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Gus Cairns

in this issue

The number of people in the world's poorer countries receiving HIV treatment jumped by 35% last year, a World Health Organization report reveals (page 13). If progress is maintained, more than half the people in the world who need HIV treatment will be getting it next year. Not enough, but amazing when you consider that in 2002 the figure was 3%.

Treatment depends crucially on testing, and, in people at high risk of HIV, frequent testing. Sixty per cent of the world's HIV-positive people have never tested, and 30% remain undiagnosed in the UK. As *Upfront* opposite reveals, the UK lags behind a number of other countries in how frequently people take HIV tests, though progress is being made.

Testing mainly has to be about reducing the number of people who turn up with AIDS. Most AIDS deaths are avoidable, but every time a chance to test is missed the avoidable inches towards the inevitable. When researching our piece on HIV testing strategies (page 4), the most common remark people made was we have to change the "testing culture" in the UK. Whether failing to test is due to shame and anxiety in the patient, or ignorance and fear of giving offence in the doctor, we have to turn HIV testing into something routine.

Who would want to have an HIV test if the result were isolation from the one group of friends you have? Such is the situation of many African immigrants to the UK, who turn to the established network of African churches as the nearest thing to a home from home. Some may fear that pastoral embrace may become cold rejection if they mention their status, or that they will be pressured into dumping their pills and praying for a cure. As Kerri Wells' feature shows (page 8), the reality is more complex, with pastors and churchgoers finding ways of reconciling modern medicine with the power of prayer.

Increased testing is also mentioned as a preventive measure, diagnosing people when they are at their most infectious, youngest and most sexually active. Yet raising testing rates to near-universal in places like Australia hasn't reduced HIV incidence in gay men. Maybe it will in the longer term, but, like most other things in HIV prevention, testing is not the 'magic bullet' that will stop the epidemic in its tracks.

Neither will two other ideas, microbicides and pre-exposure prophylaxis. But swallowing a couple of pills before you have sex or using a protective lube could at least provide additional safety and a wider range of choices for people who want to stay safe. The big question now, debated on page 14, is not whether we'll find something that works, but whether we can persuade governments to pay for it.

Only one thing has ever reduced once-feared diseases to things of the past – a vaccine. Like everything else so far in the history of HIV vaccine research, the modest success of the AVAC/AIDSVAX vaccine (page 12) may be a false dawn. Certainly researchers shouldn't go overboard in celebrating 23 fewer infections than expected in a study involving 16,000 people. But if they find that something really is working in the blood of the volunteers, then 24 September 2009 may go down in history.

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upfront

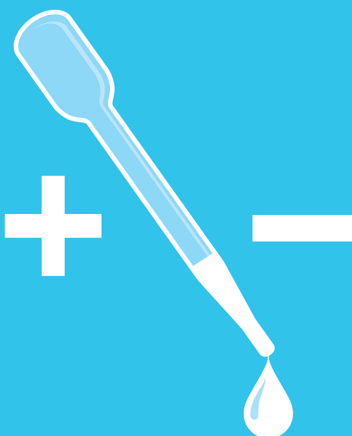
Test early, test often…how could the UK improve its HIV testing rates?

Although rates are improving, gay men in the UK still take HIV tests less often than their counterparts in comparable countries, and nearly half of African men with HIV in the UK still don't test until they've developed AIDS.

In our feature overleaf, we'll look at what can be done to improve the situation. But what do the figures actually show?

More than 90% of gay men in the US have taken a test for HIV at some point, according to community surveys, and more than 95% in Australia. [1] In comparison the annual *United Kingdom Gay Men's Sex Survey* showed that the proportion of UK gay men who have ever taken a test rose to 66% in 2007 (the last year we have full figures for).[2]

People don't test often enough, either. The most recent *Gay Men's Sex Survey* – admittedly with data collected in 2005 – found that the proportion of gay men who'd taken a test in the last twelve months was, at 32%, far lower in the UK than it was in Australia or the US.[3] In the US three-quarters of gay men have tested in the last year, while in Australia half have taken a test in the last six months.



In the UK African community, testing rates are lower than in gay men. In the 2007 BASS Line survey of over 4000 Africans in the UK, only 47% of respondents had ever had an HIV test.[4]

Late diagnosis

There are two reasons why it's important that as many people with HIV are tested as possible. One is that once people are diagnosed with HIV, the majority immediately start taking fewer HIV transmission risks. A bit late from their point of view – but highly protective of others. The US Centers for Disease Control have estimated that in the immediate post-diagnosis period people reduce their risk behaviour by 70%,[5] and a study that followed women living with HIV in the slums of Nairobi found that they maintained a long-term reduction in risk behaviour of 30 to 40%.[6]

The earlier you are diagnosed, the more likely you are still to be in the acute stage when you're very infectious: between a quarter and a half of all HIV is acquired from people who have recently caught it themselves. [7,8,9]

But the most important reason to increase testing rates is to diagnose people before they become ill. The Health Protection Agency's statistics [10] show that a third of newly diagnosed people in the UK overall, a quarter of gay men and nearly half (47%) of heterosexual men are diagnosed with CD4 counts below 200. The British HIV Association [11] found that a quarter of all HIV-related deaths were directly due to patients being diagnosed too late to respond to treatment.

People who died due to late diagnosis were twice as likely to be young (under 30) than people who died for other reasons, and more than twice as likely to be 'non-white'.

Some successes

It is important to say that the testing situation is improving and that there is already some evidence of culture shift. In Scotland, in 2002 only half of the gay men interviewed in community surveys had ever taken an HIV test. In contrast, yet-to-be-published figures from 2008 now show that three-quarters have ever tested and nearly half have tested in the last year. [12,13,14]

In the *Gay Men's Sex Survey*, which may sample a broader range of gay men, the 2007 figure of two-thirds of respondents having ever tested is an increase from under half in 2001. In gay men the average CD4 count at diagnosis has risen from 350 in 2000 to 410 in 2007, and in heterosexual men from 150 to 230.[15]

We have high testing rates in some groups. One of these is pregnant women, where the UK has one of the best rates in the world: about 95% of women are tested during pregnancy. As a result the proportion of babies infected by HIV-positive mothers has fallen from 16% in 1998 to between 2 and 4% now (though this figure could still be improved).

Similarly, testing by people who go for sexual health check-ups has risen. In 1998 only half of gay men and a quarter of heterosexuals attending genitourinary medicine (GUM) clinics included an HIV test in their check-up. This proportion has now risen to 86% in gay men and 95% in heterosexuals.

But not everyone goes to sexual health clinics, or needs to. What can we do about offering HIV tests in other places? Turn to page 4 and we'll find out.

don't live in ignorance: how do we expand hiv testing?

Should everyone take an HIV test?
Gus Cairns investigates.

