

HIV treatment update

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HIV treatment update

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In this issue



Gus Cairns
Editor

There's an unusually diverse mix of topics in this issue of *HTU*. You might say they span the 'before, during and after' of the HIV diagnosis experience.

The piece on pre-exposure prophylaxis (*PrEP wars*, page 8) returns to a topic we've covered before, but which, as we show, is one of the most hotly debated ideas in HIV right now. Using medicines, including vaccines, to prevent rather than treat disease has always been a controversial issue, from MMR to water fluoridation, because the benefit/risk calculation feels trickier: how can you be *sure* you aren't giving people what may harm them, to prevent what they might not get anyway?

Such feelings are often deeply held, not always rational and, in the case of HIV, can reach a particular sharpness. This is partly because advances in the tolerability of HIV medicines have happened so fast that many still see them as toxic drugs no one would take unless faced with death. But it's also because people ask the obvious question: "Why don't they use condoms?" – usually followed by a lament for the lack of efficacy of safer-sex campaigns. This isn't the place to go into why people don't, but the fact that many don't means we need more alternatives, and PrEP is a possible – though not unproblematic – one.

Tales of the late diagnosed (page 4) made me feel angry as I was researching it; so many near-deaths – and a tragic case of someone who died of AIDS, but could have been saved any time in the previous three years if only she'd been given an HIV test. No one is specifically to blame, though: as the piece makes clear, patient awareness, doctor awareness, testing availability and the fear of HIV all conspire to create a situation where far too many people still test far too late. A critical issue not only for their own health but, because they have spent all that time with detectable viral loads, for the health of partners too.

Finances for the over-50s (page 12) had rather the opposite effect. There are certainly a lot of people around, like 'Michael' in the article, who face poverty in old age because they never assumed they would *be* old, and because they were out of the job market for years. The piece, however, reminds us that this is an issue shared with a lot of people who don't have HIV (many HIV-negative people also leave it very late to prepare for their older age), and that there are possible remedies we may not have thought of.

One interesting aspect of the late-diagnosis and PrEP articles is that they don't directly concern the health of *HTU's* core readership – people with HIV. By definition, PrEP is for HIV-negative people, and we've already been diagnosed, late or otherwise. And yet people living with HIV are deeply involved in activism around both these questions.

This is partly because many of us are only too well acquainted with the harm that HIV can do, and we want to spare others the same experience. But it's also because HIV activists tend not only to care passionately about their cause but are also an unusually scientifically literate bunch. We know what is likely to work and what's likely to be a dud. Precisely because we are now living longer lives, it gives us the chance to give something back and to contribute as positive citizens.

Upfront

It's tough to make predictions

by Gus Cairns

"Generic HIV drugs 'less effective'", said the BBC headline. The article continued: "Any rise in the use of cheaper, non-branded HIV drugs could see more patients with treatment failure, doctors warn."

This news looked worrying, and as soon as it was posted on the BBC website, people flagged it up on social media websites.

In the last issue of *HTU* (see *The generic generation*, *HTU* 213), we looked at how many people's HIV drug regimens will probably soon feature cheaper generic versions of some antiretrovirals. Potentially, first-line regimens may be made up of entirely generic drugs within five years.

We discussed the cost advantages, but also whether this might reduce the efficacy of people's meds. This might happen if, say, a double- or triple-drug fixed dose combination (FDC) pill like *Atripla* (tenofovir, FTC and efavirenz) or *Kivexa* (abacavir and 3TC) were easier to take than the drugs as separate pills.

We also looked at whether there might be pressure to substitute a slightly less-effective drug, available as a generic, for a slightly more effective one that was still on-patent.

But the BBC report looked like it was saying generic drugs were worse because they were generics. This is still a widely held misunderstanding.

In fact, in order to sell their drugs, generic manufacturers have to show that the active ingredients in their products are chemically identical to, and reach levels in the body which are no more than 5% above or below, branded-drug concentrations.

The BBC report seemed to have found a study that said the opposite. When we looked into it, however, the study they cited¹ – in the prestigious *Annals of Internal Medicine* journal – seemed familiar.

We realised we'd reported on it last summer, when its lead author Rochelle Walensky, of Harvard Medical School, presented it at the International AIDS Conference in Washington.

The study did not say generics were

inferior. In fact, the news it gave was almost entirely good. Using generic HIV drugs would save the US health system nearly a billion dollars a year.

However, the researchers went further, and this is where the confusion started. They asked: let's just suppose that generics *are* somewhat inferior. What if adherence is a bit poorer to separate pills? What if 3TC is a little less potent than FTC? What if people just don't like getting different-coloured medicines?

So they fed into their model a worst-case scenario, within the boundaries of what's at all likely. What if generic FTC and efavirenz (plus branded tenofovir) were 7% less potent than the three drugs put together in *Atripla*? What if the generics failed for one in 20 patients in the first year, rather than one in 40, as is the case with *Atripla*?

If you made those assumptions, the mathematical model they used predicted that you'd lose 4.4 months from the average HIV-positive person's lifespan. Those 4.4 months were what the BBC report seized on.

People consistently misunderstand mathematical models. We treat them as infallible oracles and then feel lied to when they turn out to be wrong. But a mathematical model is not intended to be reality, which is far too complex to model.

Furthermore, people tend to confuse input with output, which is what happened here. The BBC report assumed the reduced effectiveness of generics was a finding, the sausage that came out of the machine. It wasn't; it was one of the assumptions used as input, the meat fed into the mincer.

This wasn't helped by Harvard Medical School putting out a press release that made it look as if the lower efficacy of generics *was* a finding.

"The switch from branded to generic antiretrovirals would place us in the uncomfortable position of trading some losses of both quality and quantity of life for a large potential dollar savings," Walensky is quoted as saying. 'Would place us' sounds like a prediction, doesn't it? Not

'would place us if our assumptions turn out to be true'.


The meat in this case was also of decidedly dodgy quality. There's only one study referenced in the paper² that found better clinical outcomes in people given a combination pill than separate drugs. The difference was quite significant in this case, but the study group – homeless people in San Francisco – may have very specific difficulties with adherence. Other studies reported on aidsmap.com either found no difference³ in clinical outcomes in people taking more pills or didn't take into account the fact that people on more pills are likely to be on second-line HIV regimens and may be sicker.⁴

They also cite three studies suggesting that FTC could be slightly more effective than 3TC, but this is disputed by a World Health Organization (WHO) analysis.⁵

All these factors could mean that taking people off combination pills could impact on treatment success, and it's perfectly valid to calculate what the impact could be. But if the assumption that using generics might impact on adherence or viral load doesn't stand up, then you save your \$1 billion with no shortening of life expectancy.

WHO wrote to the *Annals* journal, criticising the way the research was done and adding that adherence was only a problem if all-generic FDCs were forbidden by patent law. License generic tenofovir, and you solve the problem.

In the end, the BBC changed its headline to 'Study questions generic HIV drug use', which it did. But they still write "[Researchers] say, based on modelling and trial data, that generic medicines may be slightly less effective."

Enough, still, to worry some patients who find a generic pill in their clinic prescription. But like most predictions, it's dependent on the assumptions we make. Garbage in: garbage out. As the immortal baseball player Yogi Berra said: "It's tough to make predictions, especially about the future." 

Tales of the late diagnosed

Early testing
saves lives
and
money



Gus Cairns talks to four people who were diagnosed with HIV only just in time to save their lives – and the daughter of one who wasn't.

Now that antiretroviral therapy (ART) works so well, we can sometimes forget how remorseless a virus HIV can be if left untreated. Yet you don't have to go to countries with poor treatment access to see what AIDS looks like. Even in the UK, people are still turning up at hospital desperately ill, with no immune system, and with severe pneumonia, cancers, wasting, dementia... everything we used to associate with HIV in the bad old days.

Why? Late diagnosis. One of the aims of the recent National HIV Testing Week was to try and bring down the number of people in this situation, the late-diagnosed. These are the people tested for HIV far too late, when they have turned up somewhere – often in hospital – with CD4 counts in single figures. Sometimes they may have been scared to test, but often it's because they never suspected they had HIV. Some have avoided healthcare services, but too many have known something was badly wrong and been tested for everything but HIV.

Most pull through, but some don't. We talked to a number of people diagnosed very late to see if there were any common factors in their experiences.

But first, how much of a problem is late diagnosis among people in the UK?

