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# aids treatment update

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This month's *ATU* examines the uncertain future of HIV treatment and care in the UK. Although better drugs are being developed, future NHS funding changes will lead to some compromises. Shouldn't patients lead the agenda on what the compromises will be, rather than doctors and managers?

These uncertainties illustrate how life with HIV is challenging, but surely this is better than an early death from undiagnosed or untreated HIV? At least that's what I thought until a well educated friend recently died of untreated - possibly undiagnosed - AIDS. He told nobody he was sick, leaving his friends and family in shock.

In the UK, for every two diagnosed people there is another person whose HIV infection is undiagnosed. One-in-five diagnosed people who should be on treatment are not. Bottom line: not testing and not getting treatment means not benefiting from imperfect, but lifesaving, anti-HIV drugs.

Increasing testing opportunities is a start, but how many people in our own circle of friends are in denial about the need for testing, for treatment? In order to stop more unnecessary HIV deaths we have to tackle individual and collective denial, which - surprisingly and uncomfortably - inhabit the very communities most affected by HIV.

**page 3** In *An Uncertain Future* we ask whether HIV treatment will get better or worse in the years to come? Will we look back at 2006 and say, 'We never had it so good'? Or will 2006 be the 'dark ages' of HIV treatment, like pre-1996?

**page 8** Will we have more or less choice when a new method of NHS funding hits HIV clinics in 2008? In *Payment by Results* Michaela Dyer, Director of NHS Services for TP Medical - an independent consultancy that helps people make sense of the new NHS - examines in detail how NHS funding could be provided in the future, and considers the possible implications of each outcome for the delivery of HIV services.

**page 12** Two of the UK's most visionary, influential and outspoken HIV experts, Professor Brian Gazzard and Dr Mike Youle, answer Derek Thaczuk's difficult questions about *The future of HIV treatment*.

**page 16** The latest HIV statistics and a new study that questions whether people on anti-HIV treatment really need to take vitamin supplements are amongst the items in *News in Brief*.

**page 18** No-one likes change, but you have a choice if you use your voice, says the UKC's Paul Clift in *Patient Power!*



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# an uncertain future

will hiv treatment get better or worse?  
*by Edwin J Bernard*

## What will the future hold for HIV treatment in the UK?

This month's *ATU* looks to the future, and asks whether we will continue to benefit from current UK standards of HIV treatment and care, which, for those who are able to access them, are arguably the best in the world. Or will we have to give up what some doctors call "convenience" but which we call "side-effects" and "a worse quality of life" in order to make sure that the books are balanced, so that NHS care remains free? (And we are already hearing about NHS hospital managers who are misinterpreting rules of NHS eligibility in a way that excludes non-UK/EU citizens - or at least hands a hefty bill to the patient, thereby deterring them from accessing and benefiting from HIV treatment).

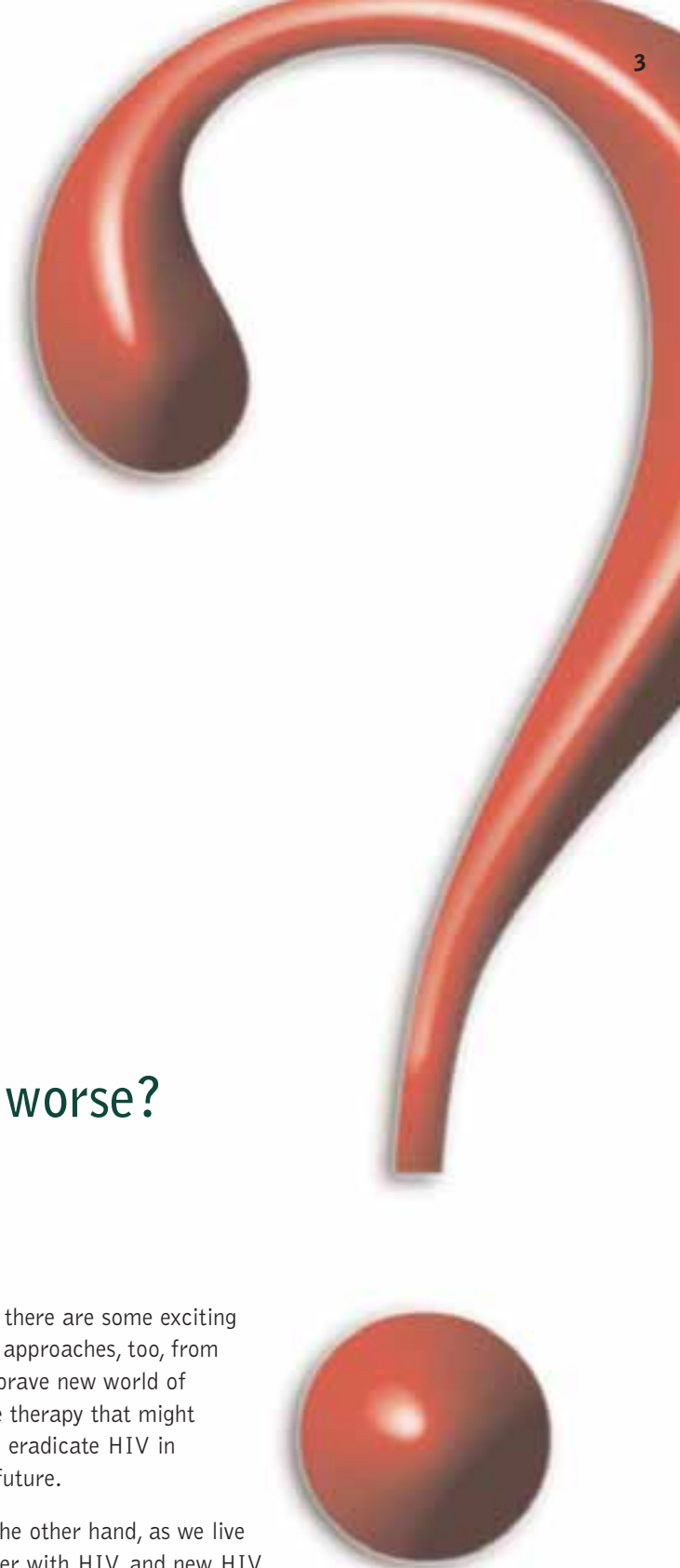
On the one hand, there's more, and potentially better, anti-HIV drugs due to come along in the next few years, because the HIV treatment 'pipeline' is fuller today than it has ever been. Not only are there new drug classes - like integrase inhibitors and chemokine antagonists - but also new drugs and new formulations from the current classes.

And there are some exciting new approaches, too, from the brave new world of gene therapy that might even eradicate HIV in the future.

On the other hand, as we live longer with HIV, and new HIV infections and new HIV diagnoses continue to add to the number of people who require HIV treatment and care, it's clear that NHS services are having a hard time coping with an increasing patient load. Add to that a cash-strapped NHS, and changes to the way that HIV treatment and care will be funded in 2008, and we have a lot of uncertainty, which may result in some very tough compromises.

