV clinics, a step away from the computer-and-sofa-shop Mecca that is London's Tottenham Court Road. His office is tiny (three people can just squeeze in) but it is sited directly opposite the reception desk; one of the first people new patients are likely to catch sight of is Chris or his job-share colleague Angela. If not, they'll get to meet them.

"We see nearly all newly diagnosed people," says Chris. "Consultants, psychologists, health advisers, nurses literally bring them to our door. We have nine appointment slots a week for a first assessment with the newly diagnosed."

Garry Brough, Chris's predecessor and now Chair of the Bloomsbury Patient Forum, adds: "We got 38% of all our new patients to do a course for the newly diagnosed last year, a far higher uptake than for out-of-clinic courses offered by voluntary organisations."

Chris, Garry and Angela are not there because they're qualified health advisers, or social workers, or counsellors. They are there solely because they're Bloomsbury patients too. The Bloomsbury clinic should probably be the UK's model for the way it has welcomed patient advocacy as a specific part of its services and has incorporated patient advocates into its management. It does not just give patients support; it doesn't just have a patient rep on one of its committees as a 'community adviser'; it has put patients into positions of real power. "I've been on nearly every one of this hospital's management committees," says Chris.

The disadvantage of getting your feet under the committee room table, of course,

is that you can be accused of becoming a poacher-turned-gamekeeper and ending up as just another kind of NHS bureaucrat. But Chris and Garry both insist they remain representatives of, rather than advisers to, their community.

"Our jobs do to some extent overlap with health advisers here," says Chris, "but we are trusted to act 'outside the box' – sometimes literally, in that we'll meet patients outside the clinic." In other clinics, there may be less overlap – for instance, where there is a paid assessment and referral post, and patient reps may act more purely as advocates and peer educators.

"We are by definition an 'expert patient'," says Garry. "It's the difference between giving advice and sharing experience. Chris, for instance, saw one patient, who was severely anxious about his diagnosis, refusing to see psychologists or health advisers or to consider treatment, eleven times outside the clinic. We got him back into care, on to medication and even helped him get a job."

Chris gives another example of helping patients to disclose: "Most recently we've had a couple of women patients who were scared of disclosing to their consultant that they were pregnant in case they got a lecture about safer sex or pressure to have an abortion."

Referral goes both ways. The patient advocates refer patients to health advisers and counsellors when they have specific psychological or prevention needs and refer to over 80 other organisations. They have an arrangement with Camden Citizens Advice Bureau, which runs an in-clinic session once a week: "We do all the psychological and needs assessments in advance. It can take

organisations a while to trust that patient representatives can refer to a professional standard but once they know us they are happy to deal with us."

Part of the support offered to patients and the means to keep them engaged in their care is referral to the support group, the Bloomsbury Patients Network, which Garry chairs.

This patients' forum was the first formalised HIV-related patient representative body.: "It originally came from a visioning exercise run by the clinic in 1999," says Garry. He and colleague Peter Twist volunteered to provide patient input but at first it was a struggle to get other patients interested, apart from a core handful.

Things changed because a specific issue came up – the clinic's lack of a specialist HIV pharmacy on-site – and Garry and Peter organised a patient survey, which became a launch pad to get people involved. A small grant from the Millennium Awards in 2002 funded monthly patient forums. These still run, alternating news and information forums with experiential workshops. Average attendance is about 25, "though last year the maximum for a forum was 83", says Garry.

This early success in getting patients involved eventually led to the local primary care trust, Camden, funding Garry's part-time patient representative post in 2004, and expanding it to a full-time job-shared position in 2006, with the appointment of Angela.

Chris started in 2008, although he had been a volunteer facilitator of patient workshops since the mid-1990s. "We can show that we're cost-effective," he says. "I pitch for the money for workshops to Camden, and because they are in-clinic

and well-attended we can do our whole programme for less than £14,000 a year.”

The Mortimer Market Centre, the sexual health clinic which contains the Bloomsbury Clinic, is unusual in not being run by a hospital trust, and this may have helped in circumventing typical hospital hierarchies. However, there is no reason why the model could not be replicated elsewhere.

