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HIV treatment update

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Each feature in *HTU* is also reviewed in advance by a readers' panel of people living with HIV. We are grateful to our panel for their knowledge, attention and enthusiasm. If you would like to be a member of the *HTU* readers' panel, please email **info@nam.org.uk**.

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In this issue

Gus Cairns
Editor

Does the world have the political will to end HIV? This isn't a rhetorical question. We could probably do it.

We have eradicated one disease, smallpox, while another, polio, is nearly gone. By using vaccines, you will point out, something we don't have against HIV. True: but these are highly contagious diseases, spread with a touch or a breath, like that other epidemic we have so far failed to contain, tuberculosis.

HIV is, on the other hand, hard to catch and if someone takes the treatment for it, they can become, to all intents and purposes, non-infectious. Modellers show that if you could test people often enough, diagnose them soon enough, treat them fast enough, you could get to the crucial point where the average person with HIV has a less-than-50% chance of infecting anyone else in their lifetime.

Yet HPTN 052, the study that finally proved that, arrived just at the wrong time: a couple of years into an economic crisis in the rich countries which have funded HIV treatment. A potential disaster; history shows this virus can mount a rapid comeback if the pressure is taken off.

The answer, as Laura Gonzalez Lopez finds out on page 5, may partly lie in new ideas like the 'Robin Hood' financial transaction tax, which would skim off a tiny percentage of bankers' profits. But it also lies in countries with expanding economies and significant local HIV problems taking more responsibility for containing their epidemics and those in neighbouring but less well-resourced countries.

The reason they don't is partly due to massive economic inequality between rich and poor. It's also partly due to political corruption and healthcare systems unsuited to dealing with the multifactorial causes of HIV. (This hasn't, though, held back South Africa or Brazil, two of the most economically unequal countries in the world.)

But it's also to do with stigma. A number of the countries with the worst HIV problems also have the worst records of stigma and discrimination against groups most vulnerable to HIV.

Russia, for instance, is still vehemently opposed to a harm-reduction approach to HIV and hepatitis prevention in injecting drug users. The Global Commission on Drug Policy is only the latest body to have critiqued this approach as counter-productive.

But the stigma that it's probably most crucial to address is that against men who have sex with men (MSM). As we are reminded on page 10, there is a resurgent HIV epidemic in MSM in a lot of countries where HIV in other groups is either declining or was never that common.

This is largely caused by growing opportunities to observe, connect with and emulate gay role models and lives, but in some countries this is meeting violent opposition from conservative societal and religious cultures – making it hard or impossible to develop MSM-specific prevention or treatment services. At this pivotal moment, it's vital to get across that public health is not served by criminalising gay men. We have to confront homophobia if we are to defeat HIV.

Upfront

Switching drugs for cost reasons – the patient experience

by *Gus Cairns*

In April 2011, the London Specialised Commissioning Group (LSCG),[1] which funds HIV treatment in the capital, issued a new set of messages to clinics on HIV drug prescribing.

The purpose was to save money. The HIV budget had not been raised despite an increase in patient numbers and the LSCG's aim was to save £8 million in two years that would otherwise have come from measures such as reducing clinic services.

The LSCG negotiated agreements with several companies through which the cost of their drugs would fall if sufficient volumes were purchased (that is, if more people in London were prescribed them). The two most significant deals concerned the dual-NRTI pill *Kivexa* (abacavir/3TC) and the protease inhibitor (PI) atazanavir (*Reyataz*). The new prescribing framework stated that people should not be given sub-optimal treatment or suffer serious side-effects.

Most of the increased use of *Kivexa* would occur by prescribing it to people starting HIV therapy instead of *Truvada* (tenofovir/FTC) or *Atripla* (*Truvada*/efavirenz); few people would have to change from a combination they were already taking. In the case of atazanavir, however, some people would have to be switched from other drugs. It was hoped that these changes would largely be from older and less tolerable PIs.

Although we now have sufficient options in most areas to choose between drugs that are roughly equivalent in effect and tolerability, this was the first time a public funder in a high-income country had openly agreed to change prescribing practice in HIV therapy for reasons of cost rather than medical benefit. Because of this, the LSCG instituted an ongoing programme of audits of clinical outcomes to measure whether patients' health or experience suffered from the changes.

In addition, the UK Community Advisory Board (UK-CAB),[2] the national network of HIV treatment activists, commissioned its own internet survey, which appeared on various websites, including **aidsmap.com** and **i-base.info**.

The findings of the community survey are amongst the first data to come from the London prescribing changes: so far, only one audit of atazanavir use at one clinic has been presented, at the BHIVA conference in April.[3]

There were 226 eligible responses; 70% were white, 14% were black African and 78% gay or bisexual. The survey asked people if they had changed any of their anti-HIV drugs since April 2011 and, if so, whether it was their idea or their doctor's.

In fact, only 77 of the 226 had actually changed their meds – roughly one third. Of these 77, 23 (30%) had asked to change their drugs themselves; the main reason for requesting a change was side-effects (16 cases). In the 54 whose doctor asked them to change, the main reasons were 'to do with cost savings' (32 people) or 'because of new prescribing arrangements' (18 – many respondents ticked both of these reasons). No more than four respondents in the survey changed their drugs due to virological failure and/or resistance.

Of those asked to change, only 31 (57%) actually did so. Twenty-two individuals did not change and these may largely overlap with the 22 who said they weren't happy with their doctor's explanation for the change. Eleven individuals (23%) said they were not given the option to remain on their previous treatment and two said they were not consulted at all; they just turned up at their clinic and found a new prescription waiting for them.

Of 41 people who answered whether their health had been affected by the change, six (15%) said it had got worse, 12 (30%) said it had improved, and 23 said there was no difference.

The biggest specific change was the one you'd expect: 56% more people were on atazanavir after switching treatments than before, and 78% fewer on the older PI *Kaletra* (lopinavir/r). There were smaller switches towards both *Kivexa* and darunavir/r (about 25% more) and away from *Truvada* (17% fewer). Given the small numbers, however, these only represent movements of 10 to 20 patients from and to specific drugs.

Self-selected surveys like this can't estimate actual changes in the patient population because they only include people motivated enough to answer a survey.

The individual comments are often the most interesting data. Some people were happy to change treatment: "I trust my doctor"; "I was impressed how open they were about the reasons"; "I suggested it myself as a way to save money"; "I support the changes, the NHS needs to save money, but patients should be able to access independent advice".

But the majority who left comments on changing were, perhaps inevitably, the less-than-happy. Several mentioned feeling 'pressured' by their doctor or feeling 'stress' about moving on from regimens that were working. "Why break something that doesn't need fixing?" said one; another said "If I'd not been an articulate gay man I might not have resisted the pressure to change." Only a couple saw it as a matter of principle not to change, but several said the way it had been handled had led to a breakdown of trust with their doctor.

The most significant finding, however, may be that few patients actually answered the survey, despite pretty wide publicity, and of them, how few had changed.

Michael Marr, UK-CAB Chair, commented: "This survey is encouraging. From over 25,000 people on treatment in London, we found very few examples of problems from the changes. By pressuring the pharma companies to reduce their prices, HIV services in London have saved over £6 million while maintaining some of the best care in the UK."

● More data will be presented at the next UK-CAB meeting and to the LSCG, and will help supplement audit data to be presented at forthcoming BHIVA conferences.

Global AIDS funding

Will the world pay up to end HIV?

We are at a critical point in the history of the HIV epidemic. We potentially have the tools to end it but, asks guest writer *Laura Lopez Gonzalez*, where will the money come from?

This year, the Global Fund to Fight AIDS, TB and Malaria marked its tenth birthday. Conceived at the 2000 G8 summit in Japan, the Fund garnered more than US$2bn in pledges from donors when it was launched in 2002. By 2009, it had put almost 2.5 million people on HIV treatment and was underwriting the cost of about half of all HIV treatment in developing countries. It had also grown to account for two-thirds of TB funding worldwide, in an effort to tackle the leading cause of death among people living with HIV.

Just a year after the Fund's creation, George W Bush created the President's Emergency Plan for AIDS Relief (PEPFAR). The United States is now the largest government donor to the HIV response globally, accounting for about 54% of international funding, according to the Joint United Nations Programme on HIV/AIDS (UNAIDS). In its first five years, PEPFAR prevented more than 740,000 AIDS-related deaths in the African countries in which it worked and had, on average, almost halved general mortality in people living in these countries.[1]

But in 2008, the global recession hit and both the Fund and PEPFAR began to feel the repercussions. In 2009, almost 15% of donor pledges to the Fund went unpaid; in 2010, almost a quarter failed to materialise.