The Prime Minister recently said of the NHS, "I genuinely believe the best is yet to come with more lives saved, stopping more pain and distress."<sup>1</sup>

Will that be true for HIV treatment and care? Read on...



## A bright today

The current crop of anti-HIV treatments means that, for most, life with diagnosed HIV today has never looked brighter. With nineteen different anti-HIV drugs approved for use in the United Kingdom (UK), this should provide ample choice for you and your doctor to find a drug combination that is likely to work, even if you have had a lot of treatment experience.

For the first-timer, there are now enough alternatives to try new combinations at least three more times until you truly run out of options. A study presented at the British HIV Association (BHIVA) conference last Spring found that, on average, people who began their anti-HIV treatment between 1996 and 2002 had around fifteen years before they needed to move to 'salvage' therapy<sup>2</sup>. Meanwhile researchers from the United States (US) are positively optimistic about the longevity of current treatment options. They recently calculated that the average person starting anti-HIV treatment for the first time in 2004 - with a CD4 count between 200 and 350 cells/mm<sup>3</sup> - would have enough drugs to last between 21 and 25 years<sup>3</sup>.

Last month's article, 'From salvage to salvation?' explored further the treatment options for individuals with a lot of treatment experience - and drug-resistant HIV - and concluded that they should have enough new choices to put together a treatment regimen that works for years rather than months. Consequently, very few people in the UK are likely to run out of treatment options in 2007.

## Why, then, do we need more drugs?

Some doctors think that we don't necessarily need more drugs because the combinations we have are already very powerful. However, there are problems with some drug combinations due to interactions, some drugs are cross-resistant to other drugs in the same class, and, of course, there are tolerability and toxicity issues with every anti-HIV drug. All of these factors substantially reduce the number of drugs that can be combined into a potent anti-HIV regimen, as well as the options for subsequent regimens. Consequently many doctors still think it is a good idea to find new - and better - drugs.

Other doctors think that, because adherence is an issue for many people, we want drug regimens requiring fewer pills, less often. So, new formulations have been - and continue to be - developed that cut down on the number of pills that are required to be taken, or allow for once-daily dosing. They think the ultimate goal is one anti-HIV pill, taken once a day, and this will finally arrive in the UK this year in the form of a fixed-dose drug combination of efavirenz (*Sustiva*) and *Truvada* which combines tenofovir (*Viread*) and emtricitabine (FTC, *Emtriva*).

However, this pill - which was approved in the US last July where it is known as *Atripla* - will reduce the pill burden of the most commonly-used first-line treatment combination from two tablets once a day to one tablet once a day. This is hardly a revolution. In addition, some doctors, including Dr Mike Youle (see interview on page 12) have concerns about the central nervous system side-effects (e.g. dizziness, mood changes, depression) of efavirenz-containing regimens, meaning it wouldn't be suitable for everyone.

## What about side-effects?

Nevertheless, the most commonly cited reason why anti-HIV drugs don't work over the long term is because they have unpleasant and often worrying side-effects. The most recent - and relevant - example of this comes from a 2005 BHIVA audit<sup>4</sup>, when they asked every HIV clinic in the country to explain why people taking anti-HIV treatment for the first time needed to change their treatment.

More than one reason could be given, but the main reason why people switched treatment was because of side-effects (the kind that are noticeable and hard to live with) and/or toxicity (particularly high blood fats and sugars which increase the risk of illness in the longer term). In contrast, fewer than a third of people who changed treatment did so due to virological failure, some of which might have also been caused by people not taking their drugs regularly because they experienced, or possibly even just worried about, side-effects.

Other reasons for a switch included 'adherence difficulties', 'patient choice', and 'treatment simplification' - all of which suggest that for many people taking anti-HIV treatments for the first time, current drug choices are nowhere near perfect.

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top six reasons why people stop drugs		top six targets for new drugs?
side-effects/toxicity	1	fewer or no side-effects/toxicities
virological failure	2	more potency; able to work against drug-resistant HIV
adherence	3	easier to take, e.g. no food restrictions, fewer pills, less often
choice	4	all of the above
simplification	5	easier to take (see 3 above)
poor CD4 response	6	more potency (see 2 above); drugs or vaccines that improve the immune system directly

the guidelines contained a list of drug prices to allow comparisons to be made between regimens. "We are cognisant that it would not be right in the framework of medical ethics to ignore the issues of costs," the guidelines authors wrote. "These issues become more important as more expensive drugs are developed which have no clear advantages in terms of antiviral efficacy, but may add to the convenience for patients."<sup>5</sup>

An example of how cost is already affecting our treatment choices can be illustrated by looking at BHIVA's 2006 recommendations for which nucleoside/tide (NRTI) background regimen best goes with your non-nucleoside (NNRTI) drug - either efavirenz (*Sustiva*) or nevirapine (*Viramune*) - or ritonavir (*Norvir*)-boosted protease inhibitor (PI), like lopinavir (*Kaletra*), fosamprenavir (*Telzir*) or saquinavir (*Invirase*).

Effectively, the choice comes down to *Combivir* (AZT/3TC), *Kivexa* (abacavir/3TC) or *Truvada* (tenofovir/3TC). Although all have potential side-effect drawbacks, AZT (zidovudine, *Retrovir*; also found in *Combivir* and *Trizivir*), like d4T, is associated with fat loss, although this occurs at a slower rate than d4T<sup>6</sup>, and new research has found that both drugs are now also associated with diabetes<sup>7</sup>.

During a debate at last Spring's BHIVA conference - sponsored by GlaxoSmithKline (GSK), who manufacture and market both *Combivir* and *Kivexa* - Chelsea & Westminster Hospital's Dr Mark Nelson emphasised that *Combivir* was significantly cheaper than the others<sup>8</sup>. Despite acknowledging that *Combivir* had limitations compared to the two alternative combination pills - including twice-daily dosing and the risk of lipoatrophy - he said that cost may

### What's wrong with this picture?

Unfortunately, the focus in new drug development isn't necessarily about drugs that are better for us to 'tolerate'. This is because, although drug company scientists can check for short-term side-effects, as well as look for possible signs of longer-term trouble, it's difficult to *really* know whether or not there are longer-term side-effects until a drug has been taken by a lot of people for several years.

The most obvious example of this is lipodystrophy. It's taken a long time for experts to understand which drugs are most associated with which body shape changes (facial and limb fat loss, and neck, breast or stomach fat gain) and metabolic changes (increased blood fats, and insulin resistance, leading to

increased risk of heart disease, stroke and diabetes).

It took seven years for lipoatrophy (fat loss) to be demonstrated to be strongly associated with d4T (stavudine, *Zerit*) resulting in BHIVA's 2003 treatment guidelines finally recommending against its use for people taking anti-HIV treatment for the first time.

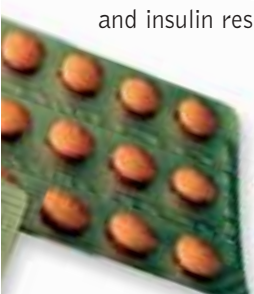
Nevertheless, four years after the UK stopped recommending it, d4T remains one of the most commonly used drugs in the developing world because it is cheap, despite its obvious shortcomings. Could something similar ever happen here?