One of the most important factors in structuring patient advocacy into the clinic, says Garry, has been the active support of the clinic’s consultants and clinical lead. Lip service to the idea of patient power has not been enough, he says, citing other London clinics where patient advocacy groups have never taken off. The active support of the clinic’s HIV consultant or another key professional with the power to nominate to committees and mobilise money has always been necessary.

Chris says: “One of our top doctors tells his newly diagnosed patients that ‘If you only meet a consultant, you only get half the story’, and here I think we’ve proved the worth of patient advocates at helping patients stay involved in their care.”

### Advocating for the advocates

The question of how to apply the Bloomsbury model to other clinics and encourage the growth of HIV patient advocacy groups led to the creation of Forum Link in 2004.

Forum Link is an umbrella group whose members include twelve clinic patient groups and three area service-user forums, mainly in London but with groups in Brighton and Eastbourne. Paul Declé, the patient representative for FRONTLINE HIV Forum at the Chelsea and Westminster Hospital’s Kobler Centre, the UK’s largest HIV clinic, has acted as Forum Link’s facilitator. Forum Link is now undergoing the transition to a fully fledged voluntary organisation and Brad Hepburn, formerly of north London Oasis and the National AIDS Trust, is overseeing the change, applying for funding to support a paid development manager, and seeking trustees.

Paul says: “Garry came to us at Chelsea and Westminster to talk about how they’d managed to get patient advocacy off the ground there. Bernard Forbes, representing the patient group at the Wharfedale Clinic at St Mary’s Hospital in Paddington, was also there and I said ‘I see the potential for an umbrella group.’”

FRONTLINE HIV Forum is probably more representative than the Bloomsbury forum of the degree of activity currently possible for most patient advocacy groups: “We have a very limited amount of pharmaceutical industry funding. We have meetings once

a month and the Kobler’s clinical nurse specialist attends every one, and we will usually get someone in from a specific department such as the pharmacy. We typically get ten or so patients turning up although we have about 50 to 60 in regular correspondence on our email list.

“It serves as a really useful channel of communication about issues that affect patients; for instance, we had a good education session and dialogue recently on how electronic patient records work.”

Paul Clift is a part-time patient representative at King’s College Hospital in south London. He comments: “The Bloomsbury Forum has the advantage of paying its reps more and having meeting rooms. Here, it’s a real challenge to find somewhere for the patient group to meet.” Nonetheless, with fewer resources, he offers a similar advocacy and support service, with *ad hoc* appointments for the newly diagnosed.

Forum Link tries to support patients who are setting up forums in other clinics. It is fair to say that the patient advocacy movement has faced a struggle and nowhere else has yet achieved the levels of involvement seen at the Bloomsbury.

Far from supporting the idea, says Brad, many clinics dread the idea of allowing a patient representative to have an influential voice in the clinic. He cites the example of another London hospital where, despite having a number of highly articulate patients, representation has never really been accepted. “In the end, we had to tell their patients, ‘If you want to come to a patient forum, come to the Bloomsbury.’”

Paul Clift comments that, in this sort of case, “One way forward is to try and get buy-in from a range of senior clinicians and managers who may be collectively able to outvote one powerful but obstructive person.”

The main fear held by healthcare professionals, he adds, is that treatment and care will be compromised and the decisions of doctors questioned by ill-informed patients and their representatives. But in a world where patients are becoming increasingly involved in such things as treatment guidelines, this paternalist attitude should be a thing of the past. There is extensive literature to show that the benefits of patient involvement far outweigh the disadvantages.

“Clinics are now under pressure themselves from the Department of Health and other managerial bodies to provide patient liaison,” adds Brad. Like Garry and Paul Clift, he emphasises that the support of a paid ‘insider’ is essential: “At too many clinics, once a patient rep is there, they are

expected to do everything. No: you have to have an engaged insider to liaise with managers who may want nothing to do with an ‘expert patient’ to begin with.”

