

nam

www.aidsmap.com
issue 158 july 2006

aids treatment update

better practice

why GPs need to be integrated into HIV-positive care *page 4*

primary care at HIV clinics

is your clinic providing GP services? *page 14*

immunisation guidelines

new vaccination guidance for HIV-positive people *page 8*

does efavirenz cause depression?

a new study suggests otherwise *page 3*

news in brief

anti-HIV therapy adds thirteen years to post-AIDS survival *page 13*

LGV continues to spread amongst HIV-positive gay men *page 13*



in this issue

Some GPs have never been exposed to diagnosed HIV-positive patients because in the past, HIV clinics have made it easy for us to use them as a one-stop-shop, negating our need for a GP.

This has led to a vicious circle that needs to be broken because some GPs continue to miss undiagnosed HIV, since they're not HIV-aware.

Besides, sooner or later, we will all require an HIV-knowledgeable GP, because GPs will need to prescribe medicines that your HIV clinic can no longer afford - like lipid-lowering and anti-diabetes drugs, and antidepressants.

If you have a GP that already knows about HIV issues, you probably live in an area where your local Primary Care Trust (PCT) provides the 'carrot' of locally enhanced services. This means GPs get paid extra to provide good quality care for HIV-positive people. Sadly, many need this financial enticement in order to learn more about HIV and take on HIV-positive patients.

We need to put pressure on our local PCTs to provide locally enhanced services in every area, but until that utopia exists, why not ask your clinic, or other HIV-positive people, to help you find a local GP that is HIV-aware.

Good luck!

page 3 This month's *Upfront* asks whether efavirenz (*Sustiva*) is the primary cause of depression in people taking this anti-HIV drug, since a new study from France suggests that other factors may be to blame.

page 4 In *Better practice*, we explain why GPs need to be integrated into HIV-positive care, and examine the barriers - and possible solutions - to this uniquely British problem.

page 8 Dr Anna Maria Geretti, lead author of the the most comprehensive immunisation guidelines ever produced for HIV-positive adults, explains why HIV-positive people need special consideration when it comes to vaccinations.

page 12 *News in Brief* features a calculation that anti-HIV therapy adds more than thirteen years to post-AIDS survival. Plus further details of the current LGV outbreak in the UK that is disproportionately affecting HIV-positive gay men; why anyone on triple NRTI therapy should consider changing to something more potent; and news about a potentially serious heart condition that affects one in every 200 HIV-positive people.

page 14 Is your HIV clinic providing GP services? Compare their policies to the six UK clinics who answered our snapshot survey regarding the provision of primary care at HIV clinics.



aids treatment update

editor Edwin J Bernard
sub-editing & proofreading
 Anu Liisanantti
production Thomas Paterson
design Alexander Boxill
printing Cambrian Printers
ISSN 0969-4706
copyright ©NAM Publications
 2006 All rights reserved
charity number 1011220

AIDS Treatment Update
 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 Fiona Boag
 Dr Ray Brettle
 Professor Janet Darbyshire
 Heather Leake Date MRPharmS
 Dr Martin Fisher
 Professor Brian Gazzard
 Professor Frances Gotch
 Dr Margaret Johnson
 Dr Graeme Moyle
 Dr Adrian Palfreeman
 Kholoud Porter PhD
 Dr Steve Taylor
 Professor Jonathan Weber
 Dr Ian Williams
 Dr Mike Youle

For more information about *ATU's*
 medical review panel, please visit
www.aidsmap.com/atu.

about NAM

NAM is a charity that exists to support the fight against HIV and AIDS with independent, accurate, up-to-date and accessible information for affected communities, and those working to support them.

For more information, and details of our other publications and services, please contact us, or visit our website, www.aidsmap.com.

disclaimer

The publishers have taken all such care as they consider reasonable in preparing this newsletter. But they will not be held responsible for any inaccuracies or mis-statements of fact contained herein. Inclusion in this newsletter of information on any drug or clinical trial in no way represents an endorsement of that drug or trial. This newsletter should always be used in conjunction with professional medical advice.

supported by



Does efavirenz cause depression?

by Edwin J Bernard

Efavirenz (*Sustiva*) is one of the most popular anti-HIV drugs in the UK and, out of all the non-nucleosides (NNRTIs) or protease inhibitors (PIs) available, it is the drug that people starting therapy for the first time are most likely to take.

Although it is well established that the most common side-effects of efavirenz occur in the central nervous system, and studies have shown that up to 50% can experience side-effects relating to sleep disturbance during the first few months of treatment, there have been conflicting findings on the link between efavirenz and the development of depression.

Some clinical trials have found that the psychiatric side-effects of efavirenz – including depression, suicidal thoughts, aggression, paranoia, and mania – are very rare. Depression has been reported in around 2% of people on efavirenz and other psychiatric side-effects have been reported in fewer than 1% of people on the drug. Around one person in every hundred discontinued efavirenz due to psychiatric side-effects. However, other studies have found higher rates of depression in people taking efavirenz.

Adding to the body of evidence against the link between efavirenz and depression is a new study from France, published in June. This study examined the effects of switching 178 people from an anti-HIV treatment combination that included a PI, to a combination that included efavirenz. The outcomes were compared with 177

similar people who continued to take their PI-based treatment combination.

During the first year of the study, a similar number of people taking either efavirenz or a PI were diagnosed with depression. Although more people on efavirenz experienced side-effects bad enough to switch away from the drug, this was due to bad dreams, dizziness and headaches, and no-one stopped treatment because of depression.

In fact, rather than efavirenz being linked to depression, the investigators found that both younger age and a previous bout of depression were linked to a greater risk of developing depression during the study, regardless of which anti-HIV drugs they were taking. "Contrary to the idea widely held among HIV-infected patients, physicians, and researchers, our data showed no evidence of efavirenz having an effect on the risk of depression or suicide in the first 48 weeks of use – or even up to 36 months of use," the researchers wrote.

A study published last November attempted to examine efavirenz's side-effects in a different way, by monitoring the drug's psychological effects in a 'blinded' study, in which the 303 participants did not know which drugs they were taking. Again, the study's investigators saw no differences in the levels of anxiety or depression between the 200 participants on efavirenz and the 103 not on efavirenz.

