

# hiv treatment update

## never had it so good!

with so many new, drugs choosing the right combination is more important now than ever *page 8*

## electronic patient records

what do hiv-positive people think? *page 12*

## upfront

US and China amend their hiv-positive visitor bans *page 3*

## news in brief

most hiv-related discrimination comes from healthcare staff *page 16*

why does mother-to-child hiv transmission still occur in the UK? *page 17*

## risky business

why people with hiv still can't get life insurance? *page 16*



# in this issue

Welcome to a new year, and a new name for NAM's monthly UK-focused newsletter, *HIV Treatment Update* or *HTU*. Since 1992, the newsletter has provided people living with HIV, and healthcare professionals, with cutting-edge HIV treatment news. To say that there have been many developments in HIV treatments since the newsletter was launched is something of an understatement.

In 1992, HIV was essentially untreatable; instead, doctors tried to ward off the symptoms of advanced HIV disease, or else tried to treat the illness that led to someone with HIV being given an AIDS diagnosis.

Today, HIV infection *is* treatable; if you are diagnosed before you have an AIDS-defining illness, you're now unlikely ever to receive an AIDS diagnosis. In addition, some of us who received AIDS diagnoses in the past are now in better health than ever before. NAM has consistently responded to the changing nature of the HIV epidemic, and so it makes sense that our newsletter changes its name to reflect the realities of HIV treatment.

The vast majority of you have agreed that a name change is long overdue. For those of you who raised the following concerns please rest assured that, in our editorial, we certainly will endeavour not to marginalise the experience of long-term survivors who were diagnosed with AIDS in the pre-HAART era (myself included), nor will we ignore the global AIDS pandemic.

Rather, we are hoping to make it clear to readers old and new exactly what this newsletter is about.

**page 2** *Upfront* focuses on changes to current restrictions for HIV-positive visitors to both the United States and China. Amazingly, China now has the more humane policy.

**page 4** With so many new drugs - maraviroc (*Celsentri*), raltegravir (*Isentress*) and *Atripla* - coming to a clinic near you, we may have *Never had it so good*. However, choosing the right combination is more important now than ever. We asked expert HIV clinician, Dr Martin Fisher, to help guide us through the maze.

**page 12** One of the hot topics of 2007 that will continue into 2008 is the widespread concern over privacy breaches via national databases. Recent proposals to make all patients' records accessible electronically throughout the NHS is pushing a lot of people's buttons. Paul Clift found out what HIV-positive people think of *Electronic Patient Records*.

**page 16** In *News in Brief*, we assess the latest state of HIV in the UK; learn that US doctors are now recommending starting anti-HIV treatment at a CD4 count of 350; and discover that most HIV-related discrimination appears to come from healthcare staff, despite a lack of clinical evidence.

**page 18** It's now possible to get it in South Africa and the Netherlands, but in *Risky business*, Johanna Gornitzki explains why people with HIV in the UK still can't obtain life insurance.



## hiv treatment update

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For more information about *ATU's* medical review panel, please visit <http://www.aidsmap.com/cms1177634.asp>

## about NAM

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## us and china amend their hiv-positive visitor bans

by Edwin J Bernard

Two major world powers - the United States and China - recently announced plans to change current restrictions on HIV-positive visitors. However, whereas the US proposals will still require HIV-positive visitors to disclose their status, and adhere to several conditions in order to obtain entry for up to 30 days, China says it is committed to remove all restrictions on HIV-positive visitors.

Eleven other countries also completely ban people with HIV from entering - even for a short trip - without special permission: Russia, Iraq, Saudi Arabia, Libya, Sudan, Qatar, Brunei, Oman, Moldova, Armenia, and South Korea. This policy has been condemned by many human rights and AIDS organisations, such as UNAIDS, who point out that they serve no useful purpose at all and are highly discriminatory.

Since the late 1980s, the US has effectively banned routine entry for people with HIV. HIV-positive individuals wanting to visit the US have to go through a very complex and costly procedure and obtain a special visa that can take months to get hold of. People with HIV who have travelled to the US without this visa have sometimes been stopped by immigration or customs officials, detained, and deported.

On World AIDS Day 2006, US president, George W Bush, announced that he'd issued instructions to allow for "a more streamlined process" with "a categorical waiver" that would make it easier for people with HIV to travel to the US. After the details of this process were quietly released in November 2007, however, it has become clear that the new proposals

include further restrictions and do not benefit HIV-positive people at all.

The new process is not "streamlined" for the HIV-positive individuals, who must still declare their HIV status to officials and apply for a visa in person at a US consulate or embassy several months before their intended trip. The process simply removes some extra paperwork for the consulate or embassy by cutting out the "additional step of seeking review and decision by [the Department of Homeland Security] prior to granting of the non-immigrant visa."

A factsheet produced by US-based charity, Immigration Equality, which works on behalf of HIV-positive asylum seekers and immigrants, notes, "the proposed regulations are disingenuous. Although the proposed rules use the words "streamlined" and "categorical" to describe the new waiver for HIV-positive travellers, there is nothing "streamlined" or "categorical" about this waiver."

Nothing appears to have changed for the better with the new process, as people with HIV will continue to be treated differently from those with other medical conditions. HIV-positive short-term visitors will still need to submit extensive and intrusive evidence - including providing adequate assurance that they will "comply with medical advice against engaging in behaviour that would risk transmitting the infection to others" - during their visa interview at a US embassy or consulate months before a planned visit, which cannot last for more than 30 days in any calendar year.