Things may be changing, slowly: several new patient groups have started up recently or are in the process of doing so, including ones at the Trafalgar Clinic in Woolwich, south-east London, and at the North Middlesex Hospital in north London.

Why does there need to be a specific patient advocacy organisation when people with HIV have a number of voluntary organisations to support them?

“I hope patient advocacy is a purer model, allowing for more direct communication from patient to provider,” says Paul Declé. “Voluntary organisations can be in a position where if they shout too loud, they lose funding and the lights go off, and their perception of the issues can be distorted by the need to keep their jobs.

“We feel clinic advocates are in a better position to sense what the grass roots are concerned about, and certainly our different member forums consistently report the same issues coming up: GP liaison and shared care, for instance.”

The same, he says, can apply to internally funded NHS bodies such as PPE (patient and public engagement) groups: they can self-censor or be sidelined if they get too critical (“though it depends how the criticism is brought forward”, adds Paul Clift, citing some over-strident demands in the past).

“That’s why,” Paul Declé continues, “we are trying to have as wide a spread of funding as possible and as wide a power base too. We won’t have an executive director, and [we] have three co-chairs from different forums with different skills and perspectives.”

What advice would you give to patients who want to set up an advocacy group, I ask.

“Pick an issue,” says Paul Declé, “and do a survey about it like they did at Bloomsbury.

“Then you need at least three people as your core team: they had Garry, Peter and Chris at the Bloomsbury. This needs a lot of persistence to start with and one voice will probably not get heard. You do need a supportive insider to open doors for you.

“In general, however, we are finding that the message is getting through, and clinics are becoming less suspicious of patient power.” **nam**

### More advice

To contact the Forum Link Project, email [admin@forum-link.org](mailto:admin@forum-link.org) or phone 020 7738 0258.

To contact the Bloomsbury Patients Network, email [chris.sandford@nhs.net](mailto:chris.sandford@nhs.net).

# Treatment: what really works best?

The new edition of the HIV treatment guidelines from the British HIV Association (BHIVA) is now out for public consultation. HTU editor *Gus Cairns* was one of the two patient representatives on the writing panel, and says that this stands to be the most authoritative set of guidelines yet.

**B**HIVA, essentially, is the body that represents the opinions and interests of HIV doctors and allied professionals in the UK. It doesn't have to represent patients but has gone out of its way to encourage them to take positions of influence within the organisation. There is a patient representative on its ruling Executive Committee (EC), who is an *ex officio* trustee; I was the predecessor of the current EC representative, Silvia Petretti. BHIVA also has four permanent sub-committees that each have a position for a patient rep, and regularly appoints *ad hoc* working groups, which include patient representatives, for specific jobs such as writing sets of standards and guidelines. These are usually advertised on the UK-CAB website ([www.ukcab.net](http://www.ukcab.net)).

One job I'd avoided until now, though, was anything to do with writing treatment guidelines. I knew from experience that there's no point in being a patient rep unless you do some hard work. I was worried that I would have to spend hours wading through scientific studies evaluating evidence.

Although the actual work burden was not too bad, I wasn't wrong about the amount of evidence. This set of treatment guidelines will be the first to be issued for three and a half years. They are normally issued biennially, but this time round the process of gathering and reviewing evidence had to pass an NHS accreditation process adopted in 2009 (see [www.evidence.nhs.uk/accreditation](http://www.evidence.nhs.uk/accreditation)). That meant it had to be done in a much more rigorous way.

## Sifting the evidence

Globally, there are numerous different sets of HIV treatment guidelines for different countries and different needs<sup>1</sup>. But the three most influential sets are probably the Department of Health and Human Services (DHHS)<sup>2</sup> guidelines issued in the US; the European AIDS Clinical Society (EACS)<sup>3</sup> guidelines; and the BHIVA guidelines.