### Cost matters

You might be surprised to find that we're already closer to that possibility than you think. In 2005, BHIVA's treatment guidelines first mentioned cost as an issue, and, for the first time,

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mean a choice between the best, but most expensive treatment and very good, but cheaper options, and concluded that cost was a factor that no clinic could ignore in 2006<sup>9</sup>.

The latest BHIVA guidelines continue the theme, recommending that in addition to choosing anti-HIV nucleoside backbone combinations that provide "the best potency, adherence and tolerability... minimise potential long-term toxicity and... avoid any likely drug-drug interactions [...] the cost of the regimen should also be considered."

The BHIVA guidelines also suggest that doctors who give their patients AZT-containing anti-HIV combinations should monitor for fat wasting with DEXA scans (a fat measuring x-ray-type machine, and something that is unlikely to be available at most HIV clinics). Since the guidelines concede that "the relative costs of the individual NRTIs is becoming an increasingly important factor in defining treatment pathways in naïve patients," it does imply that AZT remains recommended in the 2006 BHIVA guidelines primarily because it appears to provide a cheaper alternative. But what is the cost of AZT if you also add in the cost of regular DEXA scans and/or *New Fill* treatment to correct facial wasting? And more importantly, what is the cost of AZT to an HIV-positive individual who experiences fatigue from AZT-associated anaemia, and who might not be able access DEXA or *New Fill* at their clinic because cost limits access to these technologies as well?

### It's not all bad, is it?

Since October 2005, when *ATU* first reported on the issue of cost as a factor in treating HIV in the UK, it has become increasingly clear that cost really *does* matter due to increasing

pressure being placed upon HIV clinics to balance the books. Back in 2005, Professor Brian Gazzard warned that, "painful choices which are already a reality for many other specialities of medicine, will become our reality too."<sup>10</sup> The kind of choices he foresaw included making trade-offs between using cheaper drugs that might have unwanted side-effects or are otherwise harder to take "versus other support services, like the wait for pharmacy, the wait to be seen in outpatients, the length of appointment time, the frequency of appointment times, the ability to provide support nurses such as adherence nurses," and so on.

In a bid to make sure that we don't yet have to compromise too much on anti-HIV drug choices, some of these changes have already taken place, notably at some of the larger HIV clinics in London who have overspent their shrinking NHS budgets primarily because they are being overwhelmed by an influx of newly-diagnosed patients (increasing, on average, at around 13% a year, according to the latest figures from the Health Protection Agency<sup>11</sup>).

Some cost-saving initiatives actually make sense, and are being welcomed by many HIV-positive people. One that is already proving popular in some clinics is the provision of anti-HIV drugs by home delivery, which not only saves HIV clinic pharmacies 17.5% in VAT, but also means that we don't have to hang around the hospital pharmacy waiting for them to dispense our drugs.

In addition, some clinics have found ways of arranging for their more stable and/or expert patients to have fewer consultations with HIV specialists. Various methods are being attempted: spacing out clinic visits to two or three times year, rather than the usual four;

providing consultations by email or telephone; or using highly knowledgeable specialist nurses that often have more time - and possibly also a better 'bedside manner' - than some HIV consultants.

However, certain cost-cutting changes are creating problems for some HIV-positive individuals. Many clinics now have much stricter prescribing policies and are limiting - or totally eliminating - the provision of medications not strictly considered HIV-related, such as antidepressants, asthma drugs, or dry skin treatments. Instead, they are being asked, politely-but-firmly, to register with - and preferably disclose their HIV-status to - a GP in order to obtain these drugs.

This only makes sense if they can find a GP with an open list who is knowledgeable enough about HIV to provide them with appropriate care. However, many GPs have no experience of HIV-positive patients, and both they and us are nervous about them taking on our non-HIV-related care. Although increasingly more GPs are being given basic education about HIV, some people argue that this is too little, and/or too late in order to provide good quality GP services to all currently diagnosed HIV-positive people.

### A brighter future?

From a scientific point of view, however, the future of anti-HIV drug treatment appears even brighter than it does today. New drugs from new drug classes (which attack HIV at different points in its lifecycle), as well as a new generation of drugs from current drug classes - NRTIs, NNRTIs, PIs and entry inhibitors (EIs) - continue to be developed. In fact, there are about 25 new anti-HIV drugs in the drug development pipeline, and a further 25

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or so different immune-enhancing therapies are also being explored. However, drug development is a long and risky process, and many of these will never become available.

Both Dr Youle and Professor Brian Gazzard are extremely excited about the potential of integrase inhibitors for individuals new to treatment as well as more treatment-experienced people. This completely new class of drugs inhibits the third HIV enzyme, integrase, which splices HIV's genes into human cells.

Merck's integrase inhibitor, codenamed MK-0518, is the furthest along in development. It's already available in an Expanded Access Programme for highly treatment-experienced individuals and could possibly even become approved for these people in the US before the end of 2007.

A little further behind is Gilead's integrase inhibitor, codenamed GS-9137 (also known as JTK-303). Few people have taken this drug, but we should know a bit more about how it works in highly treatment-experienced individuals a little later this year.

Even further behind is GlaxoSmithKline's integrase inhibitor, codenamed 364735, which began safety, tolerability and potency studies in a small number of HIV-positive people last October.

### More in the pipeline

Another new class of anti-HIV drugs that we might be using soon are chemokine antagonists. Pfizer's maraviroc is the furthest along in development, and this is also now available in an Expanded Access Programme for people who have limited or no treatment options available to them due to resistance or treatment intolerance and who are failing to

achieve an undetectable viral load on their current anti-HIV regimen.

Importantly, however, maraviroc will only be available to you if you have HIV that uses a co-receptor known as CCR5 (which the virus uses to attach to CD4 cells), although a test (known as a tropism assay) is now available to measure this. Another issue with chemokine antagonists is that these drugs have had a chequered development history (see 'Do CCR5 inhibitors have a future?' in *ATU* 153; Jan/Feb 2006) due to concerns about potency and side-effects. There are many things we still don't know about the longer-term issues with this drug class - which interferes with a person's own immune system (rather than with HIV itself) - and a critical issue with maraviroc will be to look out for any longer term side-effects not yet seen in early clinical trials.

Professor Gazzard also thinks that we need more NRTIs, particularly those that work against one of the most frequently-seen and easily-acquired HIV mutations, M184V, which prevents 3TC (lamivudine, *Epivir*; also in *Combivir* and *Kivexa*) and FTC (emtricitabine, *Emtriva*; also in *Truvada*) from working. Three small drug companies are competing to produce the first of these next-generation NRTIs. At the moment, however, there's very little to differentiate Pharmasset's raltegravir, Avexa's apricitabine, and Achillion's elvucitabine, and none are likely to be available outside of clinical trials until at least 2009.