PEPFAR funding, which had increased on average by about US$0.9 billion annually since its creation, also began to flatline in 2009 and hovered around US$6.8 billion for the next three years.

The story of the Global Fund is the story of the international response to HIV: born ten years ago amid times of plenty, the Fund was successful beyond its founders' dreams. As this sense of plenty has waned, the Fund has faced shortfalls and tough choices in a shifting aid paradigm, with new debates, including who should be giving, how much and to whom. At a time when the world knows more than ever before about how to stop HIV, funding shortfalls threaten not only the gains made during the life of the Fund, but also the possibility of capitalising on recent scientific findings regarding HIV prevention. Securing the future of international HIV funding is likely to put more pressure on mechanisms such as the Fund to show value-for-money results to donor countries dealing with domestic economic downturns.

The crisis comes to a head

The impact of the global economic crisis on HIV funding became clear in 2011, when the Fund cancelled Round 11 after donors failed to deliver US$2.2 billion. Some donors – Spain, Italy and Ireland – cited domestic recessions. Others, including Germany, temporarily suspended aid after media reports highlighted alleged fraud among Fund recipients, identified by the Fund's Office of the Inspector General.

This retreat may have been heavy-handed, says Michael Gerson. He was Bush's former speechwriter and a strong advocate for PEPFAR's creation; he has since joined ONE, an international campaigning organisation addressing preventable disease and poverty, as a senior adviser.

"When the Global Fund exposed corruption in a few of its own country programmes in 2011, some legislators and countries used this information to indict the entire programme," he says, speaking in a personal capacity. "If we want transparency and accountability in aid programmes, we can't punish transparency when it happens. Fraud can be deadly and should be punished, but the exposure of fraud is an achievement – an essential commitment of effective aid."

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> **Michael Gerson**

The alleged fraud was neither new nor specific to the Global Fund. Both the Global Alliance for Vaccines and Immunisation (GAVI) and USAID have seen similar cases in recent years but, for Michel Kazatchkine, the Executive Director of the Fund at the time, the backlash was a sign of the times.

"In that economic context, the donors said: 'Okay, we can't explain to our people why we are funding countries that misuse money, so we will withhold our contributions.' That decision was somehow unilaterally taken and I think the collective effort suffered from that.

"I think the big lesson is that collective effort is possible and yet hugely fragile and this economic and financial context is putting immense pressure on that," he adds. "To me, the main collateral damage of the economic financial crises has been the decrease in political mobilisation… we've lost the concept of global solidarity in the discourse."

Although the amount of money affected by the alleged fraud was relatively small, the Fund instituted a review of its financial risk management and addressed falling donor confidence. As part of resulting reforms, Colombian banker Gabriel Jaramillo assumed the newly created position of General Manager. After criticism regarding his leadership of the Fund, Kazatchkine resigned.

Jaramillo's position is expected to reduce the heavy demands placed on former executive directors, which may have contributed to the criticism of Kazatchkine.

Laurie Garrett is Senior Fellow for Global Health at the Council of Foreign Relations, a US think-tank on international affairs. She says: "We set up these multilateral systems to look at global health problems, of which the Fund is one of the newest, but we expect these executive directors to spend their lives on planes, to appear at every ribbon-cutting

and be in every village. At the same time, they can't run their organisations... we burn these people out."

Following the reforms, and as donors returned, the Fund announced US$1.6 billion would be available for new commitments as donors returned and the Bill and Melinda Gates Foundation pledged a further US$750 million.

Newly announced funds are also partly a result of a cost-saving staff reduction at the Fund's Geneva secretariat. However, there are concerns that reforms have focused too heavily on financial management and too little on results.

Amanda Glassman is director of Global Health Policy and a research fellow at the Center for Global Development (CGD).

She says: "There's certainly been an increase in the scrutinising of spending, but there's been a [knock-on] effect because of the fear of committing errors. If you look at disbursements in 2011 into 2012, they look very low."

Open Society Foundations' (OSF) research conducted in three southern African countries found that, in some countries, the Fund had not disbursed all of the monies allotted under Phase I of some grants. In some cases, this money was deducted from Phase II renewals, according to the OSF research report, *The First to Go: Community-level effects of Global Fund shortages in southern Africa*.[2]

"The Global Fund is going to have to convey to country partners what they need to do and build their confidence to spend again," Glassman adds. "You want people to worry more about reaching the objectives and measuring results in a rigorous manner than whether or not they've submitted a photocopy of a receipt or the original."

Similar concerns have been expressed in commentaries published by the Global Fund Observer (GFO), a news service run by the Nairobi-based Global Fund watchdog, Aidspan. An October 2011 article[3] said this fear of spending may also apply to secretariat staff, who are in danger of becoming micro-managers as they nervously attempt to minimise and even eliminate risk.

The waiting game

The Fund has now said it will open new funding opportunities to countries in late September 2012 and begin making decisions on applications by April 2013.

As countries await these opportunities, they are struggling to deal with the gap in what, until now, had been regular funding opportunities from the body, according to international humanitarian organisation Médecins Sans Frontières (MSF). This situation was reported in MSF's March 2012 report: *Losing Ground: How funding shortfalls and the cancellation of the Global Fund's Round 11 are jeopardising the fight against HIV & TB*.[4]

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> **Michel Kazatchkine, former Executive Director of the Global Fund to Fight AIDS, TB and Malaria**

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Countries such as the Democratic Republic of Congo (DRC), Guinea and Burma are already capping the number of people who can receive antiretroviral (ARV) treatment, while Uganda will be unable to increase the number of people starting ARV treatment annually.

Treatment caps will not only jeopardise countries' abilities to meet the WHO guidelines but also their capacity to capitalise on recent research findings from the HPTN 052 study, which showed that starting people with HIV on treatment at CD4 counts of 350 to 550 (when they would otherwise have been ineligible for treatment) reduced their risk of transmitting HIV to sexual partners by 96%.[5]

In 2009, after studies showed that early treatment not only saved lives but also reduced loss to follow-up and TB incidence, the World Health Organization (WHO) revised its treatment guidelines to recommend HIV treatment initiation at CD4 counts of 350, as against the previously recommended threshold of 200. They also advocated for the phasing out of the ARV d4T (stavudine, *Zerit*), in favour of better-tolerated but pricier ARVs.

In the DRC and Malawi, plans to increase the number of health facilities providing prevention-of-mother-to-child-transmission (PMTCT) services have been jeopardised. So have ambitions in countries such as Mozambique to move more people on to better HIV treatment, in line with the WHO guidelines, according to the MSF report. Earlier treatment and better drugs have increased the costs of national treatment programmes. In September 2010, Malawi partially adopted the WHO recommendations. This at least doubled national treatment costs. In light of the cancellation and decreased Global Fund resources, which fund the purchase of almost all ARV drugs in the country, Malawi will continue enrolling new patients but will not be able to switch existing patients to newer, better tolerated drugs, according to OSF's *The First to Go* report.[6]

Dwindling alternatives

With less access to PMTCT, affected countries may also see an increase in the number of babies born HIV-positive at a time when money for paediatric HIV treatment is shrinking. The MSF report cites multiple examples of UNITAID support for paediatric HIV treatment coming to an end in countries such as Swaziland, Uganda and Zimbabwe.

The World Bank, which is the second largest multilateral donor to HIV, is also phasing out funding for the DRC, Malawi and Mozambique by 2012, as it takes on a more technical assistance role.

In Zimbabwe, Round 11's cancellation coincided with the Expanded Support Programme's end. Funded by the United Kingdom, Sweden, Norway, Ireland and Canada, this programme will be replaced with the Health Transitional Fund, which will focus on nutrition and on maternal and child health. According to MSF, this has contributed to a treatment gap of about 66,000 HIV patients in the country who will not be able to access treatment in 2012.

While UNAIDS' Zimbabwe operation is working with government to increase private sector investment into the HIV response, it estimates this will take several years to take off. In the meantime, it predicts, by 2015 about 360,000 people in the country will go without treatment, according to OSF's report.

More than ten years ago, Zimbabwe introduced an AIDS levy to compensate for decreased donor support. In 2010, the levy collected US$20.5 million, representing almost a 260% increase in collections over the previous year. This was primarily due to contributions from industry, according to a statement released by the National AIDS Council of Zimbabwe.[7]

According to Asia Russell, Director of International Policy for activist group Health GAP, Zimbabwean civil society is now advocating for its government to increase the proportion of the levy spent on treatment from 50 to 80% in order to plug the gaps.

In addition, some countries – Zimbabwe included – are reprogramming existing Global Fund grants away from HIV prevention in order to shift cost savings towards essential HIV and TB medicines and diagnostics, according to OSF.[8]

In 2011, UNAIDS released its strategic investment framework.[9] Premised on six basic programmatic activities, including PMTCT, medical male circumcision (MMC) and behaviour change, authors argue that – if implemented – the framework could avert more than 12 million new HIV infections and almost 7.5 million AIDS-related deaths between 2011 and 2020 worldwide.