A pricey problem

"Late diagnosis is dangerous – and expensive to manage," says Dr Ian Cormack, HIV consultant at Croydon University Hospital in south London.

"A year on antiretroviral therapy currently costs about £6000. The care bill for a recent patient who spent six weeks in our intensive care unit was well over £200,000, which would have been avoided if they'd tested a year before."

In his experience, for some groups, late diagnosis remains the rule rather than the exception. "I'd say at least two-thirds of my current patients here had a CD4 count below the treatment-initiation limit of 350 cells/mm³ at diagnosis.

"My patient group here is two-thirds black African and I do know people from that group who have tested late either because they think HIV is still a death sentence, or are worried about their immigration status."

But, he says, the people who really do scrape through – and the hospital had no avoidable HIV-related deaths last year, so scrape through they do – are the people who

“I'd say at least two-thirds of my current patients have a CD4 count below 350 at diagnosis.”

Ian Cormack
HIV consultant, Croydon University Hospital, south London

don't fit the typical 'high risk' demographic, the 13% of his patients who aren't openly gay men or black African people.

"The white heterosexuals are the most likely to turn up actually with AIDS-related symptoms. Them, and black Caribbeans, though we see a number of Asians too. They are often very ill and often have difficulties adjusting to their diagnosis, feeling especially isolated and stigmatised."

The bisexual man: Brian

One such person is Brian*. The north Londoner, diagnosed at Christmas in 2007, runs his own business as a wholesaler.

He started to worry "because I was looking too healthy. I tend to lose weight in the summer and pile it on again in the autumn. That year, though, I hadn't had to go on my usual October diet and at first was pleased.

"But something started to scratch at the back of my mind. I didn't feel ill, exactly. It was more that I felt vulnerable – as if I needed wrapping up and looking after. I started having dark thoughts too, not specifically suicidal but morbid. 'If I accidentally stepped in the garden pond it would be all over' – that sort of thing.

"I went back and forth to the GP a few times and they did tests for diabetes, liver function, cancers. All came back blank. Then I started losing my appetite and my GP became concerned: he could see I had unusual weight loss. Looking back, I'm wondering why he didn't just test for HIV too.

"Just after Christmas, I got a chest infection. The GP took one listen at my chest and said 'Right, we have to do something': the next thing, I was in the local A&E department.

"The moment I was there I felt better psychologically; I was being looked after, as I'd wanted. The hospital doctor said 'We need to broach the subject of your private life', and I said 'Go for it'. I realised it was important not to hold back."

And so he found himself talking for the first time about his bisexuality and his late-night cruising on London commons. He was married with two teenage children, a school governor, well known in the local community. He emphasises that he made a conscious decision not to let fear of gossip stop him telling the truth.

"The doctor was the daughter-in-law of one of my customers. I decided to trust that she'd be professional. I didn't want a stranger telling my wife, though. So I said 'Take the day off work' and told her. I considered saying I'd had a drug problem but decided there was no point in lying. She was devastated, but with the help of counselling at the Terrence Higgins Trust, we pulled through."

If there's a message he'd like to give to others, it's to update their knowledge about HIV. "In my line of business there are quite a lot of bi guys and they're the ones I always hear myths from. 'HIV is still a death sentence', 'it's mutating and is resistant to all the drugs', and so on. It's these kinds of myths that stop people from testing."

What late diagnosis does

Late diagnosis kills. A British HIV Association (BHIVA) audit in 2006¹ found that 25% of all deaths reported in people with HIV were due to late diagnosis. People diagnosed with a CD4 count lower than 350 cells/mm³ have ten times the risk of dying after diagnosis compared with those over the threshold – a 4% risk in the first year compared with a 0.4% one. Most deaths occur within the first three months after testing positive, and most in people with very low CD4 counts (under 100 cells/mm³).

The most recent data from the Health Protection Agency (HPA)² show that nearly half (47%) of people with HIV are being diagnosed with a CD4 count of 350 cells/mm³ or under, which lays them open to increased risk of illness, and a quarter (26%) with fewer than 200 cells/mm³, the point at which AIDS-related conditions start to become much more likely.

About 35% of gay men, but 56% of women and 64% of heterosexual men, are diagnosed with a CD4 count under 350

cells/mm³. Being in a high-prevalence group makes little difference – African people are just as, or even more, likely to test late, with 61% of African women and 68% of men doing so. Older people leave it later to test than younger: 61% of the over-50s diagnosed in 2011 had a CD4 count under 350 cells/mm³, compared with 48% of the under-50s.

When it comes to women, pregnant women are diagnosed earlier. This isn't because they present themselves for testing. It's because pregnant women form the only group in the UK which is universally and routinely tested for HIV unless someone specifically asks not to be. A third of all HIV tests in the UK are performed at antenatal clinics.

The biggest contrast is in the group who test very late. The proportion of gay men who are diagnosed with a CD4 count under 200 cells/mm³ – which in the US is a definition of AIDS – is 16%, but in heterosexual men it's as high as 43%.

The good news is that the proportion of late testers has been slowly declining overall, most notably in gay men: in 2002 48% tested late and in 2011, 35%. The proportion of late testers in heterosexuals has only gone down relatively slightly, from 67 to 60%. In the case of gay men, the challenge now is not to get them to test, but to test often: the HPA recommends gay men should test for HIV at least annually, and every three months if they have multiple partners, but found that in fact two-thirds of gay men who'd had a test at an HIV clinic had, two years later, not returned for another one.

The traveller: Tom

One interesting group who are increasing as a proportion of the HIV-positive population, and who may test particularly late, are UK-born people who acquire HIV while on holiday or working abroad. The latest HPA report highlights that some 15% of UK-born adults with HIV fall into this category: they are more likely to be older, heterosexual and report contact with a sex worker. And they may test especially late as they are seen, both by doctors and themselves, as falling out of classic risk categories.

One was Tom, in his 50s from Leicester. He's a reminder that late diagnosis may not only involve danger for the person who tests: in Tom's case, although he too got sick, what got him to test was the near death of his young son.

He believes he became infected with HIV abroad: he had been going to Thailand twice a year and sleeping with women there. Eventually, he found a wife there – "I could see she wasn't like the other girls" – and they have been married for eleven years. He doesn't know if he infected his wife or vice versa.

“A close relative was a staff nurse in A&E for years, and even she said 'You can't have HIV, you don't have the lifestyle'.”

Annie

He started off having jaundice and gallstones for no apparent reason, as well as kidney problems, and then developing what was thought might be anaemia. "I had every test under the sun. I even went to a haematologist who did a general blood cell screen, as I'd had anaemia before. I even asked him if they might do an HIV test. He just said 'I don't think we need to, you don't fit the profile'."

If they'd thought to test his CD4 count, they'd have found out: Tom's was 53 cells/mm³ when finally diagnosed and he was in the early stages of PCP, a type of pneumonia.

By that time, however, his young son, who is now six years old but was then three, had already spent eight weeks in hospital with pneumonia and what doctors thought was lymphoma.

"I can't help feeling guilty. For me and my wife, it was one thing testing for HIV, for him another, he's just a kid. We feel strong as a couple and my beliefs support me [he has converted to Buddhism] but I think I am going to need support when he starts asking questions about why he has to take medicines twice a day.

"I just wish they'd include HIV among the standard tests they do," Tom says. "I now hate it when they say 'We'll run some tests'. I want to know what tests? And why? What assumptions are they making? There are guys in my office who have taken more risks than me but are too frightened to test because of the stigma attached. It would be a good message if doctors just regarded it as something routine."

The fast progressor: Annie

Not all 'late testers' are older or have actually been infected for a long time. About 7% of people with HIV are 'fast progressors' who, for reasons that are still unclear, experience continued high viral replication after acute

infection that takes their CD4 count down to below the danger level of 200 cells/mm³ within two years.³

Annie was diagnosed in 2008 with a CD4 count of ten cells/mm³ and a viral load of six million copies/ml. She knows she couldn't have been infected before 2006. She had had several older boyfriends including one from the Caribbean, a group among whom, says Ian Cormack, "we find late diagnosis is common. Many are reluctant to test and struggle to accept their HIV diagnosis."

Employed in the finance sector, she worked very hard, but played hard too. She used to go to a central London hospital for regular check-ups for other sexually transmitted infections (STIs) "and never had one. So I reckoned if I'd never had an STI I couldn't possibly have HIV and, although they always offered me a test, I always declined."