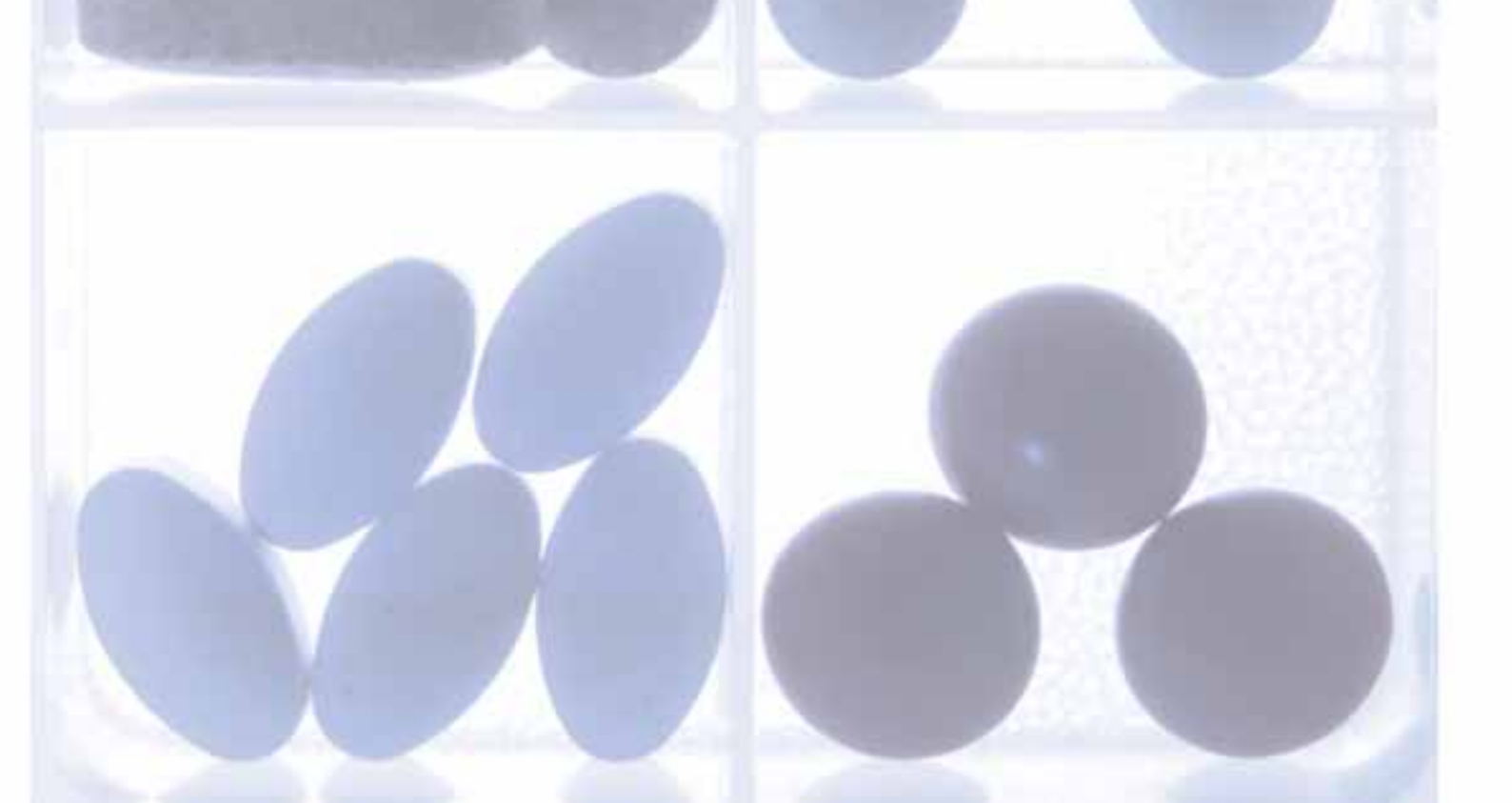
For a visa to be issued, it's also necessary for a person with HIV to be in good health, have enough

medication for their proposed visit, and to prove that they understand the "nature, severity and communicability of HIV." Under the new plans people with HIV will still be banned from visiting the US on the routine visa waiver programme and those who do so, and who are detected, could still be detained and deported.

The process will also have a negative effect on people seeking long-term residency, citizenship or asylum in the US. Under the new regulations, the US will prohibit HIV-positive visitors who enter with the new waiver from applying for a 'green card' from within the US. This means that individuals who win asylum in the US - even if their application is based on their HIV status - will never be able to get a 'green card' or become a US citizen.

On other hand China, a country not known for its commitment to human rights, has announced it will repeal its HIV-positive visitor ban, meaning that people with HIV will soon be able to enter China more easily than the US.

Democrat congresswoman Barbara Lee hopes to fundamentally change the US approach via a change in the law. She has proposed a bill that would repeal the current law and put the power back in the hands of the Department of Health. They would then decide whether HIV-positive visitors or immigrants constitute a public health risk. Depending on their analysis, the ban could be maintained or repealed. The bill is being debated this year, and as soon as we know the outcome, we'll let you know, too.



# never had it

with so many new drugs choosing the right combination is more important now than ever, *by Edwin J Bernard*

We've been waiting ten years for a new class of drugs outside of the traditional three - nukes, non-nukes and PIs - that could be taken in pill form. And now, in 2008, just like the proverbial bus, two come along at once!

With one new drug from a new drug class - CCR5 antagonist, maraviroc (*Celsentri*) - approved last November, and another new drug from another new drug class - integrase inhibitor, raltegravir (*Isentress*) - well on its way to approval by the summer, there's a lot of new information to take in, not to mention remembering even more confusing drug names.

The arrival of two new drug classes is great news for treatment-experienced individuals who were running out of options to put together a potent and tolerable anti-HIV drug regimen. But it's not just the treatment-experienced who are treated to new options this year. Finally, 18 months after it was approved in the United States, the three-drugs-in-one, one pill, once a day *Atripla* is finally with us (unless the approval mooted for late December goes awry after this *HTU* has gone to print).

However, like the *iPhone*, just because it's new doesn't necessarily mean that it's right for us. There's the whole package to consider: remember, there are plenty of existing anti-HIV drugs

that continue to work well for many of us, and we shouldn't have our heads turned by clever marketing.

So, we asked one of our trusted members of *HTU's* medical advisory panel, Dr Martin Fisher, a consultant in HIV/GU medicine at Brighton & Sussex University Hospital, and one of the co-authors of the current - and soon to be published 2008 - British HIV Association (BHIVA) treatment guidelines, to help guide us through the maze of new treatments coming to our clinics.

***HIV Treatment Update (HTU):*** Would you agree that we've never had it so good right now, in terms of choices of



# t so good!

## **drug options for people of all stages of HIV disease?**

Martin Fisher (MF): The number of drugs available has obviously increased, but as new drugs have come on board we've lost some drugs, either because they've stopped being produced - like ddC or nelfinavir - or because it's become clear that newer drugs are better, or certainly less toxic, d4T being a prime example and, now probably AZT going the same way as well. So while the total number of anti-HIV drugs has gone up, the number of drugs that we actually use on a regular basis is still fairly small.

Where I think we have never had it so good is for people who have exhausted

previous treatment options. We've now got two or three completely new classes of drugs that are going to be of massive importance to highly treatment-experienced people. And, if those newer drugs are proven to be safer, which early data are suggesting, some of these drugs will become available for people earlier on in their HIV treatment history.

**HTU:** Let's turn our attention to the first of the new drugs to be approved, the very first CCR5 antagonist, Pfizer's maraviroc (Celsentri), which has been approved for treatment-experienced patients. New drugs, and new classes of drugs, are always welcomed, but it requires a tropism test (to make sure

that your HIV only uses CCR5 to attach itself to CD4 cells) and there are also some niggling safety concerns that remain about the CCR5 antagonist class as a whole.

MF: I think that, perhaps, we're giving the drug a bit of a rougher ride than it needs, but I would agree that 'cautious optimism' is a reasonable phrase to use about maraviroc. The first thing I would say is that most of the data suggest that it's incredibly well tolerated, and poor tolerability is often the reason why people are in a situation of needing new classes of drugs. So I think we should be upbeat about the tolerability of maraviroc.

## New CCR5 antagonist **maraviroc**

The main issue is knowing whether the drug can work or not, and for that you need the tropism test. Fortunately for us in the UK, Pfizer has made access relatively easy and relatively affordable. It costs in the order of £150, but that's a one-off test, and the turnaround time is between three and four weeks, which is comparable to conventional resistance testing, and that's probably the way that we should be thinking of tropism testing anyway.