While most countries seem to be safeguarding biomedical prevention methods such as PMTCT and MMC, the OSF research found that other aspects of prevention, such as the framework's so-called "critical enablers", or programming in areas such as human rights, community-based capacity building and retention in care, were being deprioritised.

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>
> **Laurie Garrett, Senior Fellow for Global Health, Council of Foreign Relations**

Deprioritising prevention comes at a time when new infections continue to outstrip treatment coverage.

Professor Alan Whiteside is head of the Health Economics and HIV Research Division (HEARD) at South Africa's University of KwaZulu-Natal. "The problem with prevention is it is seen as a poor relative to treatment – it is long term, messy, and attributing results is difficult," he says.

He adds: "My big concern is [that] prevention will lose resources. Given there are still more new HIV infections than people put on treatment, this will be a problem until such time as we see the AIDS transition."

The concept of an 'AIDS transition' was developed by Center for Global Development (CGD) senior fellow Mead Over. It plots a strategy to minimise HIV and argues that, to end local epidemics, countries will need to sustain recent reductions in mortality and bring down HIV incidence.[10]

PEPFAR meanwhile is scaling back funding for some countries, such as South Africa. Amanda Glassman comments that, ideally, PEPFAR would look to transition their funding of non-governmental organisation (NGO) partners to government contracts with these same organisations to facilitate continuity of care – but most governments don't have a PEPFAR-sized budget to do this.

With a goal of initiating 400,000 people on ARVs annually, the South African treasury has projected that maintaining this pace in the next four years will lead to funding shortfalls.

Michael Gerson says that, although President Barack Obama has moderately increased HIV funding and made America's first multi-year commitment to the Global Fund, donations to the Fund are unlikely to see large increases anytime soon.

He adds: "In a political environment where bipartisanship is rare, AIDS has been a hopeful example of co-operation and common purpose. But during the next four years, regardless of who wins the next American presidential election, we are not likely to see the scale of funding increases we've seen in global health during the last decade."

The shifting aid paradigm

As international funding decreases, the debate over whether or not middle-income countries should continue to receive aid has heated up. These countries are seeing gains in gross domestic products, but many are also seeing a rise in inequality. Up to a billion of the world's poor now call these countries home, according to a CGD working paper.[11]

Some argue that these countries

should continue to receive aid as long as it is directed to the poorest or the most vulnerable. Others advocate that middle-income countries should charge their middle classes sufficient income tax to fund HIV treatment and prevention services.

GAVI, for instance, already limits funding to countries with a gross national income per capita of less than US$1500. When countries surpass this, funding is phased out over three years. According to a recent blog published in the *The Guardian* by Glassman and visiting CGD fellow, Andy Sumner, by 2015 GAVI will phase out support to 17 of its largest current recipients.[12]

The Global Fund's cancellation of Round 11 was not enough to sustain current grants and finance its stop-gap measures, so the board also suspended funding for some low-burden, upper-middle-income countries such as China, Brazil and Russia.

The Fund is now reviewing its policy of allocating 45% of all grants to middle-income countries, according to Aidspan founder and former Executive Director Bernard Rivers.

The move away from funding middle-income countries was proposed in 2010 by the US-based policy NGO Results for Development in a study published in *The Lancet*. The study, which developed costings for four HIV treatment and prevention scenarios, estimated that – without a cure or vaccine – as much as US$722 billion might be needed to tackle the pandemic by 2031, a third of which would be needed in Africa. Authors argued costs could be substantially lower if donors made hard choices now, including phasing out aid to middle-income countries that have the resources – but perhaps not the political will – to support programming for relatively small epidemics among vulnerable groups, such as sex workers, men who have sex with men (MSM) and injecting drug users (IDUs).[13]

Russia may be a perfect example of a country with the resources, but not the will, to address HIV. As the country's economy rose, it began to position itself more strongly geopolitically, and became a Global Fund donor. But HIV prevention efforts in the country continue to lag, according to Denis Godlevsky, advocacy officer of the HIV/AIDS International Treatment Preparedness Coalition in Eastern Europe and Central Asia. With Russia now classified as an upper middle-income country, international funding has dwindled. Meanwhile, the country continues to ignore its IDU population despite its HIV prevalence rate of almost 40%.[14]

"There are still a lot of people in Russia who believe HIV does not exist," Godlevsky says. "Basically, there is no sexual reproductive health education in schools, no condom distribution, no long-term campaigns on TV... no harm reduction services, because basically the government doesn't support harm reduction as a policy."

> "We have an emerging opportunity to drive the epidemic into the ground."
>
> **Mark Dybul, former US Global AIDS Co-ordinator**

> "In my five years with the Global Fund, what I have clearly perceived is that the most powerful message to attract funding and gain the trust of donors is to show results and cost-efficiency. To tell someone that the cost of first-line ARVs is now US$85 per patient per year, and that saves a life, is something very powerful."
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> **Michel Kazatchkine, former Executive Director of the Global Fund to Fight AIDS, TB and Malaria**

Shona Schonning, the former Program Director of the Eurasian Harm Reduction Network, agrees that Russia's burgeoning middle class is also not willing to pay to support the handful of organisations offering harm reduction services, including the provision of clean injecting equipment or methadone, which Schonning says should be a governmental responsibility.

"The whole issue is that the populations that need support are highly stigmatised in Russian society and, until recently, there wasn't a culture of making donations," she says. "The tax structure has improved and people are wealthier, but it would be a lot easier to gather money for kids with cancer than for heroin users."

In the absence of local support, one Moscow-based NGO providing harm reduction services, the Andrei Rylkov Foundation for Health and Social Justice, has launched an international campaign for donations through the online giving site, GlobalGiving.

According to the World Bank's Global AIDS Program Director, David Wilson, middle-income countries might not need financial support so much as technical support.

"It's true that HIV tends to be higher in somewhat better-off countries and to some extent that is tied up with greater mobility and inequality," Wilson says. "We're suggesting that HIV be tackled differently in countries that have resources. It doesn't mean there's not a role for international co-operation ...but the form of support it takes may be very different."

But Asia Russell argues that countries may still benefit from initial investments in HIV treatment and prevention. These could result in attitude gains that could strengthen the political will needed to ensure a long-term response to most-at-risk populations.

"What you find in many countries with higher incomes are concentrated epidemics, where inputs have been neglected for years for political reasons and where catalytic support from outside is needed initially," Russell says. "But ignoring the country because it has a higher GDP is flawed and misguided...it will not free up resources commensurate with the gap in HIV funding and it would be misinformed to think of it as a resource mobilisation strategy."

What the future holds

The United Nations estimates there is a US$9 billion gap in the HIV funding needed to meet its 2015 goals, including halving

HIV incidence and eliminating paediatric infection. Meanwhile, the Fund has already begun its next chapter, setting up an appointment committee to select the next executive director.

According to Laurie Garrett, the right incoming executive director stands to benefit from some powerful and seemingly willing allies – if he or she can effectively collaborate with them. Ban Ki-moon has been re-elected to the post of UN Secretary-General, Dr Margaret Chan has been re-elected as the head of WHO and global health activist Jim Yong Kim has been appointed as President of the World Bank.

Garrett says: "What you'll want [in a candidate] is someone who understands how to work diplomatically and collaboratively with other major institutions, who appreciates the needs of the poor, and is able to balance these against the priorities of donors in a way that minimises conflict." She says that the right candidate would need to be proficient in at least three major languages.

"I think things we can forget about are [particular] race, ethnicity and gender as prerequisites, I'd hope we were past that," she adds. But according to Bernard Rivers, the Fund plans to shortlist four candidates by November – two of whom must be women.

To fill the funding gap, the price of second-line and paediatric ARVs will have to decrease, according to the UN, which has begun advocating more heavily for the use of the World Trade Organization's Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPs) to secure lower drug prices.

Meanwhile, activists and economists have proposed the introduction of a financial transaction, or 'Robin Hood' tax, that could generate US$48 billion annually across G20 countries if implemented at the lowest proposed rate.

In the meantime, donors will have to look at how to do more with less, achieving greater efficiencies. This is something in which the Fund has a comparative advantage over donors like PEPFAR, which continues to channel large amounts of funding through US-based partners.

"You can provide funding less expensively if you don't have to go through certain bilateral US contractors," Glassman says. "From 2008, many of PEPFAR's top contractors were universities in the US – an approach that allowed for rapid, immediate scale-up. However, universities are among the most expensive of organisations to work through, particularly for service provision activities. Some have overheads of more than 100%. They don't disclose that publicly, but it's an expensive way to provide care."