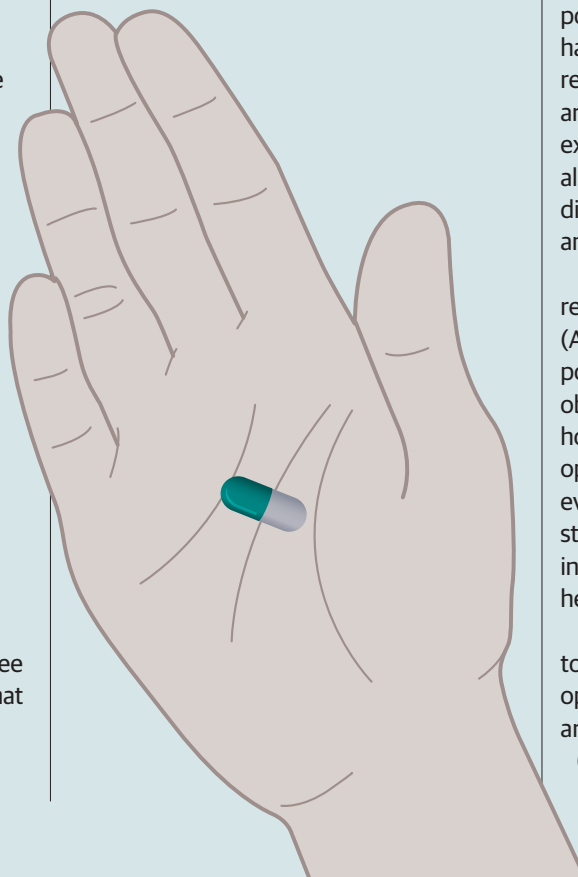
There's no set global standard for the evidence upon which guidelines are based. In theory they could simply be the opinion of a group of experts sitting round a table. Expert opinion, however, is often fallible. Doctors tend to base their opinions on their own patients, who may not be

typical; negative results and non-results are notoriously less likely to be published; even people of integrity can be swayed by studies hyped by PR firms. What you think you know ain't always so.

For this reason, most guidelines attempt to 'grade' evidence. This means that you look at each piece of scientific evidence and decide how reliable it is, and how crucial in health terms. It can be done by strength of recommendation, and by reliability of scientific evidence. There are three grades of scientific reliability. Grade 1, the best, is results from randomised trials that pit one treatment against another or against placebo. Grade 2 is data from cohort or population studies; these report what happens in large groups of patients, but results may be distorted by causes that aren't captured by the data. Grade 3 is expert opinion and case reports. There are also, in the case of the US guidelines, three different strengths of recommendation, A, B and C for 'strong', 'moderate' and 'optional'.

So you could have a strong recommendation based on weak evidence (A3). This might apply, say, where a potentially lethal side-effect has been observed but where it's difficult to say how common it is. Or you could have an optional recommendation based on strong evidence (C1), as when a rigorous scientific study establishes an outcome difference in something that doesn't crucially affect health, like a tendency to get headaches.

These grades are still fallible, however, to experts' knowledge of trials and to their opinion of how important specific outcomes are. So, for instance, one might regard a (statistically significant) 5% superiority for treatment A over treatment B in terms of





patients achieving an undetectable viral load as clinching evidence in favour of treatment A. Another expert, however, might regard the fact that, although only a small number of patients drop dead from heart attacks, 20% more do on treatment A than B as an ironclad reason to favour treatment B.

In some cases, billions of pounds may depend on the result of such disputes, so there may be bitter battles over evidence. HIV is no stranger to this, especially when the cost of drugs is involved. BHIVA was well aware, for instance, of the decision by the London Specialist Commissioning Group to recommend *Kivexa* (abacavir/3TC) over *Truvada* (tenofovir/FTC) as first-line therapy for patients with a viral load under 100,000 copies/ml.

BHIVA accordingly stepped up the calibre of its evidence grading for the most crucial recommendations, to the point where the new guidelines may be the most rigorously evaluated anywhere. Firstly, doctors writing a particular section voted on how important they thought particular outcomes were (viral undetectability, speed of viral suppression, side-effects, CD4 count, resistance and so on). They then employed a health researcher to comb through every piece of evidence pertaining to the most crucial outcomes and generate what are called 'forest plots' – diagrams that show the overall strength of evidence across the range of available studies. In this case, two of the most crucial decisions – firstly, the choice of nucleoside drugs, which involves for most patients the *Kivexa/Truvada* decision, and secondly, the choice of which third drug to put alongside those – the result was two documents, one of 52 pages and one of 146.

