

hiv treatment update

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Gus Cairns

in this issue

Life never ceases to throw surprises at us, including things we shouldn't be surprised by. One of those is old age. As the failure of young people to get pensions shows, we never really think we're going to get old.

"Restricted, boring and bleak" was the description of age, as perceived by youth, in one publication – not some Generation X novel, but a sober paper issued by the Department for Work and Pensions on why young people don't save.

They're wrong. A recent large study in the US by Princeton University and Gallup used phone polls to quiz 340,000 people aged 18 to 85 on how happy, sad, stressed and sane they felt. Who were happiest? People in their 80s.

But what happens if you had good reason to think you'd never get old? That's the position many people with HIV who were diagnosed before combination therapy have found themselves in.

As Lisa Power's analysis of the 50 Plus survey shows (page 8), a high proportion of the people with HIV who answered the survey regarded becoming old with dread – in particular because, having not made provision for old age, they'd be reliant on dwindling and possibly ignorant public services.

One positive finding of the survey, however, was that people reported greater ease with disclosure – perhaps being less likely to worry what people think. It could suggest that HIV-positive octogenarians may be less isolated, and have not quite such a bleak time of it, as they are anticipating right now.

Our other pieces also hinge on unwelcome surprises. Midwife Sally Farthing, writing about the other end of life (page 4), finds that if mums with HIV are diagnosed and treated in time, the chance they will pass the virus on to their baby is becoming minuscule – in the region of one transmission per 200 births.

Yet the actual transmission rate, having plummeted in the 1990s, is staying stubbornly at about four times that rate – one in 50. Apart from a couple of freak transmissions, most of those excess infections represent occasions when obstetricians, finding a mother they've never seen before in the labour ward, get a nasty surprise when they test her for HIV. Despite everything they can do then – caesareans, AZT drips, postnatal treatment for the baby – some kids still get infected.

Almost always, the woman has stayed away because she fears a worse nasty surprise, that she'll come round to find herself with a bouncing baby – and a deportation order.

Finally, we had another surprise last month when two presentations at the Microbicides Conference (page 14) found that many of the lubricants recommended for use with condoms may actually make people more vulnerable to HIV.

Safer-sex guidelines won't change unless larger studies confirm these findings, but it's a reminder that as the epidemic approaches its own middle age, the simplest pieces of research can still throw curve balls at us. We're sure there will be more surprises along the way.



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For more information about *HTU's* medical review panel, please visit www.aidsmap.com/cms1281087.aspx

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**NHS Pan-London HIV
Prevention Programme**

Once-a-day pills and other sticky problems

Less-than-perfect adherence to a once-a-day HIV treatment carries five times more risk of treatment failure than imperfect adherence to a twice-a-day regimen. That's one of the surprising things that came out of an adherence conference in Miami at the end of May.

We assume once-a-day regimens for HIV are a boon. The appearance of *Atripla*, the first one-pill, once-a-day treatment for HIV was hailed as a landmark when it was licensed in Europe in 2007. A decade earlier people were taking handfuls of pills two or three times a day.

A study 18 months ago showed that adherence was 4.5% better in once-daily than in twice-daily drug regimens.¹ In the NAM treatment survey in 2008, one in twelve people spontaneously mentioned *Atripla* or once-a-day dosing as the thing that most helped with their adherence.

If you miss a dose of a once-a-day regimen, however, there is a longer gap before the next one is taken, and researchers at the Miami conference warned that the consequences of poor adherence may be more serious.²

They looked at 2410 people who started HIV treatment for the first time between 2003 and 2009 and followed them for an average of 2.5 years, conducting regular interviews about their adherence with them.

Poor adherence, defined as missing at least one dose of treatment during the past month, was reported by patients in one-third of interviews.

More than one in twelve patients (8%) experienced their viral load 'rebounding'. The researchers stratified their patients into whether they missed zero, one, two or more than two doses; there was no separate analysis of patients who missed

very high numbers of doses. For patients taking a once-daily treatment, missing any dose increased their risk of viral rebound and this risk increased with the number of doses missed in the past month.

Not too surprising; but what was surprising was how much difference missing just one dose made. In comparison with people who didn't miss any doses, people who missed just one dose had *five times* the risk of their viral load rising. People who missed two doses had seven times the risk, and people who missed three or more doses had nine times the risk. This mattered: people who missed several doses also had a greater risk of dying in the study period than other people.

Unexpectedly, the same kind of effects weren't seen in people taking their treatment twice a day. In fact, no statistically significant relationships were found between missed doses and either an increased risk of viral rebound or of death.

So 100% adherence may be easier on a once-a-day regimen but if you do miss doses the consequences are more serious than on a twice-a-day regimen. For someone who's not confident of near-perfect adherence, once-a-day treatment may be more risky.

Just the fact that a conference is organised where every single presentation is about adherence tells you how important it is to successful HIV treatment.

Another way to get a sense of this is to take a look at some of the ways in which doctors, researchers and drug companies would like to track people's adherence to medication.³

Currently, methods include just asking patients how many doses they've missed, counting how many pills are left in their container and keeping an eye on how often people come back to the pharmacy for a new supply. The trouble is, none of these are foolproof: people almost invariably

overestimate their adherence and can also confound the system by building up pill stockpiles or giving them away.

There are devices which record the date and time that a pill container is opened and show both the total number of doses taken and whether they have been taken on time. These don't work if you stock up a weekly pillbox.

Researchers are now developing devices that use wireless technology to send the information about when the pill container was opened over a mobile phone network to the person's doctor. Speaking at the conference in Miami, one researcher showed data downloaded to her laptop that morning showing the exact times that a woman in Uganda had taken her medication over the past few days. We could see that she had missed a dose on Saturday morning.

Is this a step too far? What about privacy and personal autonomy? Advocates say that such systems have important advantages. Because they collect information in real time, they can warn doctors of a problem before it's too late. It's no good knowing that a person had a treatment break a month ago. If doctors knew immediately that a patient was having problems with adherence they could intervene and offer support in good time. Seeing a couple of missed doses could, for example, be the trigger for a nurse to phone and see what the problem is.

Some people don't think even such a system goes far enough. Hitherto, no method of monitoring adherence shows whether someone has actually *swallowed* the drug. So even more high-tech methods are being developed, embedding a supposedly harmless antenna, mini-magnet or microchip inside the pill, which sends a signal when swallowed. It might give accurate data – but would you swallow it?

happy families



Sally Farthing is an HIV specialist midwife at West Middlesex Hospital in Isleworth, west London. She praises the measures – and the mothers – who together have sent the risk of a child being born HIV-positive tumbling in the last decade, from one infection in four births to fewer than one in 50. Are we on the right track to bring the rate down even further, she asks, or will new proposals halt that progress?