> "If we wait five years, as some might be tempted to do in the current financial climate, that's not going to work because epidemics might be on the upswing as they are in Uganda. If we wait until then, not only will it be more expensive but it might not be possible. Epidemics are a lot harder to control on the way up than on the way down."
>
> **Mark Dybul, former US Global AIDS Co-ordinator**

There may be a shift away from these service providers as the need for clinical treatment trials declines, according to Glassman. But she added that PEPFAR also may need to work on the way it disburses money after recent media reports about US$1.5 billion in unspent funds.

Those formerly at the helms of the Global Fund and PEPFAR say that these organisations will have to be able to demonstrate results and value for money, now more than ever.

Michel Kazatchkine says: "In my five years with the Global Fund, what I have clearly perceived is that the most powerful message to attract funding and gain the trust of donors is to show results and cost-efficiency. To tell someone that the cost of first-line ARVs is now US$85 per patient per year, and that saves a life, is something very powerful."

Mark Dybul, former US Global AIDS Co-ordinator (leading the implementation of PEPFAR), agrees.

"Results drive money," he says. "There's a way of increasing value for money by changing the way we operate and that becomes yet another argument for securing resources."

Both men are also adamant that international funding for HIV is not a charitable movement – it's economic sense, particularly at a time when the world may be in a short-lived window within which to end the HIV pandemic, according to Dybul.

"We have an emerging opportunity to drive the epidemic into the ground," he says.

"If you look at sub-Saharan Africa, with the exception of one or two countries, you see HIV prevalences on a downward trajectory," Dybul added. "If we layer in these new prevention modalities in to these downward trajectories, there are models that show we can achieve 0.05% incidence rates, which means epidemics are completely controlled."

"If we wait five years, as some might be tempted to do in the current financial climate, that's not going to work because epidemics might be on the upswing as they are in Uganda," he adds. "If we wait until then, not only will it be more expensive but it might not be possible. Epidemics are a lot harder to control on the way up than on the way down." nam

Laura Lopez Gonzalez is a freelance health journalist based in Johannesburg, South Africa, and worked as a research consultant on the Open Society Foundation's recent Global Fund research quoted in this piece.

The gay

In the last two years, three internet surveys in Europe, the USA and Asia asked over 200,000 gay men and other men who have sex with men (MSM) about sex, safety and stigma. *Gus Cairns* looks at some of the data, and finds a mix of the expected and the unexpected and some challenging findings for HIV prevention.

HIV increasing globally in gay men

In high-income countries, gay men were the first group to start dying from HIV. Now, there are worrying signs that they may also be the last out of the epidemic. The percentage of the general population with HIV is decreasing slowly in most regions of the world but the proportion of gay men who have HIV is increasing in many of the same areas.

UNAIDS estimates that the peak year for new HIV infections was 1997;[1] here in the UK, overall HIV diagnoses per year peaked in 2005 and have since declined by 15%. In gay men, however, they increased by 35% in the same period.[2] France has seen the same pattern.[3] In the US, new diagnoses run at a steady 48,000 a year, but in young gay men they increased by a third in the last four years, and in young, black, gay men by a half.[4]

We are seeing a sequence of increases in HIV in MSM in Asian countries. In 2003, a study found that one in six MSM in Bangkok had HIV. Two years later it was nearly one in four and has stayed at that level. New diagnoses in MSM doubled in Japan and tripled in Taiwan between 2002 and 2007. The Philippines has seen a sevenfold increase in HIV diagnoses amongst MSM under 30 in the last four years. Wherever you look in Asia's expanding cities, you find high levels of HIV among MSM: one in eight in Chonqing, China (up from one in 50 six years ago), one in six in Mumbai, one in three in Yangon.[5] There are fewer reliable statistics from Africa, but surveys in high-prevalence countries there find that HIV in MSM is at least as high as it is in the general population, while in low-prevalence countries, such as Senegal, it is ten times higher.[6]

In some places discrimination against MSM is such that we've simply had no data. Up to 2009, for instance, only 158 of the estimated 350,000 people with HIV in Ukraine admitted they got it through male-male sex.[7] HIV prevalence in gay men is now estimated at 8% in Russia and Ukraine, and one survey found that a quarter of MSM in the Ukrainian city of Odessa had HIV.[8]

A dangerous situation

This is, potentially, a dangerous situation if HIV concentrates amongst MSM in countries where to seek testing and treatment is potentially to expose yourself to persecution. The potential for intensifying the oppression both of gay men and of people with HIV is obvious.

Yet the threat of HIV in MSM tends to get downplayed by some of the big global organisations. The Global Forum on MSM & HIV – see **www.msmgf.org** – was so troubled by the low level of acceptance of papers on MSM submitted to the International AIDS Conference this year, they called for rejected abstracts so they could be featured at the MSMGF pre-conference.

One excuse sometimes given for neglecting MSM is that they are hard to reach, so we don't know enough to design prevention and treatment programmes to meet their needs. It's now become a lot harder to make that claim.

y globe

In 2010, three regional surveys took place in different parts of the world, utilising a phenomenon that has led to more contact between MSM, more activism, more awareness, more sex and – unfortunately but perhaps inevitably – more HIV: the internet.

Three surveys

First off the blocks was the Asia Internet MSM Sex Survey (AIMSS), spearheaded by the Singapore-based gay website Fridae, in partnership with the University of Pittsburgh and 40 in-country MSM organisations. This was an expanded, multilingual version of the first survey ever done in Asia, which Aidsmap reported on in 2010.[9] The new survey was completed by 13,883 men in twelve countries stretching from Thailand to Japan in January and February 2010,[10] asking about their sexual behaviour in the previous six months, drug use, how they met other men, and whether they discussed HIV. It published a preliminary report in July 2010 and several papers on its findings have appeared in the last few months.[11,12,13]

The Online Buddies Men's National Sex Study (MNSS) was completed in October 2010, by 24,787 gay men in the US. It was also a collaboration between a commercial gay site and an academic institute, in this case Manhunt and the Center for Sexual Health Promotion at Indiana University. MNSS was a rather different kind of survey. Head researcher Joshua Rosenberger is concerned that an over-emphasis on HIV risk fails to capture the variety of gay men's

sex lives and turns sex between men into a problem. So MNSS asked people what they had actually done the last time they had sex – both in order to widen the discussion beyond conventional ideas of safer sex, and because it's easier to remember what you did last time than during the last six months. For the same reasons they deliberately excluded HIV status from their published papers about the survey [14, 15] and from the entertaining and inventive front-page 'report' on some of the findings which came out a year later (see **www.mensnationalsexstudy.com**).

These two surveys got nearly 40,000 gay men in two parts of the world to talk about their sex lives; two to three times as many as the single largest national survey of sex – gay or straight – ever conducted. Impressive? These were dwarfed by EMIS, the European MSM Internet Survey,[16] which took place from June to August 2010. EMIS collected six times as many responses – a total of 181,490.

EMIS was a large, European Union-funded collaboration co-ordinated by the Robert Koch Institute (RKI) in Germany, in collaboration with other research institutes such as Sigma Research in the UK, commercial websites, academics, and literally hundreds of local partnership organisations. It took place in 38 different European countries and was conducted in 25 languages.

EMIS was helped by the involvement of several commercial internet sites such as Gaydar, Manhunt and Planetromeo, which sent out individual messages to their subscribers urging them to do the survey. Germans completed the largest number of surveys – some 56,000 – but by involving local sites such as Qguys in eastern Europe, useful numbers of responses came from countries like Russia (5263 respondents) and Ukraine (1787) where we've known little before. The final report on EMIS has been delayed but the EMIS website features two community reports giving interesting interim data from the survey.[17] National reports, including raw data from the UK,[18] have started to appear.

The findings

There are far too many data to include every interesting finding – the draft report on EMIS alone comes to 248 pages and that only mentions a tiny fraction of what can be gleaned. So what follows is a sample of interesting facts and themes, rather than any systematic review.

We're going to compare some results across surveys. Researchers hate doing this, because so much depends on who answers the survey and how questions are asked but we're not scientists here, so here goes.

Age and education

The age of respondents was 38.5 (mean) in the US survey and 34.1 in the European, and the median age in the Asian one was 29. In EMIS, the age of respondents changed smoothly from 35 in the west to 29 in the east, with extremes in the Netherlands (40) and Moldova (25). In the US and western Europe, it's been getting easier to be out as gay to yourself and others for a long time; in eastern Europe and Asia we are seeing a young, educated new generation coming out for the first time.