Looking *a lot* further into the future, Dr Youle is also excited about the brave new world of gene therapy, and in particular a new technology known as small interfering RNA (siRNA) which can turn genes on and off. He thinks

that this technology could *potentially* eradicate HIV from the immune system, meaning that a cure for HIV may be approaching on the distant horizon.

How much will these treatments cost, though, and will the NHS be able to afford them?

### We never had it so good?

Unless we are fully aware of the changes that are happening in NHS funding and drug development - and we tell the people who control drug prices, decide on NHS anti-HIV drug funding levels, and set standards of treatment and care whether or not they are acceptable - it's very hard to predict whether the outlook for HIV treatment and care in the UK will be bright or gloomy.

And if HIV is, indeed, now a life-long chronic manageable condition, then we may be heading towards a conflict between patients who, understandably, desire anti-HIV drugs that are easy to swallow - preferably with the least possible long-term side-effects - and an NHS that wants anti-HIV drug therapy to cost less.

In ten years will we look back at 2006 and say, 'We never had it so good'?

Or will we be able to refer to our current standard of care as the 'dark ages' of HIV treatment, as we do now about anti-HIV treatments before the current era of potent anti-HIV combinations?

Let's make sure it's the latter. ■

### more information

Turn to page 8 for more on the NHS funding changes, and to page 18 for more on how you can help to make sure your voice is heard when it comes to making decisions about these changes and how they will affect you.

# payment by results

Payment by Results (PbR), the new method of NHS funding, has two key objectives:

- to encourage many more hospitals and companies, including charities and those from the private sector, to deliver care to patients in the NHS
- to pay hospitals on a "cost per patient basis", by setting a fixed amount of money (the national tariff) that will be paid to every hospital for treating the same condition.

The government claims that these major NHS reforms will mean that individuals will receive significant

improvements to the quality of their healthcare, the choice of treatment options available, and the speed with which they can access services.

The future funding model for HIV services is not yet clear. However, there is serious concern that these when these changes affect HIV services, in April 2008, cost, rather than individual needs, will be the driving factor.

In this article we will examine in detail how NHS funding could be provided in the future, and consider the possible implications of each outcome for the delivery of HIV services.



# will we have more or less choice in 2008?

by *Michaela Dyer*

## The national tariff explained

The new funding system represents a major change in the way healthcare is funded, and is central to the Labour government's modernisation programme for the NHS. This system is called 'Payment by Results' and it began to be implemented last year.

PbR sets a specific price - known as the 'national tariff' - paid to a Hospital Trust (which pays for local hospital and clinic services) for each episode of care. There are different prices for inpatient stays, outpatient appointments and tests. Most significantly this is an 'average' price which is paid at the same rate, no matter how complex the case, and regardless of the special needs that the patient may have.

Under the reforms, instead of being given one sum of money in April each year hospitals are paid on a cost per case basis - just like any other business - for the patients they treat. This system already covers 80% of all care delivered by the NHS - but does not yet cover most HIV services.

It was introduced to help deliver the other key NHS reforms:

- to move the majority of care from hospital-based to GP-based services
- to improve the choice offered to patients
- to improve the speed and equality of access to services
- to ensure that everyone, wherever they are in the country, receives equally high quality care.

## HIV and the national tariff today

Unlike many conditions, there has been no immediate change to the funding method for the annual costs of care for a person with HIV, which was delayed because of its specialised and complex nature.

The biggest financial element of NHS HIV services - outpatient care and prescribing costs - are currently allocated in a 'block' contract, based on the historical number of people living with HIV in the local area, and the costs of running the service. This is likely to fundamentally change in April 2008.

However; PbR is already affecting how much a Hospital Trust is paid when anyone is admitted because of illness caused directly as a result of their HIV infection. The level of funding associated with such an admission is currently £885 for an elective, or planned, admission - and £4403 for a non-elective, or emergency, admission. This will rise to £907 and £4513, respectively, in April 2007.

Most Hospital Trusts have already said that this does not cover their previous average costs of an admission.

In simple terms, this means that a hospital is under pressure to deliver all of the care for an individual within that financial limit - or risk losing money.

## What can we expect in the future?

The specific details of exactly how HIV services will be funded are still being reviewed by the Department of Health, and ATU will provide further details as and when they are announced.

However, we will now examine the 'best case', 'worst case' and 'most likely' scenarios for funding changes; and consider the impact each outcome may have on current services.

These three potential outcomes could include:

- **No change** - no move away from historical funding of HIV care based on service costs, and the number of individuals diagnosed in the local population
- **Worst case** - a move to a full 'tariff' system, with specified limits applied to the funding allocated for treatment and prescribing costs per individual
- **Most likely** - a move to a limited 'tariff'-based system, with a variation in levels of funding dependent upon the needs and complexity of individual cases

## Scenario one no change

It is *extremely* unlikely that there will be no move towards a system where the amount of funding allocated per individual requiring treatment with HIV is fixed nationally. Whatever political party wins the next election, cost containment and demand management will continue to drive the NHS reform agenda. It is viewed as the only way to make hospitals more efficient, and to reassure the taxpayer of this.

The Labour government and the Department of Health are both clearly committed to a continued expansion of this kind of funding system into all areas of NHS care. The new Chief Executive of the NHS, David Nicholson, stated as recently as early November, in a letter to all hospitals: "*There will be no dilution of purpose or slowing down of this key reform.*<sup>1</sup>"; and the Secretary of State for Health, Patricia Hewitt, has repeatedly reinforced this, stating: "*payment by results is essential both for patient choice and to ensure that we get the best value for the enormous sums of money that we are putting into the NHS.*"<sup>2</sup>

Critics of PbR say that its main flaw is that it considers all patients to be a group of people with uniform needs. They argue that individuals are unique, and providing one 'tariff' for very diverse populations is unlikely to benefit those already at a disadvantage in society.

Others argue, however, that the concept of PbR should not necessarily be viewed as an entirely bad thing. Having variations in the amount of money allocated to hospitals across the country does mean that the level of service, and treatment options available, can vary widely (this is commonly known as the 'postcode lottery'). If it is implemented properly, then a national, equal, funding system should help to address those inequalities.

## Scenario two worst case

One possible, but hopefully unlikely, scenario is that a full 'tariff' system is applied to all aspects of HIV care, including the funding for drugs.

This situation would mean that the level of funding allocated to a Hospital Trust would be fixed at a certain level for each patient; and that allocated amount must pay for all drug and care costs, with no further additional funding allocated (beyond potentially a small annual increase) to reflect the complexity of care required, or improved drug treatments, or technological advances.

It could also mean that NHS Primary Care Trusts (PCTs) - the bodies responsible for financing the costs of healthcare for their local population - will increasingly specify a limited number of drug treatment regimes that they are prepared to fund for their populations, possibly based on recommendations by the National Institute for Health and Clinical Excellence (NICE). NICE is the independent body which is charged with providing the NHS with guidance on the most clinically and cost-effective treatments; their decisions are often used to indicate whether new drugs will be funded on the NHS. Fortunately NICE has not yet reviewed the cost-effectiveness of HIV treatments, and there are, as yet, no plans for them to do so.