Dr Valerie Delpech is a consultant epidemiologist at the UK's Health Protection Agency (HPA). She says: "The whole culture around HIV testing and disclosure is very different in the UK to Australia, where I grew up. There I was used to gay men coming in for an annual HIV test."

As a result, she explains, they are detecting HIV earlier down under. Only just over half of the gay men who test positive in the state of New South Wales have had HIV for more than a year.[1] In contrast, early results from incidence testing in the UK[2] indicate that between 60 and 80% of gay men diagnosed here acquired HIV more than a year ago.

Could do better…

As we said in *Upfront* on page 3, HIV testing rates in people who go for sexual health check-ups in genitourinary medicine (GUM) clinics have risen.

But not all people at risk of HIV go to GUM clinics. In 2004 the Department of Health funded a number of HIV testing pilot projects which used a 'results-while-you-wait' fingerprick blood sample. They performed 1721 tests.[3]

A quarter of the gay men and nearly four in ten of the African people attending had never had an HIV test. The most common reason for choosing to test at the pilot project was because it provided same-day results, but a third of the Africans and one in ten of the gay men said they didn't know where else to get a test.

Three per cent of those tested proved to have HIV (55 people) – more or less the same rate of new diagnoses as among gay men who test at GUM clinics. The pilot projects did not appear to be catching people earlier in infection, as the CD4 counts of those diagnosed matched those of people diagnosed in clinics.

Towards a national testing policy

In 2006 the US Centers for Disease Control announced that they would be recommending voluntary HIV screening for everyone aged 13 to 64 in healthcare settings, *not* based on risk, and annual HIV testing for people with risk behaviour.[4] Basically, everyone would be offered an HIV test at some point.

Should the UK have a similar screening policy? Probably not. Here, HIV prevalence in the general population is a third of what it is in the US, and our epidemic is more concentrated in Africans and gay men, so the US policy would not suit.

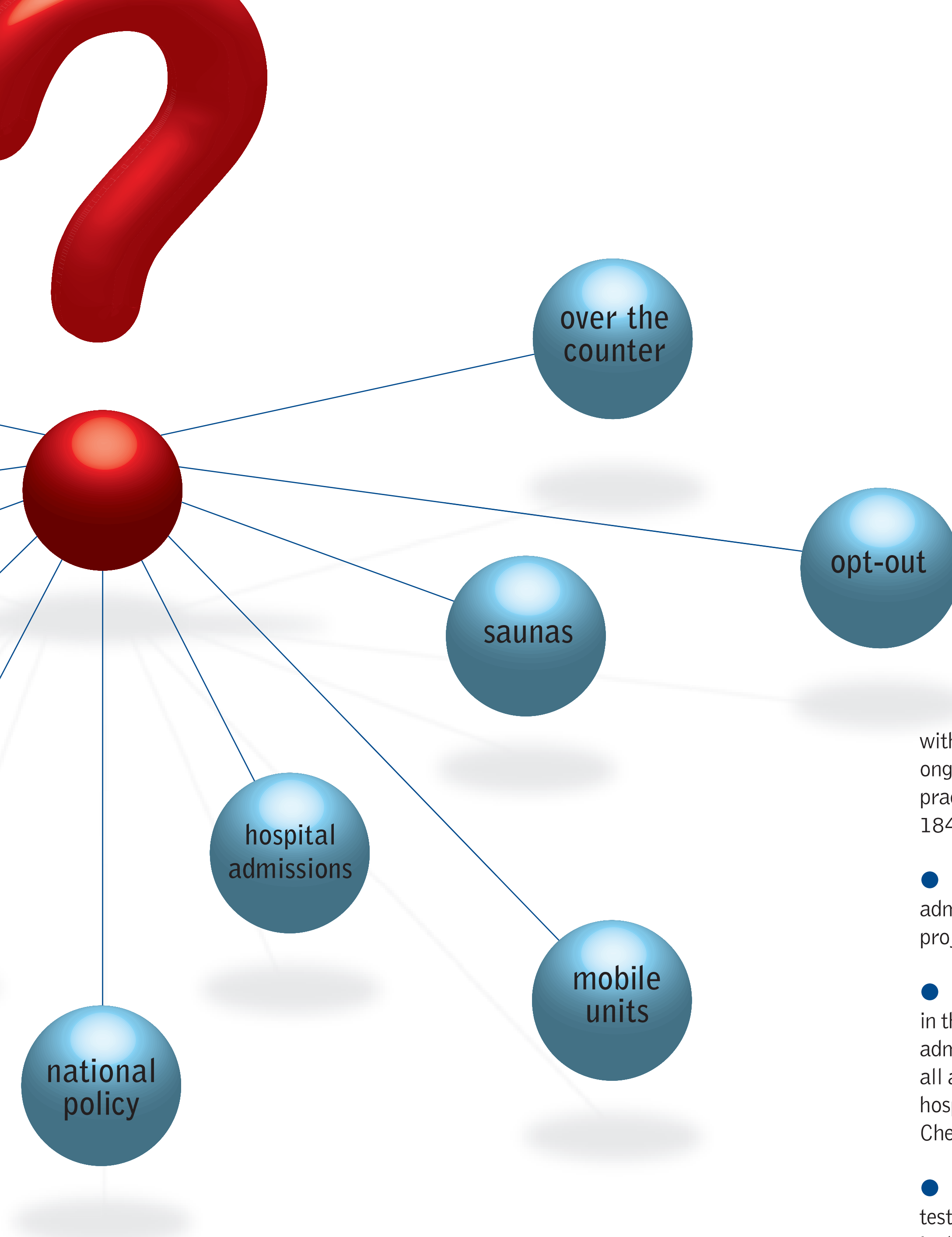
In the absence of a government policy, the UK HIV physicians' organisation, BHIVA (British HIV Association), issued its own set of testing guidelines in 2008, in conjunction with the British Infection Society and the British Association for Sexual Health and HIV.[5]

They recommended a considerable expansion of HIV testing. They said that lengthy pre-test counselling (as opposed to just giving people information) should be eliminated. They recommended that testing should be 'opt-out': it should be performed unless patients specifically turned it down. And they recommended that it should be extended to, amongst other groups: women seeking pregnancy terminations; all individuals known to be from high-prevalence countries and their sexual partners; all patients with TB, hepatitis B or C and lymphoma; all patients with one of a list of symptoms suggestive of HIV infection; and all people admitted to hospital and newly registering with GPs in areas where the local undiagnosed HIV prevalence exceeds 1 in 1000.

Putting guidelines into practice

Issuing guidelines is one thing: actually putting them into practice is another. In the US, it was found, universally testing everyone who turned up at hospital was easier said than done.