Where I think there is more of an issue is that the test can currently only detect down to a level of about 10%. So if 9% of a patient's viruses are not CCR5-tropic, it may miss that and you may inadvertently give the drug to the wrong person. Looking at it the other way round, however, means that most of the time you are going to be able to tell whether this drug's going to work or not, comparable to resistance testing when it was first introduced. In addition, newer tropism tests are being developed that can detect down to one or even half a percent of viruses.

Now, as you've mentioned, with any new drug and any new class of drug, there are always going to be concerns about long-term toxicity and there has always been, in the background, murmurings about whether CCR5 antagonists increase your risk of malignancy - lymphoma, in particular. That certainly didn't seem to be the case with the Phase III studies of maraviroc, but at 48 weeks you've got a relatively short period of follow-up compared with the two years' follow-up of another, investigational CCR5 antagonist, vicriviroc. There were some concerns about vicriviroc after several people in the Phase II studies were diagnosed with malignancies, but more recent data suggest that these malignancies may not have been related to the drug. Nevertheless, I think it's very important that we all remain vigilant, as we might with any new drug.

**HTU: Who is most likely to benefit from maraviroc right now?**

MF: In the first instance, it will primarily be taken by people who need a new class of drugs - people with a lot of treatment experience. As part of their work-up to construct a new regimen, I think tropism testing will be increasingly used alongside conventional resistance testing, and where the virus is CCR5-tropic and a new class of drugs is required, then maraviroc will be considered as part of that combination.

**HTU: Another issue, however, is that the more advanced disease you have, the less likely it will be that you will have purely CCR5-tropic HIV.**

MF: Absolutely, and certainly in the maraviroc studies where you were looking at a highly treatment-experienced group of patients, around 50% of people screened for the study were excluded because they didn't have any CCR5-tropic viruses. So it's only going to be potentially useful for around 50% of those who are heavily pre-treated.

Looking further ahead, though, I think maraviroc may well move further up the treatment agenda, as new, more accurate tropism tests become available, and if CCR5 antagonists such as maraviroc are shown to be well tolerated. If that happens, and if studies support it, we may start to see CCR5 antagonists being used as second-line or even first-line therapy instead of some of the currently used agents where there may be unacceptable levels of toxicity or tolerability for some patients.

## New integrase inhibitor **raltegravir**

**HTU: We're in the fortunate position of having another new class of drugs to talk about, too: integrase inhibitors.**

**The first of these, Merck's raltegravir (Isentress) is very likely to be licensed here for treatment-experienced individuals within the first few months of 2008. This has been the drug that's created the most excitement at conferences over the last few years, but I wonder whether the excitement still holds now that we're learning more about it.**

MF: There are two kind of trials with raltegravir: studies looking at the drug in treatment-experienced individuals, which are further along, and those looking at people starting anti-HIV treatment for the first time. Both hold different attractions.

**Let's start with talking about treatment-experienced individuals.**

MF: Merck's study in treatment-experienced individuals showed some of the best data that we have ever seen in people with triple class resistance, in terms of the chance of achieving undetectable viral loads, and also in terms of tolerability, which has driven the excitement.

But I think we should bear in mind the timeframes in which those studies were conducted. When the raltegravir studies were recruiting, most clinicians had access to darunavir (*Prezista*, a protease inhibitor approved in February 2007), which we now know to be a very effective drug as well. The individuals who performed best were, in fact, taking a combination of several new drugs - raltegravir, darunavir and T-20 (enfuvirtide, the injectable fusion inhibitor also known as *Fuzeon*) - for the

**“Where I think we have never had it so good is for people who have exhausted previous treatment options”**

## One pill, once a day *Atripla*

first time. This reminds us that we should always aim to use more than one new drug when changing treatments.

What we also have to remember is that almost all of the individuals who did not respond to raltegravir developed resistance very quickly, and it's becoming increasingly apparent that if you develop resistance to raltegravir, then the other integrase inhibitor currently in development, Gilead's elvitegravir, will not work. So we have to temper our excitement with making sure we don't use the drug inappropriately and make sure we combine it with other drugs that we know will be active, too.

**HTU:** It seems that there are some comparisons here to the NNRTI class, in that it just takes one or two mutations to create cross-class resistance. There have also been studies comparing raltegravir with leading NNRTI, efavirenz (*Sustiva*). How is it bearing up so far?

MF: The intriguing finding in the studies so far is that those patients who received raltegravir achieved an undetectable viral load much faster than the individuals who received efavirenz. The rationale for that has yet to be explained but the amateur scientist in all of us cannot help but think that that has to be a good thing. And, again, that's part of the excitement around integrase inhibitors.

**HTU:** The potential downside of raltegravir as a first-line therapy is that it's a drug that needs to be taken every twelve hours, compared with efavirenz's every 24 hours dosing. Which brings us to *Atripla*. Now, this one pill, once a day combination of efavirenz, tenofovir and FTC has become extremely popular in the US - where it was approved 18 months ago - because of its convenience. But is *Atripla* really so much more convenient, since it actually only reduces a two pills once a day regimen to one pill once a day? Do you think *Atripla*'s US popularity will repeat itself here?

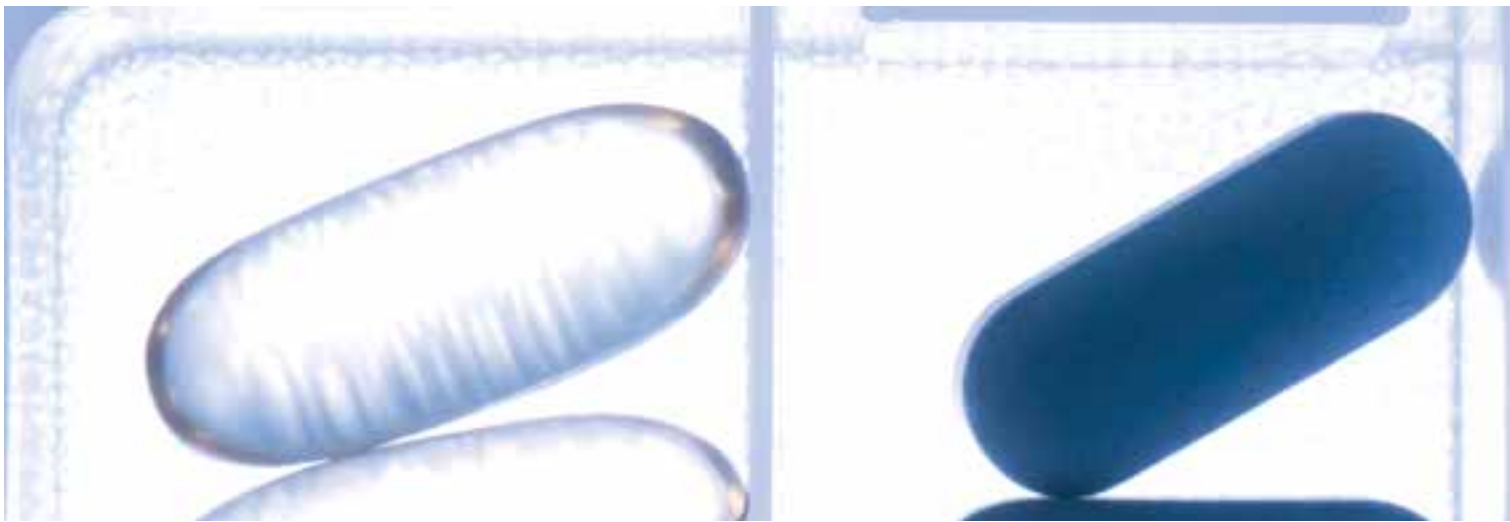
MF: I think the British are always a bit more conservative than the Americans - and that's as true for clinicians as it is for patients. I think there will be a group of people who will seize the concept of one pill once a day as being such a breakthrough that they will come into clinic the day after it's approved and ask for it. We saw that with *Trizivir* several years ago. I think the reality is that often when you discuss the pros and cons of any combination further, it will not be the panacea for everybody. I think for some people one pill, once a day, will be the best option. I think, though, that many other people will be quite happy to take more pills or more pills more times a day if the overall tolerability of that combination will be better for them. So my prediction would be that yes, *Atripla*

