

hiv treatment update



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Gus Cairns

in this issue

December 2nd, says the diary. The day after World AIDS Day (WAD), an occasion I've sometimes been cynical about in the past. So nice for the world to worry about AIDS for a day so we only have to worry for the other 364!

This year I'm not cynical, because HIV has been extraordinarily in the news in the last month, since well before 1 December. This in turn seems to have stimulated a new seriousness and engagement in the press coverage of HIV, from Cherie Blair speaking out against criminalisation in the Elton John-edited *Independent* to the National AIDS Trust anatomising the UK epidemic in *The Times*.

Much of this has been because of good news, as we say in *Upfront*, opposite. The world epidemic is shrinking; the Pope countenances condom use; we prove that HIV drugs can prevent HIV.

Coverage is also due, however, to a renewed anxiety about how the world's response to AIDS is going to develop in the future.

Some of this concerns the world epidemic. We need new prevention tools (like PrEP) precisely because the reduction in HIV cases globally is only slight and the number of infections still outstrips the number of people put on treatment. But how on earth, when we can't afford (or don't want) to pay for pills for positive people, can we pay for pills for HIV-negative ones too?

The picture in the UK, however, is what gives rise to the greatest concerns here, and is the subject of the main feature in this issue (see *The whether forecast*, page 8).

Here we face a UK epidemic that continues to grow, increasingly due to infections in gay men (ones in Africans are decreasing here, as they are in Africa), unprecedented public service cuts, brutal efficiency savings in the NHS and a wholesale revision of health administration.

I must have known something, in mild early November, about the forthcoming weather when selecting this title, as I write this a month later in snowbound London. I was expecting to find a similarly grim forecast from those most likely to be in the know about what will happen to our services. Instead, I found something even more disconcerting: amongst even civil servants and policy experts, what HIV services will look like next spring was and is still as unclear as what the weather will be like then.

Will we be going to our GPs for our HIV meds or to a handful of elite super-clinics? Will everyone with HIV on benefits be hauled in for medical exams or only a few? Will HIV prevention services stay the same or be handed over to a slick new agency with a tougher line? The picture so far is getting no clearer, even as we approach crunch time, and experts continue to disagree.

Just as uncertain, and a continuing concern, is our personal 'whether' forecast: not only whether we live to a ripe old age (see page 13) but whether we have a healthy one (*The prescription for old age*, page 4).

HIV services and the ageing population are probably the two biggest issues in the British HIV scene, so we'll return to them in the new year. In the meantime, we wish you warmer times, warmer climes, friendship and health for 2011.



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editor Gus Cairns

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Greta Hughson

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was founded by Peter Scott

contact details

Lincoln House, 1 Brixton Road,
London, SW9 6DE, UK

tel: 020 7840 0050

fax: 020 7735 5351

email: info@nam.org.uk

web: www.aidsmap.com

medical advisory panel

Dr Tristan Barber

Dr Fiona Boag

Dr Ray Brettle

David A Castelnuovo

Professor Janet Darbyshire OBE

Heather Leake Date MRPharmS

Dr Martin Fisher

Professor Brian Gazzard

Professor Frances Gotch

Liz Hodges

Professor Margaret Johnson

Dr Graeme Moyle

Dr Adrian Palfreeman

Kholoud Porter PhD

Dr Steve Taylor

Professor Jonathan Weber

Dr Ian Williams

Dr Mike Youle

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Another weapon against HIV

There has been good news this month. The Pope changed 2000 years of Catholic doctrine by saying condom use *might* under certain circumstances be OK, because it preserves life rather than prevents it. The director of UNAIDS said the world has “turned the corner” and the number of people with HIV globally is falling.

But the news that excited the most debate came from the iPrEx study, which showed it may be feasible to use anti-HIV drugs to prevent HIV as well as to treat it.¹

iPrEx stands for, translated out of Spanish, the pre-exposure prophylaxis (PrEP) initiative. The study took 2500 mainly young gay men, most of them South American, who were at high risk of HIV infection, and gave half of them a two-drug HIV pill (*Truvada*) and half of them a placebo. The HIV infection rate in the men on *Truvada* was nearly halved: the drugs cut the chance of acquiring HIV by 44%.

Not bad. But the results get complicated, and because of this reactions to the study have ranged from ecstatic to sceptical.

Animal studies had suggested that PrEP could be a lot more effective than this. In fact it was, it appeared, in people who took all their pills. Based on what participants said and the number of pills dispensed, the researchers calculated *Truvada* stopped nearly three-quarters of infections (73% efficacy) in people who took more than nine-in-ten doses.

So far, so good: if we could improve adherence, PrEP might be very effective. That shouldn't be too hard, they thought, because it looked like only one-in-ten doses was being forgotten.

However, the researchers had another, more objective measure of adherence. They looked at the 34 people who became infected with HIV while supposedly taking *Truvada*. They found very few of them

showed evidence of really having taken it. Good news in a way: few who actually took the drugs got HIV.

But they had a shock when they looked at drug levels in people who had *not* become infected. They could only find evidence of the drugs in half of them. The tests used could detect drugs up to a month after the last dose, so this was not due to the occasional missed dose. Not only were half of the men not actually taking their pills, four out of five of those were lying about it.

Why were they not taking the drugs? One reason may be the side-effect of mild nausea some reported in the first month. Something you might live with if the pills were saving your life, but perhaps enough to put you off if you were gambling on not getting HIV anyway.

Another hint came from interviews exploring participants' experience of the trial. Some said they'd found the badgering to take the pills became oppressive after a while. For a peaceful life, 40% said they were taking pills when they weren't.

In some ways, this is very exciting news. It means the 'true' efficacy of PrEP might be double that observed, and indeed the researchers calculated that if people took all their pills all the time, *Truvada* could prevent 19 out of every 20 infections. Impressive: actually better than the rate achieved by people trying to use condoms every time.

In other ways, it's not so good. If we can't improve adherence, then PrEP becomes another frustrating, not-quite-good-enough new prevention method, like the tenofovir microbicide gel (39% efficacy in the CAPRISA trial).

PrEP will only become a real option if it's very effective indeed. A single dose of *Truvada* costs \$38 a day at the US list price – and even at the discounted rates offered to

developing countries, one pill costs 20 to 30 times as much as a condom. It's going to have to be pretty effective to persuade healthcare funders to pay for it.