She realised something was wrong when the 'play' bit of her life had to go because of increasing fatigue: "By 9pm, you couldn't have got me off the sofa with a JCB." A couple of liver function tests showed worsening results; she developed oral thrush and then pneumonia. She ended up in hospital for three months: "I missed the summer."

She thinks there were a number of opportunities for testing during the two years between being infected and testing HIV positive.

"I think the public health messages have done a lot of damage. The early ones caused a lot of fear and still stick in people's minds – people quote them who were not even around when they first appeared – and the later ones made people think you could *only* have HIV if you were African or gay. A close relative was a staff nurse in A&E for years, and even she said 'You can't have HIV, you don't have the lifestyle'."

Standardising testing

People like Brian, Tom and Annie are lucky to have made complete recoveries. Ian Cormack says: "Thirty per cent of my outpatients have some sort of long-term health consequence from testing late."

He wants to see the HIV test offered in a much wider variety of areas. His team at Croydon University Hospital, including doctors David Philips and Ali Elgalib, persuaded the hospital's consultants and chief executive to start offering HIV testing as standard to all medical admissions from July 2011.

"We made the point that standardising HIV testing doesn't just protect patients, it protects the hospital as part of good clinical care," he says.

"We regularly visit the emergency room

to motivate staff to offer the test and train nurses to do it. We conducted an acceptability study among A&E patients and 84% said they'd happily take an HIV test, 91% if it wasn't a blood test. It's the doctors, I find, who are worried. They don't know how to say 'HIV test' to the patient."

One thing that would help, he thinks, is "to change from the culture of targeted testing".

Targeting made sense when the point needed to be made that gay men and African people suffered disproportionately from HIV and needed appropriately more attention, more resources – and more tests.

"The problem with targeting now," says Ian, "is that it encourages a collusion between doctor and patient not to mention HIV. The patient doesn't want to disclose, and the doctor doesn't want to ask."

Although he is pleased at the progress routine HIV testing has made in his hospital and in the community, he says that GPs' surgeries are where we will make the real gains.

"But GPs need support. We may well feel like saying 'Look here, this chap was turning up for two years with HIV-related symptoms, why didn't you test him?' but we don't want them getting defensive. We need to work out how HIV testing can be integrated into GPs' models of care. GPs need support from the top: HIV testing needs to be prioritised and incentivised; it needs to be part of the package of incentives included in schemes like QOF" [the Quality and Outcomes Framework, which rewards GPs for achieving certain health targets].

We have a long way to go in this direction. An audit conducted by the British HIV Association in 2010 found that while the proportion of people who have been diagnosed with HIV in so-called 'non-traditional settings', such as A&E, has increased by 14.4% since 2003, the number diagnosed by their GP only increased by 6.4% during the same period.⁴

The older woman: Kate

Someone whose GP could have tested her earlier was a person I could not interview, because she died of AIDS in January 2011. Rose Matthews' mother Kate was 59 when she died: "four stone, confused, scared, and not my mum any more. By the end she couldn't recognise her reflection."

Rose has made an official complaint about her doctors' failure to test Kate Matthews for HIV. Her complaint, and the GP's reply to it, make tragic reading. Kate first started to notice symptoms in August 2007 and her life could have been saved if she had been given an HIV test at any time in the next three years.

She had multiple problems suggestive

“I am registered with a GP but I am one of those men who never sought out health care, like men who never ask directions.”

Ekow, 43

of HIV: shingles, loss of appetite, swollen lymph nodes, weight loss, cognitive decline – all presented at some point.

This was not a passive or ignorant patient, either. Kate kept a diary detailing her mysterious illness and her visits to the doctor, and at one point even paid for a private scan, which returned a picture of multiple swollen lymph nodes.

The GP practice made a provisional diagnosis of lymphoma, and stuck to this even though a specialist's report said there were no signs of it: it appears the reason Kate was not given an HIV test was because she did not 'fit the profile'. She eventually tested HIV positive in the hospital where she died, too late for her to be treated and saved.

"I feel there should be an HIV screen for all new GP patients everywhere," says Rose (Kate did not live in a high-prevalence area, where this is now recommended). "My mum probably had HIV for ten years: if in 2008 her GP had offered her a test, she'd still be here now." She is now actively campaigning for a revival of general HIV-awareness campaigns, not least for GPs.

The non-presenter: Ekow

By this time you may be feeling scandalised that so many people are still developing serious illness and some dying, just because healthcare workers (and patients) don't think to test for HIV.

That's certainly part of the cause, but the last late-presenter I interviewed, and perhaps the one who had the closest brush with death, reminds us that there may always be a core of people undiagnosed with HIV – and he also taught me that I am not immune from making assumptions about someone's sexuality and risk.

Ekow is a 43-year-old man from west

Africa; he's been in the UK for 20 years, though he periodically travels back home. A quiet, unassuming man, when asked whether he feels the health services missed opportunities to test him for HIV, he says "No, to be honest."

"I am registered with a GP but I'm one of those men who never sought out health care, like men who never ask directions. Besides, apart from the odd hangover when I've had one too many at a club, I'd never been ill. There could be a lot of people in my situation, and some people inevitably will have to fall sick before they get tested."

Last year he started losing weight rapidly and also developed oral thrush. "My friends were saying, 'There's something wrong man – you not eating?'"

"But it never occurred to me I could have HIV. I'm not the kind of guy who's jumped from woman to woman."

One day he woke up and found he couldn't walk. "I was like a little old man." He eventually struggled into A&E where they took one look at him, admitted him, and tested him for HIV. "I remember, all the doctors and nurses gathered round my bed and one said 'You've got HIV'. I nearly died then!"

He nearly did. He had a CD4 count of four cells/mm³ and, when put on antiretroviral therapy, he had the severe, paradoxical complication called IRIS (immune reconstitution inflammatory syndrome), which happens when the immune system 'reboots' from virtually nothing and starts over-reacting to the original infection. He developed terrible abscesses in his neck and throat which required a tracheotomy and is still in the situation where he takes one *Atripla* pill to control his HIV but a handful of other ones to treat opportunistic infection. However, his CD4 count is now 120 cells/mm³ and on the way up.

When I ask if he has a partner, I realise I've made an interesting assumption myself: "No," he says, "not right now. I did have a guy back in Africa I used to go back and visit..." Up till then I'd been assuming I'd been talking to a heterosexual man. If I can make that mistake, it's hardly surprising if healthcare workers continue to miss cases of HIV, sometimes with fatal consequences, through trying to guess, on the basis of appearance and what people are prepared to admit, whether they should get tested or not. As Ian Cormack says, targeting is valuable to persuade those at highest risk to test, but we need to normalise it across wider areas of health care to find and care for the people who don't fit the picture. **nam**

*Names have been changed.

PrEP wars



Debating pre-exposure prophylaxis in the gay community

Pre-exposure prophylaxis (PrEP) was approved in the US in July, following trials showing its efficacy in preventing sexual transmission of HIV. But, as *Gus Cairns* finds out, it remains a controversial addition to the HIV prevention options available to gay men in the US.

Last World AIDS Day, 1 December 2012, Online Buddies (OLB) Inc. (the company behind Manhunt.net, one of the most popular gay online dating sites in the US, and its affiliated health education site Manhunt Cares) sent out a bulk email to its members informing them of its World AIDS Day campaign to increase awareness of pre-exposure prophylaxis – PrEP.

PrEP means HIV-negative people taking antiretroviral (ARV) drugs to stop them from acquiring HIV infection. A series of trials two years ago, including the iPrEx study in gay men, showed that PrEP could prevent more than 90% of HIV infections in people who took it consistently, but also that a lot of people in the trials didn't take it enough, or at all.

The US Food and Drug Administration (FDA) approved tenofovir plus emtricitabine (*Truvada*), the two-drug pill used in the trials, for use as PrEP, in July last year.

The European Medicines Agency (EMA) is still considering approval. Throughout Europe, centrally funded health systems are likely to demand more rigorous guidelines on targeting and budgeting before authorising PrEP.

