



UK Coalition of People Living with HIV & AIDS

**POSITIVE PREVENTION
BY
POSITIVE MEN**

**Developing positive-led HIV prevention
programmes for gay men with HIV**

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POSITIVE PREVENTION BY POSITIVE MEN

The rationale behind a positive-led HIV prevention programme for gay men

Written by Gus Cairns, www.guscairns.com

The idea that HIV positive people should be the principal target for HIV prevention programmes is not a new one. After all, Positive People form 50% of the people present at any HIV transmission event and yet are a minority of the population. So programmes directed at them will have a disproportionate effect.

One 1999 paper (King-Spooner) comments:

“Preventive interventions with positive individuals are likely to have a greater impact on the epidemic, for an equivalent input of cost, time, resources, than preventative interventions focused on negative individuals. A change in the risky behaviour of an HIV positive person will, on average, and in almost all affected populations, have a much bigger impact on the spread of the virus than an equivalent change in the behaviour of an HIV negative person.”

Yet throughout the history of the epidemic far fewer prevention resources have been directed at people living with HIV than at the uninfected. In a recent paper, the International HIV/AIDS Alliance suggested why:

“Most prevention strategies to date have been targeted at uninfected people to prevent them from becoming infected with HIV. Historically, there has been a reluctance to work on HIV/STI prevention with people with HIV because of perceptions that the concept of prevention for people already infected is inherently contradictory.

“There have also been justifiable concerns about victimising an already stigmatised group. In addition, there has been a reluctance to acknowledge that people with HIV have sex, and also to get to grips with the complex ethical issues surrounding people with HIV’s responsibilities towards others.”

‘Positive Prevention’ is therefore potentially an extremely effective tool against HIV, but not always one that has a positive effect on *people* with HIV. An

example is current US testing policy.

Responding to political disapproval of community HIV prevention programmes, on 15 April 2003 the US Centers for Disease Control initiated what they called the Serostatus Approach to Fighting the Epidemic (SAFE). This involved a refocusing and reallocation of HIV prevention resources on to people with HIV. Henceforward, the CDC announced, it would focus on a drive to maximise the number of people tested for HIV – some papers, indeed recommended universal testing for all adults. Once people had tested HIV positive they would be managed by “ongoing case management, medical interventions, and support for other psychosocial stressors.”

There is some justification for laying a very strong emphasis on testing as a key element in HIV prevention. According to the CDC’s own statistics, there are over 900,000 people with HIV in the USA. About 700,000 know their status. The annual incidence (new infection) rate is about five per cent a year. But if you just count those infected by people who know their status, it is less than two per cent (1.73%). Conversely, HIV incidence in partners of HIV+ people who do *not* know their status is nearly 11 per cent a year (10.79%) (Holtgrave and Anderson).

But HIV prevention for positive people cannot consist solely of testing. Exactly a year after the CDC’s policy was adopted Terje Anderson, Director of the National Association of People with AIDS (NAPWA), criticised its approach (Anderson). He said the narrow emphasis on testing and individualised counselling was inherently stigmatising:

“The lack of any mention of anything that isn’t an individual level intervention delivered behind closed doors in a doctor’s or social worker’s office – the lack of any mention of anything that happens in the community – lays individual responsibility for transmission on each person with HIV, lays no responsibility on their negative partners, makes possible no conversation about the social context that puts people at risk, and treats people with HIV as vectors of infection and not as full people.”

In other words, CDC’s strategy was to test HIV positive people, tell them not to pass their infection on, and blame them if they did.

The figures above detailing reduction in incidence after testing tell us nothing

about whether people with HIV actually modify their behaviour to reduce the chance of infecting others post-testing. And they tell us even less about how to support them in making any behaviour change, if they do.

In fact, as we shall see below, HIV incidence among the partners of tested HIV positive people is about half of what would be expected if the reduction in incidence was purely due to treatment.

- So how did those tested people managed to reduce the number of people they infected post-testing?
- What behaviour changes did they make to achieve this?
- And what could be done better to support them in those behaviour changes?