This showed in the statistics on education and where people lived. On average, more than half of respondents in all three surveys had a college or university degree. In EMIS, however, this ranged from 34% in the central-west countries (Switzerland, Germany, Austria) to 72% in the former USSR; similarly, while only a quarter of central-west respondents lived in a big city, three-quarters of east Europeans did.

In the UK, the age distribution was interesting: London had half as many men under 20 and a lot fewer men over 50 than the rest of the country, suggesting that gay men may gravitate to the capital city in their 20s but tend to move away as they age.

Sexuality and relationships

At least three-quarters of men defined themselves as 'gay' in the surveys; 13% in the US, 15% in Europe and 16.5% in Asia said they were bisexual. Very few used other definitions. In EMIS, a lower proportion defined themselves as exclusively gay in the east.

> "The percentage of the general population with HIV is decreasing in most regions of the world but the proportion of gay men who have HIV is increasing in many of the same areas."

Only a minority had a primary partner. In Asia, only 33% of men had been in a relationship for more than six months, and in the US 42% had had one for more than three months. In EMIS, the pattern wasn't necessarily what you'd expect: 41% of people in the western European countries (UK, France, Belgium) had a partner and about a third in the Mediterranean countries and the Balkans: but the highest proportion with a boyfriend was in the former USSR and a higher proportion of them lived with their partner. Western Europe, however, had by far the highest proportion of people in a long-term relationship (over ten years): 22%, compared with just 5% in former eastern-bloc countries.

Sex and condoms

About 85% of gay men in all three surveys had had anal sex during the previous six months or a year, but methodology of the US survey revealed that they certainly didn't do it every time. Only 37% had anal sex last time they had sex, and other activities were much more common: in MNSS and EMIS, three-quarters of men had given or received oral sex last time they had sex, and oral sex was more popular than mutual masturbation.

Although the condom statistics are stated in many different ways, in MNSS and EMIS at least, '[using] a condom every time' was a minority behaviour. In EMIS 58% of respondents reported at least one episode of unprotected anal intercourse during the last year. In MNSS, only 45.5% of men used a condom the last time they had anal sex and the only age group in which more than half (52%) used condoms last time was the under-25s. There was a steady decline in condom use with age, and the over-50s were, in the US survey, half as likely as the under-25s to use a condom. There were interesting ethnic differences: African-American, Hispanic, and Asian men were all significantly more likely to have used a condom the last time they had anal sex compared to their white counterparts.

In AIMSS, rates of condom use were higher, with only 41% of respondents saying they'd had unprotected anal sex over the last six months. However, it found much lower rates of use amongst its minority of HIV-positive men.

Is condom use the best indicator of risk?

One particularly fascinating finding came from MNSS and somewhat vindicated its taking the focus off condom use. The most common safer-sex strategy in the MNSS respondents was not "Use a condom with me" but "Don't cum in me". Semen was seen as highly erotic by MNSS respondents: 84%

said it was arousing, 61% said they liked the taste and 51% said they liked it inside them. But when it came to it, relatively few actually let someone ejaculate in them anally or did it to their partner last time they had sex even *with* a condom – 15.5%, to be exact (12.5% let their partner come in their anus when wearing a condom and 11.3% did it to them while wearing a condom).

Only 20% of those who let their partner come in their anus and only 23% of those who came in their partner's did not use a condom. This means that anal sex without a condom and with ejaculation only occurred in 2.5% of respondents' recent encounters. Coming in other places was more popular: 32% in their face or mouth and 25% on their chest.

This may indicate that much more nuanced safer-sex messages are needed. Gay men are attempting to use more ways to protect themselves than are endorsed by standard prevention messages. Some may be very flawed, but others may offer significant protection and should be encouraged. In the ART era, there have been few studies of the per-contact risk of HIV infection in gay men, but one that did look at this found that if withdrawal happened before ejaculation, there was less than half the risk of HIV transmission.[19]

HIV prevalence and testing

In Asia, an overall 6% of respondents had been diagnosed HIV positive, ranging from 2% in China to 12% in the Philippines. In Europe, the overall rate was 4.1%, ranging from 15.6% in the Netherlands to zero in the 163 respondents from Bosnia. MNSS in the US didn't publish HIV rates but in its 2009 survey HIV prevalence was 14.5%.

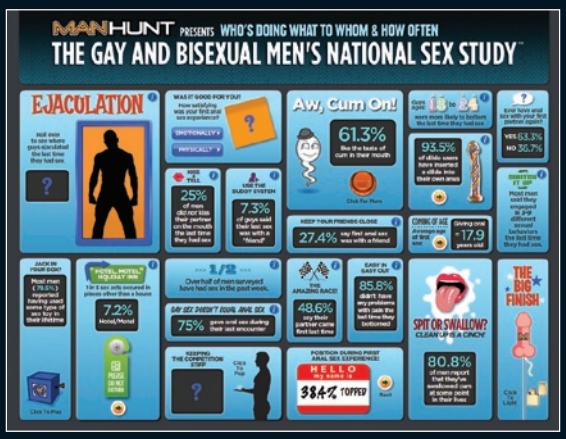
Seventy per cent of EMIS respondents had ever tested for HIV. About a third (35%) had tested in the last year – exactly the figure for the UK. Testing frequency tended to follow national HIV prevalence with high levels in western Europe, the Mediterranean and former USSR, and lower levels in central Europe, though with several exceptions. France had the highest proportion of men who had taken a test in the last year (47%) and Lithuania the lowest (20%).

One particularly alarming finding in EMIS was that there was no correlation between taking an HIV risk in the last year and having had a test. The proportion of men who'd had unprotected sex with a casual partner of opposite or unknown HIV status in the last year and who had also had a test ranged from 40% in western Europe to 20% in the Baltic states.

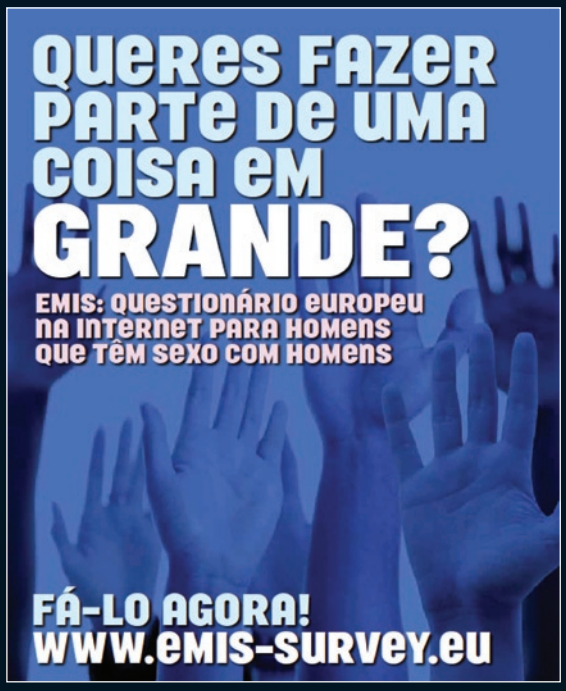
Just under 60% of Asian respondents (80% in Thailand, under 50% in the Philippines) had ever tested for HIV and

The surveys

Asia Internet MSM Sex Survey (AIMSS)
In January and February 2010, AIMSS was completed by 13,883 men in twelve countries, from Thailand to Japan.



The Online Buddies Men's National Sex Study (MNSS)
In October 2010, MNSS was completed by 24,787 men in the US.



European MSM Internet Survey (EMIS)
From June to August 2010, EMIS was completed by 181,490 men in 38 European countries.

about a quarter in the last six months, ranging from a third in Thailand and South Korea to one in five in the Philippines – a similar frequency to Europe.

HIV incidence

In Europe, the proportion of men who'd taken an HIV test in the last year who had received a positive result was used to give a rough indication of the 'hotness' of the epidemic; some worrying signs were found of a sharp increase in HIV in eastern Europe. The proportion of those who tested positive was about a third in Romania and Bulgaria and about a quarter in the other former communist countries, but only one in eight in western Europe and one in 14 in Scandinavia.

The Asian survey did not seek to establish HIV incidence in respondents in the same way, but one of its reports[20] mentions that HIV incidence in MSM in recent surveys is particularly high in some cities, especially in what has hitherto been relatively low-prevalence mainland China: last year it was found to be 5.1% a year in Nanjing and 7.6% in Chongqing, the kind of incidence only seen in rapidly expanding epidemics.

HIV treatment and treatment as prevention

The age of the epidemic was related to the proportion of men with HIV on antiretroviral therapy (ART), which ranged from just over 40% in Russia and Ukraine to 87% in Denmark and 78% in France. Older epidemics tended to have more people successfully suppressing their viral load on ART too. In the Netherlands, 88% of people on ART had an undetectable viral load, compared with only 51% in Ukraine. In Romania, Poland and Russia, fewer than 75% of people on ART had an undetectable viral load (also the case, strangely, in Norway). With the exception of Norway, ART success was also correlated with the Human Development Index of the country, i.e. its prosperity.