A prevention success

In the 15 years I have been working as a midwife with HIV-positive women, I have seen huge advances in the reduction of mother-to-child transmission. When I first began working in this area, the risk of transmission was anywhere between 25 and 40%. In 1995 we were able to reduce the risk of transmission from mother to child by two-thirds, from about 25% to about 10%, with the offer of AZT (zidovudine, *Retrovir*) monotherapy during pregnancy, intravenous AZT in labour, bottle-feeding and four weeks' AZT syrup for the baby.¹

In 1999 we had the results from the International Perinatal HIV Group, which reported that elective pre-labour

caesarean section demonstrated a further 50% reduction in transmission.²

Next we had the introduction of highly active antiretroviral therapy (combination therapy, or HAART) that enables us to achieve undetectable viral load. HAART during pregnancy, together with elective pre-labour caesarean section, bottle-feeding and four weeks of AZT syrup for the baby reduced the risk even further – to less than 2%.

Recent figures now show that women with an undetectable viral load at 36 weeks of pregnancy have the same risk of transmission (0.7%, or one transmission per 143 births) whether they have an uncomplicated spontaneous vaginal birth (normal delivery) or a planned caesarean section.³ Some studies have found even lower rates.⁴

So more and more babies are being born by vaginal birth and women with HIV can have normal deliveries.

Gone are the days of a gloomy outlook for babies born to HIV-positive women. But the data tell us that some babies are still entering the world with HIV or soon acquire it. Why? And are we doing enough to prevent children from acquiring HIV from their mothers?

A silent minority

To say that receiving a diagnosis of HIV during pregnancy is not ideal is, at the least, an understatement. Yet the vast majority of all the women I have worked with over the years are hugely relieved to have the knowledge that allows them to protect their baby from infection.



The proportion who know about their HIV infection prior to pregnancy has increased over the last five years. This is primarily due to the introduction of the routine offer of an HIV test at the first booking visit with the midwife, alongside all the other screening tests. In fact, testing of women has expanded so much, and women with HIV are feeling so much more optimistic about becoming mothers, that since 2005 the number of women in the UK who know they have HIV before pregnancy has exceeded the number of new diagnoses during pregnancy.

Clearly, though, we are missing some women – as demonstrated by a perinatal audit carried out in 2007.⁵ This audit looked at all pregnancies in the UK from 2002 up to March 2006. It showed that 95% of pregnant women were accepting the offer of an HIV test in pregnancy across the UK and that 90% of women with HIV were diagnosed before delivery. Excellent progress, and what a change from the late 1980s when 75% of women with HIV were unaware of their infection until their child was diagnosed with AIDS.

However, of approximately 3400 infants born to HIV-positive women over the four years, 87 infants (2.5%, one in 39 babies) were known to be infected. Of these, two-thirds were born to women whose infection had not been diagnosed and only one-third to women with a known HIV diagnosis.

The best news is that none of the babies born to women who received optimal care became infected. Problems

identified in those babies who *were* infected were complex. Possible contributing factors included late diagnosis, premature delivery, and additional illness, as well as being born to mothers experiencing social and housing problems, communication and immigration difficulties, denial of HIV diagnosis and medication problems.

Of the 54 women who did not have their HIV diagnosed, 35% had declined an HIV test during pregnancy and 20% had become infected during pregnancy. The rest slipped through the net for a variety of reasons and were never offered a test.

Who were these women who either declined an HIV test or became infected during their pregnancy? Is there more we could be doing to avoid the unnecessary infection of a newborn baby?

Second tests and tests for partners

The challenge remains for midwives to make sure that the women who decline an HIV test at the antenatal booking appointment are offered a test again at later visits, and that the reason for declining is established and explored. Time constraints on the antenatal visits can make it difficult for a woman to open up to someone she may have just met but referral to the specialist midwife or health adviser would allow more time and privacy for longer discussion.

Midwives also need to remember that, during pregnancy, couples will not be using condoms for contraception and could be at risk of sexually transmitted

infections, including HIV, at any time during the pregnancy. It is all too easy to assume that a test has been done at the booking visit and not to think about it again later in pregnancy.

However, the stigma and fear surrounding HIV is still all too apparent for some people who believe they will be ostracised and treated differently if they are diagnosed with this illness. Because of this they may be very reluctant to come forward for retesting.

Pregnant women themselves are somewhat targeted with a routine offer: but what about the fathers? How can we spread the message that they too need to think about the baby's welfare and have an HIV test? This is a challenge for the community as a whole as well as for midwives. A negative HIV test for Mum does not mean that baby is fully protected.

Testing partners is a huge task, but it would protect even more mothers and babies from HIV infection if we started suggesting to women and their partners that they test together. Some of the women I have cared for say to me: "If only we'd received our diagnosis at the same time, I wouldn't have been the one to be blamed. By me finding out first he assumes I am the one who infected him."

Admittedly, not all partners attend antenatal clinic appointments and sometimes women are infected by new partners they meet while pregnant, so we need to talk to women about how to discuss the offer of an HIV test with

their partners and to give them information about local testing centres and places where people can access rapid, walk-in testing (such as *Know 4 Sure*, run by Chelsea and Westminster NHS Trust); this is often helpful if there is anxiety about waiting for test results.

Newham University Hospital in east London ran a pilot project in which the male partners of pregnant women were offered HIV tests.⁶ The project aimed to reduce late diagnosis of men by offering tests at week 20 of their partner's pregnancy. Over 6000 women were tested as part of their antenatal care during a one-year period, but only 16 of their partners took up the offer. Barriers to testing may have included the fact that it involved referral to another hospital department, and that the results were not available immediately. A separate community testing project in Newham, using rapid tests, has had more take-up with men.

The National Screening Committee is reviewing the benefits of a second HIV test at the 28- or 32-week routine antenatal visit, and there have been some pilot studies of second-testing done at a couple of London hospitals. Looking at the statistics, though, the incidence of women seroconverting (becoming infected) later in pregnancy would appear to be low: roughly one HIV infection in 7700 pregnancies, compared to a general prevalence of one infection in every 575 pregnant women.⁷

The BHIVA/CHIVA (British HIV Association and Children's HIV Association) guidelines on managing HIV in pregnancy (2008) state that: "At present, although desirable, there is no suggestion that universal retesting in the third trimester will become national policy; therefore case-by-case assessment to determine whether a woman is at continuing risk of acquiring HIV infection in pregnancy is the only option with repeat testing offered."

There are two concerns about this, however. Firstly, as hospitals are seeing women earlier in pregnancy, preferably around ten to twelve weeks' gestation, in order to offer screening for Down's syndrome, some infections occurring at conception may still be in the window

period and not diagnosed at this first visit.

Secondly, the common practice of women receiving the results of their 'booking' blood tests in their notes rather than in a face-to-face interview means there is little opportunity for women to have a post-test discussion. (These blood tests consist of a full blood count to check for anaemia, blood group, haemoglobinopathy screen, syphilis, hepatitis B and HIV.)

A post-test discussion would consist of information about the meaning of a negative HIV result. The advantages of having a second test could be raised, and a conversation about sexual health in pregnancy generally would be helpful. A negative HIV result so early in pregnancy could lead to a false sense of security for everyone.