In practice, uptake rates in the US have been low and not many HIV-negative men are aware of this new HIV prevention option. In conjunction with Fenway Health, the LGBT sexual health centre in Boston, and the Harvard School of Medicine, Online Buddies researched Manhunt's users and found that even after the iPrEx study results¹ were announced, only one in five of its users were at all aware of PrEP and only 1% had ever used it, though when given a description of it, nearly 80% said they potentially might.²

For those depressed by ongoing high HIV incidence rates amongst gay men and impressed by the PrEP trial results, a campaign to alert the community to the possibility of this new HIV prevention method was needed.

"One of our guiding principles is to fill critical gaps in health promotion campaigns," says David S Novak, Online Buddies' senior health strategist. "Normally, we spotlight a variety of different issues, but this year PrEP was the obvious thing."

A mailshot and its response

Manhunt Cares compiled a page containing articles and videos about PrEP and sent out a bulk email containing the page's weblink to all its subscribers headlined "HIV Prevention Pill for Negative Men: a choice when condoms are in the way or not enough?"

They received a huge response to their mailshot. Initially, Novak says, the response was positive. But as the mailing was picked

“We're not talking about providing PrEP for people who have no difficulty using condoms...Even if people decide in the end it's not for them, offering it as an option is valuable. We are telling them 'HIV is not inevitable'.”

**Ken Mayer, medical research director,
Fenway Health**

up on by gay blogs such as Towleroad and Joe.My.God, it attracted a variety of hostile comments.

A lot of the hostile commentary was directed at the idea of condoms being “in the way” of good sex, so Manhunt Cares revised their tagline to “HIV Prevention Pill for Negative Men: Another choice for staying HIV free?” and sent out a new message saying that “It is our hope that by changing the tagline, we can refocus the attention from this campaign where it belongs — on the information that Manhunt members need to make informed decisions about their own sexual health.”

PrEP has been controversial ever since activist protests led to the closure of the first trial in humans in Cambodia nine years ago.

Joe.My.God commented: “The use of *Truvada* as an HIV preventative has somewhat fractured the HIV/AIDS advocacy movement.” The treatment-provision and advocacy organisation, the AIDS Healthcare Foundation, campaigned vocally against PrEP around the time the FDA was considering approval.

“The most serious accusation was that we were promoting a drug,” says Novak; Manhunt was accused of running a campaign funded by Gilead, the manufacturers of *Truvada*. This was not the case; the only time Online Buddies has received funding from Gilead was in 2009, to assess PrEP awareness before and after the release of the iPrEx data.

Novak adds: “In my opinion it's a pity that, because the politics of it get in the way, Gilead *aren't* putting money into promoting PrEP. That's why we felt we had to do it.”

One could dismiss the blog discussants as axe-grinders, but comments in blogs can also be the sound of an interested community making sense of an unfamiliar new idea. A review of the comments in the blogs isolates the principal concerns.

'Safer sex means condoms; pro-PrEP means anti-condoms.'

This was a frequent concern, the most emotive issue, and the one seized upon first in most blogs. For some people, condoms were the core of safer sex. Not using them was always 'barebacking' and therefore dangerous, and PrEP would subvert them:

- *If you want to bareback you have a death wish.*
- *Condoms are never in the way. That should be the philosophy, and the driving force behind all HIV prevention efforts.*

Others liked one part of Manhunt's message but not the other:

- *If they had stopped with "When condoms are not enough", then that would have been OK. But "in the way" just encourages people to think, "Hey, if I find condoms inconvenient, I'll just take this pill..." This leads down the wrong path.*

Others had more nuanced responses:

- *PrEP is a great option for some guys who are in a risky phase of their lives (we've all been there) or who suspect their partner is cheating.*
- *This is for the 'high risk' people. The ones who say: "I know I'll make mistakes so this is my insurance". I don't agree with it but they should at least have that option.*
- *Aren't arguments against [PrEP] akin to opposing handing out condoms to teens on the premise that it will cause them to have sex?*

Finally, a couple of contributors actively disliked condoms and were quite upfront about not using them:

- *Let's be honest here, guys - condoms ruin sex. They destroy any illusion of spontaneity. You get aroused...but you have to stop and slip on a piece of latex, which is not always easy to do. [This contributor was comprehensively 'flamed' by others]*
- *Condoms suck and most men agree, period.*

The second contributor didn't get 'flamed', probably because he quoted research³ (cited in HTU 212, see *The gay globe*), part of the US Men's National Sex Survey⁴ showing that 55.0% of gay men didn't use a condom last time they had anal sex.

The finding that 'use a condom every time' is minority behaviour in gay men is duplicated in other surveys.

Bob Grant, principal investigator of iPrEX, comments that just because people don't use condoms, it doesn't mean they're being irresponsible. He cites evidence showing that many gay men are trying to reduce their HIV risk in other ways. These include withdrawing before ejaculation, seropositioning (being 'top' if you're negative and 'bottom' if you're positive because HIV is ten times less likely to be transmitted that way), and serosorting - restricting (unprotected) sex to same-status partners.

"People do want to be regarded as full members of society, and they do want to be responsible", says Grant. "But serosorting is responsible too, and so is looking for PrEP. It's proactively trying to manage your sexual health."

“People do want to be regarded as full members of society, and they do want to be responsible. But serosorting is responsible too, and so is looking for PrEP. It's proactively trying to manage your sexual health.”

Bob Grant, principal investigator, iPrEX

'Offering PrEP will mean people stop using condoms.'

In fact, the evidence from the randomised controlled trials of PrEP shows the opposite: condom use went up and sexual risks went down in both the iPrEX and the Partners PrEP studies.

Anyone enrolled in these studies had free condom provision and a large amount of support about sexual health, so they may not be a good guide to how people taking PrEP will change their behaviour in the real world. Ken Mayer is the medical research director of Fenway Health. He says that "Condoms simply aren't being used as much as they once were, and people are more able to say so. We still have men coming along to our clinic saying 'I had a slip-up'" [a euphemism, implying it was accidental] but "We're not talking about providing PrEP for people who have no difficulty using condoms. But if someone comes to us and says 'You know, I really have a problem with them,' then we'll talk about alternatives, including PrEP. Even if people decide in the end it's not for them, offering it as an option is valuable. We are telling them 'HIV is not inevitable'."

In the end, we simply don't know whether the existence of PrEP will mean more or less condom use in the real world. One of the pieces of research directed at finding out is happening in the UK: the PROUD study,

an open-label study of immediate versus delayed PrEP, which started recruiting in December (see www.proud.mrc.ac.uk for details).

'Won't people get more STIs?'

This is a concern for anyone contemplating the provision of PrEP. A blog comment put it this way:

- *What about STDs? The days when one shot of penicillin treated just about everything are gone. STDs are resisting medications. Herpes is not the only luggage you may be carrying around for life.*

Certainly PrEP will not prevent other sexually transmitted infections (STIs) and recently we have seen reports of strains of gonorrhoea that are resistant to every antibiotic used against it.⁵ David Novak, however, sees an opportunity in PrEP to reduce the overall burden of STIs in gay men.

Because of the possibility of developing resistance, the FDA mandated that PrEP should never be provided for more than 90 days and that people receiving it be tested for HIV every time, before receiving a new prescription.

"This means they'll be turning up at their doctor's office every three months," says Novak, "and this means they can be screened for gonorrhoea, syphilis and other STIs at the same time" - although STI screening isn't mandatory to receive a prescription for PrEP.

'People won't take it, so it won't work.'

People's ability to adhere to PrEP has been the factor most crucial to its effectiveness. In the iPrEX study the overall effectiveness of *Truvada* PrEP was only 42% - but this was largely because only 50% of trial participants actually took the drug. In those with levels of drug in their body equivalent to taking it four or more days a week, it was 96% effective - and there were no infections at all in people who took it every single day.

David Novak makes a distinction some people have found confusing.

"It's not true to sit down in front of a patient interested in PrEP and say 'This will prevent four-in-ten HIV infections' because with an individual patient, you have to use the per-protocol result: PrEP efficacy in people who took PrEP as *prescribed*. If you do that, its efficacy is 99%."

On the other hand, he acknowledges, it's important to use the 'intent-to-treat' result of 42% - the efficacy seen in every single person who was offered PrEP, regardless of whether they took it - when you are forecasting its likely effectiveness on a population, and therefore its cost.

One blog commenter put it this way:

- *It seems to me that the ones who are at high risk a lot are the ones least likely to keep up a daily regimen.*

It depends if people are just risky people or have a specific problem with condoms. In addition, people with HIV have a huge incentive to take treatment, but will the incentive of avoiding HIV be strong enough to get people taking a dose every day?