A pilot project in New York in which triage nurses would offer HIV tests to all



medically stable people over 13 as part of standard admission procedures managed to *offer* HIV tests to nearly 100% of patients,[6] but only 6% of patients actually tested. Conversely, at a comparable project in Washington, DC, which had a specialist HIV test worker, only 10% of patients were offered an HIV test, but half of them accepted. We can imagine a world in which everyone registering with a doctor or turning up at A&E gets an HIV test, but cost and lack of time, not to mention reluctance among some healthcare workers and fear among some patients, mean that it won't happen tomorrow.

Nonetheless, a number of new Department of Health-sponsored pilot projects were launched earlier this year to gauge the best way of taking HIV testing forward, and should produce results by this time next year.

New pilot projects

The pilot projects try to cover a variety of communities and to use a variety of ways to expand testing. They are:

- **Leicester:** HIV testing of all 15 to 59 year olds admitted to hospital. Because Leicester is an area on the cusp of the 0.1% general prevalence rate highlighted by BHIVA, this will inform cost-effectiveness studies.

- **Sheffield:** piloting home-sampling test kits among men who have sex with men (using a saliva-based test at home but getting the result back from the clinic by phone). In a previous pilot project run in Brighton, the return rate of home-sampling kits when offered was 80%.

- **Brighton 1:** offering opt-out testing to all 15 to 59 year olds when registering with 19 GP practices. Brighton has ongoing 'Locally Enhanced Service' GP practices that deal with HIV (see *HTU* 184), which this pilot will complement.

- **Brighton 2:** routine testing of hospital admissions, similar to the Leicester project, but in a high-prevalence town.

- **London 1:** comparing opt-out testing in three different hospital settings: acute admissions, people having operations, and all accident and emergency cases, in three hospitals (Homerton, King's College and Chelsea and Westminster)

- **London 2 (Lewisham):** opt-out HIV testing in up to ten local GP practices, including some with high numbers of black African patients.

- **London 3 (THT):** mobile HIV testing unit, visiting money transfer shops and other venues used by African people. Will use an "assertive case finding approach", which means using interviews to estimate risk before offering a test.

- **London 4 (The GMI partnership/ Positive East):** GMI is an HIV prevention partnership for gay men formed by Positive East, the Metro Centre and the West London Gay Men's Project. This pilot compares the acceptability of two testing approaches. One offers HIV testing as part of a general health screen to Africans at Positive East. Another uses either nurses or peer educators to offer tests to gay men at the GMI Partnership organisations. The acceptability of partner notification will also be tested.

Martin Fisher is the HIV consultant at Brighton and Sussex University Hospital, who chaired the group that wrote the BHIVA testing guidelines. "I'm involved in the two Brighton projects, which we started in August," he says.

Fisher is open-minded about which settings are likely to encourage more people to test and to increase the HIV diagnosis rate. "We need to find out where the BHIVA Guidelines were right and where they weren't."

He has some reservations about non-GUM testing sites, and particularly about the idea of community-venue testing.

"We have already had one pilot project in Brighton offering gay men a rapid test result in 30 minutes," he says. "We did get a number of predominantly high-risk young gay men using the service as an alternative to going to a GUM clinic. But the point is that an HIV test is *all* they got. We encouraged them to go to the GUM for an STI check-up too, but most didn't. As a result, we have just started offering tests for all blood-borne viruses (hepatitis A, B and C plus syphilis) when people attend our ongoing community testing service at [Terrence Higgins Trust] THT South."

He also stresses that there's no point in offering people HIV tests unless you have very good referral processes in place for those who do test positive. Next month *HTU* will look at the alarmingly high number of patients who disappear from care after getting a positive test result. Community testing without good clinical referral may increase the risk of them disappearing.

Finally, Fisher is concerned about the continuing problem of false positives, given by the while-you-wait tests, at least in low-prevalence populations.

The kind of fingerprick HIV test used in 'point-of-care testing' (POCT) is up to 99.8% specific. What this figure actually means is that in a population where one in ten people has undiagnosed HIV, 982 in every thousand positive test results will be correct diagnoses and 18 will be false positives, which can be eliminated by confirmatory tests.

However in a population with only 0.1% HIV prevalence, only one third of positive test results will be correct, and two-thirds will be false before the confirmatory test. Clearly screening such a low-prevalence population would generate a lot of needlessly anxious people. The kinds of tests feasible in community settings, without immediate hospital laboratory back-up, may only really be suitable for high-prevalence populations.

Informed by the results of the Department of Health-funded pilot studies, NICE, the National Institute of Health and Clinical Excellence, plans to write its own guidelines on what kind of testing protocols will best detect HIV for gay men and Africans. It has just issued the first public consultation, requesting input on exactly what these guidelines should and should not cover.

Why don't we test?

We don't really know yet what methods would generate more frequent and earlier testing in the UK. Should we have test rooms in saunas? Test tents at festivals? Test vans in the high street? Or should we sell tests over the counter?

All the people I spoke to stressed one thing: in the UK it will not just be a question of making HIV testing more available; it will be about changing the whole national culture around testing, and the way it's regarded in high-risk subcultures.

"In the UK we have a paradox," says Martin Fisher. "Universal free and confidential testing, yet people test much less than in the USA. There's something weird going on. There is a real paucity of information about people who won't test."

One puzzling and troubling fact is that anonymous tests show about a third of all people attending GUM clinics with undiagnosed HIV remain undiagnosed after their check-up. This is a relatively small number of people, around 250 a year. Some may be people who know they have HIV but don't tell the clinic, possibly for fear of disapproval or even prosecution. But it may also indicate that it's the people most likely to have HIV who are most likely to refuse a test.

Paul Ward is Deputy Chief Executive of THT. He feels that one reason people don't test so much is structural. "In the UK health and public health have been split," he says. "The people who

In the USA and Australia people test much more regularly. Here we have universal free and confidential testing, yet people test much less. There's something weird going on.
Martin Fisher, HIV consultant, Brighton and Sussex University Hospital

commission HIV testing have not been the people who commission HIV awareness and behaviour-change programmes."

THT has been slowly extending the range of community testing programmes it runs. The relative success of the 2004 pilot led to THT offering their 'FasTest' service at 34 locations, 16 of them in London.

In London, it has been running a service for the African community at Peckham Pulse healthy living centre (now run by the Metro Centre), and for gay men it runs HIV testing clinic rooms at two gay saunas, Chariots Limehouse and Shoreditch. But in the saunas the results aren't given 'while you wait'. "All the samples taken get sent away," says Ward. "We feel it's inappropriate to offer people results at a sex-on-the-premises venue."

General unease about what might happen if people received a positive HIV result when drunk or high has held back community-venue testing in the UK for a long time. In 2006 a study of attitudes to POCT amongst NHS staff, commercial gay venue owners and HIV-positive gay men uncovered a general sense of unease about such testing that was exemplified by a remark made by one interviewee that ended up as the paper's title: "There is such a thing as asking for trouble."[7]

Four areas of concern were identified by the investigators: confidentiality; the appropriateness of using 'fun' venues for such a serious health matter; the provision

of support for individuals having a rapid HIV test; and, the potential impact on venues offering tests.