Midwives, as a profession, need to be clear at the first test that a repeat test may be needed later in pregnancy and be sensitive to any concerns women may have. Women may also fear that HIV treatment will damage the baby or themselves.

There is good evidence that even diagnosing HIV infection late in pregnancy – at delivery or even within 48 hours after birth – can still offer a reduction in the risk of mother-to-child transmission. Most hospitals can have an HIV test result back within 24 hours and some even have access to point-of-care tests (where results are available in 20 minutes).

Even without previous treatment, treatment during labour and postnatally for the baby, plus the avoidance of breastfeeding, will reduce the risk of transmission to approximately 9%. A woman diagnosed in labour would be recommended oral tablets of nevirapine (*Viramune*), an elective caesarean section, an AZT drip, and combination therapy for her baby.

It is never too late to test, particularly if a woman has had no antenatal care. All blood tests for infection can be carried out on labour ward and obstetricians should be open to the idea of perinatal testing.

Breast versus bottle: what should we say?

Some interesting developments surrounding the use of bottle-feeding for women with HIV were announced at the BHIVA conference in April this year, and there is guidance being prepared by BHIVA regarding breastfeeding for women with HIV.

The crucial new proposed wording for the breastfeeding guidelines reads as follows:

In the UK, refraining from breastfeeding from birth should continue to be recommended. BHIVA/CHIVA acknowledges that, in the UK, the risk of mother-to-child transmission from a woman who is on HAART and has a consistently undetectable HIV viral load is likely to be low but has not yet been quantified.

Therefore, although formula feeding is still the best and safest option in the UK to prevent mother-to-child transmission of HIV, if a woman is on effective HAART and chooses to exclusively breast-feed having carefully considered the aforementioned advice, she should be supported to do so as safely, and for as short a period, as possible.

Although this statement will be welcomed by some people, it once again places the onus on women to try and weigh up risks and percentages when dealing with choices about their baby's welfare.

It does mean that, as midwives, we can offer support rather than castigation to women who may be thinking about breastfeeding their baby, and that it does not automatically become a child protection issue.

However, will it mean that women who are under pressure from family members to breastfeed may give in to the wishes of others for fear of being thought to have HIV, rather than choosing to breastfeed because they truly believe it is best for their baby?

The benefits of breastfeeding have become a wide public health message generally, and increasing pressure and publicity surrounding breastfeeding must make it difficult for women with HIV to bottle-feed. But being asked to weigh up

risks when it comes down to your baby's health and possibility of acquiring HIV is a huge burden for a mother.

There are many women who come under intense pressure from family and friends to breastfeed and this statement may make it even more difficult for them to do what *they* feel is best for their babies. I hope midwives can offer good information and support to these women and that we do not lose the ability to supply free formula milk to women who need it.

In some hospitals the 'breast is best' ideology means that midwives may themselves exert pressure on mothers, consciously or otherwise, to breastfeed, and need to be supportive with bottle-feeding when it is necessary, showing women how to make up feeds, sterilise bottles and so on. In addition, exclusive breastfeeding and rapid weaning are far from easy and healthcare professionals need to appreciate the level of support required.

The community of people living with HIV was not supportive of this change. A joint statement by Positively Women

and the UK Community Advisory Board said that revising the guidelines now might have a negative impact on women who were struggling to do the best for their baby by bottle-feeding.

A shortened version of the statement by Positively Women pointed out that if a woman is taking HIV treatment "It is a paradox to take HIV treatment, but to then put your baby at risk of transmission... PW cautions against a mixed message being given by BHIVA." The general feeling was that it was premature to issue public guidance saying that breastfeeding might be supported under certain circumstances, and that there would be better evidence about the safety of breastfeeding while on HIV treatment in a few years' time.

Conclusions: successes and failures

Looking back over the years, there have been great strides in the medical care we offer women during pregnancy and a huge reduction in the number of babies infected during pregnancy or childbirth. Have I seen the equivalent changes in the fear and social stigma that receiving a positive HIV test result produces? I am not so sure.

As Jason Warriner from Terrence Higgins Trust recently said "One of the biggest challenges we face in the UK is that one person in four with HIV doesn't even know they have the virus, because they haven't been tested."

The wider community, and men especially, need encouragement to test for HIV in the same way they might accept screening for high blood pressure or diabetes. Early treatment enables HIV to be maintained as a long-term chronic condition rather than a terminal illness... and protects babies from infection.

The fear of a positive test result still prevents people from accessing the care they need. During pregnancy women have the added pressure to protect their babies – and they have accepted that challenge head on.

Isn't it time other members of society did the same thing? ■

For details of the "Know 4 Sure" testing scheme see: www.chelwest.nhs.uk
telephone 020 8846 6699



will a long life be a good one?

People with HIV are now living into old age – an old age many regard with fear, as *Lisa Power* from the Terrence Higgins Trust finds out.



hiv treatment update

2010 readers' survey



Please tell us what you think!

At NAM, we are always interested in hearing what people think about our information materials.

We're also always thinking of new ways to reach as many people who need HIV information as possible, and how to use our resources in the most effective (and cost-effective) way.

Last year we asked about how HIV Treatment Update (HTU) looked and what should be in it. We've used that information in the last 12 months to shape content and tone.

We've also seen a change in how we send some of you HTU – for example, we've had quite a lot of requests for email subscriptions in the last year.

This year we'd like to know more about how you seek out and access information, and the range of ways you get information about HIV, treatment and different aspects of living with HIV.

Thank you for taking the time to help HIV Treatment Update stay in touch with its readers' needs.

If you would prefer to complete the survey online, you can access it until 20 August from our website www.aidsmap.com/htu



About HTU now

1. Where do you currently get your copy of HIV Treatment Update (HTU)? (please tick all that apply)

- I receive the print edition at home
- I see the print edition at work
- I read the print edition at my clinic or HIV centre
- I subscribe to the email edition
- I subscribe to the audio edition
- I read it online
- I read someone else's copy
- Other

2. If you get your own copy, roughly how many people other than you read your copy of HIV Treatment Update?

- One other person
- 2 to 4 people
- 5+ people

3. What do you think of the following, in relation to HTU's content?

	Very useful	Useful	Not very useful
The topics covered	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The longer feature articles	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The brief news stories	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The interviews with health professionals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The interviews and personal stories from people with HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The overview of information on a particular topic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The writing style	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The level of detail	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The suggestions for further information and contacts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please give examples)

4. What do you think of the following, in relation to HTU's format?

	Very useful	Useful	Not very useful
The mix of feature articles, shorter articles and news	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The use of images – photos, diagrams and illustrations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The use of colour	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please give examples)

5. If you get the print version of HTU, what do you like about it? (please tick all that apply)

- The fact that it's easy to carry around
- The fact that I can keep my copy to refer back to
- The fact that I can read it away from my computer
- The fact that it's easy to flick through
- Other (please give examples)