> "Each survey sought to establish emotional indicators of sexual happiness, not just cold facts about viruses, condoms and semen."

One really interesting, and strong, correlation was between the proportion of people with HIV who were on ART and the growth rate of the epidemic. To take the extremes, in Denmark 87% of those with HIV were on ART and the annual HIV epidemic growth rate was estimated at 6.5%; in Ukraine just 44% of those with HIV were taking ART and the epidemic growth rate in respondents was estimated at 25%. This may be indirect evidence for the success of treatment as prevention – or it could just be an indicator that in younger epidemics, fewer people are on treatment.

Happiness, disclosure and isolation

Each survey sought to establish emotional indicators of sexual happiness, not just cold facts about viruses, condoms and semen.

EMIS asked its respondents how happy they were with their sex lives and found a wide variation. In France only 28% were unhappy with their sex lives, while in Bosnia – at the other extreme – 60% were unhappy with theirs (Brits were somewhere in the middle). Bosnians, Macedonians, Cypriots and Swedes were more than 30% unhappier with their sex lives than the British; Belgians, Dutch, Spaniards, Portuguese, Swiss and French were more than 40% happier.

One challenging correlation, presented by Ford Hickson of Sigma Research at the European gay men's prevention conference (FEMP) in Stockholm in November 2011,[21] is that there is a strong correlation in EMIS between happiness and HIV prevalence: Bosnia, sexually the unhappiest country, was also the one whose small group of respondents reported no HIV infections:

Top ten findings

1

In the US, avoiding ejaculation in a partner was a more popular safer-sex strategy than using condoms.

2

In European countries, the happier people were with their sex lives, the higher the HIV prevalence in their country.

3

In Europe, only 4% of HIV-positive men had never discussed their HIV status with a partner. In Asia, only 33% had ever discussed it.

4

In Europe, the higher the proportion of men with HIV who were on treatment, the lower the growth rate of the HIV epidemic in that country.

5

In the US, only 42% of men had anal sex the last time they had sex. Oral sex was much more popular.

conversely, the Netherlands and France reported amongst the highest rates of happiness and the highest HIV prevalence rates.

In many ways this is a no-brainer: more sex is likely to mean more HIV in a situation where condom and other safe-sex usage rates are roughly equal. In the UK, for instance, the one area that stood out for conspicuous sexual dissatisfaction in gay men was the Scottish Highlands, and highlanders also reported a distinctly lower rate of sex generally – for obvious reasons of geographical isolation.

One contrasted finding in the surveys that dealt with HIV was disclosure of HIV status. In EMIS, only 5.6% of respondents who had HIV had never disclosed their HIV status to any sexual partner, with the highest 'never' rate found in the Baltic states (13.3%).

In Asia, HIV status disclosure – to any sexual partner – was the exception rather than the rule: 67% of HIV-positive respondents had never discussed their HIV status with a partner, and in mainland China that was 88%. Perhaps as a consequence of this, a much higher proportion of HIV-positive respondents in AIMSS with a main relationship were in one with a partner of unknown or negative status: lack of disclosure makes serosorting impossible. Condom use was no higher in serodiscordant encounters or relationships than in others. In many Asian countries, disclosure of personal issues such as health is in general more taboo than it is in the West and this poses a huge challenge to disclosure-based risk reduction practices.

In Europe, as we said above, the risk was more that men may falsely believe themselves to be HIV-negative, given that recent testing did not correlate with recent risk.

> “There are enough data in these studies to keep an army of academics busy for several years.”

In fact, the HIV-positive minority formed a highly isolated minority in AIMSS, with very different risk patterns from the majority: a far higher proportion had unprotected sex, drank or took drugs, and went to saunas or sex parties, than the majority.

Much more to report

There is a huge amount of data not covered in this article, especially from EMIS: I have missed out, for instance, fascinating findings on STI treatment (showing that the UK has one of the best STI services in Europe); migration (showing that people from minority ethnic groups were almost universally at higher risk of HIV, in whatever country); travel (showing that a high proportion of gay men took their last HIV risk abroad: Germany [probably Berlin] and Spain were the most popular 'dirty weekend' destinations); and on a huge number of different ways of measuring anti-gay and HIV stigma and its effects. MNSS also had a number of other findings, including that older men have just as much sex and find it more satisfying than younger ones.

There are enough data in these studies to keep an army of academics busy for several years, and the researchers are not stopping here: the MNSS model is likely to be extended to a South American gay men's sex survey and both AIMSS and EMIS intend re-runs in the next year or two. Now it's time to pull all the data together and from them, as *Making it Count*, the UK's HIV prevention planning document says, find ways of helping MSM have the best sex with the least harm. nam

Thanks to Axel J Schmidt and Ford Hickson (EMIS), Joshua Rosenberger and David Novak (MNSS) and Stuart Koe (AIMSS) for their help with this article.

6

In Europe, the highest HIV prevalence was in western Europe but the highest rate of new infections was in eastern Europe.

7

In Asia and Europe, about a third of men had tested for HIV in the last year, though this varied from 20 to 40% according to country.

8

In Europe, higher HIV risk did not mean more testing: men who'd had unprotected casual sex didn't test any more often.

9

The European survey shows that a high proportion of gay men took their last HIV risk when they travelled abroad: Germany and Spain were the most popular sex destinations.

10

In the US, older gay men had just as much sex as younger ones – and enjoyed it more.

The new activism

Guest writer *Robert James* looks at how the whole idea of being an 'AIDS activist' has changed in the era of treatment and long life.

When I decided to do a PhD thesis on how HIV activism has changed in a developed country since the arrival of antiretroviral treatment (ART), I found it was just about the only study of this subject. This article describes a few of the changes I found.

What is an HIV activist?

Firstly, what is an activist? Perhaps more than in any other disease area, people with HIV have always been subject to stigma and discrimination, jeopardising their lives, rights and dignity. HIV activism grew out of the response to this and its philosophy was enshrined in the *Denver Principles* of 1983.[1]

Now, I found a lack of clarity about what an HIV activist is among the people I interviewed. This may, in itself, be an indicator of how much HIV activism has changed. Activism is often seen as being strongly linked to protest; the process of 'involvement' can seem too professional or sedate to be real activism. Some considered activism to be an unpaid activity, adding to the uncertainty of those employed in organisations working to promote the rights of people with HIV. As one interviewee said, "Am I an activist? I don't know... I don't know whether other people would call me an activist".

AIDS activism in the United States had a reputation for being loud, brash and dramatic, and the UK also saw its fair share of protest and drama. But activism has changed since effective ART became available to stop HIV turning into AIDS.

At the start of the epidemic, AIDS and HIV activism attracted huge interest from writers, academics and journalists,[2] but I found that almost the only activism studied now is about expanding access to HIV treatment beyond the developed world. Changes in activism in developed countries, although significant and profound, have been virtually ignored.

To find out about current treatment activism I interviewed 15 HIV activists and 15 professionals, including doctors, nurses, commissioners and policy makers working in HIV. Many had been involved for over a decade but some for only the last few years; they included British and African people, men and women, gay and straight.

Everyone agreed that HIV activism had changed from protest to involvement: activists who had started as outsiders, demanding the right to be involved in discussions about their treatment by medics and the state, were now talking *with* clinicians and government departments. In the words of one activist, "People won't listen to you these days if you just rant and rave."

Dialogue and engagement

The activists interviewed felt involvement and dialogue were effective approaches: "Engagement, does it make a difference? I'd say, absolutely, and I can give you examples." Instances highlighted as areas where involvement played a role include the development of guidance by the Crown Prosecution Service on prosecutions for HIV transmission, the shift in drug trials to include more women, and the development of equality laws to include everyone with HIV.

Although the HIV voluntary sector may now appear to be a group of professional organisations which have a calm and considered working relationship with medics and the government, many started out using very different tactics to get their messages across. A good example is the relationship between activists and BHIVA, the British HIV Association, which – amongst other things – writes the clinical guidelines about managing HIV treatment and care.

The first set of guidelines, produced in 1997[3], prompted angry protests from activists, including the disruption of conferences, for not allowing positive people a voice in the writing of the guidelines and for over-cautious recommendations on the use of new treatments. Now, not only do people with HIV sit on the BHIVA guideline writing committees, but a draft version of guidelines is also made publicly available for people with HIV, activists and other interested parties to comment on. BHIVA also has a 'community representative' on its management group and most, if not all, of its other committees. These representatives are chosen by a network of HIV activists and organisations (called UK-CAB) and not by the medics.