will take off to a certain extent when it's launched, but nowhere near to the same extent as we've seen in the States.

**How important do you think the number of pills, or once or twice-daily dosing is, in terms of drug attractiveness?**

MF: This is where individualisation is absolutely central to HIV medicine. Two or three years ago there was a real mantra that everything had to be once daily. I think the reality that we're seeing now is that for some people, that is the most important factor. For other people, twice daily is absolutely fine, particularly if side-effects are more of an issue than dosing convenience. So, to come back to the questions of, 'have we ever had it so good?' I think that we can certainly try and individualise more now than we could before, but it's important to remember that none of the drugs we have available to us is perfect. Every drug has its Achilles' heel.

**“It's important to remember that none of the drugs we have available to us is perfect. Every drug has its Achilles' heel”**





## New NNRTIs etravirine and rilpivirine

**HTU:** There are two new NNRTIs coming up from Tibotec that appear to work against virus that is resistant to the current NNRTIs, efavirenz and nevirapine. Etravirine (formerly known as TMC 125) is being studied in treatment-experienced individuals whereas rilpivirine (formerly known as TMC 278) is being studied in people new to anti-HIV treatment. Why is that the case?

MF: Tibotec have got themselves into a lucky pickle of having two good looking non-nucleosides at the same time, and it appears that we're heading towards a situation where etravirine will be marketed to people with previous non-nucleoside experience and rilpivirine will be marketed as initial non-nucleoside therapy. That's predominantly because etravirine requires twice-daily dosing, whereas rilpivirine requires once-daily dosing. Both drugs seem to be working pretty well, and both seem to be very well tolerated.

However, it's becoming clear that etravirine needs to be paired alongside another strong drug. So it will likely be used alongside a boosted protease inhibitor or one of the new classes of drugs we've already talked about. In addition, when using etravirine one has to look very carefully at the degree of underlying non-nucleoside resistance. What's become very apparent is that the more non-nucleoside mutations one has, broadly speaking, the less likely etravirine is to work. So, the critical message there is that if anybody is taking either nevirapine or efavirenz and is experiencing virological failure,

they need to get off that non-nucleoside as soon as possible because otherwise they're scuppering their chances of etravirine working in the future.

**HTU:** Rilpivirine is being touted as a direct competitor to efavirenz if Phase III studies go as well as the Phase IIb studies, which found it to be equally potent after 48 weeks, with fewer central nervous system side-effects - such as dizziness and sleep disturbance - than efavirenz.

MF: I think we may start to see efavirenz slightly pushed off its perch at some point, because where the central nervous system side-effects are not acceptable increasingly we'll see people trying alternative new drugs, such as raltegravir and rilpivirine - if they become available to people starting treatment for the first time. And as early as 2009, we might possibly also see another one pill, once a day co-formulation of two nucleosides plus rilpivirine as an alternative to *Atripla*.

**HTU:** Are there any data to show us whether rilpivirine works for treatment-experienced people?

MF: There were some very early, short-term mono-therapy data which suggested that rilpivirine was effective in virus that had previously seen either nevirapine or efavirenz, which was fairly similar to etravirine, in that the viral load reduction in treatment-experienced people was slightly less than the viral load reduction seen in treatment naive people, but nonetheless there was

definite activity there. But as you said, I think rilpivirine will be positioned in the market as a first-line treatment.

**HTU:** It does seem somewhat frustrating that there will be this once-daily NNRTI that may well work for treatment-experienced people, but which isn't being studied in that population.

MF: Well, I think that as long as we establish which non-nucleoside resistance mutations rilpivirine will work against, even if its licence is for treatment-naïve patients, I think there will be some utilisation of it by patients and clinicians in subsequent therapy if that's thought to be the best option for that person. However, we might have to learn those things from test tube data or from individual patient case scenario, rather than from drug company studies.



## Older drugs for the treatment-experienced tipranavir, darunavir and enfuvirtide

**HTU:** With all of these new drugs for treatment-experienced individuals arriving this year, I'm sure many people will be wondering where the currently approved drugs fit in. Let's start with tipranavir (*Aptivus*), which was approved for treatment-experienced individuals at the end of 2005, but which has hardly set the world of HIV treatment alight. On the other hand, darunavir - approved for the same population a few months later - appears to have been received much better.

MF: I think three different things hindered tipranavir. First, its poor tolerability, largely based upon the (200mg twice daily) dosage of ritonavir that's required to boost it. Secondly, it was followed very shortly after by darunavir which came with a fanfare of enthusiasm based on much better-designed studies than tipranavir's. And thirdly, in retrospect, one of the studies - comparing it to *Kaletra* - was possibly initially incorrectly analysed, leading to doubts about the potency of tipranavir which were perhaps unjustified. As a result of those three things it has been arguably underused in the UK. However, the resistance profiles that we get back from some treatment-experienced

individuals will sometimes suggest that tipranavir is the right drug to use rather than darunavir, and there shouldn't be an assumption that whenever you need a second-line protease inhibitor it will be automatically be darunavir. I think we need to maintain that ability to individualise, and tipranavir will be the right option for some people.

**HTU:** Now if we're talking about the right option for some people, where does a twice-daily injectable drug like enfuvirtide (T-20) fit in, when we now have these oral drugs from two new classes? Does it have a role in the future?