6. If you get the PDF or read HTU online, what do you like about this format? (please tick all that apply)

- The fact that I can have it emailed directly to me
- The fact that I can read it wherever I have internet access
- The fact that I can send it on to other people
- The fact that it's discreet
- Other (please give examples)

7. What do you think of the following, in relation to HTU's reliability and frequency?

	Very useful	Useful	Not very useful
The fact that it is a regular publication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The fact that it comes from a reliable source	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The fact that it's posted to me every month	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The fact that it's emailed to me every month	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The fact that it analyses key news for me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (please give examples)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

8. Is there anything else about HTU you particularly value? (please give examples)

About HTU in the future

9. If HTU's content was available online as soon as it was produced, would you still want to receive a paper copy?

- Yes
- No

10. Please answer this question if you are living with HIV and receive a free print copy sent to your home.

Would you consider receiving HTU in any of the following formats if NAM no longer had the funding to provide a free subscription? (please tick all that apply)

- Receive HTU as a PDF by email
- Read/download a copy of HTU on aidsmap.com
- Pick up a print copy of HTU from your clinic or a community-based HIV organisation
- Pay to have a print copy sent to your home

11. Please answer this question if you are an HIV professional and have a paid subscription for HTU.

Would you consider receiving HTU in any of the following formats if NAM no longer had the funding to provide a printed copy at the current subscription price? (please tick all that apply)

- Receive HTU as a PDF by email
- Read/download a copy of HTU on aidsmap.com
- Pay an increased subscription to have a print copy sent to you

About your information sources

12. Do you read any other magazines or printed information about HIV treatment or living with HIV?

- Yes
- No

Please give examples of this printed information.

13. How do you get this printed information?

- It's posted to my home
- I pick it up from a clinic
- I pick it up from somewhere else

Please specify other places you collect this sort of information.

14. How often do you use the Internet?

- Daily
- At least once a week
- Less often
- Never

15. Where do you use the Internet? (please tick all that apply)

- At home
- At work
- On my phone
- In a public place, e.g. at an Internet café, in a library or at other community centre
- At someone else's home
- Other (please give examples)

16. What kind of websites do you use? (please tick all that apply)

	Daily	At least once a week	At least once a month	A few times a year	Never
General information (e.g. Wikipedia)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
News (e.g. BBC, newspapers)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Social networking (e.g. Facebook, Twitter)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Media and entertainment (e.g. YouTube, iPlayer)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Email providers (e.g. Yahoo, Hotmail)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Interest groups and email lists (e.g. Yahoo Groups)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dating and relationship sites (e.g. Gaydar, Match.com)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shopping (e.g. Amazon, eBay)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Professional and technical information and tools (e.g. BHIVA, HPA, Nursing and Midwifery Council)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Listening to podcasts and other online audio files	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Watching videos	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you use other social media websites, please tell us which ones.

17. Do you use any HIV information websites? (please tick all that apply)

	Daily	At least once a week	At least once a month	A few times a year	Never
African HIV Policy Network (AHPN)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aidsmap	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aidsmeds	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Avert	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
BHIVA	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The Body	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
George House Trust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
GMFA	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
HIV i-Base	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
NAMlife	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
National AIDS Trust	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Positive Nation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Positively Women	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poz	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Terrence Higgins Trust (THT)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If you use any other HIV information websites, please list them here.

18. What sort of things have prompted you to look at these websites? (please tick all that apply)

- To keep up to date with the latest news on HIV
- When I have a specific question
- To check on information my healthcare team gives me
- When something about my health changes
- When I receive an email with updates
- Other times (please give examples)

19. Are there any features of these websites you find particularly useful?

20. Do you receive any regular information updates? (please tick all that apply)

- NAM's HIV Weekly email bulletin
- NAM's fortnightly aidsmap news email bulletin
- NAM conference bulletins
- (An)other email newsletter(s) (Please give examples)
- (An) HIV news feed(s)

Please give examples of other newsletters or news feeds.

21. What features do you like best about these sources of information?

22. What do you like least?

23. How comfortable are you in using the Internet to find information about HIV? (1 = very comfortable; 5 = not at all comfortable)

- 1 2 3 4 5

24. Are there any factors that might make it less easy for you to use the Internet? (please tick all that apply)

- Don't have anywhere private to use the Internet
- My computer is too slow or inefficient
- Access to the Internet is too expensive
- I don't feel confident using a computer
- I don't feel confident I'll find reliable information
- I just prefer to read printed material

Other (please give examples)

About reading HTU

25. As a result of reading HTU have you learnt anything about HIV, health and treatment?

- I have learnt nothing new
- I have learnt something but it's not particularly useful to me
- I have learnt something that is useful to me
- I have learnt something that seems vitally important to me

26. Please give some examples in your own words of what you have learnt.

27. As a result of reading HIV Treatment Update are you now more likely to (please tick all that apply):

- Discuss your health and treatment with your healthcare team
- Feel more confident talking to your healthcare team
- Feel better equipped to take decisions regarding your treatment and care

28. Have you made any changes to your treatment or care, or taken decisions, based on something you have read in HTU?

- Yes
- No

29. Please give us an example of what you discussed and/or what these changes or decisions were.

About you

30. Are you:

- Male
- Female
- Transgender

31. How old are you?

- Under 20
- 20s
- 30s
- 40s
- 50s
- 60s
- 70 or over

32. How would you describe your sexuality?

- Gay man
- Lesbian
- Bisexual
- Heterosexual (straight)
- Other
- Prefer not to say

33. How would you describe your ethnic background?

- White British
- White other (please specify below)
- Black African
- Black Caribbean
- Black other
- Asian
- Mixed race (please specify below)
- Any other group (please specify below)

34. What is your country of birth?

35. What is your highest educational level?

- No qualifications
- GCSE or equivalent (year eleven, at age 16)
- A-level or equivalent (year thirteen, at age 18)
- Vocational qualification or diploma
- University degree
- Postgraduate (masters or doctorate)

36. Are you employed?

- Yes, full-time
- Yes, part-time
- Yes, self-employed
- Yes, doing voluntary work
- No, student
- No, retired
- No, unemployed and seeking work
- No, unemployed and not seeking work

37. Where do you live?

- In London
- In the UK, outside London
- Outside the UK

38. If you live in the UK, please give the first half of your postcode:

39. How far away is your nearest HIV clinic?

- A mile or less
- 2 to 5 miles
- 5 to 20 miles
- More than 20 miles
- Don't know

40. Why do you read HTU? (please tick all that apply)

- I'm HIV-positive
- I work in the HIV field, in health care
- I work in the HIV field, elsewhere
- I'm a partner/relative/friend of someone with HIV
- Other (please specify)

About your HIV status

41. What is your HIV status?

- I'm HIV-positive
- I'm HIV-negative
- My HIV status is unknown
- I'd rather not say

42. If you are HIV-positive, how do you think you got HIV?

- Sex between men
- Sex between men and women
- Injecting drugs
- Blood or blood products
- Mother-to-child transmission
- Don't know
- I'd rather not say
- Other (please specify)

43. If you are HIV-positive, are you:

- Asymptomatic (no illnesses), not on HIV treatment
- Asymptomatic (no illnesses), on HIV treatment
- Symptomatic, not on HIV treatment
- Symptomatic, on HIV treatment

44. Do you receive any HIV-specific medical care?

- Yes
- No

45. If you are HIV-positive, when were you diagnosed?

- In the last year
- 1 to 2 years ago
- 3 to 5 years ago
- 6 to 9 years ago
- 10 to 15 years ago
- 16 to 20 years ago
- More than 20 years ago

Thank you for your time!