"We provided a controlled, systematic evaluation of efavirenz on anxiety and depression and found no evidence that



efavirenz-based regimens resulted in excess anxiety or depression," the investigators concluded.

Nevertheless, last year a small study from Spain found that people who continue to experience efavirenz's psychological side-effects in the longer term are much more likely to have higher than normal levels of the drug in their blood. Individuals with a blood plasma concentration of efavirenz above 2.74µg/ml at any point during the 18 month study were almost six times more likely to develop side-effects that included depression or sleeping problems than those with consistently lower blood levels.

Some people clear efavirenz more slowly than others due to a particular genetic variation. This genetic variation is common among people with a black African heritage and it may increase the risk of efavirenz-related side-effects. Testing is not currently available to find out who has this particular genetic make-up. However, therapeutic drug monitoring may be used to identify people who are being exposed to high concentrations of efavirenz.



In the 25 years since what is now known as AIDS was first described in a group of gay men in California and New York, for many people living in developed nations like the United Kingdom, an HIV diagnosis has evolved from a death sentence into a complex chronic condition.

Constantly-evolving monitoring and treatment are not the only reasons why HIV is a complex disease. Since HIV is also primarily a sexually transmissible condition and is also an unfolding global event – with legal, social and political implications – it is further complicated by prejudice, stigma and discrimination.

The UK's National Health Service (NHS) attempted to deal with some of

these discrimination issues early on by placing HIV testing within the free and confidential GUM (genito-urinary medicine, or sexual health) clinic. When it became available, HIV treatment was provided in these GUM clinics and other specialties, like Infectious Diseases, became involved, and, therefore, many doctors in general practice (GPs, who provide primary care) had limited exposure to patients with HIV.

In the 21st century, however, it is clear that both GUM clinics and HIV specialist services are struggling to meet demand. The government believes that the obvious place to relieve some of this pressure is in general practice,

and it is now their strategy to involve primary care in sexual health and HIV services. The problem, however, is that most GPs are not adequately experienced or skilled in complementing sexual health and HIV specialist care.

Nevertheless, some of our healthcare needs – including general care for non-HIV related conditions and care relating to HIV that sits naturally in general practice (e.g. facilitating referral to mental health services in the community) – may be better managed at a GP's surgery rather than at an HIV clinic. And there may be new roles for HIV-educated GPs to play in the future (e.g. the routine monitoring of CD4 counts and viral load).

better practice

Why do we need a GP?

Until now, many HIV-positive people have been able to use their HIV clinic not just for HIV care, but also for general health issues. Many clinics currently provide prescriptions for things that are definitely not HIV-related (like flu vaccines, or asthma medicine) although some are beginning to limit their prescribing to anti-HIV drugs only.

Whatever the situation in your clinic (and London HIV clinics are already under pressure to save money this year due to only a 5% increase in funding despite at least a 10% increase in patients) their prescribing policies will probably have to change in 2008. That's when a new NHS funding system known as payment by results promises to radically alter how HIV-positive patients get services, and how HIV outpatient clinics get paid for providing them (for more on this see Does cost matter? in *ATU* 150; October 2005).

In May, NAM held a one-day clinical symposium to discuss issues around the future of HIV treatment. Part of the afternoon session focused on accessing care in the context of NHS overspends, cost-cutting and payment by results; how increasing HIV diagnoses are overburdening already stretched HIV clinics (which provide secondary care); and how GPs can be better integrated into the care of HIV-positive people.

"With payment by results we will no longer be able to act as GPs and refer our patients to another specialty, for example to get a hip replacement," noted Dr Margaret Johnson, Chair of

the British HIV Association (BHIVA), at the symposium. "Therefore GPs are going to have to be involved, and that means we need to make sure all of our patients have GPs [by then]".

There is absolutely no possibility, however, that GPs will take over all HIV care - at least for the foreseeable future. "I think we're a long way from GPs routinely prescribing antiretroviral therapy," Martin Fisher, HIV consultant at Brighton and Sussex University Hospital, told the NAM symposium. "Maybe in ten years but not in the next few years."

And Judy Hague, HIV programme director of the London Specialised Commissioning Group confirmed that "the case for HIV remaining a specialised service is a strong one. People with HIV may have other health problems, and will require access to a balance of services [including GPs] but I don't personally anticipate that HIV care will move outside of specialised services [i.e. the HIV clinic]".

What can GPs do for us?

There are several reasons why registering with a GP and telling them of your HIV status may be beneficial. The GP's surgery should be more accessible and may be open in the evening for appointments. Unlike HIV physicians, GPs can visit you at home and you can also access a doctor for emergency visits after hours via your GP. They are an alternative to the specialist clinics for sorting out and treating general problems for people who are largely asymptomatic

or have only mild symptoms of HIV infection. And for people with advanced HIV disease, GPs are invaluable in helping to provide home support in association with specialist community care teams and nurses.

William Ford-Young, who describes himself as "a pragmatic 'coal-face' GP, with an interest in the GP's role in HIV management and support" is one of two GPs on the government's Independent Advisory Group on Sexual Health & HIV, and is also Chair of the Royal College of General Practitioners (RCGP) Task Group for Sex, Drugs & HIV. He argues that all HIV-positive people can really benefit from having a GP, regardless of the kind of care they receive at their local HIV clinic.

"My feeling, as a GP, is that GPs have tremendous skill and experience and a whole team at their fingertips to provide ongoing care for people with chronic conditions," he says. "Certainly, people need a specialist for the complicated HIV issues like



why GPs need to be integrated
into hiv-positive care by Edwin J Bernard

therapeutics, virology and immunology. But I think GPs are good at doing things that HIV specialists possibly aren't good at; we can manage many of the things that go hand-in-hand with chronic disease: the psycho-social issues; the relationship difficulties; the mental health-related things, like depression; and the way that a chronic disease can generally affect your feeling of well-being. These are things that good GPs deal with all the time."

Steven Ash, HIV consultant at Ealing Hospital, in west London, agrees that "there are some problems patients may have that are better dealt with by a GP, and patients miss out if they do not make use of a GP service."