During a conference call about the trial, Peruvian trial director Javier Lama revealed that while iPrEx was taking place, *Truvada* had been unavailable to people who needed it for treatment in Peru (though its two constituent drugs had been). The Global Network of People living with HIV (GNP+) pointed out that during screening for the trial, 410 men were found to have HIV, not to mention the 110 who tested positive during it. Will they get the drugs they need?

Although welcoming the trial in general, some activists were concerned that PrEP might divert funds away from HIV treatment, and raised other issues too. What if it encouraged people to self-medicate with HIV drugs? What if it created a black market for them? Two people during the trial who, unbeknownst to anyone, were actually developing an HIV infection when they started PrEP, appear to have developed drug-resistant HIV as a result. What if PrEP sows the seeds of resistance in the population, as substandard treatment did in the 1990s?

“We, as a community of advocates, must now confront difficult questions about roll-out, cost, HIV prevention messaging and the place PrEP takes,” was the message from the Global Forum on Men Who Have Sex with Men and HIV (MSMGF). The Forum pointed out that there was no chance of PrEP working in many parts of the world if it required that men self-identify as gay where doing so risks violence or imprisonment.

Other advocates, however, welcomed PrEP as another piece of evidence to support the contention that the only way to defeat HIV is to treat it.

the prescription for old age

What will happen as the HIV-positive population grows older is already the topic most frequently suggested by readers for *HIV Treatment Update* to cover. It was recently the subject of the annual community symposium at the autumn conference of the British HIV Association.¹ *Gus Cairns* reports.



Will HIV make us age quicker or die sooner? Will we have different needs to the rest of the ageing population? And will those needs be met, or do we need to start campaigning for them now? There's an awful lot we still don't know about how HIV and age may affect each other.

Part of the problem is that to any geriatrician (someone who specialises in the medical needs of older people) 'old' means over 70 at least, and there simply aren't the numbers of people this age in the positive population yet to really know if HIV will affect us profoundly – though we are soon going to start finding out.

So far, there is frank disagreement amongst clinicians as to the likely impact of HIV on ageing. At the British HIV Association (BHIVA) autumn conference, a presentation by a geriatrician, Dr Peter Kroker of the Chelsea and Westminster Hospital, predicted that few people with HIV would belong to the group of really hale and hearty elders – people who survive into their 80s and 90s with reasonably good health.

This was immediately challenged, from the audience, by another physician from the same hospital, BHIVA founder Professor Brian Gazzard, who said that he felt the additional disease burden HIV may place on the elderly will only be a relatively small one.

"Most of my older patients are fit. The data that we *will* age prematurely is not there," he said.

The older HIV patient: some facts

So what do we know? At the seminar, Brighton's senior HIV consultant, Martin Fisher, outlined the greying of the HIV-positive population. One in six of the HIV-positive population of the UK is now over 50, and in Brighton that figure rises to one in three. There are now about 2500 over-60s being seen for HIV care in the UK compared with 350 in 2000, and over 500 over-70s.

Not all of those are long-term survivors diagnosed when young. The proportion of over-50s with HIV who have been diagnosed in the last year is the same as in the HIV-positive population generally – one in six. Nearly a third of those were over 60.

This doesn't mean they've all acquired HIV recently. One-in-three people with HIV has a CD4 count below 200 cells/mm³ at diagnosis, usually because they've delayed testing; but in the over-50s that rises to 60%.

"Late diagnosis in the older person really is bad news," said Fisher. If they don't start taking antiretrovirals (ARVs) immediately, those over 50 are more likely than younger people to develop an AIDS-related condition, to do so at higher CD4 counts and, if they do, to die from it.

If they're on treatment, though, Fisher said, the situation is less clear. CD4 counts in older people on treatment do rise more slowly and achieve lower peak levels. On the other hand, older people generally adhere to treatment better and are more likely to achieve viral undetectability. This is because although they are more likely to get drug side-effects, they tend to be more stoic about them and therefore less likely to discontinue treatment.

We do know that, on average, HIV shaves about ten years off the future life expectancy of people with HIV, whatever age they are right now, compared with a similar HIV-negative person (see *How long have I got, doc?* in HTU 195): about as much as being a heavy smoker. But older people on HIV treatment appear to have no *additional* risk of death, compared with younger HIV-positive people, over and above the increased risk that comes with age for anyone.

People with HIV, even discounting the effect of factors like smoking, are about 60% more likely to get heart disease and 75% more likely to get kidney problems than the general population,

however, added Fisher. And as well as the well-known cancers related to viral infections (Kaposi's sarcoma, anal and cervical cancer, lymphoma, liver cancer), we are also more than twice as likely as a similar HIV-negative person to get lung cancer and many other common ones.

There is also the vexed question of brain impairment and dementia. We do know that about half of all people with HIV have a measurable degree of poor performance when it comes to thinking, concentration and memory (see *Scattered pictures*, HTU 186), and that the risk rises with age. However, we don't know how severe this will get in the average person.

We also know that life expectancies continue to improve. A person newly diagnosed with HIV at the age of 35 between 1996 and 1999 could only expect to live till 60. Someone of the same age diagnosed now can expect to live till 73, according to a 2008 study in *The Lancet*,² and the picture continues to improve.

Both Martin Fisher and Peter Kroker, however, were worried that this improvement in lifespan may abruptly reach a limit as people with HIV hit their mid-70s.

The cause of old age

Peter Kroker explained this. He started off his presentation quite optimistically, pointing out that, ever since the second world war, "Every ten years, in virtually the whole western world, we have gained about two years in life expectancy, and we don't really know why." In 1900, 50% of people died before they reached the age of 45. Now only 4% of people die before this age.

It used to be thought that ageing was simply a matter of the stresses of the environment (ranging from social inequality through smoking to viral illnesses) eventually outpacing the ability of the body's organs to recover from them. This probably still explains inequalities in life expectancy, such as the fact that men in Kensington and

Chelsea, west London, live on average to 84, but in Glasgow City only to 71.³

It became clear more recently that there wasn't one primary cause of ageing, however. Instead, researchers have uncovered two very intriguing findings. Firstly, there appears to be a rather precise maximum lifespan which, if everything else is perfect, we are set to die at: "Everything seems to be finely calibrated to achieve a maximum lifetime of about 120 years," commented Kroker.