Should PCTs choose to restrict access to only certain drug treatment regimes, for funding reasons, any patient wishing to access a therapy outside of these restrictions will need to make an individual case to the PCT for funds. This is already common practice in many other medical specialties, and was seen recently in relation to *Herceptin* treatment for breast cancer.

At the start of 2006, *Herceptin* had been licenced but not approved by NICE and was therefore not funded by many PCTs; however, a number of patients who wished to access the drug undertook specific individual, and successful, legal actions against their PCT.

One key concern of a move to a system where capped 'tariff' payments apply to all HIV care is that cost control will threaten the current good access to services and optimal medical management for people with HIV. In particular, this - hopefully unlikely - scenario could lead to pressure upon hospital specialists to deliver more cost efficient services.

The application of a 'tariff', if it is not sufficient to cover a hospital's genuine cost, could have the most significant impact upon HIV and other specialist services. This is because, on the whole, more simple procedures - minor surgery, dermatology etc. - can deliver their services well within their 'tariff', whereas complex specialties, particularly those with increasing drug costs, are less likely to be able to do so. In the old system, the cost savings in one hospital department could be used to offset the cost of more expensive HIV services; and clinicians relied on surpluses being generated from other departments to support their own. However, under the 'tariff' system, individual doctors find themselves under pressure to deliver their part of the service more cheaply. This places far more responsibility and accountability in the hands of clinicians, who are forced to make cost cuts in some part of the service.

One potential positive outcome of this situation is that some hospitals are already working more closely with service users to build a picture of which elements of the service they most value, so that they can shape their

“ It is critical that the new NHS funding system for HIV recognises the importance of individual patient need and clinical best practice. ”

services accordingly, reducing costs where possible and where deemed to make the least impact.

In this worst case scenario, there would have to be stark choices made, for example, between an expensive but more 'tolerable' drug regime, and the availability of specialist nurse support.

### Scenario three most likely

It is, however, likely that the Department of Health will choose to adopt a funding system for HIV which combines the strict control of a limited amount of funding per patient, with some flexibility that, for example, allows those hospitals treating very complex cases to be allocated a higher level of funding to reflect specific individual needs.

A similar system is in operation for the funding of cystic fibrosis services, where funding is allocated per patient, but is "banded" at four different levels dependent on severity of condition.

Many experts think that this system would combine improved financial control with a fair system for patients and hospitals, and still encourage patient choice. The fact that the NHS has limited funds is being increasingly debated, and this system could begin to encourage more focus on cost-effectiveness, but will this mean compromising clinical care?

Aware of the changes to come, in 2005 the BHIVA treatment guidelines said that the cost of a drug should be taken into account<sup>3</sup>. This has led to the current debate highlighted in 'An uncertain future'. If two drugs are considered to be as potent as each other, but have different kinds of side-effects, should the doctor prescribe the cheaper drug?

In other words, what role will 'patient choice' - one of the so-called main drivers of PbR - have in this decision-making process?

It's becoming clear that a Hospital Trust - seeking to manage its costs within some form of the allocated national 'tariff' for HIV care - would be under significant pressure to make this decision, or risk having to make cost savings in other areas.

Although most HIV doctors agree with HIV-positive individuals that the choice of antiretroviral drugs should be made in the interests of the individual, and solely on clinical and not cost grounds, they also recognise that it may become untenable to prescribe an expensive drug over a cheaper one, if the only variant factor is, as it is termed in BHIVA's guidelines, "convenience". Nevertheless, doctor and patients may have very different ideas of what is, and what is not, "convenient".

### Conclusion a two tier system?

One longer-term possibility, if prescribing drugs based on cost rather than so-called "convenience" becomes the case, is that individual patients could choose, if they are financially able, to personally fund the difference in cost between a cheaper regimen funded by the NHS and a more expensive, - but more "convenient" - regime.

However, no-one could consider the idea of two-tier healthcare system in the UK to be fair and equitable, and this would certainly not be seen as providing "equally high quality care".

It is, therefore, critical that the new funding system for HIV recognises the importance of individual patient need and clinical best practice. Whilst improving efficiency in a cash strapped NHS is important, the system must also be designed to ensure that any compromise must not impact directly on either choice or quality, and decisions on funding priorities must be taken alongside clinicians, individual service users, and expert groups working with those patients accessing HIV care.



# the future of hiv treatment

Is the outlook for HIV treatment and care in the United Kingdom bright or gloomy?  
We asked two of the UK's most visionary, influential and outspoken figures.

## Professor Brian Gazzard

Consultant Physician at London's Chelsea and Westminster Hospital, Professor Gazzard is not only the lead author of the British HIV Association's (BHIVA) treatment guidelines - which set the standards of HIV treatment and care in the UK - he is also the Chair of the London HIV Consortium's HIV Drugs and Treatments Group, which decides how and where the money provided for HIV treatment and care in London is spent.



## Dr Mike Youle

Director of HIV Research at London's Royal Free Centre for HIV Medicine, Dr Youle has been a world-class leader in both cutting-edge HIV treatment and HIV research for many years, and he has particular expertise in managing HIV-positive individuals with complex treatment histories.



interviews by Derek Thaczuk

**Q** What do you see as the real factors affecting patient care? What leads to a better or worse outcome, and how do you see that changing over the coming years?

Brian Gazzard (BG): If you look at randomised controlled studies, the 20% who don't respond to initial treatment are the ones who disappear from the study, who cannot take the pills. So I don't think there's any unmet need in terms of potency at all, and I think we're also doing much better at meeting the needs in terms of pill burden and toxicity.

Clearly, the worst case is the people who can't adhere. That is the big unmet need, and it's sociological, not pharmacological. These people are incapable of keeping to a daily drug schedule either because of their irregular lifestyle, or because they don't share the belief that these drugs can be lifesaving - they think alternative therapy might be better. If there is an area where we have to focus in the coming years, it is reaching out to those people and getting them to take treatment that we know will help them.

Mike Youle (MY): The real problem is the numbers of patients I see with lifestyles that aren't compatible with taking anti-HIV drugs regularly, day-in, day-out. For these people, HIV treatment is just not a priority. Now, I know that some are too mentally ill to look after themselves, and others, for whatever reason, are not interested in taking care of their health. Unfortunately, they are the people I am seeing who get sick and die. These people need more support in order to learn better how to re-prioritise their health once they are on treatment.

But generally most HIV-positive people are going to live reasonably normal life spans and will end up dying of 'normal' things like heart disease and cancer.

**Q** Where do you think the science of HIV treatment is heading?

BG: I think that the pace of new drug development will slow as the market becomes more saturated, and the new compounds offer comparatively less advantage. We are going to see studies looking at substitution - replacing either one or both of the nucleoside 'backbone' drugs with some of the newer medications, such as integrase inhibitors or chemokine antagonists. My personal view, however, is that nucleosides provide a very good backbone and that drugs like abacavir, tenofovir, 3TC and FTC may be difficult to supplant.