Please return this survey by 23 August in the envelope provided or to:
HTU Readers' Survey, NAM, Freepost LON17995 London, SW9 6BR

NAM welcomes feedback from all users of our materials and uses it to make our information appealing and relevant.

If you would like to give us more feedback on HTU or any other NAM materials, or to find out more about the materials we produce, please contact us on 020 7840 0050 or at info@nam.org.uk.

HIV has been an arena of constant change for the past 30 years. In countries such as the UK, where modern treatment advances and high quality health care are available, people with HIV are increasingly living into old age.

Science and medicine have outstripped public understanding, which lags behind, continuing to characterise HIV as a 'killer disease' and feeding the stigma associated with it.

But with good quality treatment, someone diagnosed now in their mid-30s (as is most common) can hope to live into their 70s. Studies still report that HIV cuts, on average, eight to ten years off life expectancy, about as much as smoking 20-a-day. But that's as good as or better than many other chronic, long-term, life-threatening conditions, and it continues to improve all the time, with some groups of people with HIV now on a par with the general public.

*“Having not expected to live this long, it's quite a shock to deal with the onset of old age.
White, gay man, 60”*

This should be a very good thing – but the story is not as simple as that. What quality of life will older people with HIV face? Will social care be adequate for an influx of older people with HIV?

Evidence suggests that the virus may accelerate the ageing process in some respects, even in people on treatment. Older people with HIV may need more care, or more specialised care, than average. Are we prepared for this?

The 50 Plus project

In 2008, the Department for Work & Pensions reviewed the 'Special Rules' benefits on which some people with HIV had historically depended. Assessed in the 1980s and 1990s as likely to die soon, many people were advised to leave work, cash in their pensions, dump their mortgages and enjoy the time they had left.

Now, it became clear, many were facing the reality of surviving to old age with little hope of returning to employment, on reduced benefits and, eventually, a basic state pension.

By 2008, one person in six being seen for HIV care in the UK was aged 50 or over. This is projected to double over the next five years as people live longer or are diagnosed later in life.

Terrence Higgins Trust and Age UK (formerly Age Concern and Help the Aged) identified that, while research was being done into the clinical needs of older people with HIV in the UK, there was little research on the *social* impact of ageing comparable to that being undertaken in the US by ACRIA (the AIDS Community Research Initiative of America). The two organisations received support from The Joseph Rowntree Foundation to survey older people with HIV, concentrating on social care needs within a wider context – the 50 Plus project.

The resulting report focuses on people with HIV's own views of the future. It includes recommendations for action for policymakers, the NHS, local authorities, charitable funders and HIV- and age-related organisations.

The 50 Plus project heard from 410 people with HIV aged 50 and over – one in 25 of all those currently being seen for care – about their current life and, above all, what their views of their future life were, through online and paper surveys. Forty of the respondents were also interviewed in depth.

The group broadly reflected the make-up of the HIV-positive population in that age group, including people diagnosed from the 1980s right up into the current year. The report analysed the data not only for older adults with HIV as a group, but also by comparing three of the largest sub-groups:

gay/bisexual men, black African women and white heterosexuals.

Findings

While these groups had much in common, they also had significant differences in their attitudes, needs and characteristics. Gay and bisexual men are by far the largest community of over-50s with HIV, but black African women can face complex challenges that often differ from other populations. White heterosexual people, often neglected in HIV studies, are particularly well-represented in this age group.

*“I am worried that too many clinics, hospitals and practitioners are treating me for separate illnesses. There is one hospital for my HIV, another for HPV and two GPs for cardiovascular problems.
White, gay man, 60”*

Physical health and health care: The vast majority of respondents were on HIV treatment, with over half reporting side-effects. Just under two-thirds were also on treatment for other long-term conditions.

We found almost twice as many other long-term conditions than we would expect in the general public at this age. These conditions, like high blood pressure, kidney and liver problems and arthritis, are mostly conditions of ageing but can also be exacerbated by HIV itself and, in some cases, HIV treatment.

Despite the fact that most people were registered with a GP, and most had disclosed their HIV to them, there were extensive experiences of poor treatment in primary and generalist healthcare settings. Older people use their GPs and primary care far more often than younger people; they need as strong and positive a relationship with them as with their HIV clinicians.

“The local GP I don’t think I’ve seen at all. I went to one at the very beginning and found her so unhelpful and freaked out about the fact that I was HIV...I never went back there again.

White, heterosexual woman, 55”

This indicates an urgent need to improve the quality of primary care for people with HIV and for better interaction between HIV specialists and other clinicians. Black African women and other migrants in particular reported difficulties in accessing health care and needed more support to negotiate the system.

The single most common future need expressed was for good quality treatment and health information, indicating high levels of clinical uncertainty and threats to health. Many co-morbidities reported could be improved or reduced by lifestyle interventions like good nutrition, exercise and smoking cessation. People want to know more about these issues and how to take better care of themselves.

People reported varying levels of sexual activity. Almost two-thirds were sexually active in the previous year. A quarter had one partner, but one in six (all of them gay/bisexual men) reported more than ten partners in the previous year. HIV testing and sexual health promotion services need to take this into account when planning initiatives and explicitly consider the needs of sexually active older adults. A number of people commented that they felt left out by a lot of current sexual health promotion.

Mental health: This group also reported substantial levels of depression and mental health concerns and a higher level of concern for future mental health. There is a need to identify or develop counselling, emotional support and other strategies to improve emotional wellbeing in older people with HIV.

“...feeling overwhelmed by my circumstances and the state of mind I was in that I made myself vulnerable to getting HIV...I’ve had to question why I allowed that to happen. It’s to do with guilt.”

White, heterosexual woman, 51”

Social care: Three-quarters of the respondents were concerned about access to social care (such as home helps) in the future. Given that half of them already reported mobility problems and almost half had difficulties with everyday activities, this is unsurprising. Many people expressed fears about needing to use home or residential care because of perceived prejudice and ignorance about HIV within these services – a fear borne out by some of the experiences already related to interviewees in the qualitative part of this survey.

THT advocacy workers have already come across cases of poor treatment by providers of social care services to older people. Better staff training and clear management standards for clients with HIV are needed – funders should ensure these are included amongst quality measures. Given the imminent removal of the ring fence on the AIDS Support Grant in England, and cutbacks in all the countries of the UK, it is unlikely that there will be many specialist HIV care services in the future. We are going to need to make general services acceptable and accessible to people with HIV.