One answer may be to take it only in advance of sex, but that can't mean immediately in advance. Drug level studies show that drug concentration builds up slowly in tissues, suggesting one or two doses well in advance of sex, and probably a post-sex dose too. The one completed study of intermittent three-dose PrEP, in African gay men and female sex workers, showed that while most took the first pre-sex dose, only just over half took the second dose and only a quarter the post-sex dose.⁶

'What about the side-effects?'

Some commentators were concerned about the side-effects of PrEP:

- *Even if toxicity is experienced by only 2% of those who take it, that's still a lot of HIV-negative people needlessly harming their own bodies because they don't want to use a condom.*

Others thought they would be less of a problem than for those on treatment:

- *I don't understand all the pearl-clutching about long-term side-effects. It's not like PrEP is a lifelong med. Take it for a few months or a year or two, during periods of high risk.*

While emtricitabine (3TC) seems to have little toxicity, in a minority of people tenofovir has been associated with significant losses in bone mineral density (BMD) and decreased kidney function. In the general HIV-positive population, however, the link between long-term kidney problems and tenofovir is not clear.⁷

BMD in participants in the iPrEx trial⁸ and in a smaller safety trial of tenofovir-only PrEP in America⁹ was slightly lower in people taking tenofovir than people taking placebo, but the long-term implications of this are unknown. Regular monitoring of kidney function and BMD are required by the FDA as part of their approval of PrEP.

The short-term side-effects of the first few weeks may be of more relevance. In iPrEx, twice as many people on *Truvada*

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David Novak, senior health strategist, Online Buddies

experienced nausea, almost all of it in the first month, than people on placebo.¹⁰ Although this was only 2% of those taking the drug, it may understate the low-grade side-effects felt by many people who start ARVs – which, in HIV-negative people, may be sufficient to make them stop.

'It's too expensive.'

This is a big issue. If more than the current handful of people start taking PrEP in the US, it will become very costly. A year's worth of *Truvada*, taken with even moderate adherence, would cost at least \$4000 in the US, and about £2000 in the UK.

One recent study¹¹ using the effectiveness level seen in iPrEx found that if you gave 20% of US gay men PrEP, it would cut HIV incidence by 13% over the next 20 years, but would cost \$172,000 per life-year free of HIV. However, if you only gave PrEP to the men with over five partners a year it would cost \$50,000 per life-year, which is within the US threshold for cost-effectiveness. The cost of doing this, however, would be \$3.75 billion or 17.5% of the entire US domestic HIV budget per year.

The picture changes considerably if you reduce the price of *Truvada*. Another cost-effectiveness study used figures from Peru, the country with the biggest number of iPrEx participants. There tenofovir plus emtricitabine only cost \$600 a year. The

study found that if PrEP was highly targeted in Peru, the cost per life-year free of HIV would be no more than \$500, at an annual cost of \$24m to \$152m depending on coverage.

The lesson is clear: if PrEP starts being used by more people, then it will put a strain on health systems. But this may increase the ability to negotiate price reductions, and here community pressure may be key.

'No-one will come forward for it.'

In the end, PrEP will only work in the gay community if HIV-negative men who may prefer not to think at all about HIV are prepared to come forward and take a pill that they thought only 'poz' guys needed to take. One of the most hostile bloggers saw PrEP this way:

- *PrEP is an attempt to make the other person [i.e. the HIV-negative person] solely responsible for their health. Well, that other person may be young, may not know the facts, may have been to some deep-South school, so I think the HIV-positive person does have a responsibility to tell them and not lie.*

In other words, 'You have the virus; it's your duty to protect me' – an attitude fully endorsed by the criminal law in a lot of countries and US states.

Even if people are at high risk of HIV, they may not see themselves that way.

Among the successful scientific trials of PrEP was one failure – the FEM-PrEP trial. This took place in young women in South Africa, and the efficacy of *Truvada* PrEP was zero. The researchers found that although background HIV incidence in the group of women was 5% a year, 70% thought they were "not at high risk of HIV". Stigma and lack of information or understanding may prevent people at high risk from coming forward for PrEP.

Conclusion – a hard sell

Meanwhile, in the US, the UK and other countries, HIV prevalence in gay men is still increasing. We need more than the same old safer sex messages. In PrEP, we have something that could virtually eliminate the chance of someone getting HIV if they took it faithfully.

But giving people medicines to prevent disease has always been a hot political issue in the media, even after science shows it works.

"PrEP is a hard sell. It will take time, and it may never be taken by a large number of HIV-negative people," says Novak. "But it may get us thinking in a new way about how we as gay men reconcile our need for intimacy with our safety." **and**



Finances for the over-50s

Guest writer *Emma Lunn* investigates some of the financial options for people approaching retirement age.

Michael* was 30 when he was diagnosed with HIV in 1988. Several of his friends had been diagnosed with the virus and, despite feeling well, he went to get tested.

Until his diagnosis, Michael had a good job as a computer programmer and was financially well off. He rented a flat in central London, was saving for a deposit to buy a property, and drove a sports car. Life was good.

But finding out he had HIV changed that. He fell into a deep depression; in the 1980s HIV was regarded as a death sentence and indeed several friends died. Thinking he was going to die too, he quit his job. Now aged 54, he hasn't worked full-time since.

After his diagnosis, Michael no longer saw a point in making plans for the future.

He stopped paying into his private pension and spent his savings. He moved into social housing and lived off Disability Living Allowance (DLA) and other benefits.

His health was up and down until 1998 when he started on combination therapy and his condition stabilised. He briefly looked for a job but computer programming had changed beyond recognition in the ten years he'd been out of the job market. He eventually gave up seeking work as a programmer.

Looking to change direction, Michael qualified as a personal trainer and manages to survive with a handful of clients and various benefit payments. But he lives on the breadline. As he approaches retirement, he has no savings and no idea how he will cope in old age.

The main issues

Michael's story is in no way unique. The financial situation for a lot of older people is precarious, and many have not been able to build up adequate savings. But this is especially true for people like Michael who were diagnosed with HIV at a time when it was expected to be fatal and who quit their jobs and stopped planning for the future.

Patrick Connolly of financial advisers AWD Chase de Vere says: "For those diagnosed with a potentially terminal illness such as HIV, planning for retirement wasn't likely to be their biggest priority. They were concerned with their own health, short-term financial priorities and making sure that everything was in order for their close family and dependants.

"However, with ongoing improvements

in medicine and health care, those with seemingly a short projected life expectancy can end up living for much longer than they might have anticipated. While this is clearly very good news, it can create potential problems if the individual has neglected their longer-term planning to the extent that they face financial hardship once they have stopped working."

Speaking at the 2012 International AIDS Conference in Washington DC, Lisa Power from the Terrence Higgins Trust (THT) acknowledged the unforeseen consequences of advice from support groups to those who were thought to be dying. "In the 1980s and '90s we encouraged people to give up work and go on state benefits and not be economically productive," she said.

She ran through the findings of a 2010 study by THT and Age UK, *50 Plus*, which examined ageing and HIV.¹

It found that, compared with the general population, older people with HIV are less economically active, less likely to have a financial cushion and more reliant on benefits. Many do not have enough money to manage on and have serious financial worries for their future.

Over-50s with HIV are also less likely to be homeowners and more likely to live in social or private rented housing than others in the same age group.

Other issues more prevalent than average in people with HIV, such as immigration, housing or mental health problems, can also prevent people from planning adequately for retirement.

A 2010 report on poverty and HIV by the National AIDS Trust (NAT) and THT revealed at least one-in-six people diagnosed with HIV in the UK experienced severe poverty between 2006 and 2009.²

Meanwhile, an increasing number of older people are living with HIV. The Health Protection Agency reports that one-in-five people (22%) being seen for HIV care in 2011 was over 50.³

Back in the '80s or '90s, someone with HIV was eligible for more generous state benefits than they would qualify for today. People deemed unable to work often received social housing and disability benefits.

But the current benefits system is requiring many people living with HIV to undergo assessments of their work capability in order to have their benefits eligibility reassessed. Many people on successful combination therapies may be found fit to work, but experience real difficulties re-entering the job market.

A key concern is how someone who's been out of the job market for perhaps 10 or 15

“With ongoing improvements in medicine and health care, those with seemingly a short projected life expectancy can end up living for much longer than they might have anticipated. While this is clearly very good news, it can create potential problems if the individual has neglected their longer-term planning.”