MF: I think there are two groups of individuals one needs to consider for enfuvirtide. There are a small number of people who are currently taking enfuvirtide in the UK. We have more than ten here in Brighton. Most of the individuals I see who are currently taking T-20 actually get on very well with it and, paradoxically, seem to tolerate their whole combination better than they have done with other agents in the past. There's some bizarre property with T-20, which we've never really understood, where

gastro-intestinal intolerance of the other drugs in the combination seems to be less of a problem. Nobody has ever been able to give me a good reason why, but certainly that's been my clinical experience. So there will be a small cohort of people who will want to carry on taking it. My hunch is that in a few years time they will get fed up of injecting, but my hunches are often wrong, so we'll see. But I think the newer drugs will give those individuals an option to come off the T-20 if the injecting becomes intolerable.

Now, looking at those people who haven't received T-20 yet, I think we should initially start by thinking of T-20 as another new class of drug and follow exactly the same principles: that you should use two or three new classes of drug when highly treatment-experienced patients change regimens, in order to give them best chance of achieving and keeping an undetectable viral load. Although now you can more easily use three new classes without the need to inject, for some people an injectable fusion inhibitor will still be one of those three new classes.



**“If you can construct a tolerable effective regimen that’s cheaper, it’s beholden on us all at the moment to do that. But you should never compromise on efficacy or tolerability.”**



## Doesn't cost matter?

**HTU:** But enfuvirtide costs at least twice as much as any of the other drugs, so is there not going to be pressure from the people who pay for our NHS treatments - i.e. Primary Care Trusts - to say 'only use enfuvirtide as a last resort'?

**MF:** I would argue that achieving an undetectable viral load with whichever combination you use is more cost-effective than treatment failure. And therefore, if T-20 is needed to construct a suppressive regimen then it should be used. I would also agree, however, that if you can construct a tolerable effective regimen that's cheaper, it's beholden on us all at the moment to do that. But you should never compromise on efficacy or tolerability.

**HTU:** Many readers will already have been affected by some changes at their HIV clinic in order for the clinic to save money - for example, by no longer having their non-HIV-related prescriptions filled. Originally, a different way of funding for HIV clinics, known as 'payment by results' (PbR), was due to begin in April 2008, although that is now looking doubtful. What is the current state of play?

**MF:** Most medical specialties have now shifted to a payment by results system, so, for example, sexual health clinics are now funded through the PbR system, and so is HIV inpatient care. However, HIV outpatient care is one of the few specialties that seems to have been excluded. As a result, every HIV clinic will be negotiating their own local equivalent of payment by results, which inevitably means that there will be some winners and some losers. Hopefully we'll all learn from each other's experiences and we'll be able to benefit from those who've negotiated the best rates.

**HTU:** Historically, Brighton's HIV clinic, the Lawson Unit, has been in a very good position - for example, accessing *New-Fill* before it was available in London or much of the

rest of the UK. Do you have any concerns about whether any of the new drugs will have any cost limitations here?

**MF:** All HIV clinics have to go through several steps in the process of getting a drug approved locally before it can be used. So far both our local hospital and our local Primary Care Trust (PCT - the local NHS funding body) have always been very understanding of new developments in HIV, and so far we have had no problems getting approval for any of the new drugs. That is because we have always been able to demonstrate, using good data, that there are advantages to new drugs as and when they've been developed. We have argued that even when there is an increased cost, they are either cost-effective, or for very expensive drugs, that they will be used in relatively specialised circumstances and when a consensus of clinicians recommends their use. This has led to an atmosphere of mutual trust as a result of which, I've never been faced with a situation where I haven't been able to prescribe what I consider to be the right drug for the right person.

**HTU:** Sadly, this experience hasn't always been duplicated in other parts of the UK.

**MF:** Yes, and I think this is where it's very important that we have a strong national organisation. I think we're fortunate that the British HIV Association (BHIVA) updates its treatment guidelines annually, and that we always include a section on drugs that are likely to become available for use in the next twelve months. Hopefully, then, patients, advocates and clinicians in any locality in the country will be able to use that guidance in negotiation with their commissioners. Clearly some are going to be able to move that agenda forward quicker than others but hopefully that guidance will appear sufficiently in real time to enable those negotiations.

## older drugs for the treatment-experienced

| class                   | name               | trade name      | availability     | dosed                               |
|-------------------------|--------------------|-----------------|------------------|-------------------------------------|
| fusion inhibitor        | enfuvirtide (T-20) | <i>Fuzeon</i>   | approved in 2003 | twice-daily, self-injected          |
| protease inhibitor (PI) | tipranavir         | <i>Aptivus</i>  | approved in 2005 | twice-daily, boosted with ritonavir |
| PI                      | darunavir          | <i>Prezista</i> | approved in 2006 | twice-daily, boosted with ritonavir |

## new drugs for the treatment-experienced

| class  | name                 | trade name       | availability                           | dosed       |
|--|----------------------|------------------|--|-------------|
| CCR5 antagonist  | maraviroc            | <i>Celsentri</i> | approved in 2007                       | twice-daily |
| integrase inhibitor                                    | raltegravir          | <i>Isentress</i> | currently available on expanded access | twice-daily |
| non-nucleoside reverse transcriptase inhibitor (NNRTI) | etravirine (TMC-125) | ?                | currently available on expanded access | twice-daily |

## drugs in the pipeline

| class               | name                   | trade name | availability  | dosed                                |
|---------------------|------------------------|------------|---|--------------------------------------|
| NNRTI               | rilpivirine (TMC-278)  | ?          | only in Phase III clinical trials for treatment-naïve       | once-daily                           |
| integrase inhibitor | elvitegravir (GS-9137) | ?          | only in Phase III clinical trials for treatment-experienced | twice-daily, boosted with ritonavir. |
| CCR5 antagonist     | vicriviroc             | ?          | only in Phase III clinical trials for treatment-experienced | once-daily.                          |

# electronic patient records

## what do hiv-positive people think?

by Paul Clift

When I was asked to make a presentation to the BHIVA Autumn Conference last October on behalf of HIV-positive patients on the subject of electronic patient records (EPR) and information sharing, I started out thinking it would be pretty straightforward. Experience taught me otherwise: although there may be significant clinical advantages to the proposed EPR/National Spine scheme, my research has revealed some significant disadvantages when it comes to ensuring that our HIV-related healthcare information remains confidential.

### What is the National Spine?

First though, what are EPR and the National Spine? EPR are patients' records in electronic form. The EPR will contain information about you, your current medications, allergies and adverse reactions. You may already have seen this on a computer at your local GP's surgery or at your HIV clinic, where such records might be held on the hospital's own secure system.

The proposed National Spine takes this a logical step further by putting security safeguards around the records and then making them accessible, via a national network known as the National Spine, to those clinicians who need to see them.

For example, I live in South London and this is where my records are kept, but if I am on holiday in, say, Cornwall, and am rushed unconscious to A&E in Penzance, the medics there could check my records online where they would find an existing medical condition (HIV) and the medication that I take

for it (*Truvada* + nevirapine) and take these into account when treating me.

In this example, a significant benefit (potential better healthcare outcome) has emerged along with a possible concern (do I want everyone involved in my care at the Penzance hospital to know I have HIV?).