### Some crucial recommendations

The results? BHIVA recommends *Truvada* over *Kivexa*, not for particular patients, but generally. As for the third drug, it will broaden the choice: those 146 pages found that there was a dead heat between efavirenz (*Sustiva*, also in the combination pill *Atripla*), raltegravir (*Isentress*), ritonavir-boosted atazanavir (*Reyataz*) and ritonavir-boosted darunavir (*Prezista*) in terms of efficacy, but demoted lopinavir/ritonavir (*Kaletra*).

In terms of when to start treatment, BHIVA sticks to a CD4 count of 350 cells/mm<sup>3</sup> as the starting threshold – already having decided that the study that persuaded the US guidelines to suggest 500 cells/mm<sup>3</sup> was probably influenced by healthcare conditions in the US.<sup>4</sup> However, it broadens the range of patients recommended to start earlier. This includes – though is not restricted to – patients with hepatitis B or untreated hepatitis C, and

“I’m trying in everything I do to represent the diversity of our community.”

**Roy Trevelion,**  
patient representative

patients with neurocognitive problems. And it suggests that older patients, who are particularly prone to rapid CD4 count falls, should be considered for early therapy.

This article is too short to contain the many other recommendations, but they can all be read in the consultation document.

There are, however two other sections that people living with HIV might be particularly interested in: the section on *Supporting the Patient to take Antiretroviral Therapy* and the section on *Treatment as Prevention*. Although the EACS guidelines have a section on patient readiness, the former is BHIVA's first statement in treatment guidelines of what doctors need to do in order to assist people and evaluate whether they have the right support to benefit from therapy.

The latter, as far as I'm aware, is an innovation in any set of HIV treatment guidelines. The US guidelines mention that antiretroviral therapy lowers patients' infectiousness, but makes no recommendations on what to do about it, even though the guidelines include safer-sex counselling recommendations. The current draft of the BHIVA guidelines recommends that the fact that treatment with ART lowers the risk of transmission "is discussed with all patients", and that if, following discussion, people at any CD4 count wish "to start ART to reduce the risk of transmission to partners, this decision is respected and ART is started".

### Being involved

This may all sound like a lot of work, but the individual burden wasn't so bad. The guidelines writing group included 32 people. Most were doctors skilled in their area, so

in some topic areas (how to combine HIV treatment with cancer chemotherapy, to give one example) I was happy to review the documents but take them on trust.

Now, I'm aware that I may be regarded as expert in some areas myself, so people may be thinking "Fine for Gus, but I'd never get involved in something like that myself." Don't just take my word for it. The guidelines were regarded as sufficiently important to need the input of more than one patient rep and so Roy Trevelion became the second one. Roy was diagnosed over 20 years ago but until three years ago worked as an art director for the BBC, and is a newcomer to HIV treatment activism.

He says: "I've been getting to grips with this and am very impressed with the whole process. I've read all the drafts and evidence summaries, with a medical dictionary in hand. But I actually see my lack of experience as an advantage: I think it's important to have someone who reviews these guidelines from an 'unpractised' point of view, even if this means sometimes bringing up issues that aren't easily placed in a set of clinical guidelines, such as issues of social disadvantage.

"I'm trying in everything I do to represent the diversity of our community and to include the fact that, because we are all living longer, HIV patients will face increasingly complex combinations of chronic illnesses – and resultant complications in treatment and in who treats them."

There was also a meeting with other members of UK-CAB to get wider community feedback and a larger one is planned with HIV voluntary-sector organisations.

Dr Ian Williams, chair of this writing group, is also pleased with the outcome. He says: "We've tried to evaluate outcomes across all trials instead of some, and spend most time evaluating the outcomes of most importance to patients. The fact that they've been evaluated with regard to NHS accreditation means that it will be more difficult to criticise particular recommendations."