All understandable cautions: yet strange-sounding when compared to the HIV testing programmes offered by some gay bathhouses in the US. Some bathhouse chains like Steamworks have been offering HIV testing since the early 1990s and a survey done back in 1996 found that 40% of 104 bathhouse venues in the US already offered on-site HIV testing.[8]

GPs and testing

Another question often asked is why GPs (and non-HIV doctors in hospitals) often fail to offer HIV tests to patients – even, in many cases, ones who have symptoms strongly suggestive of immune suppression.

Two UK studies have found that 70% of Africans testing HIV-positive had visited a GP in the year before diagnosis,[9] and 40% of gay men accessing health care because of symptoms due to primary HIV infection were not tested.[10]

As a result the BHIVA guidelines include a lengthy list of 'indicator diseases' that should prompt an HIV test and the Medical Foundation for AIDS and Sexual Health (MEDFASH) issued a guide for non-HIV specialists on diagnosing the undiagnosed, in 2008.[11]

Paul Ward feels "we haven't made much progress on the GP issue. In my opinion, in order to engage GPs, you have to pay them! It's clear from chlamydia screening that you have high rates in areas where GPs are paid a per-test fee to do it and low rates where they're not."

Lisa Power, THT's Head of Policy says: "I think it's because GPs generally don't like talking about sex to patients. BHIVA has made good links with people in the Royal College of GPs who are specifically interested in HIV but they don't represent the average GP." Sally Whittet, a GP in the UK's highest-prevalence area, Lambeth, feels that attitudes are changing, however.

"Yes, some GPs and practice nurses are still hesitant to bring up the subject, I think particularly with African patients because they don't want to appear discriminatory or judgemental. However in the London areas where I lecture on HIV most of the attendees are keen to diagnose more HIV. The whole point about demystifying HIV testing for doctors is to say that as long as you can refer people to appropriate care, you don't have to be an expert."

Home testing

What eventually happened to chlamydia tests is that high-street pharmacies started selling them. Will we ever see people buying HIV tests at their chemist?

In the UK, and indeed in the US, buying a test that will give you an HIV result in your own home is illegal, though they are not hard to obtain over the internet. It's never been illegal to buy a home-*sampling* kit that you send away to a laboratory. In the US, the Food and Drug Administration has been investigating HIV home-testing for years, but the stumbling block has always been how to put in place adequate support and referral structures.

Lisa Power dismisses some of these fears. "We used to hear the same arguments about pregnancy tests," she says. "Women would go off and do something stupid, the tests were unreliable, and so on. In fact everyone knows pregnancy tests are not 100% accurate and women generally do two or three tests to make sure. And everyone knows that if you test positive, you go to the doctor."

THT is calling for home testing to be legalised and regulated, with licensed kits that would also include information and phoneline referrals.

Power continues, "People are buying poor-quality tests off the net anyway. Wouldn't it make more sense to make high-quality tests people can use in the privacy of their own home available?"

She also says it's irrelevant that some people might repeatedly test for HIV instead of finding better ways to manage risky behaviour or anxiety about HIV: "We need to start treating repeat-testers as adults. Insisting they go to a doctor every time is a waste of resources."

To make home testing reliable we will need to learn more about the motivations of repeat testers and how often people will want to use test kits. If it turns out that many people would want to use home test kits whenever they think they have taken a risk,the ideal home-test would need to be one that can detect infection as early as possible, as well as being cheap and rapid.

The whole culture around HIV testing and disclosure is very different in the UK to Australia, where I grew up. There I was used to gay men coming in for an annual HIV test.
Valerie Delpech, consultant epidemiologist, HPA

Generating awareness

In fact, the problem with testing is not the 'worried well', but that not enough people are worried. When people diagnosed late are asked why they didn't test earlier, by far the most common answer is: "I didn't think I'd been at risk".

For this reason, HIV testing is as much about putting people in the frame of mind to test as it is about offering testing everywhere. Here the tried-and-tested methods of mass- and small-media campaigns are being used, with THT putting on a new Department of Health-funded 'Think HIV' campaign (see www.thinkhiv.co.uk), encouraging people to take seriously the possibility they might have HIV and emphasising the ease of testing.

Valerie Delpech feels we have a long way to catch up, but we will. "In ten years time I think we will see tests on sale in chemists," she says, "and we'll wonder what all the fuss was about." She warns, however, that extending testing will not abolish HIV: "In Australia, HIV prevalence in gay men has not gone down despite 95% testing. But it does mean they're turning up earlier.

GP Sally Whittet agrees. "I doubt if expanding HIV testing will reduce transmission. But it should reduce morbidity and prolong life." ■

NAM has recently published a new book: *HIV Transmission & Testing.* For more information see the back cover or visit our online bookshop: www.aidsmap.com/bookshop

faith in the community

Religious faith is important to many Africans in the UK. *Kerri Wells,* Health Trainer for the Terrence Higgins Trust, looks at the role religion plays in the lives of HIV-positive African people and the way faith leaders can channel strong health promotion messages.

Around a third of all HIV-positive people living in the UK are of African descent.[1] According to the BASS Line survey of HIV-positive Africans in England,[2] over 70% of black Africans are Christian and just under 20% are Muslim, while only 6% say they have no religion. The church is central to the lives of many HIV-positive African people living in the UK, and recently the role of faith leaders in promoting HIV awareness has been recognised, along with the need to provide clergy with information about HIV prevention and treatment.

Winnie Sseruma, HIV Mainstreaming Co-ordinator at Christian Aid, and herself HIV-positive, explains:

"Religion is inextricably intertwined with many African people's cultural and social beliefs and values. It's particularly important to people living with HIV as the thing people are most afraid of when they discover they are positive is that family and society may reject them.

"Many of them feel that their faith will hold them together and that's the place where they will seek solace, the church or the mosque. It gives you a sense of normality even if you do not disclose your status as you are talking about normal things. You can get relief and derive a lot of strength, and when people are facing challenges and struggles they feel that they can rely on their religious beliefs for answers."

The role of faith in the lives of African people

Informed and knowledgeable faith leaders are therefore crucial in a large section of the UK's HIV-positive population finding support and acceptance at their place of worship.

Edith Biryabarema was diagnosed with HIV 19 years ago and spent some time at Mildmay Hospital in east London recovering from TB. Here she met Dr Jeanette Meadway who is also the Minister-in-Charge of St James' Church in Stratford. Edith began attending the church and gradually recovered her health with Jeanette's support. Edith says:

"I met Jeanette when she was my doctor. I didn't know she was a Reverend. I had TB 15 years ago and the doctors gave me a month to live. But I got better and every day, I thank God. Faith plays a part in your health; without faith everything else is useless. God made us for a reason and until that purpose is finished we are here."