At the moment the system is being piloted in a small number of GP practices. If all goes to plan - and what does in the NHS? - over time, all patient records, including those at your HIV clinic, will be held electronically, although it will be several years before this happens, if it happens at all.

### Finding out what HIV-positive people think about EPR

In order to find out what other people think about such benefits and concerns, I asked a dozen HIV patients' groups and organisations<sup>1</sup> around the country to put to their members four questions:

- Are you aware of the proposed National Spine?
- How do you feel about your details being uploaded to the National Spine?
- Does the clinic share info about you with your GP?
- How do you feel about proposed safeguards - 'sealed envelopes' etc?

Additionally I checked for information from Connecting for Health<sup>2</sup>(the NHS body that is charged with implementing EPR and the National Spine) as well as Patient Concern<sup>3</sup>(the national patients' rights organisation), the *British*

*Medical Journal* and the House of Commons Health Select Committee<sup>4</sup>.

To start with, Connecting for Health views illness as a clinical issue, which may be stating the very obvious but, as we know, HIV is not an exclusively clinical issue. It has significance far beyond that, reaching into many non-clinical areas of life, including social, political, legal, religious etc. Non-clinical aspects inform patients' views on this topic to a considerable extent. Moreover, we live in a highly complex society in which we are bombarded with information, and finding out about the pros and cons of EPR competes with



dealing with other, perhaps more immediately pressing, life concerns.

It should not be surprising to learn, therefore, that there is a significant lack of knowledge about EPR and its application in clinical information sharing. Indeed, North Yorkshire AIDS Action (NYAA) spoke for all respondents when they commented that

“many, if not most, people are simply not yet aware of what is being implemented. Even if they are, the information on the NHS website is somewhat detailed and daunting, and many people simply glaze over when faced with trying to understand it all. Significant effort by organisations such as NYAA will be needed to inform people of what is being done in a balanced and informed way”.

But why should such organisations have to bear the onus of informing people - surely this is the job of the implementing body, in this case the Department of Health and its various agencies?

### What are the benefits?

The clinical benefits are fairly self-evident - it would make it much easier for care providers in the NHS to access patient information accurately and quickly, without the need to wait for the delivery of paper records. Also, in the event of an emergency, a patient's history is available anytime, anywhere (in principle, at least). Patient Concern points out that there are a number of potential benefits in a well organised electronic record system: “it should mean that records no longer go missing and are easily available in an emergency. We should be able to see our records far

more easily. It can also enable us to record if we have a Living Will, so that this cannot be overlooked.”

It should also mean that those people with complex health issues such as co-infections will not have to explain this every time they access healthcare. Or to put it bluntly, as one respondent did: “A&E won't kill people because they don't know they have certain conditions”.

### Widespread concern for information safety

However, the idea of a centralised database that contains all of a patient's treatment information is a concern, and Patient Concern highlights the situation with patients with stigmatised conditions, such as mental health and HIV.

Many respondents expressed the anxiety that any computer-based system can be hacked, on the basis that there have been a number of well-publicised 'leaks' from other big IT databases, and this gives rise to worries about the safety of information on the Spine.

The Black Health Agency told me that their stakeholders felt that their personal information would be open for all to see. Indeed, Vivienne Nathanson, Head of Science and Ethics at the British Medical Association, has stated clearly that she is especially concerned about the security and confidentiality of the records<sup>5</sup>

If, as happened last April, newly-qualified doctors can find their personal details, including their sexual orientation, accessible electronically<sup>6</sup>, why should patients feel confident that their own records and details will not be similarly accessible?

While it is true that CfH gives some strong reassurances that this will not happen, primarily because it is proposed to be a 'closed' system, patients still have significant concerns that need to be addressed in the wake of last November's child benefit records scandal<sup>7</sup> when the personal details of 25 million people were lost by HM Revenue and Customs.

Currently, there is room for choice in whether or not we agree for our details to be uploaded to the Spine. According to CfH “your records will automatically become part of the new NHS Care Records Service over the next few years *unless you object*” (my italics). This means that there is an opt-out option as well as further options to upload some, but not all, of your details. For example, you can allow basic medical information to be held on the National Spine, but ask that your HIV-related information be held in a 'sealed envelope' for which access can only be gained with your clear permission. This opt-out method is complicated, however, and requires not only that you know about and understand these options, but also that you are also able to communicate effectively with your doctor.

North Yorkshire AIDS Action commented that, “although there are options for patients to have information safeguarded, so that it is only accessible to a limited number of 'need to know' clinicians, there are also clauses which allow this to be overruled. There is concern that these conditions could too easily be used to access patient information that has

supposedly been 'sealed'. These concerns are heightened by the criminalisation of HIV transmission; rightly or wrongly, there is a feeling that somehow different government departments may access electronic databases, including the Spine, in the search for evidence".

A respondent from Brighton added "my fear is that the safeguard against unauthorised people reading my notes will be cut at some point to save money and replaced with a wishy-washy 'we promise not to look' policy" - a fear which is shared by Patient Concern.

### Concerns about abuse of information

Following on from these concerns, it should come as no surprise that concerns were also expressed that EPR might become a tool for assessing eligibility for NHS treatment and care.

This is a real concern, and not only for people whose eligibility for NHS services is unclear. During my time as Patients' Representative at Brighton's HIV clinic, I was approached for advice by a black British person, born and raised in London, who was grilled over their immigration status at a local GPs practice. With the National Spine, it should be possible for any healthcare professional to check for eligibility to NHS treatment and care. What

questions will be asked if someone presents themselves to a clinical centre and their name is not on the computer? And what the repercussions for the undocumented migrant who has no record but is in need of healthcare? It would appear that EPR might have the potential to sustain, not diminish, existing healthcare inequalities.

### Overriding our decisions for the greater good?

CfH tell us that EPR will be used, among other things, to 'compare treatments to see what works best' and to 'manage NHS services and finances'. If we put these two ideas together, EPR appears to have the potential to override the individual doctor/patient discussion. A defining feature of HIV medicine as it has evolved in the UK is the shared model of doctor/patient relationship, in which decisions - for example, about which regimen is best for the patient - are often, but sadly not always, reached by doctor and patient together. Connecting for Health appears to have the potential to push this to one side by providing information to NHS commissioners to allow - or justify - a financial rather than clinical preference for a particular treatment regimen. However, optimal levels of care and treatment are not arrived at by glancing at a balance sheet for a one-

size-fits-all solution because one-size-fits-all does not exist. This may not be the intention of EPR, but that does not mean that it will not be used in this way.

In fact, many respondents expressed the feeling that information shared is not always used to optimal advantage. As an example, I might outline my own experience with an episode of shingles a few years ago. I was advised to see my then GP, who was already aware of my HIV infection - indeed, it was recorded in my notes. Despite this, the GP prescribed the correct drug (acyclovir) but at the usual dosage, ignoring recommendations to prescribe a higher dose for longer in patients who are immunocompromised. One of the claimed reasons for this was higher cost of a higher dosage; in other words, budgetary cost overrode recommendations in the British National Formulary! What price shared information? Perhaps it's not surprising that there was wide concern that GPs are currently insufficiently HIV-aware.