There will be arguments, he acknowledges, and the whole point of issuing a draft for consultation is to allow arguments to be made for recommendations to be changed. But he's confident in the robustness of the process that has led to BHIVA's new treatment recommendations. [nam](http://www.bhiva.org/TreatmentofHIV-1_2012.aspx)

*The consultation draft of the new BHIVA HIV treatment guidelines can be read online at* [http://www.bhiva.org/TreatmentofHIV-1\\_2012.aspx](http://www.bhiva.org/TreatmentofHIV-1_2012.aspx)

# News in brief

As well as our news reporting, the news pages on our website include selected stories from other sources. Here we highlight stories from the last quarter – visit [www.aidsmap.com/news](http://www.aidsmap.com/news) for the full news reports and references to the original sources.

## SUPPLEMENTS

### Extra vitamin D “no help”

There is little evidence that giving people with HIV vitamin D supplements helps strengthen their bones or avoid fractures, a systematic review of studies has found.

It is well-established that people with HIV tend to have lower bone mineral density – a condition that can lead to osteoporosis and fractures – and also that their levels of vitamin D, which helps build bones, are lower than average.

Because of this, it has been thought that giving vitamin D supplements might help ward off bone problems. This research found no evidence that supplementation helped, however. It concluded that people with HIV tended to have other risk factors for low vitamin D, such as black ethnicity, high blood pressure, lower levels of exercise, and being overweight.

The reviewers found that people with HIV experience an approximately 5% reduction in their bone mineral density when they start therapy, but the cause is unknown and it may have no clinical consequences. They also found that the drug efavirenz (*Sustiva* – also in *Atripla*) was associated with low vitamin D levels.

[www.aidsmap.com/page/2207048](http://www.aidsmap.com/page/2207048)

## VACCINES

### Monkey vaccine most robust yet

An experimental vaccine tested in monkeys has provided the highest level of protection yet seen and may form the basis of new human HIV vaccine candidates.

The most effective formulation of the vaccine produced an 80% reduction in the risk of infection from SIV, the monkey equivalent of HIV, after one exposure. When animals were infected, their resultant viral load was 100-fold lower than in non-vaccinated infected animals

and three infected animals developed an undetectable viral load.

The most effective form of the vaccine contained four fragments of SIV genetic material contained in two different vectors – the shells of harmless viruses that help ‘smuggle’ the vaccine inside cells. Vaccines that worked in animals have failed in humans before because they only worked against a narrow range of viruses; so this time the researchers deliberately used a form of SIV with a different genetic make-up to the fragments in the vaccine, and also one known for its ability to resist neutralisation by antibodies.

The vaccine prevented four out of five infections in monkeys given one exposure to SIV. Half the unvaccinated monkeys were infected with SIV after one exposure, whereas it took three exposures to SIV before half of the vaccinated monkeys were infected.

The researchers now plan to take a vaccine based on one of the most effective designs into early human studies.

[www.aidsmap.com/page/2205713](http://www.aidsmap.com/page/2205713)

## TESTING

### Early-infection test fails to detect HIV

A rapid ‘fourth-generation’ test used in some UK clinics works fine as an HIV antibody test, but fails to detect very early HIV infection, before the body has made anti-HIV antibodies.

Laboratory testing can detect a viral protein called p24 that appears soon after HIV infection (as well as detecting antibodies), thus shortening the length of time immediately after being infected with HIV when people do not test HIV-positive. Most people start to test HIV positive for antibodies after about a month and adding in p24 detection can halve this, to 12 to 14 days after infection.

*The Determine HIV1/2 Ag/Ab* test is the first to offer the combination of

antibody and p24 in a rapid test, meaning results can be given at point of care.

Two studies from Malawi and the UK, however, found that the *Determine* test failed to detect acute HIV infection (people infected for less than a month) in a third of samples in London and three-quarters of patients in Malawi (where laboratory conditions may be more difficult). Worse, in the Malawi study it also ‘detected’ the p24 protein in 14 out of 838 people who were in fact HIV negative, a false-positive rate of one in every 60 tests.