Secondly, it has become clear that ageing is not just a question of gradual decline, but that at the end of life, a mysterious process takes over that *accelerates* ageing. It's as if at a certain point people lose their resilience so that "something whose physiological impact is relatively slight, such as a hip fracture, triggers rapid ageing". Many of us may have had a feisty granny who survives into late old age but who suddenly seems to 'give up' after some relatively trivial event.

The sign that the person has entered this zone may be that they start to display "frailty". This is a specific clinical syndrome in older people which includes unintentional weight loss, muscular weakness, exhaustion and low activity, and Fisher said that his older HIV-positive patients were at least three times more likely to develop frailty as other old people, especially if they have a low CD4 count.

There are even some clues, from animal studies, as to what might trigger this self-destruct cycle. Researchers produced longer lifespans in middle-aged mice by feeding them carefully calibrated doses of an immune-suppressant drug called rapamycin (*Sirolimus*).⁴ Rapamycin works by making immune cells sluggish, so they proliferate less rapidly. Might the sudden ageing seen at the end of life be a phenomenon like AIDS – an overactivation of immune cells which burns out the system?

Will HIV accelerate ageing?

This might spell trouble for people with HIV, and Kroker is concerned that, as people age, HIV infection – whether treated or not – may have

While it's clear that untreated HIV infection mimics age, it's not at all clear that people who are on treatment from diagnosis will age prematurely Professor Brian Gazzard

characteristics that mean that people with HIV age quicker.

He is most concerned about the threat of cancer. "I expect that the effects of HIV will increasingly be augmented by the ageing process," he warned the conference, adding that "I especially expect cancer rates to rise exponentially when patients come towards the end of their 60s and older."

He quotes from a study in *The Lancet* that compared patients with HIV to patients who had received transplants and were on immune-suppressant drugs,

in order to try and compare cancer rates in two groups of people with low CD4 counts.⁵ The researchers found that both types of lymphoma and liver cancer were at least twice as common in people with HIV as they were in transplant recipients. Given, however, that these cancers are related to Epstein-Barr virus and the hepatitis B and C viruses, lifestyle factors in people with HIV can't be ruled out as the reason for higher rates of cancer.

Fisher suggested that HIV infection gives people a biological age considerably in advance of their actual one: so cardiovascular and kidney function is often characteristic of people ten years older; bone mineral density of people 15 years older and so on. And Kroker points out that HIV infection and age produce very similar immune defects.

One could split the population into groups in terms of mortality, he said. Leaving aside the 4%, previously mentioned, who died aged under 45 of things like accidents, childhood cancer, and so on, there are two distinct categories. There are the two-thirds of people who live beyond the age of 75; in this group the average life expectancy is 90 and they essentially die of old age. This leaves 28% of people who die between the ages of 45 and 75. This includes people where bad genes, bad luck or poor lifestyle has led to a failure to achieve the maximum lifespan.

"I fear that most HIV patients will be in this second category," was Kroker's sombre conclusion.

Looking on the brighter side

Brian Gazzard isn't so sure. He explained the comments he made at the seminar to *HTU*.

"In terms of the biochemistry," he says, "the problem is one of finding the right controls. The studies may have established that there is more immune activation [and potential burnout] in people with HIV compared to the clean-living laboratory assistants they tend to use as controls.

"But what you need to do is compare them to people with the same lifestyles who happen to be HIV-negative: gay

men, people from Africa, and so on. Gay men are more likely to have other infections like CMV" (cytomegalovirus, which may cause cancers).

"The same applies to brain impairment. Do you compare it to people who've never touched a drug in their lives, to people who've taken drugs in the past, or to people who were on crystal meth last night?"

A clue he may be right was provided by a survey at St Thomas's Hospital (quoted in *Scattered pictures*). This found more brain impairment in gay men with HIV than in the general UK population – but scarcely less in the HIV-negative gay men it picked as controls.

"Then," says Gazzard, "we need to appreciate that this is all about relative risk, not absolute risk. Some of these cancers are rare. It's clear there is a somewhat raised risk of them in people with HIV, but twice the risk of something rare is still rare.

"While it's clear that untreated HIV infection mimics age, it's not at all clear that people who are on treatment from diagnosis will age prematurely; the length of time untreated may turn out to be crucial.

"I'm against predicting a holocaust where one has not yet happened. I think the evidence that there will be a lot of dementia and premature ageing in people with HIV is still pretty slim."

Complex care needs

Whichever scenario applies to people with HIV, no one is in disagreement that as we age we will present with complex care needs, and it may be a bit of a puzzle as to which doctors or set of specialists should be in charge of our health care.

Should older people with HIV be managed differently from their younger peers? The problem is that there are very few data to go on, because few drug studies have been done in older people with HIV, as they often have other conditions besides HIV and are frequently on other medications.

We need better links between the NHS and social care services, and better preventative programmes to help people live healthier, fitter and longer lives

Garry Brough,
Terrence Higgins Trust

Despite his early gloomy predictions, Peter Kroker says that, with ideal management, people with HIV "have the potential to make it into their mid-90s and beyond. But how do I help them get there?"

And who should be in charge of their care? "Do we retrain HIV physicians in general medicine?" asks Martin Fisher. "Or train other specialists to take an interest in HIV? Do we persuade gerontologists who normally only deal with the over-80s to get involved? Do we make a concerted effort to re-engage with GPs, who are quite used to

managing older patients with common and complex needs?

"The ideal way forward is probably a combined clinic with specialists physically in the same room, but this may be difficult for smaller clinics and given the direction the NHS is following."

From outside HIV, Peter Kroker is much clearer. "I don't think geriatricians should manage antiretroviral therapy," he says. "I don't think I would have the time or the intellectual capacity to look after another 20 HIV patients in an outpatients' clinic that already has 8000 attendances a year. This group would get lost in such a set-up."

Social care needs

Whatever will happen to HIV-positive seniors over the next few years, we will not only have medical treatment needs, but also social and care needs.

Garry Brough, who works for the Terrence Higgins Trust (THT), gave the third presentation at the community symposium. He ran through the findings from the *50 Plus* survey that THT and Age UK (the new charity arising from the merger of Help the Aged and Age Concern) conducted and which THT's Lisa Power wrote about in *HTU* this July (see *Will a long life be a good one?* in issue 198).