Edith was encouraged by Jeanette to take an active role in the church and she is now the Assistant Warden.

I met Jeanette at her church. "It's important that churches involve people with HIV," she says; "Not just sitting in the pew, but actively; people with HIV have much to offer their communities. If Christianity was as it's supposed to be they would feel totally accepted.

"Jesus said he would accept anyone who came to him. When people go through difficulties their faith helps a lot as you think God has a plan for you, which may just be different to what you thought."

The problem of 'cure by prayer'

Acceptance and encouragement can be compromised when churches encourage people to pray to be cured and stop taking their antiretrovirals (ARVs). Although this is rare, there are a small minority of pastors from different denominations who choose to remain vague about healing and HIV and, often inadvertently, lead some members of their congregations to stop treatment.

The message that God cures HIV through prayer is not necessarily intended to mean "without medicine". But it can be misinterpreted by congregation members.

"The instances where people have actually stopped treatment are not as rare as we may think," says Winnie Sseruma. "A combination of strong religious beliefs and massive doses of denial, fear and sometimes mental health issues often lie behind these decisions."

Faith and HIV in Action[3] is a report examining a survey of African faith leaders and churchgoers in England, conducted by the National African HIV Prevention Programme (NAHIP) in 2007-08. The 66 participants were Christian faith leaders, church elders or clergy or congregation members of black-majority churches. All but two were Protestant and 63% defined themselves as Pentecostal, a movement within Christianity that places special emphasis on a direct personal experience of God through the baptism in the Holy Spirit.

Only a small proportion of respondents (15%) were aware of people in their congregation living with HIV, while 12% were sure there were none and nearly three-quarters were unsure.

All but two leaders participating (97%) knew that 'There are HIV medicines that can help people with HIV to stay healthy', though two-thirds did not know that almost one in 20 of all black Africans living in England was living with HIV.

When it came to asking more theological questions, most leaders surveyed had reasonably liberal or compassionate attitudes: 84% disagreed with 'HIV/AIDS is punishment from God for sin', and 70% disagreed that 'the suffering of those living with HIV/AIDS should be exalted as a virtue'.

Attitudes towards whether HIV infection can be cured were rather different. Only a slight majority believed that 'There is no cure for HIV infection once someone has it'. And three-quarters believed there are people who have been cured of HIV through prayer alone, although no-one felt that taking antiretrovirals 'showed a lack of faith in God'.

If someone with an undetectable viral load stops their antiretrovirals, their viral load may remain undetectable for quite some time. At this point people may believe that they have been cured of HIV by prayer and their experience used as an example within a church to encourage others to stop treatment.

Often churches rely on donations from the congregation, so if a church leader develops a reputation for 'curing' people, more people will attend and more money will be donated.

Faith and HIV in Action comments: "The belief that there are people who have been cured of HIV might become problematic, especially for people whose adherence to antiretroviral therapy leads to an undetectable viral load which is subsequently interpreted as a cure."

Unfortunately there have been cases of people dying after stopping their antiretrovirals, believing they will be cured by prayer. African organisations recognise a need to engage faith leaders of all denominations in discussions about HIV prevention and treatments.

Edith Biryabarema says: "People respect their pastors and listen to them; pastors should learn about HIV and how it's treated. I disagree that prayer on its own can cure HIV. I've seen people who have become born-again Christians and stopped their medication, and a friend of mine died because she stopped. She didn't even remember her children and thought she was in Uganda."

She adds: "In my opinion, young people are not taught the dangers of HIV in schools. Pastors should be teaching them how to protect themselves. Will our children just think that if they get it they can pray it away?"

Faith leaders bridging the gap between medicine and the Bible

However there are also faith leaders engaging in HIV prevention and treatment messages.

Reverend Mary Grace Masarakufa is the pastor at the Power Arena, a Pentecostal church in east London. She has organised two 'Interceders Conferences', in December 2008 and August 2009, after recognising the role of the church in health promotion. The Power Arena's website explains their philosophy on HIV:

"Many people who are living with HIV seek support and guidance from God and so it is important that we educate and empower faith leaders so that they in turn can use their influence to raise awareness and understanding.

"We aim to encourage people to access voluntary testing and treatment services. This is part of a co-ordinated campaign to make sure people know the facts about the disease. Faith leaders have the power to influence many thousands of people. Our goal is to encourage them to use that power to raise awareness in their communities."

Jeanette Meadway, who spoke at the Interceders Conference, explains:

Church leaders have been helping people with HIV since the times when HIV equalled death, but they now...need to help them to live.
Winnie Sseruma, HIV Mainstreaming Co-ordinator, Christian Aid.

"Doctors and pastors are seen as being in two separate camps and people won't turn their back on religious knowledge so will instead follow the pastor. Pastors don't follow scientific arguments. But my faith is that God created all the atoms and molecules and proteins so that we could create drugs when we put them together."

Jeanette Meadway was involved with a leaflet produced by Mildmay Hospital called *Prayer or Medicines for HIV - must there be a choice?* which is available in many HIV clinics. The leaflet is aimed at Christians with HIV who may have been advised to stop treatments and use prayer. It explains the medical facts about HIV as well as including passages from the Bible to support the the concept that prayer and medicines work together to make people well.

It explains: "It doesn't show lack of faith when we use medicines. Medicines are not different from everything else in creation. God gave them to us to use."

HIV toolkits and training for faith leaders

The African HIV Policy Network (AHPN) has also recognised this dilemma with a range of resources.

Edna Soomre, Policy Officer at AHPN, explains that faith leaders can bridge the gap between medical and spiritual advice:

"This June AHPN relaunched toolkits for Christian and Muslim faith leaders and we are developing a clergy course to give faith leaders factual HIV information. The training has been developed with Southwark Diocese and will be piloted there – we can't save the world in one go but we have to start somewhere."

AHPN has worked with different churches and mosques to produce sensitively presented information. The toolkits use the Bible and the Koran to explain how religious leaders can support and help people with HIV. Clergy are offered training in basic knowledge of HIV prevention, testing, transmission and treatments and then given the toolkits to use with their congregation, aiming to cascade the basic facts to more faith leaders and congregations.

There will also be a World AIDS Day event at Southwark Cathedral on November 28th, which will be led and developed by people living with HIV, and there will be a seminar at the Cathedral on September 19th to develop the event. The event is open to anyone, of any denomination, who identifies with the Christian faith.

Winnie Ssemura was involved in the production of the Christian toolkit. She explains: "The leaders within the churches and mosques have an amazing reach and if they use that power responsibly they can make an enormous difference.

"When you talk to some church leaders they get incredibly defensive. It is true that they have been helping people with HIV since the times when HIV equalled death, but they now need to understand that instead of waiting to help people to die they need to help them to live."

