

# hiv treatment update



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# in this issue

After five years, and more than 50 issues, this issue will be the last edition of *HIV Treatment Update* edited by yours truly. (You can read more about my take on the changes in the HIV landscape during that time on page 12.)

I took over the editorship of NAM's newsletter in October 2003. That month, Mohammed Dica became the first person in England to be successfully prosecuted for reckless HIV transmission. This led to a great deal of fear and confusion – much of which has not dissipated – over the possibility of prosecution for passing on HIV to our sexual partners.

Much has been achieved, notably when Dr Anna Maria Geretti testified in a Kingston courtroom in August 2006 that scientific evidence was unable to definitively prove timing and direction of transmission. But prosecutions for the transmission of HIV – and now hepatitis B (see page 18) – continue in the UK. Abroad, the situation is much worse – in many places the bar for prosecutions is set much lower.

Globally, the criminalisation of HIV exposure and transmission and, in some countries, of people with, and at risk of, HIV, threatens much that has been achieved for those of us living with HIV. That's why I am drawn to human rights issues – notably criminalisation – as the focus of my future work both here in the UK and internationally.

Edwin J Bernard

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**page 4** When would you start treatment? What are your biggest worries about it? If you're on it, how has it affected you? These were some of the questions NAM asked in *The NAM treatment survey*. Gus Cairns analyses the results – and the participants' illuminating comments.

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**page 16** In *News in brief*, we discover that a record number of people are now accessing HIV care in the UK, and find that some of us may have an exercise intolerance due to the impact of HIV treatment on the heart.

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## **hiv treatment update**

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34.asp

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

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# Adherence and long-term treatment success

by NAM's editorial team

Taking your HIV medication correctly (the technical term for this is adherence) is the single most important thing you can do to make sure your HIV treatment works well over the long-term.

Adherence above 95% has been the 'gold standard' ever since the publication of the landmark adherence study in 2000<sup>1</sup>, which found that adherence above 95% was the level associated with the lowest risk of treatment failure in several past studies.

However, recently there has been conflicting evidence over just how critical it is for a person to maintain adherence above 95%.

## Understanding adherence levels

	Doses of once-daily treatment missed in past month	Doses of twice-daily treatment missed in past month
<b>&gt;95% adherence</b>	No more than 1 dose	No more than 3 doses
<b>&gt;90% adherence</b>	No more than 3 doses	No more than 6 doses
<b>&gt;80% adherence</b>	No more than 1 dose a week	No more than 3 doses a week
<b>&lt;40% adherence</b>	At least 3 doses a week	At least 3 doses a week

In December's *HTU* we reported on a Spanish study<sup>2</sup> which found that there was only a very small difference in rates of viral rebound over one year between people who missed no more than one in ten doses (90% adherence) and people who missed no more than one in five doses (80% adherence).

But according to a new study<sup>3</sup> by investigators from the Canadian province of British Columbia, adherence of less than

95% is still associated with a substantially lower chance of a good response to treatment.

The study followed patients for four years and used a relatively relaxed definition of treatment success which permitted patients to spend up to a third of the time with detectable viral load. However, even this modest goal was substantially less likely to be met if adherence fell into the 80 to 95% range, when compared to adherence above 95%.

It also found that people who took less than 80% of their medication (people likely to be missing doses on a weekly basis) had only a 10 to 15% probability of achieving and maintaining a good response to treatment during the four-year follow-up period, while those taking between 80 and 95% of all doses had no more than a 41% probability of a good response to treatment.

## Help with adherence

One of the questions we asked in NAM's online treatment survey (the subject of our main article, which begins on page 4) was: "Please tell us about things that have helped you in taking HIV treatment."

A quarter of respondents to the English survey (367 in all) chose to add comments at this point. (We haven't yet translated the comments from the surveys completed in other languages.)

A number of factors were mentioned repeatedly as helping people adhere to their treatment. The most frequently mentioned idea was an alarm, most often a mobile phone alarm, that prompted people to take their pills: in fact, one in five respondents mentioned this as something they used.

Other things mentioned frequently were pill boxes, mentioned by one in ten respondents, and "one pill, once a day", mentioned by one in twelve, over half of whom specifically named

the efavirenz/tenofovir/FTC combination pill, *Atripla*. Another 18 people mentioned other once-daily regimens, making this the second-most cited aid to adherence.

One respondent combined both a pill box and *Atripla*: "I have a small plastic 'bullet' which holds my Atripla; it rattles with my body movement from time to time and reminds me if I haven't taken the pill."

Support from friends, family or partner was mentioned as important by 6% of respondents and the importance of a daily routine by 5%. "Just knowing I'll die if I don't", or variations on that theme, was also an important motivation.

Other respondents used this space to give us short biographies or confessionals, which were sometimes very moving. Here are two examples of how and why people consciously choose to adhere to their treatment, day in, day out:

"I was an irresponsible single man when I became infected with HIV, I worked hard and partied harder. My diagnosis in 2002 changed my life entirely. I've now got a partner who is also positive and we help and support each other through the bad days. Drugs can keep you alive, but you have to believe it's worth taking them first."

"I think the love I have for life and my children encourages me to take them. I have young children and I would love to see them through their childhood and adulthood and get educated while I am alive. I don't want to die now, when they are so young. Who will look after them if am not responsible enough to take my medication? I have a lot to live for."

For more information and tips on adherence, visit NAMlife's adherence pages: [www.namlife.org/cms1254857.aspx](http://www.namlife.org/cms1254857.aspx)

# the nam treatment survey

When would you start HIV treatment? What are your biggest worries about it? If you're on it, how has it affected you? These were some of the questions NAM asked in a recent online survey. Gus Cairns analyses the results – and the participants' illuminating comments.

It all started earlier this year when I was asked by Professor Ian Weller of University College Hospital in London if I'd speak at the biennial Glasgow Congress on Drug Therapy in HIV Infection, which he chairs. The subject was "When to Start Therapy? the Patient's Viewpoint".

I was honoured, but daunted, because I had no idea what most patients thought about when to start taking treatment. I know what I'd thought: I started AZT in 1989, with very mixed feelings, and subsequently stopped HIV treatment altogether for four years. No enthusiast, me. That was in another era, when it really was possible to doubt if the drugs were any better than the disease. When combination therapy finally came along, my ten T-cells and I clutched at it like a drowning man. I had no idea, though, what a newly diagnosed patient in the era of 'manageable' HIV thought about antiretroviral drugs.

In addition, international guidelines changed last year. Given the results of the large SMART study and others, which indicated that there was a benefit to starting treatment earlier, the three most influential sets of treatment guidelines (the US, UK and European ones) now recommend that treatment is started at a CD4 count of 350, rather than 200. Had this important change filtered through to

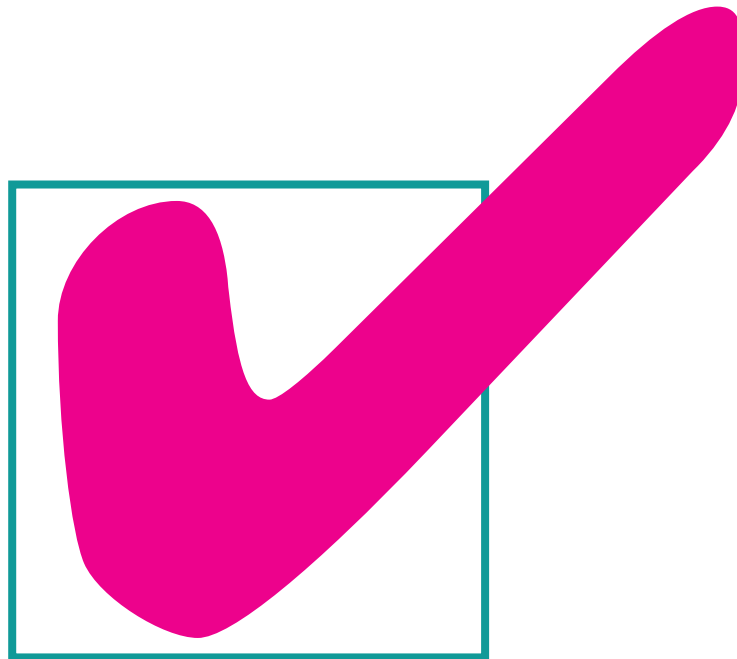
the patients, and did they go along with it? I'd no idea.

There have of course been studies of patient opinion on treatment before, mainly focusing on what drives good and poor adherence. One US study from 2003<sup>1</sup> found that adherence was a dynamic phenomenon that changed over time with patients' changing beliefs, attitudes, emotions, and daily and larger life events. It also found that intentional non-adherence was often driven by side-effects. In 2007, Rob Horne of Brighton and Sussex University Hospitals found very similar results<sup>2</sup>: adherence to HIV therapy was driven by a constantly shifting trade-off in patients' minds between the experience and fear of side-effects (like my AZT-caused anaemia) and the perceived necessity for the medicine (like my ten T-cells). But these were relatively small studies conducted before the guidelines changed and concentrated solely on adherence. I felt I needed more to go on.