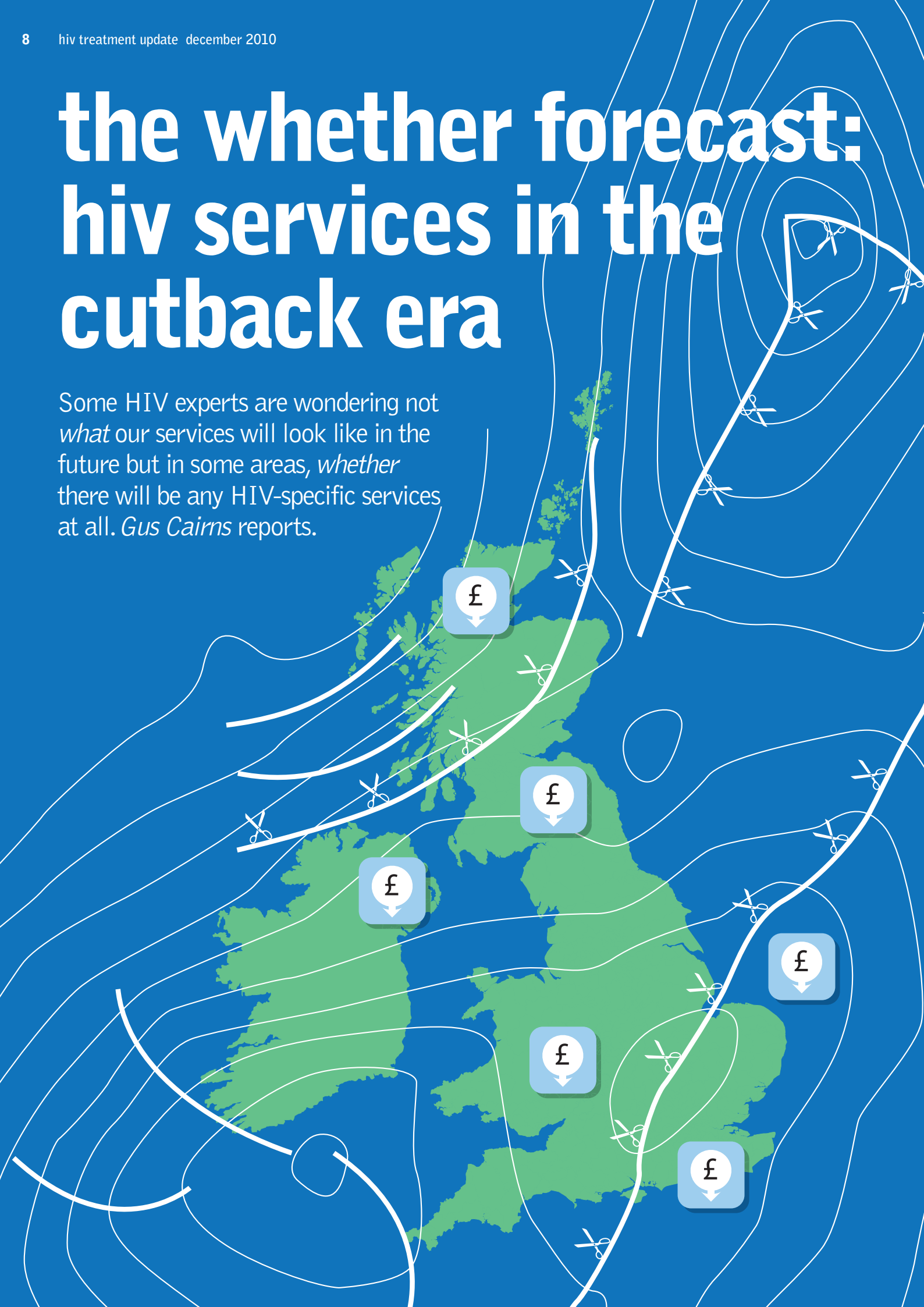
"We need better links between the NHS and social care services," says Brough, "and better preventative programmes to help people live healthier, fitter and longer lives.

"We should especially concentrate on exercise," he adds. "This is one of the very few things that makes a real difference to most heart problems, bone density, blood pressure, cholesterol levels and depression, as well as helping to reduce social isolation." Studies have also shown that exercise, in both middle⁷ and old⁸ age, can cut the prevalence of dementia by 40 to 50%.

The prescription for healthy living in old age for people with HIV is, then, the same as it is for everyone. *Don't smoke, don't stress, do exercise well, eat well, and think well. Remain interested in life and it will remain interested in you.* ■

the whether forecast: hiv services in the cutback era

Some HIV experts are wondering not *what* our services will look like in the future but in some areas, *whether* there will be any HIV-specific services at all. *Gus Cairns reports.*



Cold and frosty, but with sunny prospects: the NHS White Paper



Early on, people in the HIV and disability activist movements, insisting that they were regarded as equal players in decision making about their health, adopted a slogan: "Nothing about us, without us". In the White Paper that sets out the coalition government's vision for the NHS in England,¹ they use, as one of their guiding principles, a version of the same slogan ("No decision about me without me").

It may therefore be a bit ironic that this document contains reforms so radical that they may mean the end of some HIV-specific services.

The NHS White Paper is not the only policy document that will affect the future of HIV services over the next half-decade. There is, of course, the government's Spending Review (SR),² which will make an 8.3% cut in government spending in real terms over the next four years and a 29% cut to departmental budgets.

Yet the NHS is specifically exempt from cuts, and the White Paper pledges that: "We will increase health spending in real terms in each year of this Parliament". So why are these reforms likely to radically shake up HIV services?

Firstly, the cost of medicine rises faster than the cost of living. There are around 90,000 people living with HIV in the UK, and each year, around 7000 more are diagnosed. Add to this 8% increase, the increase in the proportion taking antiretrovirals due to treatment

guideline changes and you have a projected increase of 11% in the HIV drugs budget alone. The health spending increase comes nowhere near compensating for this, and the government has made it clear that, while the NHS is exempt from cuts in the provision budget, it will still have to share the pain. Specifically, it demands £20 billion in efficiency savings by 2014 (out of an annual NHS budget of £105 billion),³ and a huge 45% cut in NHS management costs.