It is also recognised that when faith leaders give incorrect information such as that prayer alone can 'cure' HIV, it is other faith leaders who are best placed to challenge them. Edna Soomre says: "It's much more powerful if one Pentecostal leader speaks to another and uses religious text to challenge misinterpretations that put people's lives at risk."

LEAT (the London Ecumenical AIDS Trust) has recently published *Speak Out, Act Now*, a leaflet on HIV from a Christian perspective. This also bridges medical facts and biblical beliefs, tackling the stigma people sometimes feel within their place of worship: "Faith-based communities have a special role in speaking up in order to break the silence surrounding HIV and AIDS".

LEAT also provides a range of services, many of which are aimed at black and minority ethnic communities, including training for faith communities and HIV prevention work with youth groups, as well as hosting London's HIV Community Chaplaincy (which is open to people of any faith and no faith).

Difficulty coming to terms with an HIV diagnosis can be compounded if someone feels they have acted against their faith, or will be rejected by their community. One service LEAT offers is the Pluspoint Project, a low-cost psychotherapy service for those affected by HIV. It employs "a therapeutic model ideally suited to the issues raised by HIV in which the emphasis is philosophical and reflective rather than medical or psychological".

The Pope and condoms

When religious leaders give different advice than medics this can cause confusion and detract from health promotion messages, as highlighted by the Pope's comments earlier this year.

On a trip to Africa he said that HIV was "a tragedy that cannot be overcome by money alone and that cannot be overcome through the distribution of condoms, which can even increase the problem." Rather, he said, the solution lies in a "spiritual and human awakening" and "friendship for those who suffer".

His comments caused *The Lancet* medical journal to retort in an editorial that the Pope's statement: "was outrageous and wildly inaccurate ... by saying that condoms exacerbate the problem... the pope has publicly distorted scientific evidence to promote Catholic doctrine".

Winnie Ssemura says: "I totally disagree with the Pope. We have to use everything in our capacity to reduce the transmission of HIV and condoms have to be part of that package."

Islam: the supportive role of the mosque

Despite controversies it is clear that for many African people living with HIV in the UK, their place of worship is a major support network. Recognising that faith leaders are in a strong position to educate and support people with HIV is something that should perhaps have been receiving more emphasis.

HIV and Faith[4] is an AHPN-led discussion on the ways faith leaders can work with HIV organisations. Crucially, Muslim clergy have also been involved in its development as well as helping to develop AHPN's Muslim toolkit. Sheikh Bashir from the North Brixton Islamic Cultural Centre, who was also part of the *HIV and Faith* discussion, says:

"Our brothers and sisters living with HIV do not deserve to be discriminated against. It is my fervent hope that these resources, *insha-Allah*, bring about a positive change in attitudes among Muslim and Christian leaders. Through our leadership we can protect our communities by raising awareness about HIV and AIDS."

The *Islamic Approach to HIV/AIDS: Enhancing the Community Response*[5] is a document summarising the learning and action points from the 3rd Muslim Leaders' Consultation on HIV/AIDS, arranged by AHPN, Camden Primary Care Trust and Lambeth Primary Care Trust.

It urged "all Muslim communities and their leaders to be concerned about the HIV epidemic, show compassion towards people living with HIV, encourage people to go for HIV testing and promote collaboration including inter-religious co-operation on HIV work."

Conclusion

As antiretrovirals become more sophisticated and easier to take, it is important that people living with HIV are encouraged to adhere to their medication whilst receiving the spiritual support they require. The work already done by AHPN, LEAT, various faith-based organisations and others will hopefully help to ensure that faith leaders of all denominations are at the forefront of ensuring people attending places of worship are equipped with the right information about HIV. With the right training and support for faith leaders, a collaborative approach to giving HIV-positive people medical and spiritual advice can be fostered.

An HIV diagnosis can cause a profound personal crisis for people who fear their status cannot be accommodated by their faith.

As Winnie Sseruma says: "The main mode of transmission is sex and the inability of many religions and cultures to properly address sex, sexuality and sexual relationships is behind that. I think some religious leaders are of the view that if people are good in God's eyes they should not be getting HIV and therefore need healing."

It is a welcome development that HIV organisations are now recognising that many people, not just from the African community, need to find support from their church and their faith, rather than in isolation or solely from secular HIV organisations. ■

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news in brief

Vaccines

HIV vaccine success: is it real?

Scientists are pondering a large HIV vaccine study which found that people who received the vaccine were 31% less likely to acquire HIV.

This is the first time a large human study of an experimental HIV vaccine has ever given a positive result.

Some advocates are concerned that the low overall number of infections in the study means that the finding could be due to chance. If, however, the results are real, they challenge current theories of how an HIV vaccine might work. "Some of our preconceived notions about what to measure and what we think is important might have just been turned on its head," commented Colonel Nelson Michael, Director of the US Military HIV Research Programme (MHRP), which conducted the study with the Thai government.

The six-year RV144 study involved 16,402 Thais aged 18 to 30 and gave half of them a placebo and the other half two vaccines: four doses of a 'prime' vaccine called ALVAC over six months and two doses of a 'boost' vaccine called AIDSVAX over the same period. The vaccines were designed to work in different ways: ALVAC by stimulating immune CD8 cells that kill off HIV-infected cells (it would therefore suppress, but probably not prevent, HIV infection) and AIDSVAX by stimulating antibodies which, in theory, could block HIV from infecting cells in the first place.

The problem was that AIDSVAX had previously failed another large clinical trial in 2003 and, although a large trial of ALVAC has not taken place before, a vaccine based on a similar concept failed the large STEP trial in 2007. Expectations for the RV144 study were so low that a large group of scientists wrote a letter to *Science* journal in 2004 saying that the $120m trial was a waste of money and was not based on a clear scientific rationale.

The results are therefore a surprise and activists warned that they could be a statistical fluke. Although 16,000 people were involved in the trial, there were only a few HIV infections: 74 placebo recipients became infected with HIV and 51 vaccine recipients. This finding was 'statistically significant', which means that there was a less than one-in-20 probability that this result was due to chance. But a few more infections in vaccine recipients or fewer in those given placebo would have made it not significant; Jerome Kim, the vaccine's product manager, said that although 31.2% was the observed protective effect, the true rate could be anything between near-zero and 50%.

If the results are real, they are extremely exciting but effectively send HIV vaccine research back to the drawing board once more. The vaccine did not reduce the HIV viral load in those infected; nor did it create 'broadly neutralising' antibodies of the type thought necessary to prevent infection. Discovering exactly how it did work may take years.

Dr Anthony Fauci, the Director of the US National Institute of Allergies and Infectious Diseases (NIAID), said: "This is the beginning of a new HIV vaccine research effort, not the end." But he added: "This is a welcome and exciting result in a field characterised by disappointment in the last two decades."