Summary

This paper will argue that:

1. HIV positive people are in a significant position to make a difference to HIV incidence
2. There is evidence that strategies used by HIV positive gay men are already making a difference to incidence
3. First, knowledge, and secondly, disclosure of HIV status are crucially necessary for these strategies to work
4. Anticipated stigma and rejection inhibit HIV positive men from making the best use of these strategies
5. 'Safe spaces' like the Internet, are being used by gay men with HIV as places in which to identify each other, to disclose and to negotiate HIV-reduction strategies.
6. Paradoxically, some of these strategies may make gay men with HIV more vulnerable to other sexually transmitted infections, but sexual health education for gay men with HIV is a neglected area

7. Unbiased education for HIV positive gay men about HIV transmission risk in different situations should form a core part of positive-led prevention
8. Training and peer support to help HIV positive men to disclose to sexual partners should also form a core part of positive-led prevention
9. Different people with HIV will need different levels of information and types of help with behaviour-change, which may at times seem contradictory
10. The long-term diagnosed with HIV are an untapped resource. Their experience of living with HIV and their accumulated knowledge could make them ideal peer supporters and mentors of the newly-diagnosed, and help them achieve strategies for safer sex.
11. An HIV prevention programme led by visibly HIV-positive people themselves, reinforcing strategies that gay men with HIV *already use*, stands the best chance of helping people with HIV adopt and maintain HIV risk-reduction behaviour, in line with the social diffusion model of behaviour change.

1. HIV positive people are in a significant position to make a difference to HIV incidence

People with HIV form 50% of the people present in any non-medical HIV transmission event, and prior to disclosure 100% of those with the knowledge of their status – as long as they *do* know it. They also have the knowledge of what it is like to live with the condition.

Recent UK convictions imply that, in the eyes of the law at least, they carry 100% of the criminal liability for transmission too.

People with HIV do not just have knowledge and responsibility; they also potentially have the power, through measures like disclosure, condom negotiation, knowledge of transmission risk factors, and choice of partner, to ensure, to quote the catchline of a US-based prevention campaign, that “HIV Stops With Me” (see www.hivstopswithme.org).

HIV negative people – who must rely on trust to ascertain a partner’s serostatus, and testing to ascertain their own – are not in the same position of power. They can establish concordance with a regular partner if they both go and get tested together. But it is much harder for them to establish concordance with a casual or new partner because that relies on them asking questions of the other partner person then deciding whether or not to trust their answers. The positive person only has to do one thing – disclose.

Testing people with HIV will obviously bring down infection rates in itself because many will be start taking antiretrovirals. A study of gay men in San Francisco (Porco) calculated that the average HIV infectivity of the population declined by 60% after the introduction of HAART.

However other studies have found that this did not result in immediate declines in incidence, but rather increases (Katz); HIV incidence doubled from 2.1% a year to 4.2% a year in San Francisco between 1995 and 1999. Mathematical modelling (Law) has calculated that it would only take a 30% increase in serodiscordant unprotected sex to counterbalance a 50% decline in infectiousness.

This underlines the importance of testing, because it suggests that if incidence in the partners of tested HIV positive people is indeed less than a sixth of that in the partners of untested people, then a large proportion of HIV must be

transmitted by untested people or those infected since their last test.

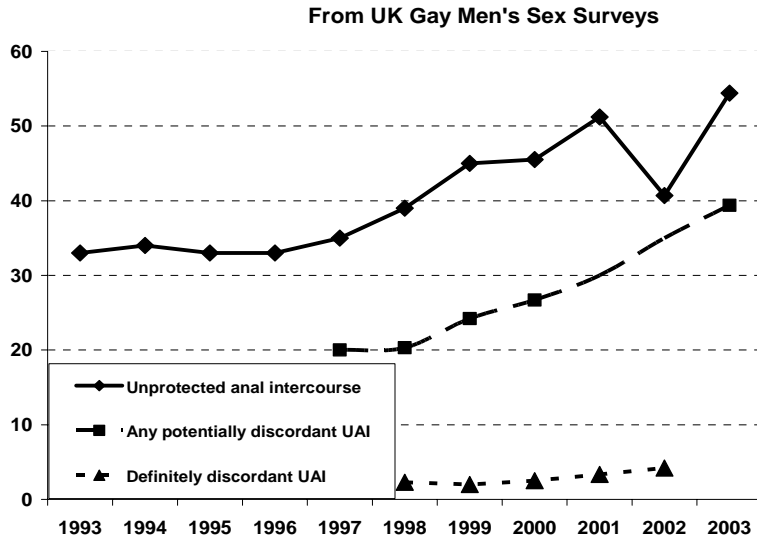
This has led, in the USA at least, to calls for universal HIV testing –with two surveys (Sanders, Paltiel) showing this would be cost-effective – and more recently with a change of heart in prevention activists leading to the decision to allow the sale of over-the-counter HIV tests (Cairns). It is more doubtful if universal testing in the UK would be cost-effective, as we still only have a third of the USA's HIV prevalence. And prevention experts and public bodies alike do not seem to be ready for self testing. Maybe they should be.