Secondly, not all HIV services are run by the NHS. Local authorities run social care, and from next year will take over local responsibility for public health – including HIV prevention – from the primary care trusts. Local government is expected to cut 28% from its budget, and that may mean paring everything but statutory social services to zero. The ring-fenced protection for the AIDS Support Grant,⁴ £30 million allocated to local authorities in proportion to their HIV-related social care needs, was abolished, just before the election, by the last government.

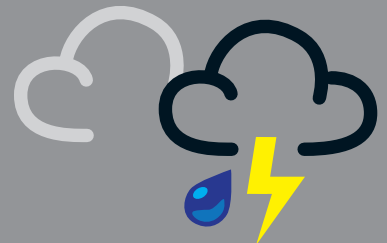
Thirdly, about 45% of people with HIV are unemployed⁵ and others on low incomes. Cuts in the benefit budget will happen too, to the tune of £18 billion over the next four years. This includes the replacement of Incapacity Benefit with a time-limited Employment Support Allowance, an across-the-board 10% reduction in Housing Benefit, including a cap on rents, and possible health assessments of everyone claiming Disability Living Allowance.

Finally, HIV used to be one of the 'specialised services', 35 disease areas which, because of their complexity and/or cost, were commissioned on a regional or national basis rather than by local primary care trusts. It was therefore not subject to variations between local trusts, and its regional management meant that it largely remained within the remit of clinics at large hospitals. No more: as of 2010, HIV has been removed from the list of specialised services.⁶

A central plank of the White Paper is to make consortia of GPs responsible for commissioning (funding) virtually all health provision in their local area. Although there remains a provision that very specialised and/or expensive services will be commissioned by an overseeing body called the NHS Commissioning Board, there is doubt amongst HIV service providers whether HIV these days is specialist enough, in an era where most people on treatment are stable, to warrant separate provision.

Once HIV is bundled into local services, many people predict that the GP consortia will impose cost reductions with a determination that has been lacking in the big hospitals, and we will see the end of consultant-delivered HIV care for the majority of patients.

Unsettled times ahead: the view of the Terrence Higgins Trust



Paul Ward, Deputy Chief Executive of the Terrence Higgins Trust (THT), does not mince his words when it comes to his predictions for HIV. "I think services for people with HIV are going to go through the biggest single change since the start of the epidemic," he says. "There is a good chance we will see significant reductions in voluntary sector provision and its almost total disappearance in some areas."

In terms of medical care, he says, we are likely to see a big shift from HIV care in hospitals to HIV care in local health facilities, though not necessarily by GPs.

He acknowledges that there have been predictions that uncomplicated HIV

treatment will become part of local, non-hospital-based health care for years, and it hasn't really happened. "This time round, though, I think it's different. There really is a lot less money to go around, and there will be a different set of commissioners in the driving seat."

The consortia of GP practices that would commission services would, for a relatively specialist condition like HIV, need to be large and look after a whole region such as Yorkshire or the North West.

But, he warns, "Experience shows that, once you get GPs in charge, there will be a lot more emphasis on value for money."

This doesn't mean the HIV sector would have no say in how services were configured. As *HTU* Readers' Panel member Robert James points out, GPs may decide that HIV is such a "messy and complicated" area, they will farm the whole process of commissioning out to a health consultancy – which could be a private firm but could equally be an organisation like THT.

Dr Mike Youle, an HIV specialist who has criticised substandard HIV care in the past, doesn't necessarily think this is a bad thing. "The NHS is slow to use the possibilities of e-clinics, home delivery of drugs and all the things that free up time and allow concentration on real clinical services."

And David Castelnovo, a specialist HIV nurse in Brighton, agrees. "We as NHS trusts have not been very good at managing our budgets... it's only recently that we adopted home delivery, which saves £1000 per patient per year in VAT alone."

Paul Ward predicts that the stable majority of people on HIV – the people who have no need to change treatment – may be increasingly managed by specialist nurses like David who are attached to one or more local clinics.

When it comes to social care, Paul predicts a shake-out of services "bigger than that in the late 1990s when many of the old drop-in centres closed.

"Local authorities are facing cuts of 35% to social services. They will have to cut provision to the bone, to only cater for the people to whom they have a clear statutory obligation: children, the elderly, and a few adults such as those with severe learning or other disabilities or mental illness. THT sees many, many people with high social care needs who, nonetheless, are not *statutorily* eligible for social care."

He regrets the ending of the ringfence for the AIDS Support Grant but thinks that the scale of the funding cuts would have overshadowed any difference made by keeping it: "Even before it went, in the last few years it was getting hard to show that all of the money was getting to people with HIV."

In response to the changes, THT is planning to increase the services it provides via the internet and over the phone, and predicts a lot of other organisations will have to do the same. "Organisations may not have paid staff to provide in-person services or, if they do, won't necessarily have a building to do it from."

LifePlus, THT's new website (see box opposite) is an example of this new kind of provision. A Department of Health kitemark is now available for health and social care information, and providers can apply for accreditation under it to certify the information they produce is reliable and up to date.

A separate NHS consultation on a proposed information strategy, covering everything from websites to patient records and health audits, is currently underway.

But not everyone uses the internet. African people in particular have reported that they prefer one-to-one, video or interactive services and that, if they do use the internet, they often do so in places where confidentiality is a problem. Paul Ward points out that despite this stated preference, a study from Homerton Hospital presented at the Vienna International AIDS Conference this year⁷ found that African women were avid readers of HIV information websites.

When it comes to prevention and public health, the situation is different in that the government, in shifting responsibility for public health from PCTs back to local authorities, has allocated *new* ringfenced money for its provision.

However Paul Ward is quite sure that prevention programmes and interventions will be more tightly controlled than before. This is because the other, central plank of the new NHS strategy is to rely on *outcome*, rather than process, measures. This means scrapping a lot of the Labour targets such as waiting-list times. In the case of HIV prevention, anything that doesn't get local HIV and STI infection rates down will have a hard time justifying being funded.

Ward thinks that there is room for unfairness and discrimination in this new slimmed-down world, citing especially the new wave of people ageing with HIV (see *The prescription for old age*, page 4) who may have specific needs such as gay-friendly and HIV-aware care homes. He also believes that many people will suffer from the changes to welfare benefits.