There will also continue to be interest in compact regimes, or using a single drug that might do everything that combination therapy currently does, such as using a boosted protease inhibitor (PI) like *Kaletra*.

Of course, the stumbling block to a cure has been the pool of latently infected cells, and I think there will be intensive efforts to find ways of stimulating and eradicating that latent pool. I think there's a small chance that might even work.

MY: Theoretically, there are loads of drugs coming through. Whether the drug companies will be willing to push them all through to fruition is uncertain, but I think they will be, because (a) they want to do something exciting and talk about it, and (b) there'll always be a market, especially in the developing world, where they can still make some degree of profit - although it does depend on how India and China affect pricing through patent law and the production of generic drugs.

The only cure I can see on the horizon is gene therapy using small interfering RNA (siRNA), which could *potentially* eradicate HIV from the cell.

**Q** What are most promising drugs in pipeline? Do you see anything poised to significantly alter the current standard of care?

MY: Integrase inhibitors look fabulous, and I think chemokine antagonists are somewhat less interesting, but still very good. The once-a-week fusion inhibitor, T-1144 - Trimeris, follow-up compound to enfuvirtide (T-20) is showing early promise - but it will have to be cheaper than T-20, otherwise it just won't be prescribed in the NHS of the future.

BG: I think most people would say integrase inhibitors look very potent; it's the only drug class you could see potentially replacing NNRTIs for use in the treatment-naïve. That will depend on the fragility of the compound [i.e. how easy it is for HIV to become resistant to it] and whether there are side-effects we haven't seen. For 'salvage' therapy, I think the biggest unmet need may well be another nucleoside analogue drug. You run out of nukes for the backbone more quickly than anything else. However, it's very hard to talk about specific drugs or drug classes over a longer timeframe, because drug development is a very uncertain business.





**Q** So far, therapeutic vaccines and immune modulators have taken a back seat to anti-HIV drugs. Do you see immune-based treatments playing a larger role?

MY: Therapeutic vaccines won't work. At best they're going to be mildly beneficial. There may be some immune modulators that come along in the future, but not at the moment. Some interesting work is currently being done in the test-tube on CCR5 antibodies, so theoretically it's not impossible. However, the amount of money required to evaluate these things is so great that it's unlikely that any profit-focused drug company will be interested. The only immune modulator that made it to large-scale trials, interleukin-2 (IL-2), proved to be too toxic, and Chiron has already given up on it.

BG: Well, I taught Dr Youle everything he knows, so I can't disagree with his answer! So I think the chances a therapeutic vaccine will have any impact is virtually zero. I think the chances IL-2 therapy will have any impact is virtually zero.

**Q** With *Atripla*, we've finally managed to achieve the goal of one pill, once a day for some people starting anti-HIV treatment. How much easier is dosing likely to get and is even less-frequent dosing necessarily better?

BG: One pill once a day is going to be difficult to improve upon. But I do think there is a real market for once weekly pills and/or injections. I think that an infusion for ten minutes on a Saturday morning of the drugs you need for the week could appeal to a lot more people than you might think - not just, say, injection drug users, but people who can't bear the thought of taking pills every day. Having people turn up each week for their injections would certainly help us make sure that they were taking their treatment.

MY: Although I have concerns about the central nervous system side-effects of efavirenz, *Atripla* is good for the people who can tolerate it, and want to take one pill once a day. However, it probably won't be available on the NHS unless it costs the same as efavirenz and *Truvada* currently costs. I think there's definitely a market for once-weekly injectables, but I think they'd have to be self-injected by the patient, rather than healthcare staff.

**Q** Much more attention is now being paid to the healthcare costs and cost containment. How is that going to affect the future of HIV care as we've discussed it?

BG: Drug costs are already a major issue in the developing world, and it's becoming much more of an issue in Britain, too. However, NHS funding pressures have already led to drug companies considerably reducing their UK prices for *Truvada* and fosamprenavir (*Telzir*), and it will drive *Kaletra* costs, too. It will happen increasingly.

MY: I think the prospects are frankly going to get worse, unless drug companies cut their prices, or the NHS provides more funding. However, I should point out that antiretroviral therapy is the most cost-effective therapy ever known to mankind - other than smoking cessation<sup>1</sup>. If the NHS really wanted to make health care as cost-effective as it can be, it should stop all kidney transplants, it should stop all coronary artery bypass grafts, it should stop all therapy for cancer in people over the age of 40, and use all the money to treat HIV, because that is more cost-effective! Cost-effectiveness can't possibly argue that everyone with HIV shouldn't be treated. If those patients aren't treated, then they'll be filling hospital beds, which is very expensive indeed. In 1996, we had HIV patients in over 250 beds. Currently, we've got fifteen HIV in-patients.

HIV treatments funding is a political issue. I've got a patient who needs two drugs only available via Named Patient Expanded Access Programmes and I now have to fight to get my hospital administrators to pay for the £1100 a month handling charge that Merck wants for its integrase inhibitor. But in real terms, £1100 a month for that patient is totally irrelevant because otherwise he'll be in a hospital bed costing much more than that a day!

**Q** Are there other areas of care, besides drug costs, where money can be saved?

BG: No, I don't think so. The only cost drivers are the costs of hospital in-patient care and the costs of drugs. Everything else is miniscule, really. One of the costs that aren't drug-specific is how often you have to see the patient. I think, perhaps, that there will be a very slow evolutionary change where we will move to see the people who are doing well once every six or nine months rather than every two or three, as we currently do.

MY: I remain appalled at the inability of NHS management to be run in the same way that businesses are run. There are professional standards for doctors, where are the professional standards for hospital administrators, and how can they be made accountable for their inaction or misaction?



**Q** If "the best possible care, regardless of cost" is not realistically available, then what level of care is "good enough"? And who gets to decide what constitutes "good enough"?

BG: As I've said, I don't think we are lacking for potent drugs any more, so the difference is going to lie in levels of toxicity. But I don't think there are going to be major differences there either. So I think we're actually where we need to be, apart from that relatively small number of patients who need more drugs for salvage.

The UK government is already indirectly saying, "We're going to limit your budget, it's up to you how you spend it but you can't have everything". Within a limited budget difficult choices will have to be made between expensive drugs offering minor advantages and the other large element of cost of HIV care which, of course, are salary costs. Many people, I think, would accept the inconvenience of a slightly higher pill burden in return for a smooth visit to the clinic with minimum waiting times, maximum amount of results being available on-line, and services being available when they need them.

As to who decides, increasingly, I think, it will be whoever pays.

MY: The difficulty with socialised health care is that you pay in a certain amount and you have a right to a certain proportion of benefit, but the proportion you have a right to is unclear. I don't actually think that people, therefore, have a right to every kind of therapy. I think the vast majority of people in the UK don't understand that - they think they should have access to everything they want. But unfortunately we're living in a political system where that's not available. Nevertheless, if I was poor, I wouldn't necessarily save up to have a Rolls-Royce; I'd rather have a Fiat Panda while I'm waiting. Do you see my point?