Getting involved in treatment activism, patient involvement in the NHS, or volunteering in – or even setting up – a community organisation means engaging with systems that all have their own structures and languages, whether relating to medicine, commissioning, management or law. This knowledge barrier can be intimidating and a deterrent, but those who overcome it become empowered by their deeper understanding to debate with professionals on a more equal basis.

> "Engagement, does it make a difference? I'd say, absolutely, and I can give you examples."

The change from protest to involvement has brought a greater emphasis on knowledge of where and how to get involved; this has become a common goal of conferences for people with HIV in the last few years.[4] Patient involvement was a relatively new and unusual development in health care at the time the HIV epidemic started, and the success of partnership working between patients and doctors in HIV gave added impetus for it to become one of the primary goals of NHS policy.

Patient groups

Another important change since effective ART became available has been the formation of patient groups rather than community groups.

From the 1980s onwards, a multitude of community-based HIV organisations appeared: some, such as the Terrence Higgins Trust in London and George House Trust in Manchester, were set up to do HIV prevention work and provide services to people with HIV and AIDS; others were self-help groups where people with HIV met to support each other. In London, Body Positive, Positively Women (now Positively UK) and later the UK Coalition[5] formed as self-help groups and went on to become large organisations employing staff and providing services. Many local groups adopted the Body Positive name and attached the name of their town or area, such as Brighton Body Positive or Thames Valley Body Positive (now Thames Valley Positive Support).

Many smaller groups have since closed, partly as a result of funding cuts but also because needs changed with the arrival of ART. Community groups, such as Positively UK and OPAM (the Organisation of Positive African Men), continue to exist, but ART, and the fact that many people with HIV are now working, has led to a relocation of peer support from the community to the clinics. During the last ten years, patients and staff at a number of clinics, particularly in the London hospitals, have set up groups for people with HIV using those clinics. Although these groups are concerned with social issues affecting people with HIV, their primary focus is the clinic and care of people with HIV at their hospital.

The internet, too, has enabled a migration of peer support to online, virtual communities such as PozFem and myHIV.org.uk.

In summary

The change that ART brought to people with HIV was extraordinarily dramatic in its impact on lifespan and quality of life. But it has changed activism too: if you liked angry, dramatic protest it can feel as though HIV activism has disappeared, but in reality it has mutated into a more subtle form. From being outside protesting about decisions made by other people and demanding to be let in, activists have now come inside. nam

Since his HIV diagnosis in the late 1980s, Robert James has, for much of his time, been involved in HIV groups and advocating for people with HIV. He has recently completed a PhD thesis looking at the history of HIV activism in the UK. He is planning to co-author a book on HIV activism and would like to contact people involved in HIV activism in the past. You can contact Robert by email at: r.james@bbk.ac.uk

News in brief

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

PREVENTION

The road to PrEP

Over the next three years, up to 33,000 people may take part in 22 studies worldwide of pre-exposure prophylaxis (PrEP – giving HIV-negative people drugs to prevent HIV), the International Association of Physicians in AIDS Care (IAPAC) meeting *Controlling the HIV epidemic with antiretrovirals*, was told in June. Dr Jim Rooney of Gilead Sciences, the manufacturer of *Truvada* (tenofovir/FTC, the product used in the vast majority of these studies), said that these studies were crucial to establish whether PrEP may be less, or more, effective in clinical settings than in randomised, placebo-controlled trials. Trials are ongoing or planned in the UK, France, Latin America, Thailand and several African countries, as well as in the US. The US Food and Drug Administration voted for approval of *Truvada* as PrEP in May this year but confirmation, expected in September, is subject to a Risk Evaluation and Mitigation Strategy document. In Europe, the European Medicines Agency has issued a draft paper on the general requirements for licensing HIV drugs for prevention.
➲*www.aidsmap.com/page/2403757*

EPIDEMIOLOGY

Lack of testing fuels UK epidemic

In the UK, most HIV infections in gay men are transmitted by the undiagnosed, Valerie Delpech of the Health Protection Agency (HPA) told the IAPAC meeting. She commented that good access to antiretrovirals in the UK has not led to a reduction in new infections: the annual number of new HIV infections in gay men changed very little between 2001 and 2010, with between 2000 and 3000 new infections each year. The UK performs relatively poorly in testing and diagnosis; it is thought that at least a quarter of people with HIV are undiagnosed and only 15 to 25% of gay men have an HIV test in any one year, she said. HPA modellers have calculated that one-third of the 40,000 UK gay men living with HIV are infectious and nearly two-thirds of those are undiagnosed. Further work by University College London has found that nearly half of new infections are acquired from men who themselves have been infected in the last six months, many of whom will have a very high viral load.
➲*www.aidsmap.com/page/2393389*

SEXUAL HEALTH

Big increases in STIs in England

There was a significant worsening in the sexual health of people in England last year, data released by the Health Protection Agency (HPA) show. Cases of gonorrhoea and syphilis were up by 25 and 10% respectively against a background of a 2% increase in all sexually transmitted infections (STIs). The increase in gonorrhoea is especially worrying as it is becoming hard to treat, owing to the emergence of antibiotic-resistant strains. Gay men and other men who have sex with men (MSM) had high rates of STIs. The number of gonorrhoea cases in gay and bisexual men increased by 61% compared to 2010, chlamydia by 48%, genital herpes by a third, syphilis by over a quarter and genital warts by 23%. Three-quarters of syphilis cases in 2011 were in this group, as were 50% of gonorrhoea diagnoses. Some 16% of infections were in the throat, which may be asymptomatic.
➲*www.aidsmap.com/page/2374770*

PREVENTION

Intermittent PrEP may lead to poorer adherence

People may find it significantly more difficult to adhere to pre-exposure prophylaxis (PrEP) if it is taken intermittently than if it is taken daily, according to a study from Kenya. The IAVI E001 study found that average adherence among the individuals taking daily treatment was 83%, but fell to just 55% for those taking intermittent therapy. A total of 67 men who have sex with men and five female sex workers were recruited to the study, which lasted four months. They were divided into four groups: two which took daily *Truvada* PrEP or placebo and two which took it every Friday and Monday, plus an extra dose after sex if they had it. Adherence to the post-sex dose was especially low, at only 26%. Nevertheless, the authors believe that intermittent dosing may still be appropriate "if intracellular drug levels, which correlate with prevention of HIV acquisition, can be attained with less than daily dosing and if barriers to adherence can be addressed".
➲*www.aidsmap.com/page/2379540*

CONCEPTION

NICE: Sperm washing not needed if HIV-positive partner on treatment

Draft UK guidance on fertility treatment says that sperm washing may not be necessary for couples where the man has HIV and the woman does not, as long as the man is on effective antiretroviral treatment and unprotected sex is limited to days when his partner is ovulating. The National Institute for Health and Clinical Excellence (NICE), which issues recommendations to the NHS about the most effective and cost-effective treatments to provide, does not exclude people with HIV from access to fertility treatments, such as intrauterine insemination (IUI) or *in vitro* fertilisation (IVF). NICE has also removed a previous recommendation that the implications of the parent's HIV infection for the child's welfare "should be taken into account". The authors insist that their recommendation is limited to the situation of a heterosexual couple wishing to conceive who limit unprotected sex to days when the female partner is fertile (ovulating).
➲*www.aidsmap.com/page/2364056*

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DIAGNOSIS

'Glandular fever' symptoms may be HIV

HIV infections in people with suspected glandular fever are often missed, according to a study from the south London boroughs of Lambeth, Southwark and Lewisham – the area of highest HIV prevalence in the UK. Retrospective testing of 1046 blood samples submitted for glandular fever screening showed that 11 people (1.3%) were in fact infected with HIV and that three-quarters of these infections remained undiagnosed after the patient had seen their GP. A request for an HIV test was submitted at the same time as a request for glandular fever screening for 11% of patients. Three of these patients (3%) were found to be HIV-positive. A further 45 patients (4%) had a subsequent HIV test within a year of their glandular fever screen, two of whom had HIV. In the remaining 694 samples, six undiagnosed HIV infections were found, three of which had been recently acquired. Primary care has an important role in the expansion of HIV testing. People with primary HIV infection may experience a seroconversion illness and consult their GP, presenting with symptoms including fever, muscle aches, sore throat and rash.