"We need to recognise that there will be a big impact on people with HIV, and we will need to fight for their rights and help increase employment amongst people with HIV."

Dark skies, but glimmers of sunshine: the view of the National AIDS Trust



Over at the National AIDS Trust, Policy Director Yusef Azad has a slightly different take on the prospects facing us.

He hopes that HIV may yet remain a specialist service commissioned by the NHS Commissioning Board and suggests

that there is still everything to play for in terms of making the case that HIV commissioning needs specialist expertise.

“Our concern is not so much that drugs will not be paid for – they will. But GP consortia may not, for example, understand the importance of services such as psychological support for people with HIV.”

He adds that there is still no answer as to how open-access self-referral services like HIV and GUM clinics will fit with commissioning by GP consortia. Interestingly, two important open-access services – dentists and opticians – will be within the remit of the NHS Commissioning Board, not GPs. Could HIV be the same?

Even if the NHS Commissioning Board does commission HIV outpatient services, this does not preclude the greater involvement over time of GP practices in treatment and care of people with HIV, he adds. The proposal for greater patient choice of GP may allow for some practices to work in partnership with HIV clinics in provision of treatment and care.

Azad is encouraged that, although the AIDS Support Grant has gone, a letter from Eric Pickles, Secretary of State for Communities and Local Government, confirms there will continue to be a specific amount relating to HIV social care within the general ‘formula grant’ given to councils and that it will increase from £20.5 million in 2010-2011 to £36.2 million by 2014-15. This, he says, was a direct result of NAT’s campaign to retain a distinctly funded allocation for HIV social care in the Comprehensive Spending Review.

“This may not be ringfenced but it is an acknowledgement that the number of people with HIV is going to keep on growing and their social care needs will increase,” says Azad.

However, because it doesn’t *have* to go on HIV services, “a specific case in each local authority will need to be made to spend this money on HIV, and not something else more acceptable.”

He explains how the benefit system will change.

“For some time now any new applicant claiming medical inability to work has been placed on something called Employment Support Allowance (ESA) instead of Incapacity Benefit (IB), and people on IB are being ‘migrated’ over to ESA. The difference between the two benefits is that with ESA there is less emphasis on proving that people can’t work and more of a presumption that they will be able to again soon. People who qualify will only be able to access ESA for a maximum period of a year, unless they are severely disabled. After that they will almost always have to go on to regular Jobseeker’s Allowance and prove they are actively looking for a job, or stop receiving any employment-related benefit.

“This is just an arbitrary limit when it comes to a long-term condition like HIV,” he says. “A medical barrier to entering the workplace does not automatically disappear after a year, and we are maintaining that people should be treated on a case-by-case basis.”

There are a lot of problems with these face-to-face assessments (known as Work Capability Assessments) for people with HIV, which NAT has recently set out in its report *Unseen Disability, Unmet Needs*.⁸ It will be a challenge, Azad says, to ensure a fair assessment system for benefits in the context of massive cuts to the benefits budget.

In terms of prevention, he is concerned that handing public health back to local authorities will create an unhelpfully rigid distinction between prevention and treatment services. “A lot of HIV treatment has prevention implications,” he says.

However he welcomes the proposed ringfence within local authority budgets around public health: “This could be a positive development. There’s always been a tendency for clinical care to suck all the money out of prevention. People more often hammer on their doctor’s door because they’re in pain than because they’re worried about their eating or exercise habits.”

The new world of HIV service provision is going to be a tough one. “There will, whoever they are, be a new set of commissioners who will be asking very tough questions about the impact and effectiveness of everything and who won’t necessarily have any loyalty to the HIV sector.”

Besides, he adds, the wind of change is already upon us, and organisations are already falling by the wayside. Crusaid, for example, closed this year and its Hardship Fund is now administered by THT.

“There is a whole new range of players,” he says, “and we will need, to every one of them, to make the case for maintaining the standard of HIV treatment, as a public health issue.”

A blast of fresh air? How the cuts may help us



Much is still uncertain about the impact of the cuts. An alternative model doing the rounds in London is that, far from services being provided locally, HIV health care in the capital should be provided by six ‘super-clinics’ at the biggest teaching hospitals.

Which model you prefer probably depends on where you live, your state of health and whether you prefer convenience to expertise or vice versa and it’s far from clear what changes will occur in HIV services in the coming years. As we write, it is even uncertain as to whether the national HIV drugs budget will expand by the projected 11% rise in people needing them. We also don’t know yet who will deliver HIV prevention work in London next year. There is a feeling that much is yet to play for.

Some people we spoke to think that the impact of the cuts may be positive for a lot of people with HIV.

David Castelnovo says: "The forthcoming changes are not all doom and gloom. Some of the reforms are inevitable. Our social care needs *have* changed and with people affected by HIV mostly dying in their old age, shouldn't social provision, with a few complex exceptions like the needs of newly arrived immigrants, be

redirected toward the problems of getting old with HIV?"

He adds that he is "horrified" by the level of unemployment in people with HIV. "We should be doing much more to help people into employment, and it's an area THT should be addressing with increased interest."

Dr Mike Youle agrees: "All those who take the jump into work have, in my opinion, benefited hugely from it and

this includes people with severe long-term HIV. It is vital we support this process and make their lives as easy in work as out." ■

HTU will continue to cover the impact of changes in treatment, care, prevention and social care over the coming months. If you have experienced changes in services or other aspects of the cuts, email info@nam.org.uk with the subject heading 'Information for HTU'.

Life Plus: a new service model

In response to the challenge of enabling an increasing number of people to manage HIV as a long-term condition, the Terrence Higgins Trust and people living with HIV have collaborated to create an innovative new service – the Life Plus project.

Life Plus, funded by the Elton John AIDS Foundation, and developed with the support of George House Trust (GHT) and NAM, will help people living with HIV to manage their health and their treatment using face-to-face, telephone and online support.

The new resource will include a web-based health and social care support system tailored to individual needs: the more people use the service, the more tailored to individual needs it can become. It will also provide an online space where people can privately and securely store information about their treatment - CD4 count, viral load and much more - enabling people to monitor their own health and take an active role in their care. People living with HIV will be able to submit questions which will be answered by accredited health trainers.