This paper, however, concentrates solely on behaviour change and how to facilitate it rather than testing policy. The decrease in incidence from tested partners cannot be due entirely to reduced infectiousness due to their taking HAART . No more than 74% of the tested US HIV positive population is taking HAART (McNaghten) of which no more than 80% are virally suppressed at any one time. Therefore, at best, one would expect incidence in the partners of tested HIV positive to be about 40% of those with untested partners. Instead it is about 16% of that figure. In other words The reduction in HIV infectivity only accounts for about half of the reduction in incidence.

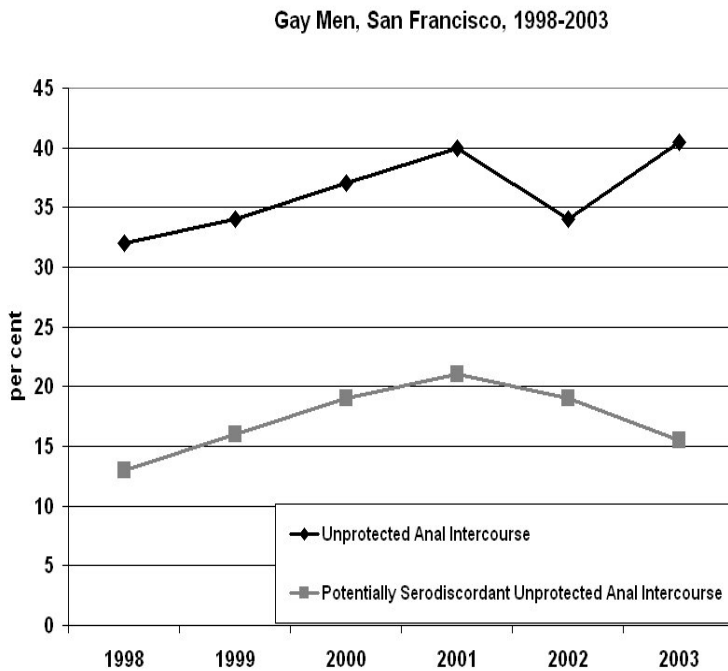
What accounts for the other half?

Surveys report conflicting findings on whether HIV positive people as a group generally end up having more unsafe sex than HIV negative men – or, to put it in more charged terms, whether they are irresponsible drivers of the epidemic, or doing as much as they can to stop it.

On the one hand – in the most recent fully-published UK Gay Men's Sex survey, (2003), 39.4 per cent of gay men with HIV said they had 'probably or definitely' been involved at least once in an incident of the highest-risk sexual behaviour – being the active partner in unprotected sex with someone HIV negative. In contrast, 6.5 per cent of HIV negative gay men said they had 'probably or definitely' been the unprotected passive partner of someone HIV positive.



On the other hand, a recent US meta-analysis of 11 studies (Marks) found that the prevalence of high-risk sexual behaviour (unprotected sex that is 'potentially serodiscordant', that is with someone of negative or unknown HIV status) was between 53-68 per cent lower in HIV-positive individuals aware of their status than in HIV-positive individuals unaware of their status.



And this graph (above - from the San Francisco Department of Public Health) shows that while unprotected anal sex among gay men in the USA has either

stabilised or continued to increase, the amount that is potentially serodiscordant – that is, which could transmit HIV – has declined. This can only be due to gay men using one of the harm-reduction methods detailed below.

There are two necessary conditions for any attempt to reduce HIV risk through reducing the amount of unprotected sex that may pass on HIV. Men first have to know their HIV status. Then they have to do something to ensure that HIV is not passed on.

How can they do this? Well, they can use condoms – and according to the most recent gay men’s sex survey, 55% of HIV positive men still do so consistently. They can try to reduce risk by other methods such as only having sex if they know they have an undetectable viral load (but see below).

Or if they have unprotected sex, they can choose only to do it with other people with HIV.

This phenomenon, called **serosorting**, can only happen if one other condition is fulfilled. HIV disclosure has to happen.

Because of this, a recent upsurge in studies documenting serosorting behaviour, some of which are detailed below, has led to the asking of a question: should more HIV prevention money be directed towards enabling HIV positive people to disclose their status and/or take other measures to avoid passing on HIV to negative partners?

Media coverage of what *appears* on the surface to be HIV positive men taking increased risks with others has led to anguished questioning among HIV prevention experts, a lot of hostile media coverage and intensified stigma against people with the virus, and has probably contributed to the climate that has enabled successful criminal prosecutions.