➲*www.aidsmap.com/page/2357556*

TESTING

US set to approve HIV home testing

HIV home testing is soon likely to become legal in the United States, following a unanimous vote in support of the *OraQuick In-Home HIV Test* by experts advising the Food and Drug Administration (FDA). The test may be made available over the counter and is designed to be used without medical supervision. The user swabs an absorbent pad around their outer gums; results take 20 minutes. This would be the first home test for any infectious disease available for purchase by US customers. The test kits come with details of free telephone support. While professional kits cost less than $20, the home version is likely to be about $60. Studies found a very low rate of false-positive results from the kit; only two in 10,000 HIV-negative samples tested HIV-positive. There was a rather high number of false HIV-negative results, with seven in 100 samples containing HIV registering as HIV-negative. So a negative result does not completely eliminate the possibility of an infection, especially after a recent encounter. However, the panel felt the benefits of the test outweighed its potential risks and could provide an important way to make HIV testing available to more people.

➲*www.aidsmap.com/page/2356465*

News picks from other sources

Police HIV advice 'outdated and stigmatising'

The Guardian | 18 June 2012

Police forces are perpetuating incorrect stereotypes about people with HIV through guidelines that suggest officers can be infected with the virus through spit and sharing toothbrushes, say campaigners.

➲*http://bit.ly/MqQEGq*

Nobel-prize winning Barre-Sinoussi optimistic about cure

BBC Health | 7 June 2012

The scientist who won a Nobel prize for her work in first identifying HIV says she at last believes finding a cure for the virus which causes AIDS might be possible.

➲*http://bbc.in/MV3aer*

Evidence that man cured of HIV harbors viral remnants triggers confusion

Science | 11 June 2012

Only one person has ever been cured of an HIV infection, and a presentation about the man at a scientific meeting in Sitges, Spain, has caused an uproar about the possibility that he's still infected.

➲*http://bit.ly/NwtiNI*

References

Switching drugs for cost reasons – the patient experience [p.3]

1 See www.londonscg.nhs.uk
2 See www.ukcab.net
3 Marshall N et al. *Switching to atazanavir due to therapeutic tenders: short term outcomes*. 18th BHIVA conference, abstract P195, 2012.

Global AIDS funding [p.4]

1 Bendavid E et al. *HIV Development Assistance and Adult Mortality in Africa*. JAMA, 307(19): 2060-2067, 2012.
2 Open Society Foundations *The First to Go: Community-level effects of Global Fund shortages in southern Africa*. Awaiting publication, 2012.
3 Rivers B et al. *The Report of the High-Level Panel – Strong and Thought-Provoking, but with Worrying Flaws*. Aidspan, GFO Issue 160, 13 October 2011.
4 MSF Issue Brief *Losing Ground: How funding shortfalls and the cancellation of the Global Fund's Round 11 are jeopardising the fight against HIV & TB*. Médecins sans Frontières, 2012.
5 Cohen M et al. *Antiretroviral treatment to prevent the sexual transmission of HIV-1: results from the HPTN 052 multinational randomized controlled ART*. Sixth International AIDS Society Conference on HIV Pathogenesis, Treatment and Prevention, Rome, abstract MOAX0102, 2011.
6 OSF, op. cit.
7 PlusNews *Improved AIDS levy collections fill part of funding gap*. IRIN, 2012.
8 OSF, op. cit.
9 UNAIDS Issues Brief *A new investment framework for the global HIV response*. Joint United Nations Programme on HIV/AIDS (UNAIDS/JC2244E), 2011.
10 Over M *Achieving an AIDS Transition: Preventing Infections to Sustain Treatment*. Center for Global Development, 2011.
11 Glassman A et al. *Global Health and the New Bottom Billion: What Do Shifts in Global Poverty and the Global Disease Burden Mean for GAVI and the Global Fund?* Center for Global Development, Working Paper 270, 2011.
12 Glassman A, Sumner A *Vaccines need to reach the poor in middle-income countries too*. The Guardian, 13 June 2011.
13 Hecht R et al. *Financing of HIV/AIDS programme scale-up in low-income and middle-income countries, 2009-31*. The Lancet, 376: 1254-1260, 2010.
14 Mathers BM et al. *Global epidemiology of injecting drug use and HIV among people who inject drugs: a systematic review*. The Lancet 372: 1733-1745, 2008.

The gay globe [p.10]

1 UNAIDS *How to get to zero: Faster. Smarter. Better. World AIDS Day Report, 2011*. Joint United Nations Programme on HIV/AIDS, 2011. See http://bit.ly/KAmE7o
2 Health Protection Agency. *HIV in the United Kingdom, 2011 report*. Health Protection Services, London, 2011. See http://bit.ly/MzmQ81
3 Le Vu S et al. *Population-based HIV-1 incidence in France, 2003-08: a modelling analysis*. Lancet Infect Dis 10(10):682-687, 2010.
4 Centers for Disease Control and Prevention *HIV Surveillance – Epidemiology of HIV Infection (through 2010)*. CDC, Atlanta, 2012. See http://1.usa.gov/Nvh8sJ
5 van Griensven F et al. *The global epidemic of HIV infection among men who have sex with men*. Curr Opin HIV AIDS 4(4):300-307, 2009.
6 *ibid*
7 Utyasheva L *HIV and the law in eastern Europe and central Asia*. Global Commission on HIV and the Law, UNDP, 2011.
8 UNAIDS *op. cit.*
9 See www.aidsmap.com/page/1437431
10 Koe S *Asia Internet MSM Sex Survey 2010 preliminary report*. Fridae news, 23 July 2010. See http://bit.ly/N83BbG
11 Wei CG et al. *Sexual transmission behaviors and serodiscordant partnerships among HIV-positive men who have sex with men in Asia*. Sex Transm Dis 39(4):312-5, 2012.
12 Wei CG et al. *HIV disclosure and sexual transmission behaviors among an internet sample of HIV-positive men who have sex with men: implications for prevention with positives*. AIDS Behav, epub ahead of print, 2011.
13 Wei CG et al. *Patterns and levels of illicit drug use among men who have sex with men in Asia*. Drug Alcohol Depend, 120(1-3):246-9, 2012.
14 Rosenberger JG et al. *Sexual behaviors and situational characteristics of most recent male-partnered sexual event among gay and bisexually identified men in the United States*. J Sex Med 8(11):3040-50, 2011.
15 Rosenberger JG et al. *Condom use during most recent anal intercourse event among a U.S. sample of men who have sex with men*. J Sex Med 9(4):1037-4, 2012.
16 See www.emis-project.eu/final-report
17 See www.emis-project.eu/community-1 and www.emis-project.eu/community-2
18 See www.sigmaresearch.org.uk/gmss/year/yr2010 and www.emis-project.eu/national-reports
19 Jin FY et al. *Per-contact probability of HIV transmission in homosexual men in Sydney in the era of HAART*. AIDS 24(6):907-13, 2010.
20 Wei CG et al, 2012, op.cit.
21 Hickson F *Towards better sex with less harm for gay and bisexual men in Europe* FEMP, Stockholm, 2011. See http://bit.ly/Mzouqd

The new activism [p.16]

1 See www.actupny.org/documents/Denver.html
2 E.g. For the US picture: Patton C *Sex and Germs: The Politics of AIDS* South End Press, Boston, 1985; Shilts R *And the Band Played On* St Martin's Press, New York, 1987; Epstein S *Impure Science: AIDS activism and the politics of knowledge* University of California Press, Berkeley, 1996; in the UK, Richardson D *Women and the AIDS Crisis* Thorsons, London, 1987, Carter E, Watney S *Taking Liberties: AIDS and Cultural Politics* Serpent's Tail, London, 1989.
3 Gazzard, B, Moyle G et al. *British HIV Association guidelines for antiretroviral treatment of HIV seropositive individuals*. The Lancet, 349(9058): 1086-1092, 1997.
4 For example, the conference organised by Positively UK, 'No Decision about Me, without Me', 24 September 2011. See www.positivelyuk.org/docs/2011_Winter_No_Decision_Web.pdf for report.
5 The full name of the UK Coalition was the 'UK Coalition of People Living with HIV and AIDS'. Body Positive and the UK Coalition closed after some of their funding was withdrawn while Positively Women changed its name to Positively UK in 2011.

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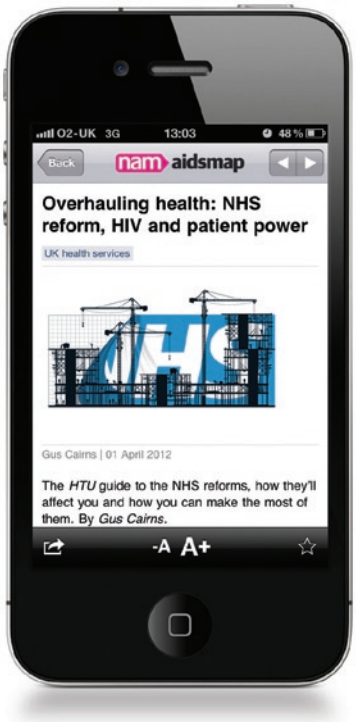

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