**Q** With cost becoming an issue everywhere, will the differences between the developing versus the developed world remain as clear-cut in the future as it is now?

MY: The differences between the 'developing' and 'developed' world are already rather blurred. The quality of HIV treatment is really due to proximity to skill and care, and that varies with the political landscape of individual countries. Some people in parts of sub-Saharan Africa already get better care than some people in parts of eastern Europe. In the US, in South Carolina, people are already dying because they're on an ADAP (AIDS Drug Assistance Plan) waiting list.

BG: While I accept that there are a number of inequalities of healthcare across the United States, I think this is a magnitude different to at least 75% of the world population who are unable to access antiretrovirals at any time and will die needlessly and prematurely.

**Q** People don't receive HIV treatment until they're diagnosed. Should the UK follow the US lead and make HIV testing a normal part of medical diagnosis?

BG: I think there's increasingly going to be much more widespread testing. You can use the model of testing everybody, like in the US, or make it more targeted, like in the UK. Already in the UK any gay male who goes to a sexual health clinic will be tested every year on an opt-out basis - unless they specifically say they won't have an HIV test, it will be included as a routine test. I think that will increasingly happen in other healthcare settings.

MY: There's no doubt in my mind that the people who get sick and die of HIV are the people who don't get tested. We've got two people in our intensive care unit at the moment because they were only diagnosed once they were very ill. If we don't move to widespread opt-out testing then we're going to continue to have people who die unnecessarily.

## statistics

## One in every three UK HIV infections remains undiagnosed

On average, for every two people living in the United Kingdom with diagnosed HIV infection, another person is living with undiagnosed HIV infection, according to the annual report on the sexual health of the nation from the Health Protection Agency (HPA).

The group of people most likely to be undiagnosed are ethnic minority heterosexual men. Many gay men and other men who have sex with men (MSM) are also undiagnosed, however, in particular those that belong to an ethnic minority, as well as those who are older and/or are not part of the 'gay scene'.

In addition, on average a third of people newly diagnosed with HIV were diagnosed too late to benefit from optimal treatment, greatly increasing (by up to ten times) their chances of dying within a year of diagnosis. This increased to two in five ethnic minority adults. Women are often only diagnosed after they become pregnant following a routine antenatal HIV test, and a separate report from an east London hospital found that many consequently don't have an undetectable viral load when they deliver, increasing the risk of mother-to-child transmission. Doctors think that many of these women delayed coming forward for medical care because they were worried about their entitlement to free NHS care.

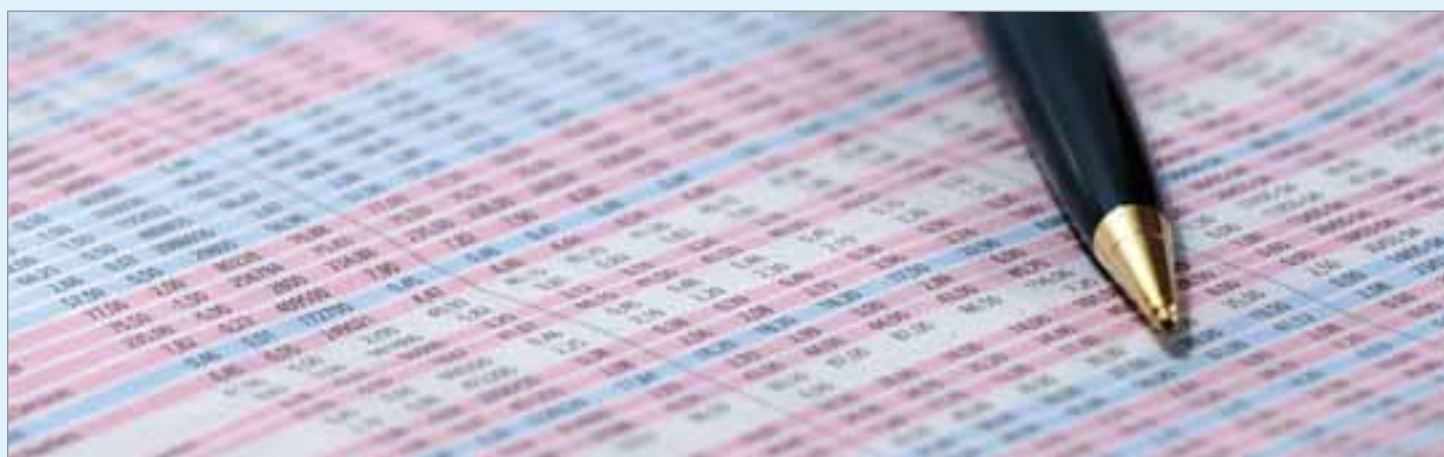
A third report also notes that the UK has one of the fastest growing HIV epidemics in Europe with approximately 7,500 new diagnoses reported for 2005 so far. Although many

(2,760) of these newly-diagnosed individuals acquired their HIV infection through heterosexual sex in Africa - and fewer were diagnosed in 2005 than in 2004 - more (2,356) gay men and other MSM were diagnosed with HIV than ever before.

It's not totally clear, however, if the increases in new diagnoses that were seen amongst gay men and other MSM are due to more HIV antibody testing, more new infections, or a mixture of both. Although some evidence suggests that gay men and other MSM are testing more often - because an HIV test is now supposed to be routinely offered to everyone who has a sexual health check-up at a GUM clinic - one in five weren't offered a test, and one out of every thirteen who declined testing left the clinic with undiagnosed HIV infection.

The HPA report also noted that people with HIV in the UK were more likely to be diagnosed with certain sexually transmitted infections (STIs). In fact, three quarters of all cases of LGV and around 45% of cases of syphilis involved HIV-positive gay men or other MSM.

Worldwide, there were 2.6 million new HIV infections in 2005, bringing the global total to 39.5 million. Eastern Europe and Central Asia have the fastest growing epidemics, but 66% of all the world's HIV infections are in sub-Saharan Africa. A million people in this region were receiving HIV treatment in June 2006 - just a quarter of those who needed it.



## complementary therapies

## Do people on treatment really need vitamins?

Many HIV-positive people take nutritional supplements or vitamins in the hope that they will help support their immune system or to help prevent or lessen the side-effects of drugs they are taking to treat HIV or other infections.

In the past, studies have looked at micronutrient levels in people not taking HIV treatment and there has been some evidence that, in people who are not taking anti-HIV treatment, the use of a multi-vitamin tablet can have a modest effect on the immune system. Other studies have found that people who are not taking treatment have low levels of micronutrients such as selenium.

Now a US study has looked at levels of micronutrients in people taking HIV treatment. It found that zinc was the only micronutrient that was commonly deficient in



people on HIV treatment. But even in the 40% of men and 36% of women with low levels of zinc, it did not seem to have a negative effect on either CD4 cell count or viral load. However, people with higher levels of zinc tended to have lower viral loads, but this effect was very small and not statistically significant.