“...fear that in case I need to be cared for, the carer would be as ill-informed and prejudiced about HIV as the rest of the general public.

Bisexual man, 51”

Money and work: People with HIV aged 50 or over were, in comparison with their peers, less likely to be economically active and far less likely to have a financial cushion for their old age. Almost half sometimes or never had enough money to manage on, and they expressed serious fears about how they would manage financially in the future. Black African women were the worst off financially.

While around a third of respondents were working, almost as many were reliant on state benefits. Half of those surveyed were not confident that they understood their entitlement to benefits and many were worried about possibly losing benefits in the future. Returning to the workplace, while it may be good for financial security, for mental health and for long-term wellbeing, is not an easy thing for many people who have

long relied on disability benefits, and is simply not possible for some.

People with HIV aged 50 or over need support to stay in or re-enter the workplace – where possible; where not, they need good, clear advice on benefit entitlements. They also need access to debt counselling and financial planning as an integral part of long-term condition management.

“I would like to go back to work but I can’t afford...because of the rent and...there’s many out there like me. If we had the opportunity...there are many people out there that are willing to move on with their lives.

Black African man, 55”

Housing: Home ownership was lower in this group than amongst their peers, and they were more likely to be in council or housing association stock or in private rented accommodation. Widespread concern about needing to go into a care home or sheltered housing in the future – perceived to be unlikely to be supportive to people with HIV – again featured. Additionally, gay and bisexual men feared homophobia within these settings. HIV organisations need to work with providers of social housing and care homes for older people to help them audit their policy and practice around HIV and gay issues.

“I am somewhat fearful of a lonely old age. In practical terms, if I become mentally or physically frail, the prospect of being the only gay man in an old people’s home is very frightening indeed.

Gay man, 52”

Social wellbeing and seeking support: Many people reported social isolation and a need for greater social contact, including a need for general social support, which is currently more likely to be met in services for older people than those for HIV. However, there was a clear overall preference for using HIV organisations to get services.

Although many people reported good service from particular agencies in both sectors, no UK service was widely identified as being suitable for older people with HIV. Rightly or wrongly,

the perception from many was that mainstream organisations for older people may not understand HIV and both HIV services and those for older people need to work together to change this.

Many older people were using volunteering as a route to social contact with other people with HIV – volunteering opportunities for older people with HIV need to be maximised. Not only would this increase social involvement, it could also contribute to making services more representative of and appropriate to older adults with HIV.

Working as a health care worker ...I have seen and heard the nurses stigmatise patients. I've heard them say make sure you always wear gloves and use plastic spoons, plates ... I think one day I am going to be ill and I am going to be treated the same way.

Black African woman, 51

Disclosure and discrimination: The greatest surprise within the findings was the overwhelmingly positive or neutral outcomes reported by people disclosing their HIV status. This differs considerably from some narratives within the HIV sector, which can posit disclosure as a negative and dangerous action. In talking with colleagues about this finding, we have faced responses from “of course that’s true” to “but that can’t be right”. It seems that the whole issue of disclosure and its genuine impact is ripe for exploration and discussion.

This finding did vary between groups and settings, however, and those negative outcomes could have important consequences. No African woman, for example, reported an improved relationship from telling their partner, though many reported good outcomes from other family and friends. There is a need for services to constructively support older people with HIV in making informed decisions about disclosure. Further research into the impact of disclosure should also be undertaken with a balanced all-ages sample of people with HIV.

My Mum just carried on drinking her tea. I never had any fear of telling anyone I got it.

Gay man, 50

Hiding my rape from people, I thought that was harsh, but HIV is worse. HIV is like you are a slut, or you sleep with gays. People back home... won't come to your house, your children will be mocked.

Black African woman, 51

One in five people did report experiencing discrimination in a variety of ways in the past year, either because of age or HIV status. Overall, people were as likely to report age discrimination as HIV discrimination, but in two areas – health care and provision of goods and services – HIV discrimination was by far the higher. Given the theme running throughout the research of problematic relationships with primary and non-specialist health care, it is clear that the NHS and other statutory bodies need to show greater leadership in challenging HIV stigma. A good example of this is the recent Welsh Assembly inquiry into HIV discrimination by healthcare professionals.

A number of other examples of good practice were identified, including four projects from the US, which could easily be adapted to the situation in the UK. They included an employment project, a project providing targeted advocacy for LGBT older people, a speakers’ bureau for older people willing to talk about HIV and sexual health to their peers and a care home for LGBT people, which specifically welcomes people with HIV.

The US has benefited from HIV and ageing experts, working within both medicine and policy, collaborating to improve services for older people with HIV and challenge age and HIV discrimination in their respective areas.

Finally, in terms of the specific populations examined within the report, it was clear that, while much about HIV and ageing bound them together, each group showed strong and specific characteristics. Gay men had immense fears for the future around how care services would cope with any gay man, let alone gay men with HIV, yet they

also felt marginalised within a youth-obsessed gay culture.

Black African women had by far the hardest time overall, coping with poverty, poor housing, treatment access and migration issues, as well as major HIV stigma within their cultures.

White heterosexual people reported considerable isolation, financial concerns and a sense that existing services did not prioritise their needs.

This research is far from the last word on HIV, ageing and social issues in the UK, but should be seen as the start of a dialogue between older people with HIV, organisations that provide services and policymakers and funders. Older people with HIV face an uncertain future in many ways; the knowledge generated by this report enables us to change for the better how our society supports them in that challenge. ■

You know this is a new life for me, I am living again. This is my chance of living. I don't think if I was at home I would get my 50th birthday – that's for sure.

Black African woman, 51

For more information

A summary of findings will be available at the 2010 International AIDS Conference and subsequently from both THT and Age UK. The full report will be published online by the Joseph Rowntree Foundation (www.jrf.org.uk). Further data, including all statistical charts and the full literature review, are available from www.tht.org.uk/50Plus.

All queries and requests for further information should be addressed to lisa.power@tht.org.uk or Lisa Power, Policy & Information Director, Terrence Higgins Trust, 314-320 Grays Inn Road, London WC1X 8DP.

news in brief



Gay men

Stress increases HIV risk for gay men

Stressful life events appear to increase the risk of HIV infection for gay men, Canadian researchers have found.¹ However, the risk appears to be due to stressed men taking more risks with sex rather than because stress in itself increases susceptibility to HIV.

“We observed that gay and bisexual men... who reported stressful life events were at increased risk of HIV infection, and there was evidence that this effect was at least partially mediated by sexual risk behaviour,” comment the investigators.

In the study, 123 gay and bisexual men testing HIV-positive were matched with 240 gay and bisexual men who tested negative.

All subjects completed a questionnaire asking about their recent experience of 35 stressful life events. The men diagnosed with HIV reported a median of three recent stressful life events compared with two in those who were HIV-negative. One in three HIV-positive men reported more than five recent stressful events compared with one in five HIV-negative men.