Patrick Connolly, AWD Chase de Vere

years will find employment. Even those with a trade or skill may find that technological developments mean their area of expertise has changed completely. And for those who make it to the interview stage, explaining a long gap on a CV due to illness can be difficult, with employers often wary of hiring someone with a history of illness.

Low retirement savings

It's not just the HIV-positive community that isn't saving enough for retirement; the general population is not adequately planning for the future either.

According to the Department of Work and Pensions (DWP),⁴ around eleven million people are not saving enough to achieve the pension income they are likely to want or expect in retirement, and fewer than one-in-three adults are contributing to a pension.

Financial experts often recommend that people start to save into a pension at the age of 25 but most people are much older when they start. Meanwhile, according to a Workplace Pensions Survey by the National Association of Pension Funds (NAPF), 8 in 10 of the people choosing to stay in paid work beyond state pension age will do so because they will not have enough money to stop working.⁵

However, the *50 Plus* study found that over-50s with HIV report twice as many other long-term health conditions as their HIV-negative peers, with many reporting mobility problems and difficulties with everyday tasks. So working past retirement age - or working at all - to earn enough money to live comfortably might not be an option.

"If someone has already retired early, then the options for further contributions to pensions are limited as they'd need to start working again in order to be able to afford that," says Ruth Whitehead, an independent financial adviser. "Getting another job in the current economic climate is not easy."

Benefits

It's important for anyone who is unable to work or on a low income to check which benefits they could be entitled to and keep up with changes to existing benefits.

According to NAT, currently more than 10% of people accessing HIV treatment in the UK claim DLA.⁶ From April 2013, DLA will be replaced with a new payment called Personal Independence Payment (PIP). Like DLA, it will consist of two components: 'mobility' and 'daily living' (see *What's happening to benefits?* [www.aidsmap.com/page/1793223] in HTU 203 for more information.)

All new claimants will be assessed under the new system, and all existing DLA

claimants reassessed.

A major reform of the benefits system in October 2013 will include the introduction of Universal Credit (UC), replacing a range of existing in-work and out-of-work benefits including Income Support, Employment and Support Allowance, Jobseekers Allowance, Housing Benefit, Child Tax Credit and Working Tax Credit.

The new system is intended to make it easier to take on work as it's available, without suddenly losing all your benefits.

The government has undertaken to ensure that no one, whose situation has otherwise not changed, ends up worse off when transferred to UC. However, a report produced by The Children's Society and Disability Rights UK has warned that up to half a million people with disabilities could lose out under UC once it is fully implemented.⁷

Existing claimants' current levels of benefit will be protected at point of transfer to UC. However, they will have their level of benefit frozen with no increases to take account of rising prices and they may see their support cut immediately if their circumstances change.

Once you reach pension age, there are other benefits you may be entitled to, such as Pension Credit, Cold Weather Payments or Winter Fuel Payments, and a free TV licence. Make sure you look into all the benefits available to you.

Pensions

The most common way to save for retirement is a pension, as this offers certain tax advantages on contributions. When you retire, or reach a certain age, a pension scheme pays you a regular income for life. The sooner you start paying into a pension the higher your income in retirement is likely to be.

There are three main types of pension: state, personal and company (also called occupational).

If you're working, you usually build up the right to a basic State Pension and possibly an additional State Pension. The amount of basic State Pension you'll receive will depend on the National Insurance (NI) contributions you've paid or are treated as having paid. The current maximum State Pension is £107.45 per week.

The government also pays means-tested Pension Credit for those who have not accumulated enough NI contributions.

There are plans to introduce a £144 a week universal State Pension for new retirees, probably from 2017. Entitlement will be based on at least 10 years' NI payments, with a 35-year NI contribution record needed to get the full amount. Currently you can buy

“As long as you are still earning, you can contribute to a pension and claim tax relief. This means a pension may still be a good option. However... a more attractive option may be to contribute to ISAs and perhaps flip your ISA pot over to a pension.”

Tom McPhail, head of pension research, Hargreaves Lansdown

extra NI years; it's a good idea to contact the Future Pension Centre on 0845 3000 168 to confirm your position and see what your options are.

Many people invest in either a personal or company pension as well. For these, the earlier you start saving, the better. Under a new law, anyone not currently enrolled into a workplace pension, aged between 22 and state pension age, and working in the UK, will be automatically enrolled into a pension scheme into which the employer will be legally obliged to make a contribution. This is referred to as 'automatic enrolment' and there is more information about it at www.gov.uk/workplace-pensions.

"The general advice for people, even those approaching retirement, is that it is usually better to do something than nothing at all," says Connolly, "This will certainly be the case if the government introduces a universal state pension which can effectively do away with means-tested benefits in retirement."

Up until now, for anyone over 55 the tax advantage of contributing to a personal pension was considerably diminished by the charges taken out during the first ten years in commission and fund fees. Even in a good year the growth on investment could be eliminated by these charges during the first ten years of the plan. A new, more transparent system is now being introduced whereby financial advisers have to charge

up-front for pension advice, and ask people explicitly whether they want that fee to be taken as commission from future pension payments. Financial advisers also have to disclose if they are 'tied' to the products of particular companies or if they are free to offer advice on the full range of products available.

Take action

The first thing you should do is seek professional advice. The Pensions Advisory Service (www.pensionsadvisoryservice.org.uk) is a non-profit organisation that provides independent advice on all aspects of pensions. As well as the information on their website, you can call its pensions helpline on 0845 601 2923.

Which? magazine also provides transparent information on financial services and enables you to compare charges and performance across pension providers, although you may have to pay a small charge for this service.

If you would like to find an independent financial adviser (IFA), then the website www.unbiased.co.uk may help you find one in your area. You can also search for an adviser with particular expertise, such as pensions or investments.

There are a number of financial advice firms that specialise in the needs of gay people or people with HIV. These include Isis Financial Planners (www.gayfinance.info) and Compass Mortgage and Insurance Services (www.compassindependent.co.uk).

Some general advice about pension and retirement is also relevant.

"As long as you are still earning, you can contribute to a pension and claim tax relief. This means a pension may still be a good option," explains Tom McPhail, head of pensions research at financial advisers Hargreaves Lansdown.

"However... a more attractive option may be to contribute to ISAs [Individual Savings Accounts] and perhaps flip your ISA pot over to a pension if you feel that is appropriate in the run up to your retirement."

Patrick Connolly agrees that the best approach to save for retirement is a combination of pensions, which provide initial tax relief but are quite inflexible, and ISAs, which can still be tax efficient and are more flexible.

"Those with HIV or other serious illnesses may prefer to focus on ISAs as they may require the extra flexibility, particularly if their health deteriorates or they want to more easily pass assets to their dependants," he says, "However, the potential downside is that it is easier to spend all of the proceeds of ISAs and so have very little or nothing left to live on."

Annuities

If you have saved for your retirement, it's important to shop around for an annuity when it's time to retire. An annuity is designed to give you a monthly income until you die.

Comparing different annuity providers can save you money, rather than buying an annuity from your pension company.

Annuity rates depend on several factors; a crucial one is health. Someone with an illness or condition that means they are unlikely to live as long as a healthy person will be entitled to an 'enhanced' annuity – which means more money to live on.

Being HIV positive, or having other health conditions, may qualify you for an enhanced annuity so it's important to declare this when buying one.

Stephen Lowe, director of specialist annuity firm Just Retirement, suggests the following for a HIV-positive person looking at their annuity options:

"Specifically ask [your] financial intermediary or pension company whether they provide enhanced annuities and volunteer to disclose [your] medical and lifestyle information.

"We do quote for HIV and AIDS and an enhanced rate may be provided depending upon factors such as diagnosis date, treatments, CD4 count, viral load, and AIDS-related cancer. Simply put, the best way of obtaining an accurate quote would be to provide recent medical letters which include these details."

Life insurance

If you're married, in a civil partnership or have children, life insurance (or assurance) can help your dependants financially after your death. And if your partner were to die first, a pay-out from their life insurance policy could make a big difference to your financial situation.

It used to be impossible to get this kind of cover if you were HIV positive but successful lobbying of the insurance industry means this has changed.