The researchers also found that although many people in their study were taking nutritional supplements, this didn't have any effect on how well their HIV treatment worked in terms of CD4 counts and viral loads. However, they did not measure other aspects of health, such as quality-of-life or physical wellness. Consequently, if you currently take vitamins or other nutritional supplements, you can afford to do so, and you feel better for it, there's no reason not to continue taking them.

## new drugs

## Tipranavir unlikely to be approved for people new to treatment

A trial that compared the protease inhibitor tipranavir (*Aptivus*) – which is only approved for 'salvage' therapy – plus two different boosting doses of ritonavir (*Norvir*) with lopinavir/ritonavir (*Kaletra*) as a first-line therapy has been stopped after 60 weeks of what was intended to be a three-year trial. It seems that using a low dose (100mg twice daily) of ritonavir to boost tipranavir (500mg twice daily) was not as potent as *Kaletra*, whereas using a higher ritonavir dose (200mg twice daily) was more toxic. Consequently, tipranavir has fallen between two stools and will now almost certainly not be licensed as a drug for treatment-naïve individuals.

## travel

## US eases HIV travel restrictions



The White House has announced that it will ease - but not remove - current restrictions barring short-term HIV-positive visitors from entering the United States. The announcement only affects people travelling on tourist and business visas that allow entry for up to 60 days, however, and does not fundamentally alter US immigration policy. It is unclear whether HIV-positive tourists will still have to declare their HIV status to US officials to benefit under the new rules. Although the entry ban for people with HIV has been in place since 1987, a member of the recently elected US Congress has promised to introduce legislation that would completely remove all restrictions.

As you will have read in this issue, big changes are afoot in the way that our HIV treatments are chosen and prescribed. What concerns me is that these changes are being imposed on us, rather than being arrived at in consultation with us. But, as you will see, we do have a choice, and we can use our voices to make a difference.

### Who decides on anti-HIV regimens at individual clinics?

This is usually the clinic's management team, which is usually made up of senior doctors. Where a patients' forum exists, the management team may include a patient on the team as well. If this is the case in your clinic, it makes good sense to get your views known via the patients' forum so that they can influence the decision-making.

This might sound Utopian, but a few years ago, while I was the patients' representative in Brighton, we had a discussion in the clinic management team about *New Fill*. One of the doctors suggested that the first few patients receive it free, but after that everyone would have to pay. "Over my dead body!" I thought, and made a strong case that no charges should ever be imposed. Everyone listened, and agreed. In other words, success can be achieved if we speak out!

Not all HIV clinics have patients' forums, but it is government policy to include patients in treatment and care decisions. The Department of Health website on Patient and Public Involvement (PPI) notes that, "the NHS has an obligation to involve patients in decisions about their health

care" and that "engaging and informing patients is at the heart of good clinical practice. There is clear evidence that shared decision-making, in which patients negotiate with clinicians the best course for themselves, can lead to better adherence and better outcomes."<sup>1</sup> Earlier this year I approached my current clinic in south London with a view to establishing a patients' forum and found the senior doctors welcomed the idea; we are now working together on developing it. Maybe you and your friends could do something similar at your clinic.

Those of us who are able might also be advised to argue our case individually for a particular regimen, as I was able to do when I started treatment (see 'Making an informed choice', in *ATU* 150, October 2005). I wanted an anti-HIV combination that didn't include AZT - due to my concerns over its association with fat loss - or efavirenz (*Sustiva*), because I wanted to avoid the central nervous system symptoms that often accompany this drug. So I told my doctor that I had researched all the options and that I preferred a slightly more expensive drug combination. He prescribed it to me because he recognised that I would have better adherence over the long term, and that this would end up being more cost-effective than other combinations offered to people taking treatment for the first time.

### Who influences the clinic decision-makers?

The British HIV Association (BHIVA) - the HIV doctors' professional body - issues treatment guidelines every year

that all HIV clinics ought to follow (although some don't!). They also provide guidelines on other standards of HIV care that influence how HIV services are delivered.

BHIVA mainly listens to the patients' point of view via the UK Community Advisory Board (UK-CAB), a network of HIV-positive people and community advocates. Members of the UK-CAB sit on various BHIVA committees, so if you want to influence the influencers, join the UK-CAB email list. It's free and open to all HIV-positive people.

### Who will set the Payment by Results (PbR) tariff?

The Department of Health. However, if you live in England and Wales it makes sense to start with the your local Primary Care Trust (PCT), which is responsible for planning and securing the provision of HIV services in your area. Each PCT has a commissioner that oversees the NHS funding of HIV services in your area. London, however, is a special and complex case, with over thirty Primary Care Trusts (PCT) and multiple commissioners. In any case it pays to develop a working relationship with your local PCT HIV services



# patient power!



### further information

To find out more about patient forums, and other local HIV advocacy groups, start by asking staff at your HIV clinic.

- You can also contact the NHS 'patient power' service, PALS (patient advice and liaison services), which will be able to put you in touch with your local HIV PCT commissioner. Visit [www.pals.nhs.uk](http://www.pals.nhs.uk) or call NHS Direct on 0845 46 47.
- To join UK-CAB visit [www.ukcab.net](http://www.ukcab.net)
- To search for your local HIV advocacy organisation, visit 'organisations' at [www.aidsmap.com](http://www.aidsmap.com).
- The UKC can be contacted via [www.ukcoalition.org](http://www.ukcoalition.org) or on 020 7564 2180.
- HIV Scotland can be contacted via [www.hivscotland.com](http://www.hivscotland.com) or on 0131 558 3713.

commissioner, and to exert informed pressure on them. This person is more likely to listen to a patients' advocacy group that can demonstrate that it speaks for many patients rather than to one or two individuals, however committed they are. If you want to make a difference on this level, then, it really pays to get in touch with local and national HIV advocacy organisations. Examples include the UK Coalition of People Living with HIV and AIDS (UKC), Feedback South London, Manchester's George House Trust, and North Yorkshire AIDS Action. Funding arrangements are different in Scotland. HIV Scotland is the leading HIV policy organisation north of the border, and will work on your behalf.

### Everyone's voice counts!

Finally, if you are concerned about these changes but don't have the time, energy or inclination to become really involved, then, at the very least, please fill in and return the occasional questionnaires and surveys from organisations like NAM and UKC. Your answers help inform - and fund - their work on issues like these, and really can make a difference, too.

you have a choice  
if you use your voice  
says Paul Clift



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## Where to find out more about HIV

### ■ Find out more about HIV treatment:

NAM's factsheets, booklets, directories and website, keep you up to date about key topics, and are designed to help you make your healthcare and HIV treatment decisions. Contact NAM to find out more and order your copies.

### ■ Information events in London

On the last Monday of every month, an expert speaker discusses an HIV treatment related topic. Entry is free. The next topic is 'keeping healthy in 2007' and will be held on 27th January 2007. For more details, go to [www.aidsmap.com/forums](http://www.aidsmap.com/forums).

### ■ [www.aidsmap.com](http://www.aidsmap.com)

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