Barriers to integration

"It comes down to the right patient seeing the right doctor for the right thing," said Martin Fisher at the NAM symposium, but he added that "there are a lot of barriers" to the integration of HIV into primary care. "Some of those barriers are with the GPs, who are scared about HIV," he said. "Then there are problems with secondary care. I think we're a bit too precious and not very good at letting go, and I think we need to. And then I think there are barriers around patients being scared of their GPs having

sufficient knowledge [about HIV]. We have to get over these barriers and make sure GPs get involved."

Understandably, this is causing a lot of anxiety, not just amongst HIV-positive people and the community groups that advocate for and support them, but also amongst many GPs and HIV physicians.

So far, however, no clear policy has emerged regarding who will lead this integration of GPs into HIV-positive people's care. For example, neither the DoH, nor the NHS, nor many of the leading bodies involved in either specialist HIV care or general practice - including the RCGP, BHIVA, the British Association of Sexual Health and HIV (BASHH) and the British Medical Association (BMA) - have agreed on how best to educate GPs about HIV.

Lack of trust

We are now in the unfortunate situation where the people who have lived with HIV for the longest time have the least trust in GPs. This is likely because most of the people initially affected by HIV in the UK - gay men, injecting drug users and sex workers, all of whom were marginalised from society - often experienced prejudice, stigma and discrimination from their GPs during the Thatcherite 1980s and early 1990s.

In fact, a survey undertaken last year at a north-east London HIV outpatient

clinic, and presented to the BHIVA Conference this March, found that 85 out of 1687 patients (5%) had experienced HIV-related discrimination from their GP in the past^[1]; gay men were much more likely to have experienced this discrimination than African men and women.

Since December 2005, the Disability Discrimination Act has protected anyone diagnosed HIV-positive from being discriminated against in a healthcare setting, since they are providing services (one of the areas covered under the Act). It is, therefore, unlawful for GPs not to provide the same services to an HIV-positive person that they provide to HIV-negative people, or to discriminate in the standard of service or the terms on which the service is provided.

However, the law cannot change attitudes overnight, and there still does appear to be a lot of concern from HIV-positive people over another, related issue: a perceived lack of confidentiality, particularly around informing third parties - e.g. employers, insurance companies - about their HIV status. This continues to be a common reason given by HIV-positive people for not involving their GPs.

For example, Ealing's Steven Ash tells *ATU* that "around 10% of our patients have no GP. Another 30% do not allow us to communicate with their GP, and the GP is therefore unaware of their diagnosis."

William Ford-Young says that although in the past he's heard some horror stories about issues such as a lack of respect for confidentiality, things have much improved. And where they haven't, "it's important that patients, and patients' organisations, challenge wherever they are finding bad practice."

Better communication needed

"HIV remains the only condition whereby you can go from your diagnosis to your death without your GP ever



knowing about it," notes Dr Ford-Young. "In this day and age, that's appalling."

One of the problems is that the 1974 Venereal Disease Regulations - which provide for strict confidentiality within the GUM clinic - may be preventing good and clear communication between HIV clinicians and GPs and we, as patients, are often caught in the crossfire.

At the moment, HIV physicians can only keep a patient's GP informed of medication and other important treatment information if the patient gives them permission to do so. However, the simple act of asking for permission may create unnecessary anxiety, and suggests that there is something inherently wrong in the GP having this information. Like any successful relationship, good communication can remove uncertainty, mistrust and fear.

Dr Ford-Young's RCGP Task Group has been trying to improve communications between GPs and HIV physicians for several years. "I think the waters have got very muddied with secondary care providing a primary care service for a lot of HIV-positive patients," he says. "To help remedy that, we are working on processes of safe communication, safe prescribing, and sorting out who's responsible for doing what," he says. "We're working quite hard to make sure that HIV-positive people can have good GPs, but obviously this only works well if GPs are aware of their patient's HIV status."

Brighton's Martin Fisher agrees communication must improve - not just between GPs and HIV physicians, but also between HIV-positive people and GPs. "It's important to have that dialogue with GPs because if we don't involve them, and if the patient doesn't tell them, they're not going to know what medications we've prescribed and that could lead to GPs prescribing drugs that interact, or change a drug we've prescribed, like a statin [lipid-lowering drugs, many of which can interact with anti-HIV medicines],

through no fault of their own," he told the NAM symposium.

Enhancing services

Happily, many individuals and organisations are beginning to work together to try to find solutions to these problems.

The Medical Foundation for AIDS and Sexual Health (MedFASH) - a charity supported by the BMA - recommended that all people with HIV should have access to good quality GP care encompassing prevention, diagnosis, treatment and care as part of their 'Recommended standards for NHS HIV Services', published in October 2003 and endorsed by the Department of Health (DoH). A year later, they produced an excellent booklet, *HIV in*

primary care, aimed at educating GPs about myriad HIV issues - from HIV tests to drug-drug interactions.

Later this month, BHIVA is hosting a one-day workshop comprising many HIV professionals, representatives from the DoH and Primary Care Trusts (PCTs), and many patient advocate organisations, including NAM. Focusing primarily on how best to improve access to HIV care throughout the UK, it will also include a discussion of how GPs can best be integrated into the care of HIV-positive people.

And in several areas of the country, GPs are being educated about HIV at locally-run workshops. In Brighton, they've been running an interactive two-day HIV education course for interested GPs and their practice nurses since 2004, resulting in at least eight GP practices in Brighton and Hove providing what is known as locally enhanced services for HIV-positive people. "We're not

expecting GPs to provide HIV care," explains Martin Fisher, "we're expecting the GPs to provide the primary care for people who also happen to have HIV."

Education is the solution

Surinder Singh, a south-east London GP with a special interest in HIV, and the second GP on the government's Independent Advisory Group on Sexual Health & HIV, noted at the NAM symposium there is "great variability with where locally enhanced services are available."

These services are funded by individual PCTs and, thanks to the government's decentralised funding of NHS services, funding decisions are left to the discretion of these PCTs. "So in south east London we don't have any,"

continues Dr Singh, "and that doesn't seem all that equitable. The patient should come first."