So working with Keith Alcorn, NAM's Senior Editor, and the team at NAM, we devised a comprehensive online survey and put it on aidsmap, NAM's website. We made it quite detailed, and in order to extend it to as many of aidsmap's international readers as possible, translated it into Spanish, French and Portuguese. It went online on 12 September 2008.

As I write, the survey is still online but is due to be finished before this edition of *HTU* goes to print. The results published here represent data collected up to 10 December 2008 but, because we had a large response early in the survey, results are unlikely to change significantly.

It is important to remember that people responding to internet surveys like this are a self-selected sample. They were, presumably, people who had access to a computer, people who were interested enough in HIV to visit aidsmap and respond to the survey, and people who knew enough about treatment to understand the questions. This means they can't be taken to be representative of the entire HIV-positive population, even those on treatment. However, we believe that the answers to some of the questions, such as those about people's concerns about treatment and their experience of side-effects, at least indicate which issues are likely to predominate in the HIV-positive population more generally.



## The survey structure

A total of 2194 people with HIV have answered the survey to date. The majority, about 69%, answered the English survey, but there were respectable returns to the Spanish (16%) and French (13%) surveys. There wasn't much usage of the Portuguese survey, with only 36 respondents.

The survey was divided into four sections. Its initial aim was a fairly narrow one: to find out whether patients were aware of the new guidelines recommending starting HIV treatment at a CD4 count of 350 and whether this had made a difference to their own decisions on when to start. For this reason, although we didn't want to exclude anyone, we initially asked people if they lived in a selection of developed countries (in North America, Europe, Japan and Australasia) that appeared on a drop-down list.

If they didn't live in one of these countries, they were not excluded from the survey, but answered a separate section of it. This didn't ask for demographic information such as

gender, age and ethnicity, but it did ask if people were on treatment, what their concerns and doubts were about it, and what side-effects they had experienced. The people answering this section were also asked about three additional concerns, which we felt were more relevant to respondents in resource-limited settings: whether they were worried about accessing drugs, whether they could maintain a regular supply, and whether cost was a factor for them.

We also asked all respondents if they knew about the new guidelines' recommendation on when to start HIV treatment and if they were aware of the importance of adherence.

For respondents in the named developed countries, we asked if they were drug naive (had never been on treatment), were on treatment currently, or had started treatment but subsequently stopped. We also asked for demographic information.

They were then guided to three different sections which asked the same questions about their concerns before starting therapy – in other words, what their concerns were *now* if they were considering starting or restarting HIV treatment, and what their concerns *had been* if they were already on it. People who had never taken treatment were

asked at what CD4 count they would start. People already on treatment were also asked about when they started, at what CD4 count, what their concerns were now they were taking it, and also about side-effects.

In retrospect, it would probably have been better to ask the same questions of all respondents. We got a higher than expected response from people in resource-limited countries, and some felt a sense of injustice at being excluded from certain questions.

"The survey was targeting only some continents. Africa, Uganda in particular, was not mentioned. In Uganda HIV therapy is started only when CD4 is 200. Can the next survey also cover Uganda?" asked one. Another commented: "This survey only seems to be interested in the countries on the list."

Others pointed out that in parts of the world which are seen as resource-rich, drug access and cost could be an issue too. A US respondent said: "In the USA, HIV robs many of living a life. I was a well paid professional but now if I were to work I would lose my social security disability and Medicare. The USA is so quick to help the rest of the world while many HIV-positive US citizens lie on sidewalks."

## Country of residence and treatment status

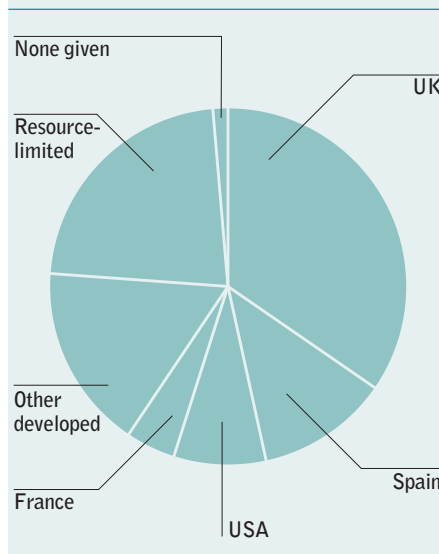
Of the 2194 people with HIV who responded to the survey, not surprisingly, the best-represented country was the UK, but it was by no means a majority: just over a third of respondents (36%) said they were living in the UK.

Another quarter came from Spain, the USA and France, 17% from other developed countries, while just under a quarter (22%) came from resource-limited countries. A higher proportion of people who answered the Spanish (32%) and, especially, the French (46%) surveys came from resource-limited countries. People responding to the Spanish survey were no less likely to be on treatment, but the proportion of people in the French survey on treatment was lower. This may reflect differences in treatment availability between Latin America and Francophone Africa.

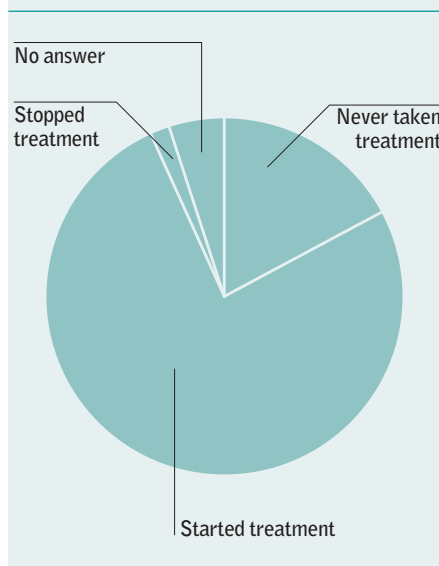
In the developed countries, over three-quarters of respondents (77%) were on treatment, while 17% had yet to start. One of the striking results from the survey was the tiny number of respondents who were on treatment breaks – just 29 people, or 1% of the total. It is unclear whether this reflects a very small proportion of people taking 'drug holidays' or if it is because people who have stopped treatment are less likely to read and correspond about HIV – probably a bit of both.

In the resource-limited countries, just under half of the respondents (49%) were on treatment and 39% were not (12% didn't answer).

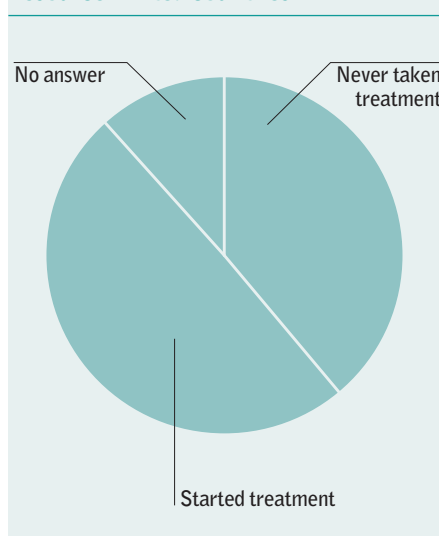
Breakdown of respondents by country of residence



Treatment status – developed countries



Treatment status – resource-limited countries



## Demographics and CD4 counts

Our respondents were in the majority quite new to treatment. Half of them had started treatment since 2004; a third since 2006; and one in six in 2008. One respondent said he was filling out the survey on the day he was diagnosed.

As mentioned above, we only asked for demographic information about the people who responded from the developed world. This provided a picture of a middle-aged and predominantly white gay male population. The average age of respondents was 35 to 40, and 88% described themselves as white. Only 10% of respondents to the English survey were women, but that proportion rose to nearly a quarter in the other three surveys. Similarly, only 15% of the English survey respondents said they were heterosexual but that rose to 32% in the French survey and 45% in the Spanish. These figures might have been different if we had included respondents from resource-limited countries in this section.

The answers to our questions about CD4 counts provided the strongest evidence that this was a treatment-aware and well-informed group of people. One surprising result was that only 11% of respondents to the English survey said they had a CD4 count under 300, and even fewer in the other three languages.

The majority also answered "yes" to the question "Did you know that the



## Concerns about therapy

recommended time to start treatment in Europe and North America is when your CD4 count is around 350 cells/mm<sup>3</sup>? – although this may have been prompted by the way the question was asked. Eighty-five per cent answered “yes” to this overall and 70% of respondents in resource-limited countries answered “yes”.

Drug-naïve patients in developed countries were asked when they would start treatment. Nearly half (47%) said “When my clinic advises” but the other half had a target: 37% said they’d want to start as soon as or even sooner than the guidelines suggest, at a CD4 count of 350 or above. Only 15% said they’d start at 300 or lower and only 4% would wait till their CD4 count reached the previous guideline level of 200 – so the new guidelines seem to have been taken on board, for aidsmap readers at least.

In contrast, when the people on treatment in developed countries were asked what their CD4 count was when they had started, less than a quarter (24%) had started at a CD4 count over 350 and 42% at a count under 200. In addition, around one-sixth had started treatment in the pre-HAART days – before 1997. Taken together, these data suggest that, broadly speaking, people were starting treatment in line with the guidelines that applied at the time they were judged to be ready to start.