Anti-HIV drugs

Smoking lowers atazanavir levels

A study[1] from New York has found that smoking significantly reduces the levels of the protease inhibitor drug atazanavir in the blood. The study looked at 67 people who had been taking the drug for more than six months and divided them into people with 'substance-related disorders' (SRD) and those without. Atazanavir levels were measured before and after a directly observed dose of the drug. Of those with SRD, 91% smoked tobacco (49% of the whole group) and 38% smoked marijuana (18% of the whole group).

The researchers found that atazanavir levels in smokers were one-third of what they were in non-smokers and levels in marijuana users 40% what they were in non-users. Half the tobacco smokers and over a third of marijuana users had trough levels of atazanavir below the levels required to suppress HIV. It has been reported that most participants were taking atazanavir 'boosted' by ritonavir. While the reason for the decreased levels of atazanavir is unclear, the researchers indicated that increased levels in smokers of the liver enzymes that process drugs might be the reason.

Brain impairment

Younger people with good CD4 counts don't get brain impairment

Researchers in Argentina[1] have found that as long as HIV patients are under 45 years old and have CD4 counts over 350, they have no evidence of brain impairment. A large American study reporting at the beginning of this year[2] found that 53% of people with HIV had measurable brain impairment, and that 10% had it badly enough to experience difficulties in everyday life.

The Argentinean survey looked at 260 patients, 60% of them on HIV therapy, and used a psychological scale called the International HIV Dementia Scale (IHDS). Over-45s were 3.5 times as likely as younger people to have scores suggestive of dementia. In contrast to some other findings, patients not taking HIV treatment were no more likely to have dementia than patients on treatment as long as their CD4 counts were over 350.

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In another study,[3] the incidence of brain impairment in children with HIV was found to have fallen tenfold in the era of HIV combination therapy. HIV encephalopathy (inflammation of the brain) progressively impairs thinking and motor skills and can result in dementia. It was quite common in 1995, with 2% of children under 10 suffering it. By 2002 this had fallen to 0.2%.

Anti-HIV drugs

New booster works as well as ritonavir

Researchers have discovered a new booster drug that rivals ritonavir in raising blood levels of atazanavir (and presumably other protease inhibitor [PI] drugs).[1]

The drug, GS-9350, developed by Gilead Sciences, works in the same way as ritonavir, though without having any anti-HIV effect itself. By commandeering the liver enzymes that process drugs in the body, it stops them eliminating the therapeutic drug. The level of this drug in the body and/or the length of time it stays there are thereby increased.

Ritonavir was originally developed as an anti-HIV drug itself but was found to have intolerable side-effects at full dose. The discovery of its boosting effect, however, made it possible to reduce the number and frequency of doses and increase the potency of other PIs such as saquinavir, fosamprenavir, atazanavir and darunavir. Ritonavir's manufacturers Abbott also make their own lopinavir/ritonavir combination pill, *Kaletra*.

The dose of ritonavir used as a booster is at most one-sixth of the dose used as HIV therapy, but many patients still experience side-effects, especially diarrhoea and raised levels of blood fats (lipids).

In trials, 42 HIV-positive volunteers received either 100mg or 150mg of GS-9350 or 100mg of ritonavir plus the standard dose of 300mg of atazanavir once daily, plus tenofovir and FTC. It was found that the 150mg dose of GS-9350 produced identical levels of atazanavir to 100mg of ritonavir.

GS-9350 is not without side-effects of its own. Three patients on the drug discontinued the study due to a rash, which was relatively mild and went away when the drug was stopped.

Treatment access

Six in ten people who need treatment can't access it

The latest report on progress towards universal access to HIV treatment,[1] published by the World Health Organization, shows that although four million people in the world now get treatment, up from three million a year ago, this still only represents 42% of the people in low- and middle-income countries who need it.

The report identifies pregnant women and children as being the groups most in need of improvements in access to care. Although 38% of children diagnosed with HIV who need treatment now get it and 45% of HIV-positive women who are pregnant receive treatment to prevent mother-to-child transmission, the biggest deficit lies in diagnosing them in the first place; only 21% of women in low- and middle-income countries received an HIV test last year, and only 15% of children born to HIV-positive mothers were tested before they were two years old. It is estimated that globally 40% of people with HIV now know they have the virus.

The report estimates that, by the end of 2008, between 3.7 and 4.3 million people were receiving HIV treatment (including 276,000 children), up from 2.9 million the year before. For the first time, the proportion receiving care in sub-Saharan Africa now exceeds the global average, with 44% of those who need it receiving care, up from 33% a year ago. The parts of the world with least coverage were north Africa and the Middle East, with 14% of those who need HIV drugs getting them, and eastern Europe and Central Asia, with 23% coverage in low- and middle-income countries.

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the perils of success: what if the new prevention methods work?

A debate[1] at the International AIDS Society (IAS) Conference in Cape Town in July, sponsored by the IAS and the AIDS Vaccine Advocacy Coalition (AVAC) looked at how to prepare for microbicides and pre-exposure prophylaxis (PrEP). *Gus Cairns* reports.

Within a couple of years' time, we may know if two crucial new HIV prevention approaches will work. If they do, what then?

A microbicide is a substance that can be incorporated into a lubricant, gel or barrier such as a diaphragm that will stop HIV transmission during sex. And PrEP is the concept of HIV-negative people taking anti-HIV drugs in advance of sex (or needle-sharing) to prevent HIV.

Crucial trials of these new prevention methods will start announcing their results soon. In 2010, we'll have results from the biggest microbicide trial to date, the Microbicides Development Partnership trial of *PRO2000* gel.

By 2011 we'll know about tenofovir PrEP in Thai drug users, tenofovir/FTC PrEP in South American gay men, and tenofovir gel as a microbicide in South Africa. 2012 will offer PrEP results from men and women in Africa, and from a comparison trial of tenofovir as a microbicide and PrEP.

New prevention methods in HIV have had setbacks in the last few years, but following a promising result for the microbicide *PRO2000* announced earlier this year, prevention advocates are daring to believe that positive results could be on their way.

Carl Dieffenbach, director of the AIDS Division of the US National Institute of Allergies and Infectious Diseases (NIAID) laid out an apparently straightforward development strategy. "The first thing we have to do is to prove that these concepts work. Then, with the current agents, we have to develop alternative dosing schedules to maximise adherence. We need to engage our partners in social marketing programmes that are also pieces of operational research. How are we going to market these products?"