Firstly, to re-emphasise: at least half of gay men with HIV continue to maintain condom use and safer sex.

Secondly, however, there is another way of interpreting the behaviour of the ones that don’t.

For a start, take the Sigma Research finding above that HIV positive men appear to be choosing to take transmission risks six times more often than HIV negative men.

There's another way of looking at those figures. Because in the UK there are at least ten times as many HIV negative as HIV positive men, in the absence of 'serosorting' (see below) HIV positive men are nine times more likely than HIV negative men to encounter someone of the opposite HIV status as a sex partner.

The fact that they 'only' have serodiscordant unprotected sex six times as often as HIV negative men actually means that they are somewhat *better* (though they could be a lot better still) at making sure the sex they have is either seroconcordant, or protected, or both, than HIV negative men. They just have the misfortune to have to try nine times as hard in order to ensure they are not one-half of an HIV transmission event

One US survey (Glass) suggests that HIV positive gay men, when they do have unprotected sex, have it twice as often with other HIV positive men than they do with negative partners. A survey of 3723 HIV positive people in four US cities from 2001 to 2003 found that half of the gay men (and a similar proportion of heterosexuals) had had sex (protected or not) over the previous three months with someone who was HIV negative or of unknown status.

Forty-five per cent of gay men had had sex without using condoms - unprotected sex.

But only 15.6 per cent had had that unprotected sex with a potentially serodiscordant partner - meaning that twice as many - about 30 per cent - had exclusively restricted their unprotected sex to other HIV positive people even though they were less likely to encounter them purely by chance.

In fact, as we will also see below, HIV positive people (especially gay men) appear to be evolving a variety of strategies other than the maintenance of 100 per cent condom use which aim to inform and protect their partners, at least from the risk of HIV. This has led to paradoxical results where an apparent rise in unprotected sex has not led to an increase in serodiscordant sex - because the negotiation of unprotected sex is associated with the mutual disclosure of HIV status, and therefore a *reduction* of the risk of passing on HIV.

HIV positive people, it is becoming clear, are evolving a set of 'attempted-safety' strategies based on disclosure that have very little to do with conventional 'safer sex' messages.

Should we help them to do so?

HIV positive people attempt to use the knowledge they have of their HIV status and the power this gives them to change sex strategies, as studies show. In one US study (Lightfoot) of young US gay men (most of them black or Latino) aged 15–24, about 34 per cent of youth with multiple partners and 28 per cent with one primary partner had unprotected anal intercourse.

However they were overwhelmingly more likely – 32 times more likely, to be exact – to have unprotected sex with other partners perceived to be HIV positive than with partners whose HIV status was perceived as negative or was unknown. A lot of the debate around HIV positive gay men has been framed in terms of their being a risk to others, and emphasising the fact that as a group they generally have more unprotected sex. The authors of this study saw it in a quite different way – as a group of people ripe for prevention interventions that could make a considerable difference to HIV transmission.

They said: “Interventions that target young men living with HIV must address the complex issues in making decisions regarding condom use. Interventions would need to focus on techniques for acquiring information from sexual partners to make a more informed decision.

“Interventions should also reinforce the altruism that young men living with HIV feel towards protecting their partners.”

Another study (Spire) presented at the 3rd IAS Conference in Rio de Janeiro this July,² found that concealment of HIV status from *regular* partners was very rare. Only three per cent of people within a long-term relationship had kept their HIV status a secret, and only one per cent was both concealing their status and having unsafe sex.

Nearly half (45%) of the subject had no steady partner and 14% were in a steady relationship with another HIV positive person.

Of the remaining 41% who were in a serodiscordant relationship, three-quarters had told their partner about their HIV and always used condoms, and just under a quarter had told their partner but despite having an actually or possibly different HIV status, the couple had decided not to use condoms.

This left three per cent of all the patients in the study who had not informed their steady partner of their HIV status. But two per cent maintained condom use, meaning only one in a hundred patients was putting their partner at risk unbeknownst to them.

These two studies sketch out ideal scenarios. In the French study, we see people in serodiscordant stable relationships who have come to love and trust each other. The vast majority of them have managed the difficult tasks of disclosure and sexual safety negotiation with each other. (A quarter of those negotiations have ended in an agreement not to use condoms – but, as we will see below, serodiscordant couples may take other harm–reduction measures.) The degree of risk achieved probably represents a near–best–case scenario when it comes to the degree of honesty and safety HIV positive people can achieve with their partners.