Probably the most detailed and interesting quantitative data from the survey came from the series of questions we asked people about their concerns before starting therapy, and what concerns they had now they were on it. We asked everyone if they had concerns about the following subjects before starting therapy, whether they were already taking it or not:

- Side-effects
- Effectiveness of the therapy against HIV
- Impact of taking therapy on stigma and confidentiality
- Issues of lifestyle and practicality
- Interactions with other drugs
- Whether they were worried about not being able to adhere to therapy
- Combining HIV therapy with complementary/traditional therapies

...and, as we said above, we also asked respondents in resource-limited countries if they were worried about access to therapy, maintaining a regular supply, and cost.

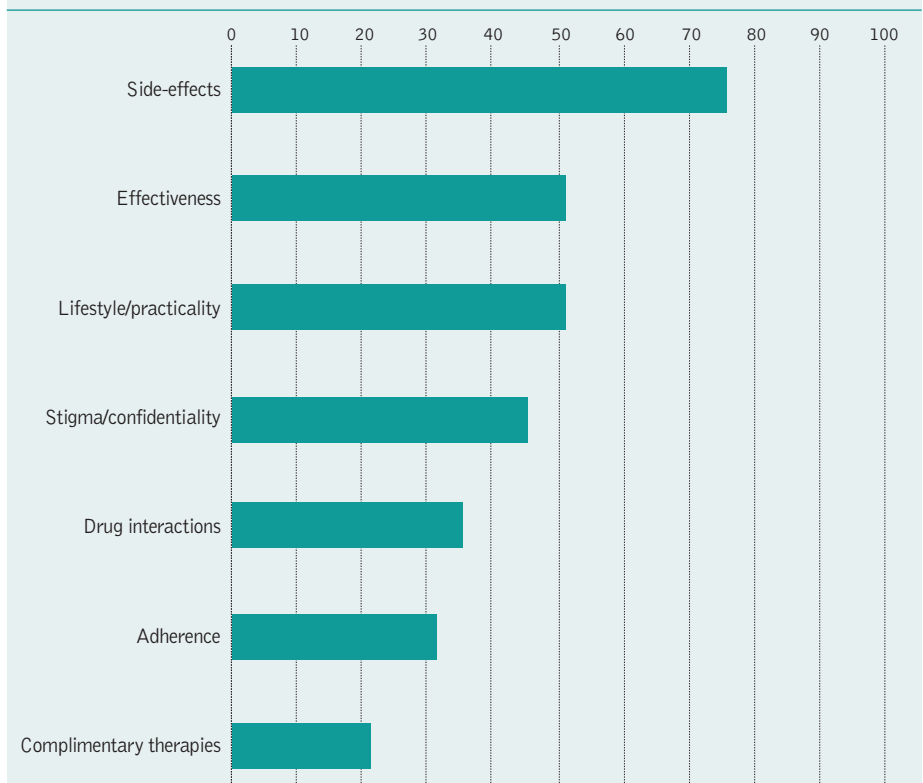
One message came through loud and clear from these questions. By some way,

the most significant worry people had before starting treatment was the fear of side-effects. Nearly four out of five people (78%) had ‘major’ or ‘important’ concerns about possible drug side-effects before starting treatment. The only other categories where more than half of respondents reported concerns were the effectiveness of the drugs (54%) and lifestyle and practicality (53%), although stigma and confidentiality concerns were important for a lot of people too.

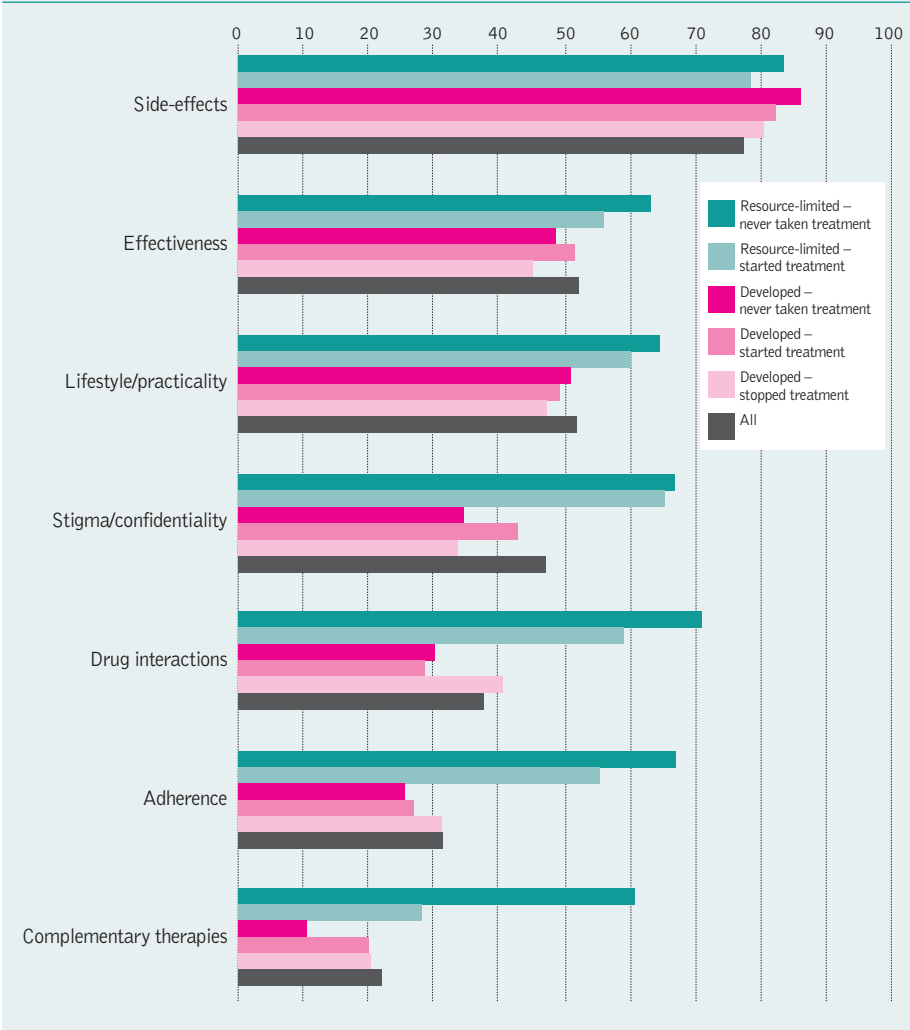
Were those on treatment less likely to have been worried about these issues before starting than people who hadn’t yet started? No: the proportion that worried about the different topics was more or less identical regardless of treatment status. This consistency suggests people were giving honest answers about their concerns and not dramatising or underplaying the issues affecting them.

There were important differences between respondents in resource-limited countries and developed-world respondents here. ►

Proportion of all respondents who have, or had, ‘major or important’ concerns about re/starting treatment



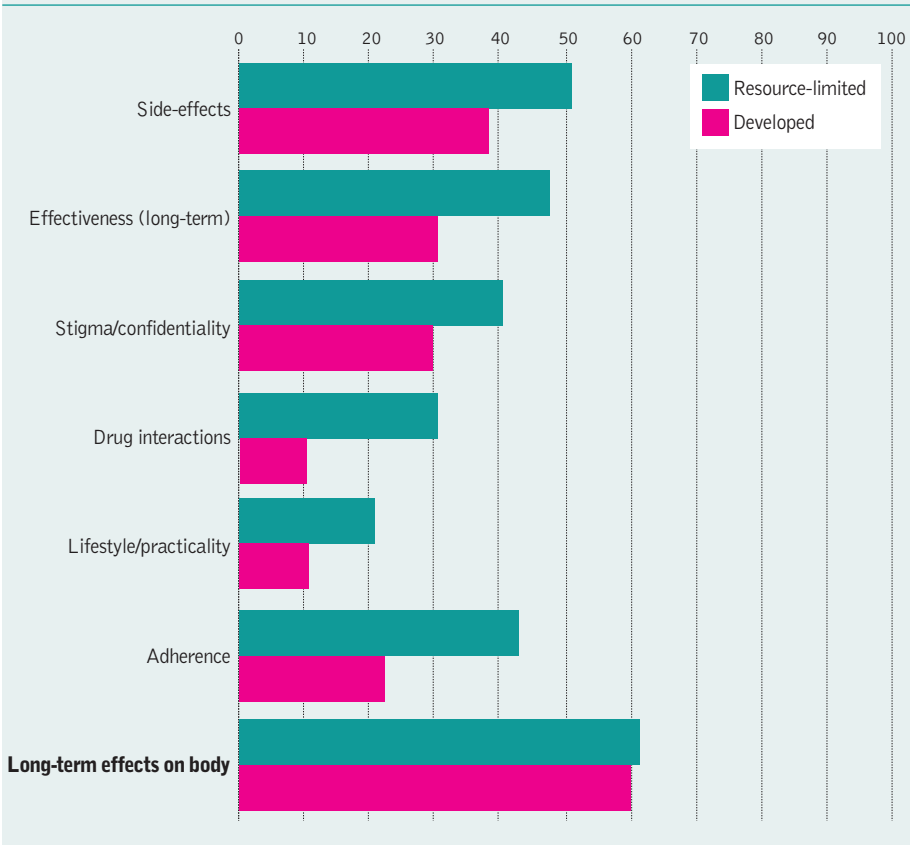
**Proportion who have or had 'major or significant' concerns about re/starting treatment**



While everyone was worried about side-effects to the same degree, people in the resource-limited countries tended to worry about nearly everything else more too. In particular, they were disproportionately concerned about drug interactions, stigma and confidentiality, adherence, and combining drugs with traditional medicine – in comparison with their counterparts in the developed world. In the resource-limited countries, people who were drug naive were more likely to cite worries than people on treatment. These differences may reflect a lack of information on treatment, as well as the very different circumstances.