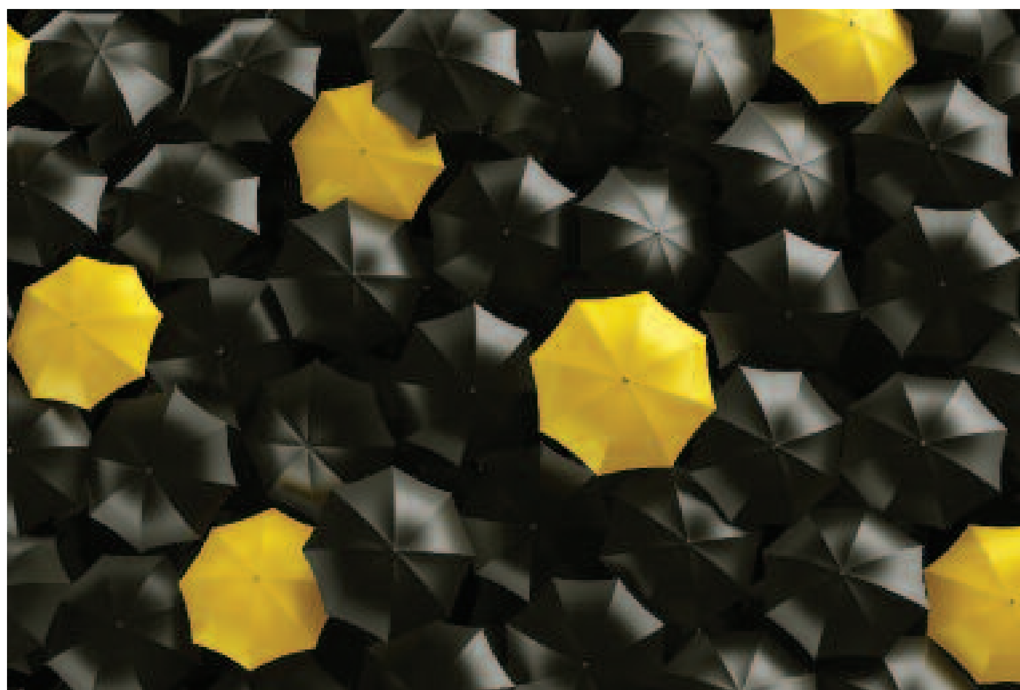
"We also need to keep working on new agents," he said, echoed by Yasmin Halima, the new director of the Global Campaign for Microbicides: "I am really worried about the lack of a drug pipeline for PrEP. If tenofovir doesn't work, we're stuffed."

Others responded that the original question of 'proof of concept' was not a simple one. What level of efficacy would be regarded as a success? The *PRO2000* trial was powered to demonstrate a protective effect of only 30%: Most panel members said that if the second trial demonstrated this, it would not be enough efficacy to take the product forward.

What would be enough? Most audience members said they would be happy with efficacy of 40 to 60% (roughly comparable to male circumcision), but some would want the product to stop at least four out of five infections (80% efficacy, comparable with real-world condom use).

Sharon Hillier, Director of the Microbicides Trials Network, defined this as the problem of the 'partial yes'. She foresaw that people would need to use a variety of different prevention methods, rather than putting all their faith in one.

"We need to identify approaches that are going to be used by a wide variety of people," she said, "which they are going to



want to use and have available. We need funders willing to buy them and regulators willing to register them. We need to make sure our successes are not just clinical."

Stephen Becker of the Bill and Melinda Gates Foundation, a prime private-sector sponsor of new prevention technologies said: "We can't wait until clinical proof of concept has occurred. We need to investigate delivery channels, how we engage with policy makers, and how we will market these approaches now."

Catherine Hankins contrasted PrEP with microbicides. Although complementary, they may have to be prescribed and marketed in very different ways.

Prophylaxis pills would always have to be prescribed and countries would need to consider strategies for PrEP availability.

"We will need to strengthen the knowledge of countries as to where their next thousand HIV cases are going to come from. Which groups do I give it to and in what way?"

HIV drug side-effects might make PrEP unpopular: "If you are going to introduce it in a country with widespread experience of lipodystrophy due to d4T, you will find widespread resistance to it."

In contrast, some delegates said that if PrEP trials came up with a positive result a black-market culture might follow. Morenike Ukpong of Nigeria's New HIV Vaccine and Microbicide Advocacy Society said: "I tell you, if a result is announced at a conference, PrEP will be on the market in 24 hours."

Professor Helen Rees, Executive Director of South Africa's Reproductive Health and HIV Research Unit (RHRU), agreed: "If PrEP works, we can't waste a lot of time debating registration, because people will vote with their feet and start to use it. There are several studies in Africa to show that people are secretly taking it already."

She emphasised the need to find out if PrEP was safe for groups excluded from the trials such as pregnant women and adolescents, and, like many delegates, stressed the urgent need to do trials of intermittent use.

With microbicides, unlike PrEP, the potential still exists that they could eventually be sold over the counter.

Acceptability studies showed that people liked microbicides. Sharon Hillier commented: "If they're going to make sex fun, people who don't consider themselves at risk and who wouldn't take a medicine might use a microbicide."

In one trial in Uganda, she said, the microbicide had an unexpected double effect: firstly, women said it made sex fun and then, because of that, their male partners were more faithful. But Dr Francois Venter, Director of the RHRU, described himself as a microbicide sceptic. It was going to be an extremely hard job persuading funders to pay for approaches with only partial efficacy, he said. "It's not just about whether these interventions work and can be promoted ethically," he said. Can health systems afford them?

Dr Yogan Pillay, Director of Strategic Health at South Africa's Health Ministry, agreed, commenting that it was challenging enough "pay[ing] for the cost of HIV treatment today and paying for TB and opportunistic infections too."

Pillay and others drew parallels between the new technologies and circumcision. Three conclusive randomised, controlled trials showing that circumcision prevented about 60% of infections in men had not translated into national programmes.

Patrick Ndase, regional physician for the Ugandan PrEP trial, said "We need to do convincing modelling studies of efficacy and cost-effectiveness so that these options become really attractive to people who are already trying to fund HIV or TB treatment. And we need to decide what language we use with the ministries and the funders that is going to make them decide to support an approach with 50% efficacy."

Zeda Rosenberg, Director of the International Partnership for Microbicides, summed up the feeling of the meeting. "We're used to scepticism," she said. "The sceptics used to say 'it won't work and women won't use it'. Now they say 'You won't be able to fund and deliver it to the people who need it'. That's progress!" ■

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Every year NAM provides information resources, like *hiv treatment update*, to thousands of people living with HIV, completely free of charge. To do this we really do rely on the generosity of people like you to help us continue our vital work. You can make a difference today. Please make a donation by visiting **www.aidsmap.com/donate** or by ringing us on **020 7840 0050**.

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.
- **www.aidsmap.com**
  Visit our website for the latest news about HIV & AIDS, a fully searchable treatments database and a complete list of sexual health clinics in the UK.
- **THT Direct**
  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 Phoneline**
  An HIV treatment phoneline, where you can discuss your issues with a treatment advocate.
  0808 8006 013
  Mon-Wed, 12pm-4pm