### Making EPR more acceptable

Some HIV-positive individuals did respond favourably to the concept of EPR, but they tended to have certain characteristics in common: they are 'expert patients' who can already navigate and negotiate their way through the NHS; they have an open relationship with their GP, which would imply an existing degree of confidence about disclosing their HIV status; and their eligibility to NHS care and treatment is incontestable.

This suggests that EPR might be more widely acceptable to patients when a number of conditions have been met:

- HIV has to be normalised at societal and political level. For this to happen, HIV-related stigma and discrimination have to be addressed.
- NHS IT systems have to be fully robust and secure and be seen to be so before any system is implemented.





- GPs would have to be HIV-aware, and be able to guarantee that information shared with them is used well and appropriately.
- Patients should have real control over information about them. France serves as a model for this; legislation was passed in June 2004 to create a Dossier Médicale Personnel (DMP). The DMP contain will a range of health information which can be viewed online; access will be controlled by patients who will legally own their record.<sup>8</sup>

Until most – if not all – of the above are implemented, currently too many concerns remain for EPR to be universally acceptable to many people living with HIV. For these expressed concerns to be assuaged, further consultation with HIV-positive patients across the entire demographic is needed. This could begin with CfH commending a dialogue with existing clinic-based patients' forums and the UK Community Advisory Board (UK CAB, the network for community HIV treatment advocates across the UK) who would, I am sure, be eager to engage.

## further information

Electronic patient records will only cover GP notes to begin with, and if you are taking anti-HIV drugs and your GP has a record of them, this might go in your record unless you 'opt out' – which you are allowed to do. Don't panic, though – electronic patient records are currently just being tested in a few places in England, and will not be rolled out nationally for a while yet. A four page briefing paper from Terrence Higgins Trust provides more details about how electronic patients records may affect people living with HIV. This is available from: [www.tht.org.uk/informationresources/publications/policybriefingpapers/summary\\_care\\_records.pdf](http://www.tht.org.uk/informationresources/publications/policybriefingpapers/summary_care_records.pdf).

We will be covering more about EPR in the future. Past issues of ATU have also covered patient confidentiality and electronic records, including [ATU 159](#) (August/September 2006 'How confidential is confidential'); [ATU 166](#) (May 2007 'Acceptable standards') and [ATU 169](#) (August/September 2007 'Keeping it confidential').

Further information about the work of the UK CAB can be found at [www.ukcab.org](http://www.ukcab.org)

# news in brief

## hiv in the uk

### Latest report released on HIV in the UK

The Health Protection Agency (HPA)'s annual report on the UK's sexual health finds that gay men, black African women and men, and black Caribbean women and men, remain the groups most disproportionately affected by HIV.

Although sex between men remains the most common route of HIV transmission in the UK, the HPA says there is increasing evidence of heterosexual transmission of HIV in the UK's black African and black Caribbean populations.

The HPA estimates that there are around 31,000 gay men living with HIV (diagnosed and undiagnosed) in the UK, and that almost 9% of gay men in London are HIV-positive, with the HIV prevalence amongst gay men elsewhere in the UK being 5%.

Around 2,700 gay men were newly diagnosed with HIV in 2006, a total similar to the highest-ever annual number of new diagnoses recorded in 2005.

Gay men living with HIV were particularly likely to be diagnosed with a sexually transmitted infection. Over a third of syphilis cases were in HIV-positive gay men, as were 75% of LGV cases and approximately 20% of all gonorrhoea diagnoses.

Although late diagnosis of HIV continues to be a problem, gay men were the group most likely to be diagnosed with HIV in a timely manner, with just 20% diagnosed with HIV in 2006 found to have a CD4 cell count below 200 cells/mm<sup>3</sup>.

Late diagnosis continues to be much more of a problem for black Africans, with 41% of black African men and women diagnosed in 2006 having a CD4 cell count below 200 cells/mm<sup>3</sup>.

The HPA estimates that 4% of black Africans in the UK are HIV-positive, and that almost 50% of new HIV diagnoses in 2006 were amongst this population. The total number of HIV-positive black Africans in the UK (diagnosed and undiagnosed) is estimated to be 24,800. There were just over 3,000 new HIV diagnoses in black Africans in 2007.

The report notes that the UK's black Caribbean population is also disproportionately affected by HIV. The HPA estimates that 3% of new HIV diagnoses in 2006 were seen in black Caribbean men and women. One quarter of these were late diagnoses.

## hiv policy

### Start treatment earlier, say new US treatment guidelines

New guidelines from the US Department of Health and Human Services (DHHS) published last December join the European AIDS Clinical Society treatment guidelines, issued last October, in recommending that antiretroviral therapy should be started by all patients with a CD4 cell count of 350 cells/mm<sup>3</sup> or below.

They also recommend that antiretroviral therapy should be offered to certain groups of patients regardless of CD4 cell count. These include pregnant women, hepatitis-B coinfecting individuals who require anti-hepatitis B therapy, and individuals with serious kidney disease.

The guidelines acknowledge, however, that for most people, the benefits of antiretroviral therapy at CD4 cell counts above 350 cells/mm<sup>3</sup> are uncertain, and state that decisions about treatment in such patients "should take into account the potential benefits and risks associated with therapy, co-morbidities, and patient readiness and willingness to adhere to long-term treatment."

## hiv in the UK

### Most HIV-related discrimination comes from healthcare staff

Almost a third of HIV-positive individuals surveyed at a London HIV clinic have experienced HIV-related discrimination, according to a new study. Worryingly, half of the individuals who reported discrimination said that it had involved healthcare professionals - many of whom were working in the NHS, including doctors, nurses and dentists.

HIV-related discrimination (or the fear of such discrimination) can have far-reaching consequences, including a failure to test for HIV or access HIV care. Some research even suggests that discrimination may contribute to HIV risk behaviour, although this study found no such relationship.

"Our findings highlight the urgent need for the Department of Health to implement its action plan for combating HIV-related discrimination in the UK, inside as well as outside the NHS", conclude the investigators.

# news in brief

## hiv therapy

### Better understanding IRIS

Sometimes, people who begin antiretroviral therapy can experience a new flare-up – or temporary worsening of – one or more of their illness or symptoms. This is known as immune restoration inflammatory syndrome (IRIS).

Experts believe this is due to the fact that a newly strengthening immune system often has an excessive response to dormant infections.

A new study from the United States had found that the following factors were associated with an increased risk of an IRIS illness:

- Having a lowest ever CD4 count below 100 cells/mm<sup>3</sup>.

- Starting anti-HIV treatment with a combination of drugs that included a ritonavir-boosted protease inhibitor.
- Having a very large (2.5 log or greater) drop in viral load soon after starting treatment.

In those who experienced IRIS, illness developed about a month after starting anti-HIV treatment, and their median lowest ever CD4 cell count was 20 cells/mm<sup>3</sup>, indicating very advanced immune suppression.