Forums will enable people living with HIV to build communities, and offer support to each other around all sorts of topics, from treatment and adherence to safer sex and disclosure. Online support and advice will also be available for those who feel they need further help.

The Life Plus project also provides a new face-to-face support service in

areas with high rates of HIV prevalence; Brighton, Birmingham, Glasgow, Cardiff and Manchester (the latter with GHT). THT's health trainers will encourage and support people to manage their condition on a one-to-one basis. They can meet people living with HIV at their clinic, a THT/GHT centre or even their home, or offer advice and support over the phone, or online.

Chris, from Aberdeen, has been HIV-positive since 1999 and helped develop the service: "I've been working with my health trainer for about a year now. Since then my view on living with HIV has totally changed; I feel more positive, confident, in control and aware of what's happening. Before I was always on the fringes but now I go to seminars and conferences on HIV and am getting involved, and that's something I wouldn't have done before."

Eileen Nixon, HIV nurse consultant and research fellow at the University of Brighton, is on the Life Plus project advisory group: "Part of the reason I wanted to get involved with this project is that I believe we can learn a lot from this and other long-term condition models.

"There are some great examples of people taking an active role in their HIV care, and health trainers can support patients to do this, especially at times of change, as when considering starting ARVs. For patients with other health conditions as well as HIV, some may find it useful to have additional support to manage multiple hospital appointments.

"What's exciting about the Life Plus project is that the third sector and the NHS are working together to identify what services are needed and who provides them. Anything that helps people to engage in decisions about their health care is a positive step and, with HIV changing so much, really helpful."

Caspar Thomson, NAM's Executive Director, says: "We now have plenty of evidence that the more involved individuals are in their care and treatment, the better their health.

"To become involved in a meaningful way people need good quality, authoritative information that supports them at every step of their journey with HIV. People have different needs, learning levels, circumstances and backgrounds; so that information has to be delivered in as many different ways as possible, including online and face-to-face. The Life Plus project will extend the scope and reach of existing information in ways that have not, until now, been possible."

- If you are living with HIV and want to share your experiences, test the new service or give feedback:
- Or if you are a health professional, work for an HIV charity or support people living with HIV and want to know how the Life Plus project will help to promote your service to people living with HIV:
- Please contact Verity Glasgow at verity.glasgow@tht.org.uk

news in brief



HIV in the UK

HIV cases decline: but not in gay men

The annual report on the UK HIV epidemic from the Health Protection Agency (HPA) reveals that the number of new HIV diagnoses declined last year for the fourth year in a row.¹ So far 6630 new diagnoses were logged in 2009 (more may be added as records come in), a decline from a peak of 8000 in 2005.

This is entirely explained by a decline in the number of HIV infections acquired abroad. For the first time since 1999, the number of diagnoses in gay men (2760) exceeded the number in heterosexual people infected abroad (2240), and diagnoses in gay men have been at the same level for three years. Gay men represent 40% of the UK's positive population but, for the first time in ten years, a slightly higher proportion of new diagnoses (42%).

A higher proportion of heterosexual infections, about a third, took place in the UK – far more than ten years ago, when it was about one in ten.

The HPA estimates that there are now 86,500 people living with HIV in the UK: three times as many as ten years ago. A quarter of these are undiagnosed: the number accessing care is 65,000. The HIV-positive population is ageing: one in five is now over 50.

People are still being tested far too late. Half of adults were diagnosed with HIV with CD4 counts of below 350 cells/mm³, which is when treatment is recommended to start. A quarter of gay men and half of heterosexual men are diagnosed with CD4 counts below 200, meaning they are at substantially greater risk of illness and death, and a much higher

proportion of people over 50 are diagnosed late.

Once people are in care, the UK has an excellent record of treatment efficacy: 90% of people on treatment have an undetectable viral load.

Prognosis

HIV cuts 13 years off life expectancy

Researchers have found that HIV infection still cuts 13 years off the average person's life expectancy amongst patients in the UK. Ten of those years are due to people coming forward late for testing, with CD4 counts already under 200 cells/mm³, a recent HIV conference in Glasgow heard.¹

The impact of HIV is disproportionately felt by men, whose deficit in life expectancy relative to the HIV-negative population is twice that of HIV-positive women.

Figures from the UK Collaborative HIV Cohort (UK CHIC) study, a database of 18,000 patients from 30 HIV clinics, were used to compute life expectancy at age 20: the additional extra years of life that a person could be expected to live when they reached their 20th birthday. Figures for people who, at some point in their lives, were diagnosed with HIV were compared with those from the general UK population.

The researchers found that, in the most recent time period, the life expectancy for HIV-positive people at 20 was 46 years: in other words, the average HIV-positive person could have been expected, at their 20th birthday, to survive till 66. (Note that this does not mean that HIV-positive 65-year-olds are going to die next year: life expectancy increases as you get older, as the fact that you have survived and others have died makes it more likely you will continue to live.)

Men had a considerably lower life expectancy than women – 40 versus 50 years. Why this is the case is not clear.

These life expectancies are, on average, 13 years lower than in the UK population and 20 years lower for men.

However, many of the excess deaths, were in people diagnosed with low CD4 counts who died in the first year after presenting for an HIV test. The life-expectancy deficit for people who maintained a CD4 count over 200 was 6.5 years post-2000 and in the last two years has become near-normal, presenter Margaret May said.

HIV worldwide

HIV cases fall worldwide

We are turning the corner in the HIV epidemic, the director of UNAIDS says in the organisation's annual report on the global epidemic.¹

The estimated number of people living with HIV worldwide has fallen by 20% since 2000 and, thanks to increasing access to antiretroviral therapy, AIDS-related mortality has also fallen significantly. There are now an estimated 33.3 million people living with HIV around the world, and there were 2.6 million new HIV infections in 2009.

UNAIDS estimates that 5.2 million individuals are now receiving therapy with anti-HIV drugs, of whom 1.2 million started in 2009.

However, the report also describes funding for prevention and care falling in 2009. "Many countries are under-investing and need to increase their domestic commitments to sustain and scale-up the AIDS response."

the beginning of change: the 2010 CHIVA summer camp

Following on from our issue looking at young people, in October, guest writer *Bakita Kasadha* talks to the organisers and participants in the UK's summer camp for teenagers with HIV.