These concerns abated to some extent when people started treatment, only to be replaced by others. Once people had started therapy, the proportion for whom most of the above topics were a 'major concern' was approximately halved. However it was replaced by a different concern; not worrying about immediate side-effects, but worrying about what side-effects might come along in the future. Fully 60% of respondents taking treatment said they worried about the potential long-term effects of drugs (patients in resource-limited countries also had significant concerns about continued regular drug supply [51%] and cost [32%]).

**Major concerns of respondents on treatment**





# Side-effects

What about those side-effects? Are they common and, if so, do they have a significant effect on health and quality of life? We asked all the respondents who were on treatment about a specific list of side-effects that covered most of those seen in HIV-positive patients. These were:

- Nausea/diarrhoea
- Psychological side-effects such as dizziness, bad sleep, bad dreams
- Fatigue and anaemia
- Skin rashes, dry skin, hair loss etc
- Sexual dysfunction
- Fat loss/gain/body-shape change
- Symptoms suggestive of neuropathy such as numbness, tingling and pain
- Liver problems
- Kidney problems
- Bone problems such as osteoporosis and fractures

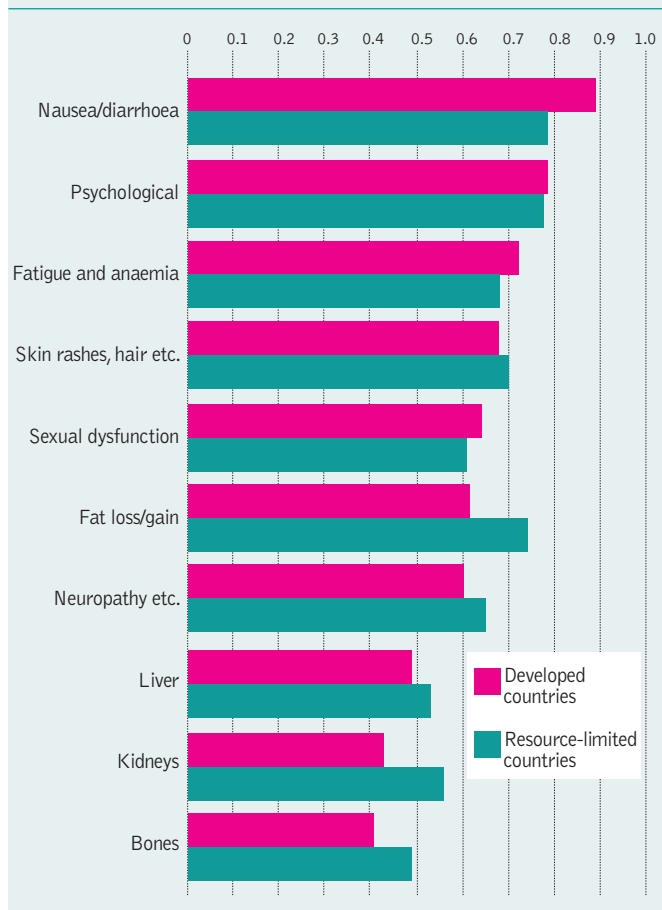
We then asked them to say if these side-effects:

- Were transient and short term
- Affected quality of life for more than three months
- Had a serious long-term effect on quality of life.

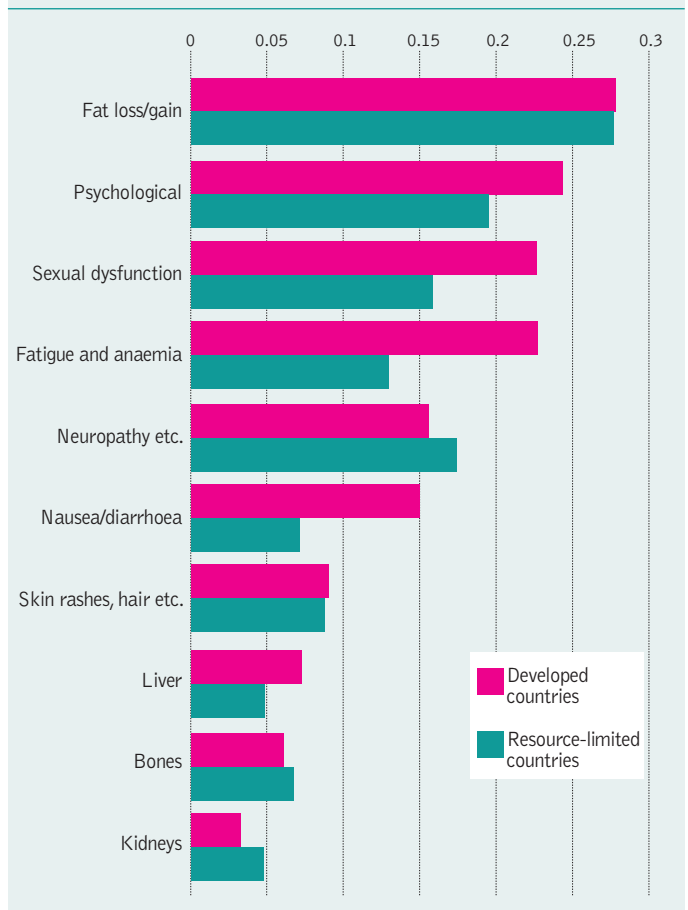
There were interesting differences between the absolute proportion of side-effects and the severity of them. A large proportion of people had experienced side effects, with 80-90% saying they had had nausea or diarrhoea and nearly as many saying they had suffered from psychological effects, fatigue or anaemia, and skin problems. These proportions may sound very high but are not that surprising given that we were asking if people had *ever* experienced them, even if only once or a long time ago. What was perhaps more worrying was that people in the resource-limited countries said they had experienced more fat redistribution and kidney, liver and bone problems, which may indicate the effect of suboptimal drug regimens such as those based on d4T.

However, frequency of side-effects is not the same as severity. When asked about the side-effects that had produced the most serious, long-term effects on their quality of life, patients everywhere came out with one predominant answer – lipodystrophy. This was by some way the side-effect most likely to have a severe effect on quality of life, especially in patients from resource-limited countries. In the developed world, patients also reported psychological problems, fatigue and sexual dysfunction – problems that patients from resource-limited countries might also experience but possibly be more stoical about. The more serious side-effects indicative of organ toxicity were in general transient – maybe because people switched therapy if they happened – and less likely to be prolonged and problematic. (Note the chart on the right has one-third the scale of the previous one: no side-effect was experienced as serious and long term by more than 28% of patients.)

Proportion of patients with any side-effects



Proportion of patients with serious, long-term side-effects



## Other comments and themes

We also asked people if they had any other comments at the end of the survey, and a quarter of respondents to the English survey (382 people) took the opportunity to comment. These comments provided such a wealth of information that it almost needs another article to do them justice. Again, people used the space for many reasons: to give us a brief life story; to sound off about doctors and the medical profession, or to praise them; to tell us what a good or bad time they'd had with side-effects; and to criticise or praise the survey itself.

Going through the comments, however, a number of specific themes emerged.

**1. Long-term survivors.** As mentioned above, only one in six respondents started therapy before 1997. However, we didn't ask specifically about date of diagnosis and it's possible other respondents had soldiered on without therapy from the early 1990s. A number mentioned being diagnosed in the 1980s; one was now 82 years old. Several mentioned the issue I cited in my own case, being put off from taking therapy because of the side-effects of the old regimes. One said: "When I first became sick AZT was the only drug. That coloured my decision to wait for other treatment."

Others just felt the survey was not designed with them in mind:

"I started therapy in 1993 and many of the questions don't apply to me, as you did what the doctors told you and hoped to stay alive."

"I had to answer 'no access to treatment' when you asked why I didn't start because I was diagnosed in 1986. There are some of us still around you know!"

**2. Doctor and patient.** Many cited a specific consultant or healthcare worker who had helped them, and were full of praise: "I have a great working relationship with my doctor and his team. I'm in two clinical trials, the doctors talk to each other and I feel very

well informed," said one. Another found nurses rather than doctors to be more helpful: "The nursing staff have been much more helpful and informative than the doctor. I do not understand what the doctor has said so ask the nurse after seeing the doctor."

A number of patients, however, mentioned that the way the NHS worked made it difficult to maintain relationships with valued healthcare workers:

"I had an excellent consultant who knew everything about me but she was in a temporary post and everyone in the clinic was shocked when she was not employed permanently. This made me lose confidence in my clinic."