Sometimes IRIS illnesses resolve themselves without any intervention and sometimes they are managed by the use of corticosteroid drugs. In this study, those who received corticosteroids did so for an average of six months.

## mother-to-child transmission

### Why does mother-to-child HIV transmission still occur in the UK?

A new report concludes that more can still be done to prevent mother-to-child transmission of HIV in the UK. The report found that there are around 30 UK cases of mother-to-child transmission each year and investigators from the Audit, Information and Analysis Unit, the Children's HIV Association, the London HIV Consortium and the National Study of HIV in Pregnancy and Childhood wanted to know why.

They found that, of the recent transmission examined in the report, two-thirds involved infants born to mothers whose HIV remained undiagnosed during pregnancy, underlining the need for all women

to have an HIV test at least once during pregnancy.

Since 2000 an opt-out HIV test has been offered to all women receiving ante-natal care in the UK. It is possible to reduce the risk of mother-to-child transmission of HIV to less than 1% with antiretroviral therapy, appropriate intervention during labour, and by not breastfeeding.

In fact, the report found that there were no cases of HIV transmission from a mother to her baby when women received the correct standard of care set out in UK HIV pregnancy guidelines.



# risky business

## why people with hiv still can't get life insurance?

by Johanna Gornitzki

In October 2004, the Association of British Insurers (ABI) produced their 'Statement of Best Practice on HIV and Insurance'. This put an end to the practice of life insurance companies basing their HIV risk criteria on someone's sexual orientation by asking about sexuality - in what has now become known as 'the gay question' - instead of basing it on an individual's actual risk.

Insurers are now only allowed to ask the following question: "Within the last five years have you been exposed to the risk of HIV infection?" This question can be followed by an optional: "This can be caught through unsafe sex, intravenous drug abuse, blood transfusions or surgery undertaken outside the EU."

Gay lobbyists, independent financial advisors (IFAs) and providers all applauded the ABI's move, arguing it has solved most, if not all, of the discriminatory problems surrounding HIV and insurance. Some, however, begged to differ.

David Sheppard, sales director at gay specialist IFA Principia Mortgages, believes there are still many unresolved issues. "Behind the scenes, I don't think the industry has changed at all when it comes to HIV-related issues, and there is still a degree of homophobia in the industry. For example, a lesbian friend of mine was refused life cover five years ago because her doctor told the insurer he was worried about her mental state of health due to her sexuality - implying she must be suicidal simply because she

was homosexual. As long as this perception prevails, it is hard to make any major changes."

Sheppard also thinks the revised question has given rise to a new problem. "The big issue I have with this is how do you define 'unsafe sex'? Will that include married couples trying for children? The new question has probably made the problem worse instead of better as there is no clarification of what 'unsafe sex' means," he says.

Responding to the criticism, Jonathan French, spokesperson for the ABI, says the organisation looked at three different options before opting for the final one. "During our consultation exercises, we looked at three different options, including attempting to define 'safe' and 'unsafe' sex and giving full details on application forms. This was rejected because companies were not comfortable with including such graphic information in their literature; plus, what is 'safe' or 'unsafe' sex will vary from person to person."

However, leaving aside the problems gay people are facing, the real issue is the lack of protection provided to people living with HIV. At present, none of the mainstream UK providers offer any life or critical illness cover to people with HIV. And for income protection, HIV cover is only provided to policyholders who took out a policy before contracting the virus and, typically, only if the virus is caught through certain types of profession (as long as the individual has taken

reasonable cautions), through blood transfusion or through physical assault.

There are, however, a couple of firms that specialise in life cover for people with HIV. Pulse is one such company. It offers life cover for individuals with HIV, underwritten by Lloyd's. "HIV is just like any other medical condition. Some people respond better to treatment than others, and for individuals for whom treatment is effective, life cover can be available," says Paul Sandilands, director at Pulse.

Last year, the firm launched a policy called Harbour in conjunction with Totally Insured Group, offering a basic level of life cover that can be enhanced by a layer of accidental death cover. The policy only offers a £10,000 sum assured over a ten-year period, however. Ron Moonesinghe, managing director of Totally Insured Group, admits it is far from perfect. "It's not brilliant but it's a start. Surely some cover is better than none."

IFA Chris Morgan of London-based Compass, which has been one of the lead campaigners for urging insurers to take a less bigoted view of HIV, is dubious though. "They are charging an extraordinary rate, which is around 30 times higher than an average policy, which is absolutely outrageous," he says.

So why are people with HIV turned down by the insurance industry? Lisa Power, head of policy at the Terrence Higgins Trust, says: "Those living with HIV are often refused life cover because people's ideas of what having HIV means is outdated. It's important

that insurance companies keep up to date with current findings on the life expectancy of people living with HIV.

"Certainly, a lot of people living with HIV feel they have been discriminated against. It may not be direct discrimination but insurance companies may still be judging people living with HIV based on outdated information."

The industry counters, however, that the challenge is not about incorporating the latest research, but rather how to estimate what long-term impact HIV would have on premiums. As Gerry Warner, protection development manager at Zurich, suggests: "One of the biggest challenges we face as an industry is trying to predict the future for those living with HIV and the impact on their insurance premiums and terms of contract."

"While we can see that there is a similarity in mortality rates for HIV and cancer over the shorter term, there is a lack of historical evidence to enable us to compare rates in the longer term. There is also currently a lack of data available on the long-term impact of HIV treatment," says Warner.

The problem is that HIV is a relatively new disease in comparison to other critical illnesses and accurate statistics are hard to find as the risk pool is also very small. Professor Donald Jeffries, chairman of the ABI Expert Working Group on HIV, explains: "At this relatively early stage in our studies of HIV - effective treatment and monitoring of individuals only took off in 1996 - all statements about life

expectancy, long-term morbidity and so on can only be projections based on modelling. The insurance industry is, of course, used to carrying out such actuarial projections, but in a potentially changing situation we must be sure we understand the behaviour of the virus in the long term."

Going forward, the ABI Expert Group on HIV has been looking at what is available in other countries, such as South Africa and the Netherlands, to see whether it would be possible for the UK market to make insurance available to people who are infected with HIV. Such a product is offered in the Netherlands but, so far, there has been a low uptake in sales.

Warren Copp, chief underwriter at Scottish Re, believes cover for people with HIV could be a possibility in the future. "The publication of further mortality studies on this group carried out on large samples and over significant time periods may enable a greater range of cover to be offered in future," he says.

Lisa Power is less optimistic. "I think it will take a long time for the rest of the world, outside of the HIV sector, to catch up and realise that people with HIV are living long and fulfilled lives," she surmises.

A version of this article first appeared in 'Cover', the market leading publication targeting financial advisers who advise on protection and health insurance issues.

## references to all articles

### electronic patient records [page twelve]

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On the last Monday of every month, an expert speaker discusses an HIV treatment related topic. Entry is free. The next forum is on January 2008. The topic is electronic patient records. For details, go to [www.aidsmap.com/forums](http://www.aidsmap.com/forums).
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