The Children's HIV Association (CHIVA) arranged its first large-scale summer camp for young people living with HIV in August. Seventy-nine 13-to 17-year-olds were given the opportunity to meet others living with HIV and learn about the virus. The participants travelled from across the UK to the venue, a private school in Sussex.

The aim of the camp was to tackle the isolation many young people living with HIV face, by bringing a big group of them together so they could meet lots of others facing the same issues.

Magda Conway, projects manager at CHIVA, was camp manager. She explains that smaller-scale CHIVA residential of up to 20 young people had inspired her to set up the summer camp.

With around 500 teenagers living with HIV in the UK, CHIVA felt it was important to have a large-scale residential event, says Magda, because "If you feel like you are the only teenager in England living with HIV, what is more powerful than being in a room with 80 others?"

The camp was made possible due to the time and efforts of volunteers. This included eight camp leaders, who were all HIV-positive, and around 30 key workers, both positive and negative. These 30 were chosen from about 100 applicants. The recruitment process was heavily reliant on the general public and included advertisements in the *Metro* newspaper. Their job was to support the young people on camp.

Jill Hellings, a volunteer at the camp, says: "Peer support is one of the most, if not *the* most, important type of

service that young people living with HIV can access."

Amanda Ely, whose role was to recruit and organise the key workers, recognised the risks involved in selecting those who may not have much experience for such an important role. She describes the make-up of the group as "fairly balanced: it was important that we had a mixed bag," though they did not have as many volunteers from black and minority ethnic groups as she would have liked.

Amanda described them as "enthusiastic and motivated". Magda commented, "For all the volunteers the message is a very big 'thank you'."

Ten adults at the camp were open about their HIV-positive status. Organisers felt it was important to have adults there with a range of backgrounds and experience. Although Amanda recognised there are parallels in people's experiences, as organisers, CHIVA did not wish to "prescribe a kind of model of what it's like being an adult living with HIV".

HIV-experienced people were essential, she says, but it was beneficial that some volunteers were facing the issue of HIV for the first time. Their encounter with young people with the virus not only enabled them to take their learning and understanding into the wider community but to increase others' understanding not only of what it's like to live with HIV but also what it's like to encounter it.

Madeline, a camp leader, noted that volunteers "were excited to be there, but were in different places with how they related to the HIV world" and was struck by how many had "incorrect or insufficient knowledge" of HIV. Max, another camp leader, says most key

workers were "fantastic. But for some, their engagement was not as much as it should be – disappointing, given how special the environment was."

Jill, a volunteer who works in the HIV sector, advises that those considering volunteering for a similar residential in the future should read up about HIV on reputable websites before they go. "Don't think that you need to try to answer questions that you really don't know the answers to. Use the skills of the other volunteers around you."

Amanda says that next year they plan to have a structure to help the more HIV-experienced volunteers to guide those with less information.

One issue that caused a lot of debate was confidentiality. The camp was organised by CHIVA but participants, volunteers and camp leaders alike were encouraged to refer to it under a different name and staff from the venue were not made aware of the status of participants.

These confidentiality safeguards were designed to ensure safety, but people worried whether not being able to mention CHIVA sent contradictory messages. Would participants feel comfortable with their status if they were not able to hint at it publicly?

Amanda commented that this was a "solution to a problem we really grappled with". All organisers wanted the young people to enter a space free from HIV prejudice to enable them to feel more comfortable with their peers. Amanda says that "it's not for us to decide to disclose people's status" and that it was important to respect the rights of the participants.

"HIV is not all that they are. HIV is not everything," she says.

Magda says: "It's difficult to not over-protect this group of young people. Revealing their diagnosis could have major negative impacts on their lives, so we strived to do everything we could for this not to happen."

Next year, though, she aims to use different facilities and offer the venue's staff training on HIV "so we can have a truly open experience."

Finding a location had proven difficult. Four schools cancelled their bookings when the CHIVA organisers tried to negotiate the level of confidentiality that they wanted. "Some simply said no to the camp once they found out that it was for people with HIV. Others said they wanted us there, but only if every single member of staff was told the young people had HIV.

"It was pretty soul-destroying. But it affirms why I do my job."

Many educational and creative workshops took place over the four days. These covered a range of subjects from explaining HIV-positive people's legal rights to magazine making.

One participant, however, commented that she wanted more activities and fewer HIV-focused workshops: "I knew why I was there," she explains. But the need for workshops and education was affirmed when it was discovered that a participant,

living in London, was not aware that there were support groups in her city.

"It was a short four days," says Madeline. "I can only hope for another camp like this. All the camp leaders, volunteers and participants took away a truly amazing experience."

Angela, a camp leader, says: "Participants were free to be who they were – without feeling worried or wary about taking their medication or talking about their sexual health and inner feelings."

She adds: "After the evening events it would be quite a struggle to get the young people to go to bed as they were enjoying each other's company." Over the three nights volunteers were reminded that the young people were just like any other teenagers: they wanted to stay up past their curfew, formed summer romances and occasionally bickered amongst themselves and challenged the volunteers.

The last hours of the summer camp involved a closing ceremony. Everyone had the opportunity to express what they had learned and what they would take away.

Despite disagreements between participants and some differences in opinions, all felt the camp was successful. One participant simply said on the last day, "I don't want to go".

The benefits of this camp go beyond those four days. Not only were young people living with HIV able to form

friendships and discover that they were not alone, but volunteers were able to educate themselves and challenge prejudices. Some were so moved by their four days that they felt compelled to question their lives.

Volunteer James Johnson said that the camp prompted massive change in his own life: "Post camp, I left my job, moved to London, and am starting work with an HIV organisation."

JD, a camp leader and Communications Officer of the CHIVA youth committee, says: "I realised I could raise HIV awareness without having to disclose my status". The summer camp empowered her to run a world AIDS awareness week at her university.

Morpheus, a participant and member of the CHIVA youth committee, says he'd like to see the camps happen every year. "It was great that it was bigger than before; you could clearly see you weren't alone. We could identify with one another." He is a little sad that he no longer felt like a full participant: "People were looking up to me."

Magda's message to the participants? "Take this with you and think about it when things are hard, as it will give you strength. And keep in touch with each other – these friends will see you through!"

Find out more about the summer camp and applying to be a volunteer at: www.chiva.org.uk/summercamp ■

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