Chris Morgan, marketing manager at Compass, HIV life assurance and mortgage specialists, says: "It took until 2009 for there to be a range of affordable and useful products available in the market place for the HIV community. There are now six providers that offer life assurance; however the terms and premiums they offer differ enormously. I recommend that people seek specialist independent advice before buying HIV life assurance.

"Life assurance can be used to provide a lump sum to support a family in the event of the death of one or both partners. We have recently been arranging HIV life assurance

“It took until 2009 for there to be a range of affordable and useful products available in the market place for the HIV community. There are now six providers that offer life assurance; however the terms and premiums they offer differ enormously.”

**Chris Morgan, marketing manager,
Compass**

policies specifically into trust for children to make certain they are looked after should anything happen to their parents."

For more on life insurance, see *Rest assured – life insurance for people with HIV* (www.aidsmap.com/page/2310816) in HTU 211.

Equity release

Another option for retirees who own a property is equity release. Equity releases allow homeowners to release tax-free cash from their homes to boost their finances in retirement. The two main types of plans available are lifetime mortgages and home reversion plans. Both types allow you to stay in your home.

Lifetime mortgages offer either an immediate lump sum or a series of payments, which are set against the borrower's home. When the borrower dies or goes into long-term care, the home is sold and the lender takes the value of the sum lent, plus the interest it has accrued.

Home reversion plans involve selling part, or all, of your home to an investment company (called a reversion company) which, in return, will give you a cash lump sum or an income for life and sometimes the option of both. When you die, if you have sold 100% of your home to the reversion company, the property will be sold and all of the proceeds will go to them. Otherwise, the

value of any portion of your home that you have not sold will pass to your estate.

To qualify for equity release you need to be over 55 (both partners if a couple), own a home worth at least £70,000, and be living in mainland UK or Northern Ireland.

It's essential to take independent professional advice before taking out equity release; it's a big decision that affects both your home and the inheritance you leave to dependants.

The schemes were the subject of controversy in the past after earlier versions ended in disaster when interest rates went up and house and share prices fell in the early 1990s. Thousands of pensioners who had borrowed against their homes found themselves in negative equity and had debts greater than the value of the properties to which the debts were secured.

Since then, most major lenders have signed up to a voluntary code of conduct administered by the Equity Release Council. Meanwhile, the Financial Services Authority (FSA) has brought home income plans within the scope of its regulation.

Looking ahead, some people with HIV may be set to inherit their parents' or partner's property. Although it's a difficult conversation to have, it's important to talk to your family to find out how they intend to leave their estate when they die – and then factor this in when planning your own retirement. It may be that you have more options than you realise.

It's never too late to start saving and, for those who have made some pension provision or own a property, it's essential that you make your money and assets work for you the best you can. [nam](#)

**Name changed to protect identity.*

More information



Find out more about state benefits and pensions at www.gov.uk.

There are many organisations that can help you plan for the future, some of which are listed below.

- Future Pension Centre (www.gov.uk/future-pension-centre)
- Age UK (www.ageuk.org.uk)
- Unbiased (www.unbiased.co.uk)
- Compass (www.compassindependent.co.uk)
- Just Retirement (www.justretirement.com)
- Equity Release Council (www.equityreleasecouncil.com)

News in brief

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

HEALTHY LIVING

Smoking has more influence on life expectancy than HIV-related factors

Much of the increased mortality seen in people with HIV can be attributed to smoking, Danish investigators report. Their study involved 2921 adults receiving HIV care in Denmark between 1995 and 2010, who were matched with 10,642 HIV-negative controls, and then followed for four years on average. Among HIV-positive participants, 47% were current smokers, 18% were former smokers and 35% had never smoked. The corresponding rates for the controls were 21, 33 and 47%. The risk of death by any cause was four times higher for current smokers compared to HIV-infected people who had never smoked, and the authors calculated that 35-year-old non-smokers had a life expectancy of 78 years. This compared to a life expectancy of 69 years for former smokers, and one of just 63 years for current smokers. The researchers calculated that the HIV-positive participants lost five years of life expectancy due to their HIV infection and that twelve years were lost because of smoking. The authors believe their findings have important implications for HIV care, showing the importance of smoking cessation counselling and support. www.aidsmap.com/page/2561382

HIV TESTING

HPA urges further action on HIV testing

England's Health Protection Agency (HPA), in its 2012 annual HIV report, drew particular attention to the need for improvement in HIV testing rates – six of its eight recommendations concern testing. In 2011, there were 3010 new diagnoses among gay men, the highest annual figure ever. HIV prevalence in the general

population was 0.15%, but was considerably higher in the black African community (3.7%) and among men who have sex with men (4.7%). Among those diagnosed, 47% were diagnosed with a CD4 cell count below 350 cells/mm³. Whereas people who attend sexual health clinics usually have an HIV test during their visit (70% of all attendees, 84% of gay and bisexual men) and coverage is extremely high at antenatal clinics (97%), an HPA audit done with 40 sexual health commissioners in high-prevalence areas found that only 31% had commissioned HIV testing at GP surgeries, and just 14% had commissioned it as part of general medical admissions to hospitals, despite recommendations by both BHIVA and NICE for HIV testing in these settings. Commenting on the report, Deborah Jack of the National AIDS Trust (NAT) made a connection between the higher rates of late diagnosis in black African people and the poor provision of HIV testing in GP surgeries. "We know that African people are three times more likely to be diagnosed through their GP than a sexual health clinic," she said, urging more commissioning of HIV testing in general practice. Testing frequency needs to rise too: 63% of gay men newly diagnosed with HIV at a sexual health clinic had not attended that clinic for testing in the previous three years. www.aidsmap.com/page/2556387

HEPATITIS C

Dual regimen cures most people with HCV genotypes 1, 2, or 3

A 12-week, once-daily oral regimen of Gilead's hepatitis C (HCV) polymerase inhibitor sofosbuvir and Bristol-Myers Squibb's NS5A inhibitor daclatasvir, without interferon or ribavirin, produced sustained virological response rates (SVRs – equivalent to cure) for most treatment-naïve, HIV-negative people, and appeared effective regardless of HCV subtype. Various combinations of sofosbuvir

plus daclatasvir, with or without ribavirin, were tested in an open-label trial. SVR rates ranged from 88 to 100% in patients with genotypes 2 and 3, and 100% in those with the supposedly harder-to-treat genotype 1, with an overall SVR rate of 93%. As promising as the sofosbuvir plus daclatasvir combination appears to date, its fate is uncertain. Earlier this year Gilead indicated that it would no longer pursue development of this particular regimen, sparking several online petitions, and is thought to be focusing on its own NS5A inhibitor GS-5885, allowing the company to produce coformulated combination pills. Once individual drugs are approved and marketed, however, clinicians will be able to mix and match them.

www.aidsmap.com/page/2552256

RESISTANCE

Drug-resistant HIV falls in Western Europe

There has been a significant fall in the proportion of treatment-experienced HIV-positive people in Western Europe with resistance to antiretroviral (ARV) drugs. A retrospective study looked at 20,323 people treated with ARVs between 1997 and 2008 in seven countries. Eighty per cent had, at any time point, at least one major resistance mutation to at least one ARV; two-thirds had resistance to a nucleoside (NRTI) drug, half to a non-nucleoside (NNRTI) and one-third to a protease inhibitor. However, there was "clear evidence" of a reduction in resistance to NRTIs and protease inhibitors after 2001. The proportion who had run out of treatment options peaked at about 30% in 2000, but with the introduction of new drugs and drug classes, this had fallen to below 1% in 2008. The results stand in contrast to those of a recent Australian study that predicted life expectancy would be reduced due to the exhaustion of treatment options.

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News picks from other sources

CMV

CMV may contribute to amount of HIV hiding in cells

The presence of cytomegalovirus (CMV) in blood and semen is associated with higher levels of HIV DNA in blood. A US study involving 113 gay men recently infected with HIV found that 46% of the men tested positive for CMV, a common and usually asymptomatic virus of the herpes family. The presence of CMV in immune-system cells and longer duration of HIV infection were both associated with higher levels of HIV in cellular DNA. CMV was not, however, associated with HIV viral load in blood or semen. This means that while CMV did not seem to influence the amount of infectious HIV viral particles in the blood, it was associated with more proviral DNA – the instructions to make HIV – integrated into the genetic code inside cells. The association between CMV infection and proviral DNA only became significant after participants had been infected with HIV for more than 120 days. Many approaches to a cure for HIV depend on finding ways to reduce the amount of proviral HIV DNA hiding in long-lived reservoir cells, as this is the source for new virus when people come off treatment. The investigators conclude: "Future studies should determine if persistent CMV replication can be targeted as a strategy to reduce the size of the latent HIV reservoir."