Stresses relating to relationship problems, bereavement, money, employment and crime were all significantly more common in men who tested positive, as was health-related stress.

Experiencing a greater number of stressful events was associated with an increased likelihood of reporting unsafe sex, defined as unprotected receptive anal intercourse with an HIV-positive partner, or a partner of unknown HIV status. Men who'd experienced at least five stressful events were 2.5 times more likely to test HIV-positive, but this was almost entirely

explained by the fact that they were more likely to have had unsafe sex too.

Prevention campaigns for gay men should promote safe strategies for coping with stress, the researchers suggest.

Side-effects

Lipoatrophy may be for life

The fat lost from the face and limbs due to the side-effects of some anti-HIV drugs may not be restored when the drugs are discontinued, an American study has found.¹

The Fat Redistribution and Metabolic Change in HIV Infection (FRAM) study found that a group of HIV-positive patients were no less likely to have low levels of body fat five years after the start of the study than they were at the start.

The FRAM study compared body fat in 477 HIV-positive patients and 211 HIV-negative controls at the start of the study and then again five years later. At the start of the study 77% of patients with HIV were on treatment; during the five years 14% more started therapy, but another 10% stopped.

Soon after it was introduced, combination therapy for HIV became associated with changes in body-fat distribution, called lipodystrophy. Particularly distressing for patients was the loss of fat (lipoatrophy) from just under the skin, which led to a wasted appearance in the face, limbs and buttocks.

At the start of the FRAM study, patients with HIV already had significantly lower levels of subcutaneous fat than their HIV-negative peers, but the investigators wanted to see if these differences persisted, and so repeated their analysis after five years of follow-up.

At baseline, 48% of HIV-positive patients had fat loss, and this had

increased to 53% after five years. Of the HIV-positive patients diagnosed with lipoatrophy at baseline, 82% still had fat loss five years later.

Discontinuing treatment with d4T, the drug most associated with fat loss, only resulted in an average annual increase of fat in the leg of 1%.

People generally gain subcutaneous fat with age. The male HIV-positive patients gained about the same amount of leg fat over the five years as the HIV-negative ones (a 14% increase), but because they started with less they were still leaner. The difference was particularly marked in HIV-positive women, who gained no limb fat at all.

The investigators conclude that “there is no relative recovery from lipoatrophy when HIV-infected participants are compared to controls.”

Anal cancer

High rate of cancer cells in anal warts

Anal cancer is 80 times as common in people with HIV, with an annual incidence of one case per 784 HIV-positive people compared to one per 62,500 in the general population.¹

However a US study has found much higher levels of ‘hidden’ anal cancer in gay men with anal warts, with one in 33 gay men and one in 20 of the HIV-positive ones having anal warts that harboured cancer cells.²

The investigators believe that their findings could have implications for the management of anal warts.

The many strains of human papillomavirus (HPV) can be grouped into two types: ones that cause the visible cauliflower-like warts and some strains, especially 16 and 18, that do not cause

For breaking news from the International AIDS Conference in Vienna visit aidsmap.com

obvious warts but are associated with anal, cervical and other cancers.

The investigators looked for evidence of hidden anal cancer or pre-cancerous cell changes in anal warts that had been removed from 320 gay men, 50% of whom were HIV-positive.

Examination of the tissue showed that 34% of men had high-grade pre-cancerous cell changes; the presence of anal cancer cells was detected in 3% of men.

Of the eight men with anal cancer, seven were HIV-positive, and HIV-positive men were nearly twice as likely to have high-grade pre-cancerous cell changes.

Neither CD4 cell count nor viral load was associated with an increased risk of pre-cancerous cell changes, but CD4 cell counts were lower among the patients with anal cancer (218 versus 441 cells/mm³).

The researchers describe finding cancerous changes in warts usually seen to be caused by viruses with low cancer risk as "unsettling" and say that their findings imply that all anal warts in gay men should undergo analysis to detect any cancer.

Efavirenz

Efavirenz not associated with birth defects

The widely used drug efavirenz (*Sustiva*), also a component of the one-pill-a-day treatment *Atripla*, has not been recommended for use in pregnant women, because while it was being developed it was associated with birth defects in rats. Specifically, these were neural tube defects, causing spine and brain defects.

However, a new meta-analysis of studies¹ has found that treatment with efavirenz during the first three months of pregnancy (when defects are most likely to arise) does not increase the risk. The prevalence of neural tube defects in infants exposed to efavirenz during the first three months of gestation was 0.08% – well within the range seen in the wider population.

There have been conflicting data about the use of efavirenz and the risk of birth abnormalities during pregnancy, and as a result treatment guidelines have adopted a cautious approach towards the use of the drug by pregnant women.

The researchers found 16 studies of efavirenz use in pregnancy, covering 1132 live births: the rate of any birth abnormality in these was 3%, whereas it was 4% amongst the 7163 births in women who took a combination of antiretroviral drugs not including efavirenz in the first three months. Statistical analysis confirmed that efavirenz did not increase the risk of birth abnormalities.

Overall, the incidence of birth abnormalities amongst women who received efavirenz (2.9%) is very close to ranges reported in the general population, such as 2.7% in the United States.

Only one efavirenz-exposed infant was born with neural tube defects. That baby represents an incidence of one case in 1250 births, compared to one case in 714 births reported among the general population in the United Kingdom.

"These data should provide reassurance to healthcare providers confronted with women who become pregnant while on efavirenz," conclude the investigators.

However, they comment that they cannot yet give efavirenz a completely clean bill of health because the quality of studies was low.

Transmission

Pregnancy poses HIV risk for men

The male partners of HIV-positive women are more than twice as likely to become infected with HIV themselves if their partner becomes pregnant, a study in Africa has found.

HIV-negative women were also twice as likely to become infected if pregnant, but this was accounted for by the fact that pregnant women were on average younger (and therefore more biologically vulnerable to HIV), more likely to be having unprotected sex, and less likely to be using oral contraceptives.

In men, though, the significance of the result actually became slightly stronger after adjusting for age, unprotected sex, circumcision status and the partner's viral load and CD4 count. This implies that pregnancy in HIV-positive women is an independent risk factor for increased transmission.

The study involved 3321 heterosexual couples where one partner had HIV and the other did not. In two-thirds of the couples the woman was the HIV-positive partner. During the trial there were 823 pregnancies: 27% of HIV infections in women and 21% of infections in men occurred when the woman was pregnant.

Women were 2.1 times more likely to acquire HIV when they were pregnant but only 1.5 times when this was adjusted for unprotected sex – no longer statistically significant. Men were 2.2 times more likely to acquire HIV when their partner was pregnant and 2.3 times more likely after adjustment for other risks, and this remained significant.

More research will be needed to find out why when women become pregnant they apparently become more infectious.

are lubricants safe?

The 'lubes' used most often in sex may actually make HIV transmission more likely. *Gus Cairns* explores some unnerving new findings from the 2010 International Microbicides Conference.