In the US study, the ideal scenario is what *would* be the case were the young men’s perception of their partner’s HIV status to be entirely accurate.

In many cases, the perception probably *was* accurate. The estimated number of instances of unprotected sex was 32 times greater among youth in a *committed* relationship if their regular partner was thought to be positive than if he was thought to be negative but at high risk of having other STIs (that is, in an open relationship), and 18 times more if he was thought unlikely to have STIs (that is, if thought monogamous). In many of these cases, the HIV status of the partners must have been known, rather than just a perception. The even lower degree of unprotected sex with non–monogamous HIV negative partners can be seen as a self–protection measure against other STDs.

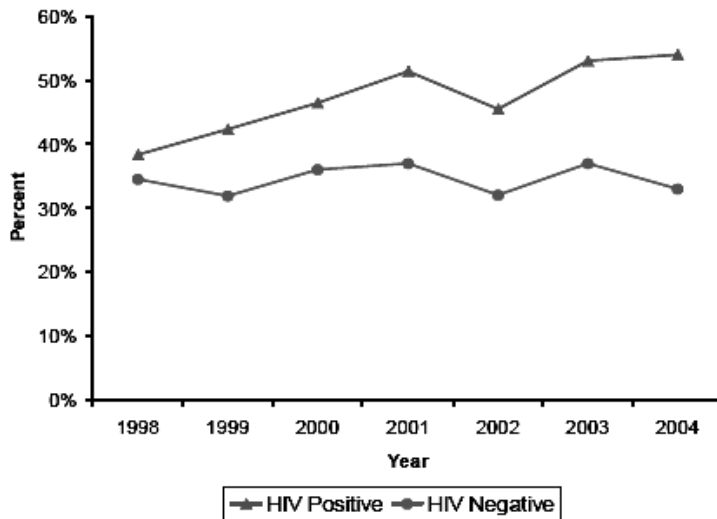
But is “probably” good enough for a risk reduction strategy?

Before we look at what prevents these ideal scenarios from happening, we need to ask: is there any evidence that strategies used by HIV positive gay men (and others with HIV) are already making a difference to HIV incidence, and should therefore be encouraged?

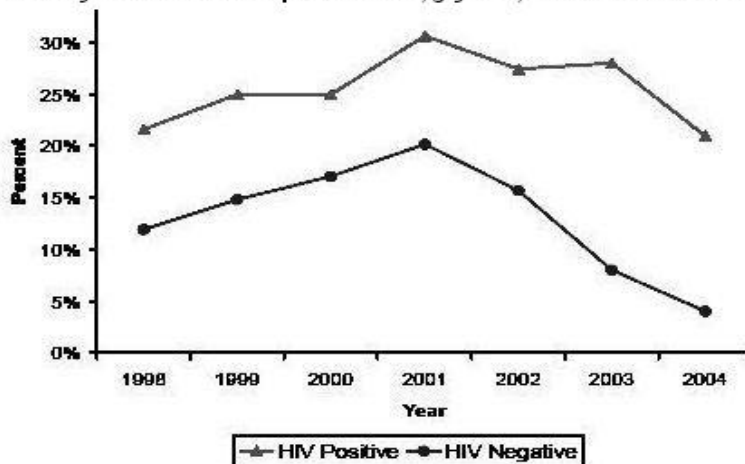
2. There is evidence that strategies used by HIV positive gay men are already making a difference to incidence

Compare the two charts below.

Unprotected sex, gay men, San Francisco 1998-2004



Potentially serodiscordant unprotected sex, gay men, San Francisco 1998-2004



* For MSM who did not know or report their HIV status, any UAI was considered potentially serodiscordant.