Dr Ford-Young agrees, but argues that HIV-positive people don't necessarily need a locally enhanced service to get the best from their GP. "The bottom line is that if you have a good quality general practice - and that's not just the GP, but the whole team - things work well for patients with HIV no matter who they are or how they've acquired their HIV infection. And those issues shouldn't have to arise because GPs should be good for everybody.

"I know that that's an ideal, and it's important to recognise that there are gaps between the ideal and reality. But educating GPs about HIV, educating patients about GPs, and creating a much better dialogue between the specialists and general practitioners can close that gap."



immunisation guidelines

Why HIV-positive people need special consideration when it comes to vaccinations, by Edwin J Bernard

After more than a year in the making, the most comprehensive immunisation guidelines ever produced for HIV-positive adults are now available to download for an extended consultation period from the British HIV Association website^[1]. They will be revised based on feedback received by mid-September, and the final guidelines will then be published in *HIV Medicine*.

Compared with our HIV-negative counterparts, HIV-positive people may have an increased risk of infection, or experience more severe disease, following exposure to vaccine-preventable diseases. The guidelines cover in detail how the risk of acquiring more than twenty infectious diseases - from anthrax to varicella zoster - can be substantially reduced in HIV-positive individuals via vaccination, some prior to, others after, exposure. In addition, the guidelines address the use of passive immunisation after exposure to infectious diseases such as measles or chicken pox.

The writing committee - which included virologists, microbiologists, infectious disease and HIV physicians, public health specialists, and epidemiologists - was headed by Dr Anna Maria Geretti, consultant virologist at London's Royal Free Hospital.

Here, she explains why the guidelines took so long to produce, provides an overview of the most important - and controversial - issues, and discusses some practical considerations, including who will pay for and provide the various vaccines.



Why the need for such comprehensive guidelines?

We realised that some important issues needed addressing. Recently, the Department of Health (DoH) revised the UK immunisation guidelines for the general population^[2], and although they mention HIV frequently, the recommendations are not very specific. The DoH had also consulted with BHIVA about the possible use of the smallpox vaccine while developing plans for dealing with a potential bioterrorist attack. Since this is a live vaccine that is contraindicated in HIV-positive people, they wanted to know what we thought about mandatory HIV testing for people who had been identified as needing the vaccine (i.e. front-line healthcare workers).

So, those were the starting points that made us think about immunisation in general. We were also aware that potent anti-HIV therapy has changed the natural history of HIV infection. First of all, improved immunity through antiretroviral therapy means that the overall efficacy of vaccination is now greatly improved in HIV-positive people. Another important consideration is that improved immunity means that some vaccines that were previously contraindicated because of safety concern (e.g. yellow fever, or the MMR - measles/mumps/rubella - vaccine) should now be reconsidered.

Now that people are living longer, and are often very well for extended periods of time, they need to be protected in the long term from infections that were perhaps less of a concern previously. For example, HIV-positive people now often wish to travel to countries with a high risk of infections. Some people also want to access jobs that may carry a risk of exposure and therefore require protection. An additional consideration is that a significant proportion of HIV-positive people may have migrated to the UK in adult life and perhaps missed vaccinations that are part of the routine childhood schedule. The DoH has issued recommendations about ensuring adequate vaccine coverage in these populations and HIV-positive people should not be excluded if vaccination can be given safely. These were some of the factors that prompted us to develop the guidelines.

Your first presentation on the guidelines was at the BHIVA meeting in Dublin in March 2005. They were supposed to be made available later that year. What made it such a long and difficult process?

The lack of controlled data, both in terms of susceptibility to infection and also how really effective these vaccines are in someone who has regained CD4 cells after starting anti-HIV therapy. For example, there are no good controlled data to determine the need for hepatitis B boosters after successful vaccination, or for deciding on the optimal schedule

for immunisation following exposure to rabies. And then there are some areas which are controversial and for which it took a long time for the committee to achieve consensus. In fact, in some areas the recommendations remain tentative, which is why we are keen to receive feedback during the consultation period. For example, the benefits of pneumococcus vaccination remain really controversial.

Pneumococcus is responsible for much of the bacterial pneumonia seen in HIV-positive people, and can cause other illness, like meningitis. A study from Uganda^[3] raised doubts about its safety and effectiveness, but other studies contradict this. How did you reach a consensus?

With great difficulty! We had a prolonged discussion where all the available evidence was discussed, and we examined the pros and cons. In the end we thought that the findings from Uganda would not necessarily apply to the UK, where most people who have a low CD4 count would be started on anti-HIV therapy, thereby reducing the risk of pneumonia seen with the vaccine recipients in Uganda. However, although the vaccine may be beneficial in the UK, there are no well-controlled data to back this up and most of the evidence for a beneficial effect comes from small studies. That's why it has been so difficult to actually achieve a consensus. We do recommend the vaccine for HIV-positive people with a

CD4 count above 200 cells/mm³ on stable anti-HIV therapy. However, the risk of pneumococcal disease is higher in people with CD4 counts below 200 cells/mm³ who are not on anti-HIV therapy which is why we say that vaccination may be considered for HIV-infected persons with CD4 count below 200 cells/mm³.

Since it is a live vaccine, the oral polio vaccine (OPV) is listed as one not recommended for HIV-positive people, especially since it has been discontinued in the UK. Why, then, is it discussed in the guidelines?

Yes, it has been discontinued, so that is not a problem for those of us in the UK. But it may be a problem for someone who travels, or who may come into contact with someone from those countries where it continues to be used who may be shedding the vaccine. So it's an indirect problem. In addition some people from sub-Saharan Africa - where it is still being used - may come into contact with this vaccine, and may even be considering getting the vaccine if they go back home. It's important for us to say that it should not be used in HIV-positive people and give guidance on the management of people who may come in contact with someone shedding the vaccine.

Travel-related risks are covered extensively in the guidelines. Rabies, for example, is dealt with somewhat controversially: you recommend that HIV-positive people travelling to high-risk areas receive a preventative rabies vaccine before they travel. Isn't this very different to what is recommended for HIV-negative people?

Overall the recommendations for travel are the same as for HIV-negative people. However, one should keep in mind that for some HIV-positive people the risk of infection and the consequences of being infected may be more significant. Furthermore, responses to post-exposure immunisation may be suboptimal. These considerations indicate that, provided the vaccine is safe, one should have a lower threshold for recommending vaccination.