"My infectious-diseases doctor only wants to concentrate on HIV. I have high lipids, blood pressure, depression, unexplained back pain and he expects my GP to monitor them. Too many doctors, too many co-pays, too many things to track." (US patient)

**3. Side-effects.** As mentioned above, this was already a major concern, and a number of patients wanted to expand on this theme further:

"I am a nurse and expected to be able to handle a lot of my side-effects but it scared me when the drugs made me feel out of control. No health professional said it would be that bad."

"Despite the success of HAART the stigma of LD [lipodystrophy] has a devastating effect. Appearance and its psychology could be better handled in the overall literature."

"I am very scared of the side-effects especially this body-changing lipodystrophy." (recent starter)

### 4. Disclosure, stigma and isolation.

Stigma was specifically mentioned by a few people, and they had mixed feelings about whether taking treatment might make this worse rather than better.

"Taking meds feels like a rubber stamp on my diagnosis; once I say I am taking

ARVs [antiretrovirals] then I have disclosed my status," said one. But another said, "With the drugs, people cannot see a difference between me and the general population. It lessens stigma and encourages people to get tested." A number mentioned they were living in extremely isolated conditions. Two, for instance, were in rural towns in Spain and one in a small town in Iceland. Others bemoaned the lack of HIV-specific social groups. For others, the isolation was self-imposed: "I think there are long-term issues of trust that have never gone away. I am extremely secretive of my diagnosis."

**5. Access and cost.** As we mentioned above, respondents mentioned struggling to secure medications, not only in the countries we would identify as being resource-limited, but also in some 'rich' countries:

"I wish the WHO could make it a law that people must be started at 350. I'm still not on treatment here in Africa having been diagnosed with HIV and TB for 13 years and seeking ARVs for ten."

"I recently lost my job and my Atripla co-payment [the amount a health insurance company asks a patient to contribute to prescription charges] is over \$300 a month. I am worried sick about this." (US patient).

**6. Mental health.** People wanted specifically to mention that emotions also swayed treatment decisions. "You did not list depression as a reason for not staying on meds," said one. Another said: "One thing you didn't mention that could delay treatment was fear. I waited almost five years to tell anyone or seek treatment: I had zero T-cells."

Another talked starkly about not knowing if they wanted to live at all: "No question allowed for the patient's decision-making to be influenced by a lack of desire to live a longer life as HIV-positive. This was my own reason for initially refusing treatment." Another had triumphed over grief, however: "Taking meds is my way of saying I want to live and not give up, even though my partner of 25 years has passed away."

## Conclusions

As we said, a number of studies have already found out what contributes to willingness to take treatment and to good adherence. In the main, their conclusions were of the "you don't say!" variety; having negative views of therapy makes you reluctant to take it; believing it will work makes you keen.<sup>3</sup>

This survey adds or reinforces several points:

- It is important to assess depression, social isolation and health beliefs BEFORE people start taking HIV drugs.
- Most patients these days are happy to start taking therapy sooner.
- The *fear* of side-effects is still extremely important, especially lipodystrophy, as is previous experience of them.
- The simplest things help most with adherence: alarms, pill boxes, once-a-day regimes.
- A partnership with a trusted healthcare provider (of various types) is as important as ever.

Many thanks to Keith Alcorn and the team at NAM for devising and putting up the survey and to Prof. Ian Weller for prompting it in the first place. A webcast of a presentation about the NAM survey can be viewed at [www.hiv9.com/webcasts/MDI/index.htm](http://www.hiv9.com/webcasts/MDI/index.htm) - look for the "Hot Topics and Late Breakers 2" section in the Congress presentations.

## What happens to the survey information?

The initial results of the survey were presented at the Ninth International Congress on Drug Therapy in HIV Infection, held in Glasgow in November 2008. The information gathered from the survey formed part of a well-received presentation on 'When to Start Therapy?: the Patient's Viewpoint'.

The Congress is an important event on the HIV calendar and brought together 3000 delegates, including HIV doctors, nurses and pharmacists from 80 different countries. It aims to provide an opportunity for those attending to learn and share good practice in the drug treatment of HIV.

Discussions after the presentation showed that audience members had recognised key themes. These included the importance of a patient feeling ready to start taking treatment, whether CD4 counts criteria for starting therapy would become less crucial over time, and the fear of side-effects as a major disincentive for taking therapy.

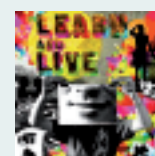
Here at NAM, feedback from people living with HIV is essential in informing our work, and the survey results will be considered carefully as we develop and shape our future projects, including our new patient information booklet on side-effects, which will be published in the next few weeks.

As *HIV Treatment Update* has a broad audience both among people living with HIV and health professionals working in the HIV sector in the UK, and is distributed free through HIV clinics, we hope that the thoughts and feelings of the people who completed the survey will reach an audience who can learn from and act on them.

There may be further opportunities to use the results of the survey in the coming months, and we would like to take this opportunity to thank everyone who took the time to complete it.

## Resources from NAM

This article covers lots of different topics relating to HIV treatment. It might have left you with questions about UK treatment guidelines, when to start HIV treatment or what your CD4 count means. Or maybe you would like to know more about adherence, side-effects or the different types of anti-HIV drugs?



Many of your questions could be answered by visiting our new website, [namlife.org](http://namlife.org) for all the facts and for personal stories written by people living with HIV.

NAM also produces a series of booklets on HIV treatment which you can order through our online bookshop at [aidsmap.com](http://aidsmap.com), by calling us on 020 7840 0050 or by emailing [info@nam.org.uk](mailto:info@nam.org.uk).

You can look at the full range in our online bookshop – titles include:



**HIV therapy**, which explains the British HIV Association guidelines,



**Viral load & CD4**, which explains what these tests are and what the results mean for you, and



**Anti-HIV drugs**, which explains the different types of drugs and the common side-effects they may cause.

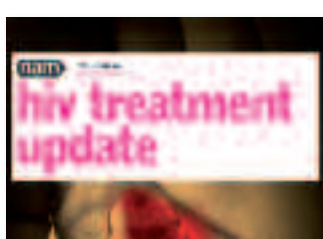
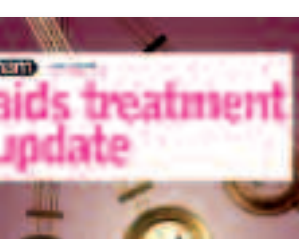
Our booklets are available free to people living with HIV in the UK and are also available free for clinics and support agencies in the UK to distribute.





# back to the future

Edwin J Bernard looks back over five years as editor of this newsletter



Back in October 2003, when I edited my first edition of *AIDS Treatment Update* (as it was known then), interest rates were 3.5% (they are currently 1%) and the average house price was just over £135,000 (currently £203,500 and also falling).

Although the number of drugs available and those prescribed have changed dramatically over these five years, some things, as we have just discovered in our treatment survey, have not changed at all. Back when I began as editor, the greatest concern for someone about to start treatment was how to avoid side-effects, notably lipodystrophy, and in particular facial fat loss (lipoatrophy).

Today, it seems, many people with HIV are still concerned about side-effects. Until not that long ago, one of the most popular strategies for people on treatment who were, quite literally, sick and tired of their side-effects was to take a 'treatment holiday', called a structured treatment interruption. The concept was discussed in July 2004 (*ATU* issue 138) and discredited following the early termination of the SMART study in early 2006 (*ATU* 154). Treatment interruptions were revisited, albeit cautiously, in December 2008 (*HIV Treatment Update* 182).

This is not the only example of the cyclical nature of HIV treatment strategies. The debate over when to start treatment has been reported many times in *ATU* over the past five years, beginning in October 2005 (*ATU* 150). By May 2006 (*ATU* 156) the old concept of 'hit hard, hit early' reappeared but it wasn't until March 2007 (*ATU* 164) that US guidelines (followed by European and UK guidelines later that year) finally recommended starting treatment before CD4 counts hit 350 cells/mm<sup>3</sup>.

What does this tell us? That what we may consider to be 'state of the art' today could be 'old hat' in a couple of years, and that in the world of HIV treatment, there are few absolutes.

### So many drugs...

In October 2003, HIV treatment choices were far fewer than they are today, particularly for people who had previously been exposed to several previous treatment regimens, as I had been.

Once you were on 'salvage therapy' – a term that smacked of desperation – you just

hoped for better drugs to come along, and preferably more than one at a time. This involved recycling drugs from the three current classes – NRTIs, NNRTIs and PIs – and possibly adding the revolutionary new entry inhibitor, T-20 (enfuvirtide, *Fuzeon*) that requires reconstituting from powder and injecting twice a day.

No wonder, then, that we heralded a new era in our December 2006 issue (*ATU* 162) with the headline, 'From salvage to salvation'. New drugs arrived in the clinic in quick succession, starting with the PI tipranavir (*Apitvus*), approved in October 2005, and darunavir (*Prezista*) approved in February 2007, and followed by the new NNRTI, etravirine (*Intence*), approved in September 2008.

"They're not perfect," I wrote, "but these better drugs have now arrived, and the term 'salvage' really is no longer appropriate for the vast majority of highly treatment-experienced individuals in the UK."