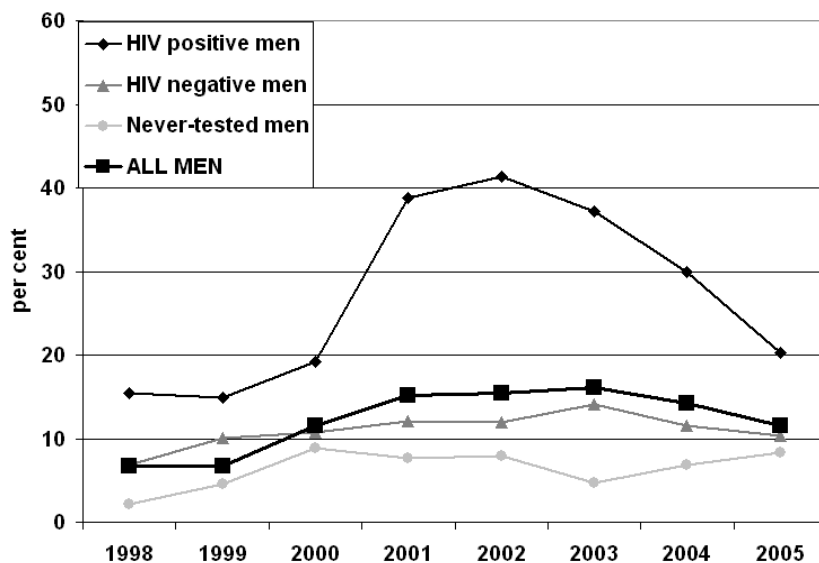
The first chart from the San Francisco Department of Public health's most recent HIV Epidemiology Report shows that unprotected sex is far more widely practised among HIV positive gay men, and that it has continued to increase among this group but has stayed level among HIV negative men.

However the second chart, from the same report, shows that the amount of potentially serodiscordant sex – the true measure of the degree of HIV risk

among a community – has declined from a peak in 2001 among both positive and negative men. Among HIV positive men the proportion reporting it declined from 31 per cent to 21 per cent and among HIV negative men from 20 per cent to four per cent. For this to have been achieved *there has to have more disclosure of HIV status* – as we know that condom use has not increased.

Similarly, in London at least, a decline in serodiscordant unprotected sex may be starting to happen amongst gay men. and among positive men the decline appears to be more dramatic. The annual survey of gay men using London gyms (Elford 2005b) between January and March each year, in which so far more than 5,000 gay men have participated, found last year that the amount of serodiscordant unprotected sex increased between 1998 and 2002, but has remained stable since then or slightly declined among HIV negative men, and has declined significantly ($p < 0.05$) in HIV positive men, from a peak of 41 per cent in 2002 to 20 per cent in 2005.

Gay men, London gyms: non-concordant UAI with a casual partner



How come HIV positive men are having *more* unprotected sex while at the same time the amount of serodiscordant sex they are having has gone down?

Clearly, by increasing the proportion of unprotected sex they had which was with other HIV positive men.

The phenomenon by which HIV comes to be brought under better control by people seeking out sex partners with their own HIV status has become called

Serosorting, and is usually applied specifically to situations where unprotected sex is being sought.

Serosorting may be one reason why an increase in STIs in gay men, especially syphilis, has not led to a concomitant increase in HIV infections. This has shaken an assumption previously used by many HIV epidemiologists – that increases in STI rates can be used as surrogate markers or predictors of increases in HIV. This has found not to be the case.

In the US huge increases in syphilis in gay men have not coincided with equally big increases in HIV.

This was first noticed in 2003 when two US cities, Seattle and San Francisco, noticed that HIV incidence among gay men attending for HIV tests was starting to decline even though syphilis rates had increased 25-fold (Buchacz). At the time this was partly put down to a lot of syphilis being spread via oral sex, and particularly among gay men, as they were unaware of this transmission route. However only 25 per cent of syphilis, it was thought, was being spread orally. Syphilis is also more contagious than HIV so can spread more rapidly through a connected network of sexual partners.

But Dr Jeffrey Klausner, San Francisco Health Department's Director of STI Prevention, commented at the 11th Retrovirus Conference where these findings were presented that there was a lot of evidence that much of the lack of a rise in HIV was due to serosorting.

A more recent study from San Francisco (CDC 2005) provides evidence that this reduction in potentially serodiscordant unprotected sex is starting to have a real effect on HIV incidence.

Official estimates of annual HIV incidence in San Francisco have remained at 2.2 per cent since 2000, down from a peak of 3.7 per cent in 1999.

However a recent study of gay men in San Francisco and four other US cities found that HIV incidence in San Francisco appeared to have in fact declined to 1.2 per cent. This finding was supported by others: incidence rates via an anonymous testing programme went from 3.9 to 2.8 per cent over the same period, and 5.4 to 3.2 per cent at San Francisco's sexual health clinics.