Preventing rabies is a classical example of an infectious disease that ought to be dealt with differently in HIV-positive people. Our patients are travelling more and more, and many are travelling to countries where rabies is still endemic - India, Pakistan, Thailand, Vietnam. However, because post-exposure prophylaxis for rabies needs to be done differently compared to HIV-negative people - you may have to use more doses of the vaccine and test for antibody responses more frequently - it makes sense to recommend a preventative vaccine. In fact, the rabies guidelines have taken a long time to write because they are so complicated, and there's very limited evidence to inform them. Along the same lines, a traveller with HIV may want to consider a typhoid vaccine, and if in doubt about the risk, it may be better to take the vaccine than not.

You mentioned earlier that the DoH consulted with BHIVA on the smallpox vaccine. What recommendations did you come up with?

At the moment the only people receiving the smallpox vaccine are those who have been identified in the UK to be the first-line response team in case of a bioterrorist attack. We felt that there had to be some guidance in case an HIV-positive person is asked to be part of that particular front-line team, or if the hypothetical scenario of a bioterrorist attack becomes real. We say that if someone has a real risk of exposure to smallpox, then they should be given the vaccine. However, if the risk is only hypothetical, we recommend against the vaccine because it's a very poorly tolerated vaccine with a lot of side-effects. It can be nasty even in people who are HIV-negative and it would never get approval for use nowadays! However, if there was a bioterrorist attack and there was a real risk for HIV-infected patients, then we would recommend the vaccine, as the risk of vaccination would be less than the risk associated with the infection itself.

Measles is relevant to many people right now. Recent outbreaks have



been reported in the UK, and it can cause serious illness in people with HIV. Given that the live measles vaccine itself may cause illness in people with HIV, what do you recommend?

Measles in HIV-infected patients with poor immunity is a devastating infection. It can cause encephalitis (swelling of the brain) and pneumonia, and has a high mortality rate. Given the current outbreak situation we definitely must make an effort now to check that our patients are immune, and - provided the CD4 count is above 200 and the person is well - we should give immunisation if they are not immune. We are recommending in the guidelines that if someone has no prior history of vaccination, or infection with measles, then they should be screened by doing a test - the measles IgG test - and if found to be negative they should be offered the vaccine. The same applies for other childhood vaccines: polio, diphtheria, tetanus. If you were born in the UK after 1962 you were probably vaccinated against these infections as a child. However, if you were born before that, or outside of the UK at any time, you might actually not have a completed vaccination history and may benefit from a new vaccine course.

How you do determine whether you've been vaccinated against infectious diseases in the past if you can't remember and/or there are no records?

There are tests that we have for certain infections, like measles or polio, but not for all. Therefore in the absence of a reliable history of vaccination it seems preferable to consider vaccination, as recommended in the DoH guidelines for the general population.

Who should shoulder the responsibility for investigating vaccination histories and providing these vaccines?

I think that patients should take some responsibility for keeping track of their vaccine records but HIV clinics should actually take the lead position over these vaccinations. The ideal situation is that we assess the need for immunisation through the HIV clinics because it's easier to control and monitor, and reliable information on clinical history and immune status is available. The HIV clinics should run all the necessary tests if indicated and make the necessary recommendations, but they should then enlist the help of GPs whenever possible to actually administer the sort of vaccines that are routinely available through the NHS.

All HIV-positive people don't have GPs, and many of those that have one are not comfortable disclosing their HIV status to them. It is not always going to be possible for an HIV clinic to refer someone to their GP to provide, for example, the MMR jab.

That was also a difficult dilemma for us when writing the guidelines.

However, I think we need to involve GPs more and more in the care of our HIV-positive patients and this is certainly very important for addressing the issue of vaccinations. I have no illusions that just by being registered with a GP and issuing a set of guidelines all recommended immunisations would automatically be given, because unfortunately we have examples from other areas of care where things don't always happen as they're supposed to in this field. Certainly, as HIV physicians, we should liaise closely with the GPs and should also place responsibility on our patients for taking good care of their health. Through this partnership it is possible to ensure that the recommended vaccination courses are started and completed appropriately.

What about travel-related vaccines?

I think that who pays for and administers travel-related vaccines is a different issue. It's probably more realistic to think that HIV-positive people will need to meet the cost if the vaccine is needed for travel just as people without HIV have to pay for these vaccines. If we are making the argument that HIV-positive people are well enough to travel to high-risk areas, and that they can have previously contraindicated vaccines because their immunity is okay, I can't really see us being in a very strong position to argue that if someone decides that they want to travel and they need a vaccine, that they should be entitled to have it for free based on their HIV status.

further information

Please address questions and feedback to
a.geretti@medsch.ucl.ac.uk

The BHIVA immunisation guidelines are for HIV-positive adults over the age of 16. The Children's HIV Association (CHIVA) produce recommendations concerning children and adolescents, available at www.bhiva.org/chiva



illness

Serious heart condition still affecting one-in-200



An expert in pulmonary arterial hypertension (PAH) - a relatively rare, but very serious, complication of HIV infection - is advising any HIV-positive individual who is feeling breathless for no apparent reason to see their doctor to investigate whether PAH is the cause.

Pulmonary arterial hypertension causes blood pressure to rise in the arteries that carry oxygen-deprived blood away from the heart so that it can be replenished in the lungs. Incidence in the general population is just one or two cases per million. Before potent anti-HIV therapy was available, it was estimated to be about one-in-200 in people with HIV.

Now, new research from France has found that PAH is no less common today than it was ten years ago. Last year, 7,648 HIV patients from 14 centres across France were screened for PAH. Of 739 found to be suffering from breathlessness - the most common early sign of PAH - thirty-five were found to have PAH after further investigation: an incidence rate of almost one-in-200.

Lead author Dr Olivier Sitbon told the American Thoracic Society International Conference, held in San Diego in May, that doctors should have a low threshold for suspecting PAH if their patient reports breathlessness.

It is currently unknown why HIV can cause the pulmonary arteries to become thickened and narrowed, leading to PAH. In addition, PAH is seen in all groups of people with HIV infection, irrespective of the cause of infection or CD4 count. It is also a much more serious disease in HIV infection, and according to a Spanish study published in 2003, just over half of the individuals who developed the condition died within three years.