Even more exciting were the new drug classes, CCR5 antagonists and integrase inhibitors, which meant that entirely new NRTI-, PI- or NNRTI-sparing combinations were possible. However, the approval of the first CCR5 antagonist, maraviroc (*Celsentri*) in late 2007, and the first integrase inhibitor, raltegravir (*Isentress*), in early 2008 also came with the realisation that the drug development pipeline had slowed considerably. There may well be a handful of new drug approvals in the next five years, but they are unlikely to be as revolutionary a development as we have just witnessed.

Interestingly, it was another innovation, the belated arrival of *Atripla* – the first modern potent combination of three drugs in one pill, and taken just once a day – that captured most mainstream imagination. *Atripla*, which contains the drugs efavirenz, tenofovir and FTC, was finally made available in the UK in December 2007, eighteen months after its US approval. "Is it the 'holy grail' of anti-HIV drugs; the treatment we've all been waiting for?" we asked in May 2007 (*ATU* 166). "If *Atripla*'s components are right for you, and the drug becomes available in your clinic, it's obviously worth considering," we concluded. "However, another potent, tolerable once-daily regimen consisting of more than one pill – or even a twice-daily regimen – may still be preferable."

### ...so little time?

Those of us who are well informed about HIV treatments know that someone diagnosed with HIV in a timely manner is now expected to live a relatively 'normal' lifespan. The concept was first expressed in *ATU* by one of our longest-standing medical advisory panellists, Professor Brian Gazzard of London's Chelsea and Westminster Hospital. "My personal view is that most people on HAART will have a normal lifespan," he told us in January 2005 (*ATU* 143).

It took a while to sink in. In 'Great expectations' (*ATU* 162) published at the end of 2006, we asked more experts, "Can people with HIV really expect to live a normal lifetime?" and we noted that "it is becoming increasingly likely that if you live in the UK, and are diagnosed and under care, that HIV/AIDS will not be the cause of your death." The latest data currently suggest that the gap is narrowing between the average lifespan of an HIV-negative and HIV-positive individual.<sup>1</sup> Another recent study<sup>2</sup> calculated that a 35-year-old diagnosed between 2002 and 2005 with a CD4 count above 200 cells/mm<sup>3</sup> could expect to live well into their 70s.

However, the concept that someone with HIV might live close to a normal life – both in terms of quality and quantity – is one that has developed slowly over the past five years. Some might argue there's still a long way to go.

Certainly, the best prognoses are for those with the luxury of an early diagnosis. As I noted in 'Rethinking when to start' (*ATU* 156; May 2006), "in the real world many people are not being diagnosed HIV-positive until their CD4 counts have fallen below 200 cells/mm<sup>3</sup>, making the debate about whether to start earlier something of a moot point... Perhaps more time, money and effort should be spent trying to overcome the many obstacles that prevent people from testing for HIV in the first place, and making sure that treatment guidelines are followed uniformly across the UK. After all, what's the point of life-saving treatment, and guidelines for their use, if so many people are falling between the cracks?"

One of the things that hasn't changed in five years are the numbers of people who are diagnosed too late to make the most of the latest advances in HIV therapy: overall 33%<sup>3</sup> of new HIV diagnoses in the UK and Ireland continue to be made when an



individual's CD4 cell counts are already below 200 cells/mm<sup>3</sup> – the percentage is even higher in black Africans.<sup>4</sup>

However, as we reported in November 2008 (*HTU* 181) new HIV testing guidelines<sup>5</sup>, issued in September 2008, “urge healthcare workers of all specialities to consider HIV testing in a wide range of situations and settings. It is part of a package of recommendations to reduce the number of late and undiagnosed HIV infections in the UK.”

In a move that could be just as significant for HIV in the UK as the life-saving treatments that have been developed in recent years, the guidelines aspire “to put an end to ‘AIDS exceptionalism’ – which suggests that HIV testing could not be handled by mainstream health services, and that specialised pre- and post-test counselling is required.” It remains to be seen, however, whether these aspirations are followed through and make the difference we all hope for.

### New directions

In so many ways, life for people with HIV has changed remarkably over the past five years, which is why NAM decided, in January 2008, to change the name of this newsletter. “Today, HIV infection is treatable,” I wrote in the first *HIV Treatment Update* editorial. “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.”

The name change was, however, just the icing on the cake when it came to changes in the look and feel of NAM’s treatment information. In October 2006, we undertook a major redesign of the newsletter after in-depth research revealed that many people who would find the information it contains valuable were put off by the old design which they found too daunting, too medical, and too difficult to get into.

One of my proudest moments as editor was revealing results of our post re-launch readers’ survey that found that the new design had a very positive impact on how the newsletter is read and rated. Of those respondents who had been readers prior to October 2005, and who expressed an opinion, 99% found the new look easier to navigate; 96% found it more appealing; and 94% found it to be more trustworthy since the redesign (*ATU* 160, October 2006).

## My Top Five Significant Events for People Living with HIV, 2003 to 2008

What	Why	Where
<b>1</b> <b>New salvage options,</b> 2005-2008	A cornucopia of new drugs has led to a substantial increase in treatment options as well as an increased life-expectancy for people at all stages of HIV infection.	<ul style="list-style-type: none"> <li>● <i>ATU</i> 162 (December 2006)</li> <li>● <i>ATU</i> 164 (March 2007)</li> <li>● <i>HTU</i> 173 (January/February 2008)</li> <li>● <i>HTU</i> 174 (March 2008)</li> <li>● <i>HTU</i> 180 (October 2008)</li> </ul>
<b>2</b> <b>Swiss statement,</b> January 2008	Rocked the foundations of the status quo for prevention, criminalisation, reproductive rights and stigma.	<ul style="list-style-type: none"> <li>● <i>HTU</i> 175 (April 2008)</li> <li>● <i>HTU</i> 179 (August/September 2008)</li> </ul>
<b>3</b> <b>SMART study,</b> January 2006	Showed that drug side-effects are much less harmful than uncontrolled HIV; points to role of inflammation in HIV-related disease; suggested earlier treatment is better.	<ul style="list-style-type: none"> <li>● <i>ATU</i> 154 (March 2006)</li> <li>● <i>ATU</i> 156 (May 2006)</li> </ul>
<b>4</b> <b>Criminalisation of HIV transmission,</b> 2003-2008	Established that HIV transmission without disclosure can be a criminal offence; led to concerns over impact on doctor-patient confidentiality and miscarriages of justice; increased stigma.	<ul style="list-style-type: none"> <li>● <i>ATU</i> 131 (November 2003)</li> <li>● <i>ATU</i> 148 (July/August 2005)</li> <li>● <i>ATU</i> 159 (August/September 2006)</li> <li>● <i>ATU</i> 160 (October 2006)</li> <li>● <i>ATU</i> 164 (March 2007)</li> </ul>
<b>5</b> <b>NHS changes,</b> 2003-2008	Cost increasingly an issue, first affecting non-EU migrants; and now, with increasing numbers living with HIV and stagnating budgets, could affect all of us.	<ul style="list-style-type: none"> <li>● <i>ATU</i> 150 (October 2005)</li> <li>● <i>ATU</i> 158 (July 2006)</li> <li>● <i>ATU</i> 163 (January/February 2007)</li> <li>● <i>HTU</i> 177 (June 2008)</li> <li>● <i>HTU</i> 181 (November 2008)</li> </ul>



An archive of *HIV Treatment Update* (and *AIDS Treatment Update*) is available in the Treatment and Care section of our website, [www.aidsmap.com](http://www.aidsmap.com).

NAM continues to evolve the way it delivers treatment information, becoming increasingly more creative in its design to help people get the most out of life with HIV. Back in December 2004 (*ATU* 142), NAM launched the first edition of the book, *Living with HIV*, which epitomised the concept of living well with HIV that *ATU/HTU* has also tried to embody. A second edition, launched in 2006, was even more of a success, leading to the launch on 1 December 2008 of [namlife.org](http://namlife.org) – a new online, interactive portal containing all of the information in the book, and more. The launch of NAM’s news-digest email for

HIV-positive people, *HIV Weekly*, in the same month as the *ATU* redesign, was another example of innovative content delivery, and *HIV Weekly* now has thousands of subscribers all over the world.

### Future challenges

There really isn’t enough space here to detail all of the changes – many, but by no means all, improvements – in the way we live with HIV.

As we live longer with HIV – and with around 7500 more of us being diagnosed each year – HIV clinics all over the country

have had to cope with increasing numbers of patients in the face of stagnating (or even reduced) funding. Some of the solutions have been creative, and even positive – annual CD4 counts are now a possibility for those of us who are on stable, successful treatment, suggesting we are becoming less medicalised than ever before (*HTU* 177, June 2008). On the other hand, the cost of treatment, which eats into most of the NHS HIV budget, is becoming more of an issue. Now that the government has announced the removal of its ban on patients paying for drugs deemed too expensive for the NHS<sup>6</sup>, will there come a time when we have to pay top-up fees to access more expensive antiretrovirals than the NHS will pay for?