The researchers in London comment that if people have suspected acute HIV infection a combination of lab tests should be used and health providers should explain to patients that HIV is still hard to test for within the first month of infection.

[www.aidsmap.com/page/2204685](http://www.aidsmap.com/page/2204685)

## OUTCOMES

### UK BME gay men do just as well on treatment

In the UK, gay men from various non-white ethnic backgrounds are just as likely to respond to HIV treatment as white gay men, a study has shown. It found that 85% of gay men achieved an undetectable viral load within a year of starting treatment regardless of ethnicity, that the average time both white and non-white men took to reach a viral load under 50 copies/ml was four months, and that CD4 increases were almost the same.

This contrasts with the situation in the US, where a study last year found that only 70% of black patients who took antiretroviral drugs had an undetectable viral load, compared with 83% of white patients.

The UK study did find, however, that black and minority ethnic (BME) gay men were accessing treatment later than white gay men and that their CD4 cell counts at the time they started treatment were lower.

[www.aidsmap.com/page/2201034](http://www.aidsmap.com/page/2201034)

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## News picks from other sources

### PREVENTION

## PEP guidelines take account of viral load

New UK guidelines for post-exposure prophylaxis (PEP) now take account of the viral load of the 'source partner' of the person seeking PEP, if they are known to have HIV.

The new guidelines now only recommend that PEP is given to individuals whose partner is HIV positive but has an undetectable viral load if the person seeking PEP was the receptive partner in unprotected anal sex. In all other cases where the HIV-positive partner is known to have an undetectable viral load, clinicians following the guidelines will explain that PEP is unnecessary. This includes all unprotected vaginal sex (whether the HIV-positive partner is male or female) and cases where the person seeking PEP has been the insertive partner in anal sex.

In a case where the source partner's HIV status is unknown, PEP is still recommended

in cases of unprotected receptive anal sex, but only if the person is a gay man or a migrant from Africa. Clinicians are told they should 'consider' PEP in cases of insertive anal sex, vaginal sex or the sharing of injection equipment if there has been an additional factor that could raise the risk of HIV transmission, such as particularly high local HIV prevalence, a sexually transmitted infection in either partner, sexual assault, acute HIV infection in the source partner and – in vaginal sex – the woman menstruating or the man being uncircumcised.

Where the source partner has HIV and has a detectable viral load, PEP is recommended in the case of anal or vaginal sex or the sharing of injection equipment and should be 'considered' in case of receptive fellatio with ejaculation (giving a blow job to an HIV-positive man) and semen getting into the eye.

The guidelines make it clear that contact with a needle or syringe discarded in a public place, and human bites, are not regarded as risky enough for PEP to be indicated.

➔ [www.aidsmap.com/page/2186929](http://www.aidsmap.com/page/2186929)

### IT Is Ireland failing its heroin addicts?

Irish Times | 9 Jan 2012

The number of heroin users in Ireland is the highest in the EU while deaths of people on methadone programmes are increasing.

➔ <http://bit.ly/ABTjct>

### WE We Could End AIDS, But Will We?

Open Society Foundation | 1 Dec 2011

There are two things standing in the way: political will and the money to do it.

➔ <http://bit.ly/zKqqil>

### PT Europe approves Gilead's HIV combo Eviplera

Pharma Times | 29 Nov 2011

The European Commission has granted marketing authorisation for Gilead Sciences' combination drug Eviplera.

➔ <http://bit.ly/jyMHEe>

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### Treatment: what really works best? [p.18]

- See <http://hivinsite.ucsf.edu/global?page=cr-00-04> for a list
- [www.aidsinfo.nih.gov/guidelines](http://www.aidsinfo.nih.gov/guidelines)
- [www.europeanaidsclinicalsociety.org](http://www.europeanaidsclinicalsociety.org)
- See [www.bhiva.org/documents/Guidelines/Treatment%20Guidelines/Current/090708TreatAdd.pdf](http://www.bhiva.org/documents/Guidelines/Treatment%20Guidelines/Current/090708TreatAdd.pdf)



# Talking points

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