New treatments for HIV-positive people with PAH are currently being investigated, the most promising of which may be bosentan (*Tracleer*). This oral drug works by blocking the action of endothelin, a hormone which occurs in higher levels in people with PAH. Although there was initial concern that bosentan may damage the livers of HIV-positive people, new research in people taking the drug for two years suggests that this is not necessary the case.

treatment news



Switch from triple nukes, even if you're doing well

An Italian study has found that people starting treatment for the first time who take a triple nucleoside reverse transcriptase inhibitor (NRTI) combination with abacavir (*Ziagen*) as their third drug are significantly more likely to experience a rebound in their viral load - even if they had achieved durable suppression of HIV - than those who take the non-nucleoside reverse transcriptase inhibitor (NNRTI) efavirenz (*Sustiva*) as their third drug.

Current treatment guidelines say that a triple NRTI regimen - usually *Trizivir* which contains AZT, 3TC and abacavir in one pill - should only be considered as a starting regimen in very occasional circumstances, for example when TB medicine is also needed (since there are interactions with most other anti-HIV drug combinations) or when one pill once a day will make a significant difference to treatment adherence. This is because several studies have found that triple NRTIs are not as potent as combining two NRTIs with another class of drugs.

The Italian study wanted to see if patients who took abacavir as a third drug, and who had initially achieved an undetectable viral load, had an increased risk of experiencing subsequent virological failure compared to individuals taking efavirenz-based therapy. They observed 744 patients who were starting anti-HIV therapy for the first time and found that those who took abacavir as their third drug had an 85% greater risk of rebound than those who received efavirenz.

Consequently, they recommend that people taking an abacavir-containing triple NRTI combination should change to a more potent anti-HIV regimen, even if they have an undetectable viral load.

If only NRTIs can be used, however (due to TB drug interactions, for example), current guidelines suggest that one possible option would be to add a fourth NRTI - tenofovir (*Viread*) - to *Trizivir*.

sexual health

LGV continues to spread amongst HIV-positive gay men

Almost 350 cases of the sexually transmitted infection (STI) lymphogranuloma venereum (LGV) - a form of chlamydia usually affecting the rectum - have now been diagnosed in the United Kingdom. Nearly all of the cases involved gay men, more than 75% of whom were HIV-positive. Coinfection with other sexually transmitted infections is being seen at the same time: one-in-four had another STI, and hepatitis C virus coinfection was seen in one-in-ten.

Epidemiological evidence suggests that LGV is transmitted via unprotected anal sex and fisting, which may also be the way the hepatitis C is being transmitted sexually; again this is primarily affecting HIV-positive gay men.

Men who have sex with multiple partners at sex parties and sex clubs appear to be most likely to be diagnosed with LGV; 71% of the men diagnosed so far reported this risk factor. LGV has now been seen in all parts of the UK, although most of the cases are being diagnosed in London and Brighton: the Kobler Centre at the Chelsea and Westminster Hospital in London is reportedly diagnosing ten new cases of LGV infection a week.

LGV can cause very unpleasant symptoms, similar to other bowel disorders, and may not be correctly diagnosed at first. In the current outbreak, the commonest symptom has been proctitis - pain and inflammation in the anus and rectum. In some cases this has been accompanied by swollen glands in the groin, and often by a discharge of mucus from the rectum (which can be bloody), and constipation.

Condoms and latex gloves are very effective at preventing the transmission of STIs, including LGV, and, once correctly diagnosed, the infection can be cured using a 21-day course of the oral antibiotic doxycycline.

latest research

Anti-HIV therapy adds thirteen years to post-AIDS survival

American researchers have calculated that today's highly effective anti-HIV treatments have added 160 months (thirteen years and four months) to a person's life expectancy once they have been diagnosed with AIDS.

Using a computer model to determine the effect six periods of anti-HIV treatment had on the survival of people with HIV after an AIDS diagnosis, they found that post-AIDS survival increased from 19 months prior to 1996 to 179 months - almost fifteen years - after 2003.

"This survival benefit greatly exceeds that achieved for patients with many other chronic diseases in the United States," they say.

references

better practice [page four]

1. Elford J et al. *Discrimination experienced by people living with HIV*. HIV Med 7 (supplement 1), abstract P93, 2006.

immunisation guidelines [page eight]

1. www.bhiva.org
2. www.dh.gov.uk
3. French N et al. *23-valent pneumococcal polysaccharide vaccine in HIV-1 infected Ugandan adults: double-blind, randomised and placebo controlled trial*. The Lancet 355: 2106-2111, 2000.

news in brief [page twelve]

Serious heart condition still affecting one-in-200

1. Sitbon O et al. *Prevalence of pulmonary arterial hypertension in HIV positive outpatients in the Highly Active Antiretroviral Therapy Era*. American Thoracic Society International Conference, San Diego, abstract 807, 2006.
2. Humbert, MD et al. *Safety profile of bosentan in patients with pulmonary arterial hypertension related to HIV: long-term results from the Tracleer PMS database*. American Thoracic

Society International Conference, San Diego, abstract A728, 2006.

LGV continues to spread amongst HIV-positive gay men

1. Ward H et al. *Lymphogranuloma venereum (LGV) in the UK: national surveillance of a re-emerging disease*. National Sexually Transmitted Disease Prevention Conference, Jacksonville, late breaker, 2006.

Switch from triple nukes, even if you're doing well

1. Cozzie-Lepri, A et al. *A comparison between abacavir and efavirenz as the third drug used in combination with a background therapy regimen of 2*

nucleoside reverse-transcriptase inhibitors in patients with initially suppressed viral loads. J Infect Dis 194 (online edition), 2006.

Anti-HIV therapy adds thirteen years to post-AIDS survival

1. Vermund SH. *Millions of life-years saved with potent antiretroviral drugs in the United States: a celebration, with challenges*. J Infect Dis 194: 1-5, 2006.

primary care at hiv clinics

are HIV clinics providing GP services? wonders Edwin J Bernard

In our lead article, *Better Practice*, it was argued that the integration of GPs into caring for HIV-positive people is inevitable. NAM has been hearing from a lot of concerned HIV-positive people regarding this move. Since each HIV clinic has its own policies we thought we'd try and find out ourselves what is happening. It hasn't been easy.