Even now, access to treatment and care remains an issue for some of us – those who attempt – and fail – to seek a knowledgeable and trustworthy GP to prescribe non-HIV medications (*ATU* 158: July 2006); those who are unable to find a dentist because of discrimination against HIV-positive patients (*ATU* 161; November 2006); and, most sinister of all, those of us who are perceived to be a 'treatment tourist' and denied any NHS care (*HTU* 181; November 2008).

When I first started editing *ATU*, the idea of ageing with HIV, and of facing the kinds of non-HIV illnesses experienced by our older HIV-negative counterparts – particularly cardiovascular disease, non-AIDS cancers, as well as liver, kidney and bone disease – was in its infancy. Today, these are some of our greatest health concerns and challenges.

And as the length of our lives increases, so do concerns about quality-of-life issues, notably around mental health. These issues have featured heavily in the newsletter over the past five years. In 'Understanding depression' (*ATU* 168: July 2007), Dr Pepe Catalan, consultant psychiatrist at London's Chelsea and Westminster Hospital, told us that: "Although we find that HIV often is a trigger, it's not always the main problem: often HIV-positive people have all types of unresolved issues." The longer we live, and the less we focus on simply staying alive, so those issues come to the fore. I know this only too well from (quite recent) personal experience!

The importance of our sexual and reproductive health has also been highlighted in recent years. I'm proud to have represented the HIV community

during the development of the first-ever British HIV Association (BHIVA) guidelines on the *Management of sexual and reproductive health (SRH) of people living with HIV infection*, which were finally published in September 2008.

They come at a time when gay men with HIV are also facing additional sexual health concerns, notably syphilis, LGV and sexually transmitted hepatitis C – all of which have been covered here in depth over the past five years. The guidelines also finally recognise that many men and women with HIV want to be parents and to have reproductive rights, although accessing assisted-conception services is still not easy.

Increased conception options are one of the reasons why Swiss HIV experts issued their vitally important statement in January 2008 about the effect of treatment on HIV transmission, which we examined in depth in April 2008 (*HTU* 175). The impact of the 'Swiss statement' is only just being felt, but the idea that treatment can be used as a prevention tool has already gained support at the highest levels (*HTU* 179, August/September 2008).<sup>7</sup>

Many other areas of living with HIV aside from HIV treatment – notably around money and work issues and HIV and the law – still require much more attention. Despite hard-won protection against discrimination in the provision of goods and services (thanks to the revision of the *Disability Discrimination Act* to include HIV from the point of diagnosis, in 2005), the stigma of HIV continues to haunt us, deeply affecting our relationships with ourselves, those around us, and society in general.

### Treatment for life

I feel confident that NAM, and *HTU*, will continue to provide the most up-to-date, relevant, accessible and impartial information about life with HIV in 2009 and beyond. As *HTU*'s new editor, Gus Cairns, wrote in an article examining whether HIV treatment was now a lifelong prospect, following the termination of the SMART treatment interruption study: "Perhaps there are worse things than popping a few pills every day. Maybe 'treatment for life' is just what it sounds like – a good thing."

This issue of *HIV Treatment Update* marks the end of an important chapter in the newsletter's history. It is the final issue, after five years, to be edited by Edwin J Bernard.

Edwin joined the staff team in 2004, though he was already well known to us as a regular contributor. He took up editorship at a time when the landscape for people with HIV was changing rapidly. Treatment was becoming simpler, side-effects increasingly manageable; the majority of people with HIV in the UK were living well, resuming full lives, holding down jobs, etc. Edwin successfully steered the newsletter to meet people's changed information needs.

He worked with NAM's marketing team on the newsletter's relaunch in 2005 which introduced a new, more accessible, design and broader content, including greater coverage of issues beyond treatment that nevertheless impacted on the health and wellbeing of readers, such as the criminalisation of HIV transmission. He has ensured that *HTU* remains one of the UK's authoritative sources of up-to-date information on HIV treatment and health, and we are very grateful to Edwin for what he has achieved.

Edwin will continue to work with NAM on specific projects but, for now, the mantle of editorship passes to Gus Cairns, who we are delighted to welcome to the NAM team. Like Edwin, he's well known to us and, of course, to you as a reader, having contributed pieces for *HTU* for some time.

**Caspar Thomson**  
Director, NAM



# news in brief

## hiv care

### Record number of people accessing HIV care in the UK

The number of people accessing HIV clinics in the UK has trebled in ten years, reflecting the record number of people living with HIV, according to figures released in late November by the Health Protection Agency (HPA). The HPA report also highlights continuing problems with late diagnosis and treatment of HIV, as well as a rise in cases of HIV acquired through heterosexual sex in the UK.

The report says that the number of new HIV diagnoses continues to be high, but has remained steady over the past four years. In 2007, a total of 7734 people tested positive for HIV. However, much larger increases have been seen in the number of people accessing treatment and care services. In 2007, a total of 56,556 people used HIV clinics, which represents a 9% increase in a single year. Moreover this is a threefold increase from the 17,911 people accessing care in 1998.

Some regions have seen particularly marked increases in the number of people accessing care over the past decade. The East of England Strategic Health Authority has seen its patient numbers increase sevenfold, while East Midlands has had a sixfold increase. The total proportion treated in London has decreased from 63% to 48%.

The report also demonstrates how the HIV-positive population has aged over the last decade. Five times as many people aged 50 and over were accessing care in 2007, compared to 1998, and they now make up 15% of those using HIV clinics.

(reporting by Roger Pebody)



## side-effects

### More information on abacavir side-effects

In April, (*HTU 175*) we reported that abacavir (*Ziagen*, also found in the combination pills *Kivexa* and *Trizivir*) had been found to increase the risk of heart attack, although this was only a significant concern in people who had other risk factors such as family history of heart disease or smoking.

Researchers had thought that the link between abacavir and heart attack could be explained if the drug was causing the small inflammatory changes seen in people taking it. Long-term inflammation can increase the risk of serious illnesses, like heart disease.

But new research suggests that this might not be the case. It found that starting treatment with abacavir actually had a positive effect on some of these inflammatory changes. An alternative explanation suggested by other research is that abacavir causes some subtle changes to the immune system that are linked to damage to important veins and arteries. Consequently, there is still some uncertainty about the link between abacavir and the risk of heart attack and further research is needed in order to provide some clearer answers.

Meanwhile, researchers in Brighton have reported that two young women developed serious liver side-effects after switching treatment to abacavir.

Both the women had been taking nevirapine (*Viramune*) with *Combivir* (which contains AZT and 3TC) and then switched from *Combivir* to *Kivexa* (abacavir and 3TC) due to concerns over AZT-associated fat loss.

However, about three months after starting *Kivexa* both women developed severe liver toxicities. Both the women had been tested for allergy to abacavir before starting treatment with the drug, and these tests had been negative. Confirming that abacavir was the likely cause, the health of their livers returned to normal once they switched away from abacavir.

Although these kinds of liver problems caused by abacavir are very rare, the doctors who reported the cases recommend that people taking abacavir should promptly report any unusual symptoms to their doctor.

(reporting by Michael Carter)

# news in brief

## hiv and exercise

### Exercise intolerance may be due to impact of HIV treatment on heart

Some HIV-positive people have been found to have a lower tolerance to aerobic exercise than their HIV-negative counterparts. Possible explanations have included a higher prevalence of anaemia or smoking in HIV-positive people, or simply a loss of fitness as a result of living with a chronic disease.

Now, researchers from France have published a small study suggesting that lower tolerance of aerobic exercise in HIV-positive people may be caused by an underlying heart problem that hasn't been diagnosed. Since all of the HIV-positive people in the study were on treatment, they suggest that antiretroviral therapy may be an underlying cause.

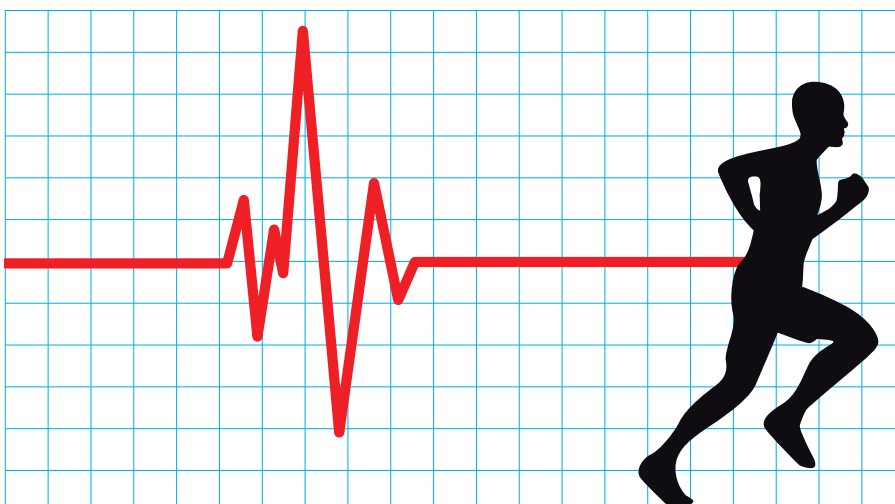
The researchers compared tolerance for aerobic exercise in a small group of HIV-positive and HIV-negative men. Other than their HIV status, the two groups were similar in their smoking and exercise habits. The HIV-positive men's results showed their hearts did not

perform as well in a number of ways – the most notable concerned mild dysfunction of the left ventricle (one of four chambers in the heart).