➔ www.aidsmap.com/page/2563497

TB TREATMENT

New class of TB drug approved

Bedaquiline, a new TB drug, was licensed for treatment by the United States Food and Drug Administration (FDA) on 2 January. Patented by Janssen Pharmaceuticals, a subsidiary of Johnson & Johnson, it is the first new TB drug since the licensing of rifampicin in 1966. In a study of patients with drug-resistant (DR) TB, 48% on bedaquiline became sputum-negative for TB versus 9% of patients on placebo. The US Treatment Action Group (TAG), along with other HIV and TB activists, support early appropriate access

to bedaquiline for people with DR-TB. Mark Harrington, Executive Director of TAG, said: "Bedaquiline will provide a major incentive for new sponsors and companies to introduce more new drugs, classes, combinations, and regimens into the clinical pipeline." Nathan Geffen of the Treatment Action Campaign in South Africa called for the drug to be made available to patients with DR-TB before it is approved there. "This demand was made as far back as 2009," he said, "yet little progress towards pre-approval access has been made in South Africa." At least 13,000 cases of DR-TB are estimated to occur in South Africa each year, one of the highest burdens of DR-TB in the world. The World Health Organization convened an expert meeting on the use of bedaquiline on 29 January.

➔ www.aidsmap.com/page/2557073

ANTI-HIV DRUGS

Tenofovir impairs enzyme that stops cells ageing

Telomeres are lengths of 'junk DNA' that sit at the end of chromosomes and stop genes from being lost in the process of cell division, exactly as the tip of a shoe lace stops it fraying. Cells that have lost their telomeres usually die and there is a theory that telomere loss is the underlying cause of a lot of the ageing process. Telomerase is an enzyme that adds units to the telomeres and keeps them working. Researchers have found that, in the test tube, the nucleotide (NRTI) drug tenofovir strongly impairs telomerase. They also found that the duration of treatment with NRTI drugs as well as biological age was associated with reduced telomere length and less telomerase activity, though this was not pinned specifically to tenofovir. The study has implications for the role of NRTI drugs in general in the accelerated ageing seen in some people with HIV, and also for the possibility of unexpected side-effects showing up after many years on treatment with tenofovir, currently the most widely used single HIV drug in richer countries. The researchers found that, while NRTI drugs in general inhibited telomerase in the test tube, only tenofovir did at the kind of levels seen in people who take HIV treatment.

➔ www.aidsmap.com/page/2567149

P Is London's gay scene self-harming through sex and drug use?

Pink News | 24 January 2013

David Stuart of gay men's drug project Antidote discusses increases in the use of methamphetamine and mephedrone in London's gay scene and an increased tendency to inject them.

➔ <http://bit.ly/WuDwpy>

Stanford lab creates HIV-resistant cells

San Francisco Chronicle | 23 January 2013

Stanford scientists have developed a technique to genetically engineer certain immune cells and make them resistant to HIV.

➔ <http://bit.ly/WpYEgs>

H Dr Mark Dybul: The big push to defeat AIDS, TB and malaria

Huffington Post | 23 January 2013

Every era offers something special. I think the most special thing about our current time is the incredible opportunity that scientific advances have provided in the field of global health, giving us the ability to completely control highly dangerous infectious diseases such as AIDS, tuberculosis and malaria.

➔ <http://huff.to/WcLRyL>

Viracept: Non-renewal of the marketing authorisation in the European Union

European Medicines Agency | 7 February 2013

Before the expiry of the last five-year period of validity, the marketing authorisation holder did not apply to renew the marketing authorisation. Consequently, the authorisation for Viracept expired on 23 January 2013.

➔ <http://bit.ly/YU6u1w>

Treatment as prevention:

Experts in the UK agree it works



Roger Pebody summarises the statement released in January that should now guide how our doctors talk to us about treatment as prevention.

In January 2013, the British HIV Association (BHIVA) and the Department of Health's Expert Advisory Group on AIDS (EAGA) published a joint position statement on the use of HIV treatment by people with HIV to reduce the risk of transmission.¹

For the first time, the document provides health professionals in the UK with a consensus statement, developed by experts in this country, which can be used to guide discussions with individuals.

Clinicians, epidemiologists, policy experts and people living with HIV contributed to the document.

The position statement affirms that successful HIV treatment is "as effective as consistent condom use" in reducing HIV transmission, while cautioning that regular screening for viral load rebound and sexually transmitted infections is required. The key points are outlined here.

As effective as condoms

The statement notes that there is now conclusive evidence from a randomised clinical trial (considered to provide a high standard of reliable evidence), to show that transmission of HIV through vaginal sex is significantly reduced when an HIV-positive person is taking effective antiretroviral therapy (ART). In the HPTN 052 trial,² a large trial which published its results in 2011, early treatment reduced HIV transmission to an uninfected partner by 96%.

"The observed reduction in HIV transmission in a clinical trial setting demonstrates that successful ART use by the person who is HIV positive is as effective as consistent condom use in limiting viral transmission," the statement says.

The document includes some explanatory notes, which point out that there has never been a randomised controlled trial of the

efficacy of condom use, compared to non-use. For that reason, there are no figures that can be directly compared. However, meta-analyses of observational studies of serodiscordant couples who reported 100% condom use have found the strategy to be about 80% effective in reducing HIV infection.³

Necessary conditions

The document states that the transmission risk during vaginal intercourse will be "extremely low", provided certain conditions are fulfilled. These are:

- There are no sexually transmitted infections (STIs) in either partner. (The document clarifies requirements for STI screening, including following sexual relationships outside a primary partnership – see box.)

Screening for sexually transmitted infections

The document notes that a sexually transmitted infection (STI) can increase the HIV viral load of a person with HIV, especially in their semen or vaginal secretions. Also, an STI in an HIV-negative person can increase their susceptibility to HIV.

For these reasons, frequent STI screening is recommended for both partners – at least every three to six months. If there is sex with people outside the couple, both partners need to have another STI screen before having sex again in order to be sure that they do not have an STI.

If there is any possibility that either partner has an STI, condoms are recommended.

- The person with HIV has had a sustained blood viral load below 50 copies/ml for more than six months, including the most recent test.
- Viral load testing occurs every three to four months (i.e. more regularly than in standard clinical care).

In the document's explanatory notes, it is explained that in HPTN 052 there was a single confirmed case of HIV transmission from a person on treatment. This individual had only recently begun ART and would not have met the UK position statement's requirement for an undetectable viral load for at least six months.

The authors say that this justifies the use of the phrase "extremely low risk". They clarify that this is not the same as "zero risk". Moreover, with the data that are available, it is not possible to give accurate and meaningful figures for the risk of transmission during a single sexual act.

Anal intercourse

The published research was primarily done with heterosexual couples and is assumed to relate primarily to vaginal intercourse. Data are not available for anal intercourse, either between men, or between men and women.

"However, it is expert opinion that an extremely low risk of transmission can also be anticipated for these practices, provided the same conditions stated above are met," according to the statement.

Discussion with people with HIV

Healthcare professionals should discuss the impact of ART on sexual transmission with all people living with HIV. For people not currently on therapy, the possibility of starting treatment in order to reduce transmission risk should be discussed.

Limitations of ART

The position statement notes that no single prevention method can completely prevent HIV transmission. Moreover, antiretroviral treatment has no effect on other sexually transmitted infections, whereas condoms can prevent their spread. [NAM](#)

You can see the full version of the *Position statement on the use of antiretroviral therapy to reduce HIV transmission at www.dh.gov.uk/health/2013/01/eaga-bhiva-hiv-statement* (it's free to download).

The original version of this article was published on [aidsmap.com](#) on 23 January 2013: [www.aidsmap.com/page/2565656](#)

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Talking points

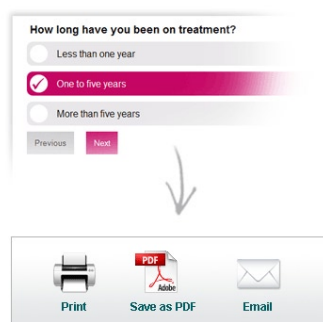
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