In May, we emailed a snapshot survey to seventeen HIV clinics across the country. We received six responses at press time - four from clinics in London, one from Manchester and one from Edinburgh.

Although their responses may not reflect what is happening at your HIV clinic, the different policies and attitudes make for interesting reading.

Do you have a policy regarding your patients having GPs?

Central Middlesex Hospital, London: We encourage our patients to see a GP, or get registered with one.

Ealing Hospital, London: We try to provide a "holistic service" and therefore end up treating many non-HIV-related conditions. This is particularly so for the 40% of our patients who either don't have a GP or do not allow us to contact their GP. We will resist any policy to change this.

Queen Mary's Hospital, London: We have an ethos rather than a policy. We encourage patients to have a GP and see their GP for non HIV-related care.

Mortimer Market Centre, London: Our policy is to advise all patients to have a GP for all the usual reasons. We keep to General Medical Council [GMC] guidance on confidentiality and communication.

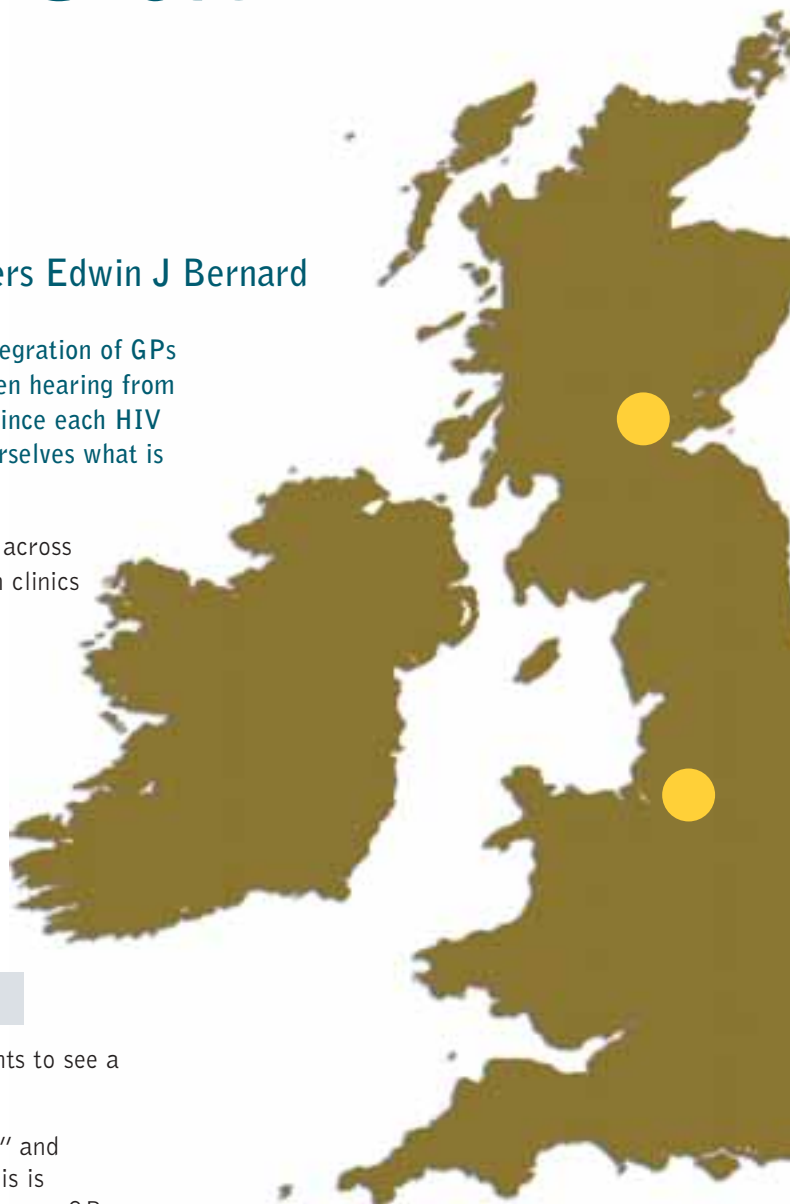
North Manchester General Hospital: We have no policy as such, but we do encourage all patients to register with a GP and endeavour to find them one if they are not registered.

Western General Hospital, Edinburgh: We have no written policy. We do not see patients for non HIV-related care outside their routine HIV appointments. If patients pitch up without an appointment, they are directed to acute receiving; if their problem is HIV related, they will be sent to us.

further information

To find out more about the Patient Advice and Liaison Service (PALS), which provides information on the NHS and health related matters and confidential assistance in resolving problems and concerns quickly, contact your local PCT or NHS Direct on 0845 46 47.

For more on the GMC's confidentiality guidance, visit:
www.gmc-uk.org/guidance/library/confidentiality.asp



Do you have a policy regarding providing prescriptions for drugs that are not antiretrovirals, but may be required due to HIV infection (e.g. lipid-lowering drugs, diabetes meds, antidepressants etc.)?

Central Middlesex Hospital: Yes. We are generally happy to prescribe these, except now that home delivery has started, prescribing these drugs is more difficult. We will have to ask GPs to do more in the future.

Ealing Hospital: We prescribe everything on our hospital formulary through our HIV pharmacy annex. Prescriptions are, therefore, free. This includes all the drugs you've listed as well as vaccines, malaria prophylaxis, etc.

Queen Mary's Hospital: We encourage people to be prescribed medication by the service which manages them. For example, we don't manage their diabetes or increased lipids, so wouldn't prescribe those medicines, but we have policies on when to refer on, where problems are related to HIV.

Mortimer Market Centre: Our clinic guide advises that patients should be encouraged to consult their GP for non HIV-related issues. If there is no GP or we have no consent for GP communication then we will prescribe for certain non HIV-related problems, though we advise patients that the GP may be the most appropriate person to be doing the prescribing.

North Manchester General Hospital: As long as their antiretrovirals are also on the prescriptions, or the patient is known to be on antiretrovirals, then these kind of drugs are issued. We try to persuade patients to get GPs and eventually for them to take over the care of and prescribing for non HIV-related conditions - but with backup phone numbers for discussions about interactions etc.