Do lubricants protect?

It's a mantra of 'safer sex': always use a condom and water-based lube. The lube makes sex more comfortable and it needs to be water-based because oily lubricants damage condoms.

But this may have also conveyed an idea that lubricants might contribute a bit to sexual safety in themselves, minimising trauma and bleeding, and offering a degree of protection in sex *without* a condom.

There's never been any data to prove this, and the evidence from one placebo-controlled microbicide study suggests that using lube is no better than 'dry' sex. The HPTN035 study was the smaller of two efficacy trials of the microbicide PRO2000 but – uniquely for a microbicide trial – it included two control arms: 1000 women got PRO2000, 1000 got the placebo gel, and another 1000 got no gel at all.¹

This trial reported a nearly statistically significant 30% efficacy for PRO2000, which got prevention advocates very excited until their hopes were dashed by the subsequent, larger, MDP301 trial. However, what was just as interesting was that the researchers found absolutely no difference in the rate of infection by HIV or sexually transmitted infections (STIs) between women who used the placebo gel (hydroxyethylcellulose, or HEC) when they had sex, and ones who didn't use gel.

So no protection there, but no harm.

Are lubricants dangerous?

Two other presentations at the recent Microbicides Conference, however, produced much more unsettling news: while HEC might not have any influence on HIV infection, commonly used lubricants might do, and negatively so –

actually facilitating STI – and possibly HIV – infection.

Pamina Gorbach from the University of California, Los Angeles, studied 302 US men and women who had had receptive anal intercourse (RAI). Her study is part of the U19 programme, which aims to develop a rectal microbicide.²

There are more straight women than gay men who have anal sex, simply because there are more of them, but gay men tend to have it more often. So Gorbach weighted her sample by recruiting women who'd had RAI in the last year but men who'd had it in the last month.

The group was 58% male, half African-American and the average socioeconomic status was poor: 21% of the group classed themselves as homeless and 35% as disabled.

Three-quarters of the group had used a lubricant the last time they had RAI. Lubricant use was less common in African-Americans (38.5%) and Hispanic people (58%). More HIV-positive people used a lubricant than HIV-negative people. Two-thirds had used a water-based one such as *KY Jelly*, between a quarter and a third had used a silicone-based lubricant and one in six an oil-based lubricant.

More than two-thirds (68%) of people diagnosed with rectal gonorrhoea and/or chlamydia had used a lube compared with a third of people who had not, and over one in nine (11.7%) of lubricant users were positive for these rectal STIs compared with one in 22 (4.5%) who did not use lubricant.

So people who'd used a sexual lubricant for RAI were more than three times more likely to test positive for a rectal

STI than non-lube users. These findings were statistically significant.

Was it because lube-users had more sex? No. Less likely to use condoms? No. Did they have more partners or more who were HIV-positive? No and no. Using a lubricant was an independent predictor of having an STI. It increased the risk in its own right.

HIV infections weren't measured so there's no direct evidence on whether lube might make you more vulnerable to HIV. But rectal gonorrhoea is used as the most accurate 'surrogate marker' for who's vulnerable to HIV in a community. An increased risk of gonorrhoea may imply an increased risk of HIV.

Which lubes are safe?

So what's going on? Gorbach's own study was too small to divide up the relative risk of different types of lube, but the suggestive findings of a test-tube study by the University of Pittsburgh suggested a mechanism.

Presenter Charlene Dezzutti and her colleagues tested for toxicity six lubricants that can be bought over the counter in the USA.³ These were five water-based lubricants (*Astroglide*, *Elbow Grease*, *ID Glide*, *KY Jelly* and *PRÉ* vaginal lubricant) and one silicone-based one (*Wet Platinum*). They tested the lubes on explants: sections of rectal lining kept alive in nutrient baths.

Four of the water-based lubricants completely stripped off the epithelium (outer layer) of cells from rectal tissue. In contrast, *PRÉ* and *Wet Platinum* caused relatively little damage. *Astroglide* caused almost as much damage as nonoxynol-9, the spermicide that has already been shown to double the risk of HIV infection.

The difference between *PRÉ* and the other four water-based lubes was that the other four were hyperosmolar or hypertonic. What this means is that they contained more dissolved salts and sugars than the fluid inside the body's own cells. When this is introduced into the rectum (or similar body cavity), it causes water to diffuse out of the cells lining the rectum into the rectum itself. The cells become leaky and can disintegrate altogether. *PRÉ*, on the other hand, was isotonic: its composition mimicked the body's own fluids, as does HEC.

The problem is that *PRÉ* has been marketed as a specialist sperm-safe vaginal lubricant for women trying to conceive, whereas the other four water-based lubes are primarily marketed to gay men as those condom-friendly lubes you should use in safer sex.

The one silicone lube tested is also aimed at gay men, and seems safe – but silicone lubes are expensive.

What should we tell the community?

“What’s our take home message here?” Gorbach was asked. The long-term message is clear: there is an urgent need to conduct further research into sexual lubricants, and probably introduce more stringent safety checks for them before licensing them for over-the-counter sale.

But what short-term message to give is much more problematic.

Gorbach said that people should choose their lubricating substance carefully; but her study itself did not rate different lubes for safety and Dezzutti's one was a lab study that only evaluated a handful, not all for sale in the UK (“And,” she commented to *aidsmap*, “*Wet Platinum* and *PRÉ* are very runny, not appealing to most people”).

How are people to know which lubes are safe? Where does it leave all those condom-distribution schemes that hand

out sachets of water-based, hypertonic lube? Should we avoid lubes altogether?

A study by the International Rectal Microbicides Advocacy (IRMA) in 2008 suggests not.⁴ Jim Pickett, its Chair, emphasises that condoms make the biggest difference: condoms-plus-lube are safer than no-condom-no-lube.

“But for the people who don't use condoms consistently, or ever during anal sex,” he adds, “I would still recommend using lube, lots of it. The damage done during dry anal sex likely trumps any damage [from] lube.”

Pamina Gorbach, however, warns: “There is no actual data showing that it is damage to the rectum during dry sex that facilitates HIV transmission. The high rates of HIV transmission during anal sex in general suggest that there is another mechanism.

“So yes, encourage lube use because it facilitates and encourages condom use. But just don't say it is actually harm reduction – we don't have any data to support that. I wish we did!”

Common sense would suggest that people aren't going to stop using lubricants.

“Until we know more, I certainly don't think we should discuss stopping the use of lube with anal sex, and people wouldn't enjoy it, anyway,” says Marc-André LeBlanc, Secretary of IRMA. “I don't think we can come to *any* grand conclusions about which lubes are safer without more research; for now, I think avoidance of trauma is still your best bet.”

Forking out more for silicone or isotonic lubes is probably not a bad idea and is unlikely to increase your risk compared with the more familiar water-based ones. If you can't afford those, there is always that freely available isotonic fluid, spit. Maybe we should market little sachets of it. ■

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