Consequently, the researchers suggest that doctors should consider providing people on HIV treatment with regular monitoring of their heart function. This would mean people could get any necessary treatment quickly and keep their heart healthy.

However, this research does not suggest that people with HIV should avoid exercise. You can find out more about the benefits of exercise and how to choose the right exercise regime for you on NAM's new website, [namlife.org](http://namlife.org). If you have any concerns about your exercise regime or are unsure what exercise is right for you, talk to your doctor or a healthcare worker for advice.

*(reporting by David McLay and Michael Carter)*



## hiv and general health

### Vitamin D deficiency common in people with HIV

Vitamin D is important to good health. It keeps your bones healthy and helps regulate your immune system. You can get vitamin D from your diet and from exposure to sunlight. HIV itself, as well as ageing, inadequate exposure to sunlight and/or a poor diet, can affect vitamin D levels.

Researchers in Holland recently found that nearly a third of the people with HIV they studied had a vitamin D deficiency. Although people taking NNRTI-based therapy were a little more likely to have low vitamin D than those on protease inhibitor-based treatment, these differences weren't particularly large.

Rather, the most significant factor was skin colour – in the study, people with a darker skin colour had lower levels of vitamin D. Whereas vitamin D deficiency was found in 19% of white study participants, this increased to 33% of participants of Mediterranean origin, 44% of Asian participants and 63% of black participants.

Because of the importance of this vitamin in bone health, which can also be affected by HIV and some antiretroviral drugs, the researchers suggest HIV-positive people should have their vitamin D levels checked, especially if they are on treatment or have a dark skin colour. Then any deficiency can be discovered early and treated.

*(reporting by Michael Carter)*

# Unsafe convictions?

Why advocates have concerns over recent HIV and hepatitis B prosecutions, by Edwin J Bernard and Michael Carter

More than 18 months after the last successful prosecutions in the United Kingdom for 'reckless' transmission of a sexually transmissible virus, two separate guilty verdicts for grievous bodily harm were handed down in English courts in November 2008.

One case, heard at Preston Crown Court, was the thirteenth successful conviction of criminal HIV transmission in the UK; the second, at Gloucester Crown Court, was the first-ever successful prosecution for 'reckless' sexual hepatitis B transmission.

These were the first successful prosecutions since the Crown Prosecution Service (CPS) produced guidance<sup>1</sup> on how and when to prosecute the transmission of serious sexual infections, and yet, in both cases, the CPS does not appear to have followed its own guidance, which states:

● Prosecutions are unlikely to take place as a result of one-off sexual encounters (the alleged hepatitis B transmission took place as a result of a single sexual encounter). "It will be highly unlikely that the prosecution will be able to demonstrate the required degree of recklessness in factual circumstances other than a sustained course of conduct during which the defendant ignores current scientific advice regarding the need for and the use of safeguards," it says in the legal guidance for prosecutors.

● Scientific evidence must be used to show that the defendant infected the complainant, but this evidence alone cannot conclusively prove the responsibility of the defendant for the complainant's infection. "The prosecutor will need to be satisfied that the complainant did not receive the infection from a third party or that the complainant did not infect the defendant," it says in the legal guidance

for prosecutors. "This means that the prosecutor will need to know about any possibility which is compatible with the scientific evidence that the complainant was infected by a third party. This means enquiries will have to be made about the relevant sexual behaviour and relevant sexual history of the complainant."

● Guilty pleas will not be accepted unless there is firm evidence proving the defendant's guilt. "We will not accept a plea to section 20 [of the *Offences Against the Person Act 1861* - reckless transmission] unless there is scientific, medical and factual evidence which proves the contention that the defendant recklessly and actually transmitted the infection to the complainant."

"These cases shame the Crown Prosecution Service for ignoring their own guidelines and policies," Chris Morley, Policy and Publications Co-ordinator at George House Trust, told *HTU*.

## Reckless HIV transmission

On November 21st, a 41 year-old HIV-positive man who pleaded guilty to 'reckless' HIV transmission was sentenced to one year in prison at Preston Crown Court.

The court was told that the man, who has haemophilia and acquired his HIV infection from infected blood products in his late teens, was thought to have infected his long-term female partner between 1994 and 1996. From press reports, however, it is unclear how the CPS proved this conclusively.

His lawyer argued that he had not disclosed his HIV infection to his partner due to the stigma attached to HIV. Condoms were used at the start of the relationship, but as the relationship developed the couple had unprotected sex. Shortly after the final separation, the man's female partner was diagnosed with HIV, as was a subsequent male partner to whom she is said to have transmitted the virus.

It is of note that the one-year sentence in this latest case is much shorter than those handed down in any of the previous cases ending in a conviction of reckless HIV transmission. This may have been



because the accused acquired his HIV infection from infected blood products.

In his sentencing comments, Judge Andrew Woolman said: "You were the victim of both haemophilia and from the misfortune of being given infected blood." He added, "It is a tragedy that I have to be sentencing you at all and I cannot restore back your health. [But] I have come to the conclusion that where a person puts their own needs before those of others there has to be some measure of punishment."<sup>2</sup>

The case appears to have strong similarities with early convictions for reckless HIV transmission, relying on a guilty plea and vague "scientific evidence", leading to concerns about the nature and quality of the legal advice the man received.

"As far as we are aware the defendant did not seek the support and advice of HIV organisations who are expert in these cases," noted George House Trust, "nor did he seem to have an expert barrister familiar with the most recent cases, none of which led to convictions."

### Reckless hepatitis B transmission

Campaigners have expressed even more concern over the first successful prosecution for the sexual transmission of hepatitis B virus on 18 November 2008, suggesting that this may be a miscarriage of justice.

The case involved a 29-year-old man who was accused of infecting a 27-year-old woman with the virus after unprotected sex. The man was convicted of grievous bodily harm at Gloucester Crown Court after entering a guilty plea, and was sentenced to two years in prison.

The two-year sentence the man received is lower than those imposed upon individuals accused of recklessly transmitting HIV, but is still at the upper end of the sentences allowed for grievous bodily harm. The woman developed chronic infection with hepatitis B. Not all patients with chronic hepatitis B develop health problems because of the infection. Should treatment be required, a number of highly effective drugs are available.

Lisa Power, Head of Policy at THT, called the conviction a "miscarriage of justice", adding, "it is entirely inappropriate for

someone to get two years for what is in most cases a treatable ... condition. But then, it's inappropriate to prosecute reckless transmission of a sexually transmitted infection in the first place."

This prosecution had a number of worrying similarities with early prosecutions for the reckless transmission of HIV. Most notably, the accused entered a guilty plea when presented with scientific evidence apparently confirming that he was the source of the complainant's infection. Like the early prosecutions for the reckless transmission of HIV, the case involved a migrant to the UK.

Yusef Azad, Director of Policy and Campaigns at NAT commented: "This is a significant and worrying case – the first successful prosecution in England for disease transmission other than HIV. Of course we want people who know they have a communicable disease to look after the health of their sexual partners, but prosecuting epidemics simply fills prisons and does nothing to prevent disease. We have serious concerns as to whether the new prosecution guidelines were properly followed in this case; we note as in the first HIV cases that it is a migrant who is targeted; we challenge the severity of the two-year prison sentence for hepatitis B which in adults is... treatable."

## HIV and the law on namlife

For more information on HIV transmission and the criminal law in the UK, visit:  
[www.namlife.org/cms1255092.aspx](http://www.namlife.org/cms1255092.aspx)

## Global Criminalisation Scan

The GNP+ Global Criminalisation Scan website, launched on 1 December, is now online at:

[www.gnppplus.net/criminalisation](http://www.gnppplus.net/criminalisation)

A living, growing document of laws, judicial practices and case studies of criminalisation worldwide, it includes data from over 150 jurisdictions worldwide.

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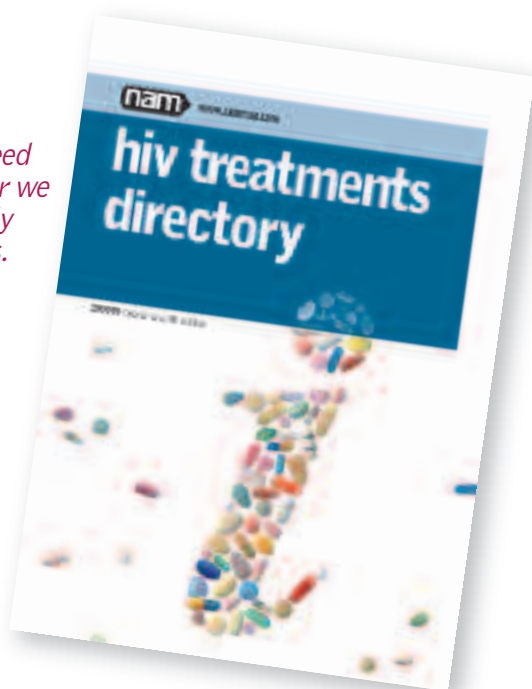


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