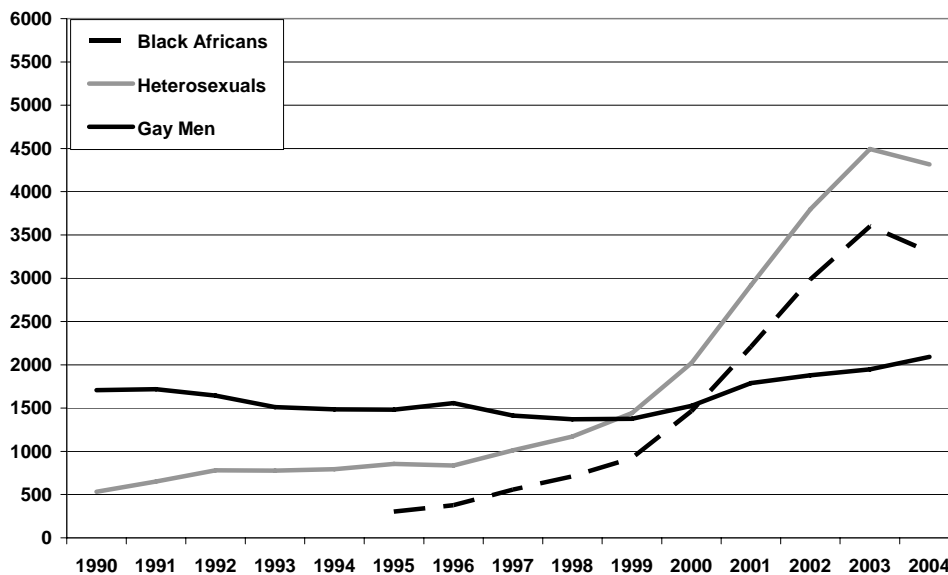
San Francisco's health director, Dr Mitch Katz, suggested that "the most likely explanation is that effective AIDS drugs have lowered the level of virus in those men who are HIV-positive and still having unprotected sex."

But Jason Riggs from San Francisco's Stop AIDS Project told several media

outlets that the decline in potentially serodiscordant unprotected sex was also a likely contributory factor.

An analysis of the latest (June 2005) HIV diagnosis figures from the Health Protection Agency shows that HIV diagnoses among gay men in the UK is continuing to increase, even as diagnoses among heterosexuals start to show evidence of a decline (probably because of reduced immigration figures from sub-Saharan Africa).

UK HIV diagnoses, 1990-2004 - Heterosexuals: gay men: Africans (of all sexualities). Includes predicted late reports



However it's important not to confuse diagnosis with incidence. Comparatively few people test positive soon after they are infected. Incidence is more difficult to measure as you have to universally test a sample of gay men and then calculate how many were recently infected.

The Health Protection Agency do manage this by anonymously testing blood samples from gay men and other groups donated at GUM clinics and in other hospital settings, and then testing them again with a so-called 'detuned' assay that only picks up infections more than six months old. Their incidence estimates among gay men who are GUM attended (who may not be representative of the general population) looks like this:



These figures, which include an estimated allowance for reports yet to be received, show a 50% increase in HIV diagnoses in gay men in the UK compared to a low point in 1997–99, and a doubling of incidence since 1999. While heterosexual diagnoses remain at twice this figure, it is worth remembering that 90% of these are diagnoses of infections acquired abroad, whereas 85–90% of gay male infections are passed on in the UK.

UK gay men are therefore still by far the highest-risk population in the UK. As to whether their risk is increasing, while the HPA incidence figures do seem to bear this out, it's important to note that these figures are taken from GUM clinic attendees who may not be representative of all gay men and that the sample size is so small that the apparent increase is in fact not statistically significant. So the jury is still out on whether some of the increase in new diagnoses is due to an increase in new infections. However it does look as though incidence has certainly *not* declined as it has done in San Francisco. Whatever has happened there needs to be investigated and then applied here.

3. Knowledge and disclosure of HIV status are crucially necessary for these strategies to work

In one analysis of an ongoing survey of gay men attending London gyms (Elford 2001), the authors detected two very different strategies being adopted by HIV positive and negative gay men to avoid infection.

In HIV negative men what the authors call “concordant UAI” and we call serosorting was mainly restricted to main partners. Over one in four (28.6 per cent) practised it with their primary partner and only five per cent with casual partners.

In HIV positive men concordant UAI was equally practised with main partners (22.2 per cent) and with casual partners (20.6 per cent).

These unprotected sexual encounters were those restricted to ones where men were fairly sure their partner was of the same HIV status. If all men, positive and negative, had an equal tendency to be uncertain about their partners’ HIV status or to be making decisions on the basis of assumptions about it, the authors argue, one would expect the lower proportion of unprotected encounters with *casual* partners to apply to both HIV negative and positive men.