Western General Hospital: We used to provide these meds via our hospital pharmacy but our pharmacy dispensing service is stretched and cannot cope. At our discretion, however, we would squeeze a non HIV prescription in, if the patient cannot get to their GP.

How are you helping patients who cannot access a local GP they trust and/or do not wish to disclose their HIV status to their GP?

Central Middlesex Hospital: We would prescribe for them, but our community workers will help them find GPs if possible.

Ealing Hospital: We encourage patients to register and use a GP. We do our best to make up for the lack of a GP if they do not wish to have or use a GP.

Queen Mary's Hospital: If patients don't wish to disclose their status to a GP, we discuss this with them and challenge their beliefs regarding confidentiality. Where there is a genuine concern - for example, their neighbour works at the GP's practice - we would help them find a different GP, and occasionally people have changed their GP to enable them to discuss their HIV.

Mortimer Market Centre: If patients can't find a suitable GP then we tell them to contact the Patient Advice and Liaison Service (PALS) or NHS Direct and we provide the telephone number. We utilise the NHS website to give information on their nearest GP surgery. If they do not trust their GP then we discuss the reasons behind this and at the end of the day must respect the patient's wish for confidentiality as per GMC guidance...as long as the patient is making an informed decision, then we respect this.

North Manchester General Hospital: We take over the prescribing and, where possible, try and find the patient a 'good' GP in their area.

Western General Hospital: Almost all of our patients have a GP who would provide primary care. If there is a problem, they are helped to choose another GP or use A&E services.

Do you maintain a referral list of HIV-friendly GPs, HIV-educated GPs, or GPs providing a locally enhanced service in your area?

Central Middlesex Hospital: We used to, but not now really. There are no local GPs who we think are specifically HIV-unfriendly.

Ealing Hospital: We know of GPs in the area who we think are good, knowledgeable and non-judgemental. Many years ago we ran a project with Hammersmith Hospital to help care for people with HIV, and thus had a "special" liaison with some GP's in the area.

Queen Mary's Hospital: We have a community clinical nurse specialist to assist with this. She knows which GPs have other HIV-positive patients, which reassures people who have concerns about confidentiality which are more to do with their fear than reality.

Mortimer Market Centre: No.

North Manchester General Hospital: Yes.

Western General Hospital: Our Edinburgh GPs are usually very helpful and we very rarely have problems. We are lucky.

thanks to our funders

NAM's treatments information for people living with HIV is provided free thanks to the generosity of:

Abbott Laboratories International & UK; Access 4; Ajahma Charitable Trust; Alan & Nesta Ferguson Charitable Settlement; Avexa; Birmingham PCT; The Body Shop Foundation; Boehringer Ingelheim International & UK; Bolton PCT; Bristol-Myers Squibb UK HIV & Hepatitis; British HIV Association (BHIVA); Cleopatra Trust; Corkery Group; Crusaid; Derek Butler Trust; Diana, Princess of Wales Memorial Fund; Government of the United Kingdom, Department of Health; East Sussex, Brighton & Hove area PCTs; The Elton John AIDS Foundation; Gilead International & UK; GlaxoSmithKline UK; Healthsure Charitable Trust; Hugh Fraser Foundation; International HIV/AIDS Alliance; Janssen-Cilag; Lloyds TSB Foundation for England and Wales; Lloyds TSB Foundation for Northern Ireland; London HIV & GUM Commissioning Consortium; MAC AIDS Fund; Merck Sharp & Dohme UK & International; Newcastle PCT; Norfolk PCT; Manchester city area PCTs; Miss Agnes H Hunter's Trust; Merton Social Services; Peter Moores Foundation; Pfizer UK & International; Positive Action (GSK); Roche Products UK Hep C; Roche Products International & UK; The Russell Trust; Salford PCT; Shire Pharmaceuticals; South East Essex PCTs; South West Essex PCTs; St. Stephen's AIDS Trust; Stockport Social Services; Thomas Sivewright Catto Charitable Settlement; Tibotec; Virco; West Sussex PCTs; Worcestershire PCT

NAM would also like to acknowledge the generous support of individual donors, and in particular Gavin Hay and Tim Cohen

Where to find out more about HIV

■ Find out more about HIV treatment:

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

■ Information events in London

On the last Monday of every month, an expert speaker discusses an HIV treatment related topic. Entry is free. The next topic is 'Feedback from the International AIDS Conference, Toronto', and will be held on 21st August 2006. For more details, go to www.aidsmap.com/forums.

■ www.aidsmap.com

Visit our website for the latest news about HIV & AIDS and a fully searchable treatments database and a complete list of HIV treatment centres in the UK.

■ THT Direct Phonenumber

Offers information and advice to anyone infected, affected or concerned about issues relating to HIV and sexual health.

0845 1221 200

Mon-Fri, 10am-10pm Sat-Sun, 12pm-6pm

■ i-Base Treatment Phonenumber

A HIV Treatment phonenumber; where you can discuss your issues with a treatment expert.

0808 8006 013

Mon-Wed, 12pm-4pm

nam

living with hiv

updated edition - july 2006

Whether recently diagnosed, thinking about starting or changing treatment or have lived with HIV for a long time, NAM's book *Living with HIV* provides answers to the questions you might find yourself asking.

“ it's absolutely great; so practical and easy to read and the personal stories really bring everything to life. I am finding useful information that I never knew and I can't believe that it is free! ”

This book is free to people personally affected by HIV, there is a charge for professionals.

Order your copy today by phoning, emailing NAM or filling the order form below and returning it to the freepost address listed.



Please use this order form to get your FREE copy of *Living With HIV*

If you are a professional, please contact NAM directly. Contact details are shown below

name

address

postcode

country

email

- We publish a range of information resources on HIV & AIDS. Please tick this box if you would **not** like to be added to our mailing list.
- We occasionally undertake fundraising campaigns to help support our work. Please tick this box if you would **not** like to receive information about them.

please return this form to

NAM, Freepost LON17995, London, SW9 6BR

tel 020 7840 0050

fax 020 7735 5351

email info@nam.org.uk

web www.aidsmap.com

ATU