The significantly greater amount of serosorting with casual partners by men with HIV can only be explained, at least in part, by the fact that it is possible for HIV positive men to disclose their status with certainty:

“Seroconcordance among negative men can only be established with confidence if both men test for HIV together. For this reason it is difficult for HIV negative men to establish concordance with a casual partner.

“On the other hand, HIV positive men can establish concordance, be it with a casual or regular partner, simply by mutual disclosure. This requires no confirmatory test.”

In short, here was evidence that disclosure of HIV status, rather than just assumptions about it, was actually happening.

However HIV positive men have to know their status before they can disclose it. Significant numbers of gay men do not know their HIV status. In the year 2000 Gay Men’s Sex Survey (Time for More), 44 per cent of respondents had never tested for HIV.

Even if a lot of those untested are correct that they are negative, this is still only an eighth of the 10.9 per cent prevalence reported from another survey of gay men in UK cities (Dodds).

Compare the situation in San Francisco in the five-city survey cited above (CDC 2005) with the situation in Baltimore. In San Francisco, even though HIV *prevalence* was the second-highest among the cities (at 24%), HIV *incidence* was lowest. In Baltimore prevalence was highest (at 40%), but HIV incidence was *disproportionately* highest, at eight per cent a year or nearly four times the rate in San Francisco.

Crucially, there was a direct link here between incidence of HIV infection and knowledge of it. In San Francisco 23 per cent of men who tested positive (anonymously) in the survey were unaware of their infection. In Baltimore 62 per cent of those testing positive did not know their status. The first step to taking any control over one's own potential to contribute to HIV incidence is to know your status.

4. Anticipated stigma and rejection inhibit HIV positive men from making the best use of these strategies

However, and crucially, that was not the whole story. Were the Baltimore men a population who had never tested for HIV? By and large, no. Eighty-four per cent of the men with unrecognised HIV infection had previously been tested for HIV. Just over forty per cent of those (a third of all those with unrecognised infection) had been tested over the previous year. However the other two-thirds who had unrecognised infection and who had not been tested during the preceding year had not done so because they were frightened, both of HIV and of the stigma against it.

Sixty-eight per cent of those with unrecognised infections had not been tested during the preceding year because they were afraid of learning they had HIV, compared with 34 per cent of those who tested negative.

And 35 per cent who were in fact positive had not tested because they were worried others would find out the result, versus 14 per cent of those who were negative.

Who are these men? The question answers itself. Baltimore had by far the highest proportion of African-Americans among the gay men surveyed, and they had by far the highest HIV prevalence overall – 46 per cent compared with 20 per cent for white men. And no less than 64 per cent of men with unrecognised HIV infection were black.

This is a population of men who suspect they are positive but are held back from testing by fear and shame. Eight per cent of them caught – or passed on – HIV in one year. Conversely, the relatively better-informed, better-tested and less-stigmatised men of San Francisco were four times less likely to catch or pass on the virus.

Shamefully, the UK's position may be closer to Baltimore's than San Francisco's.

Findings from a survey (GMFA) by Gay Men Fighting AIDS which asked HIV positive gay men if they disclosed their status before sex found that only a minority did so. It found that 40 per cent had *never* disclosed their HIV status before sex to any partner, that another 40 per cent sometimes did so, and that only 20 per cent usually did so.

That 40 per cent had never 'predisclosed' their status is startling enough; an

even more startling finding was that even when a partner did disclose he had HIV, more than half of the recipients of this knowledge still did not themselves disclose.

These findings were to motivation by the ‘Why won’t he Tell?’ campaign (see page 30 below).

This finding does not necessarily mean that all encounters where HIV status is not disclosed are unsafe ones. We have to remember that the way the survey question was framed means that it was exclusively asking about first-time sexual encounters. It says nothing about whether these encounters were unsafe or whether the men involved eventually managed to disclose.

The men in the GMFA survey are as likely as the young US men to be *attempting* to ascertain partners’ serostatus. In a piece on Positive Prevention in *Positive Nation* magazine in March 2005 (Cairns 2005a) participants from the UKC’s Midweek support group for HIV+ gay men talked about strategies they used to try to ascertain someone’s status:

- *“If his car’s new, it’s probably a Motability car. And if he’s got a blue badge...”*
- *“You find yourself poking into his medicine cabinet to find his meds”*
- *“Some guys wear the biohazard tattoo or something else to tell you.”*

Attempting to guess a partner’s HIV status, many studies have shown, is hazardous, especially as many so-called ‘negotiations’ do not take place with words. In a backroom or anonymous sex situation, people’s HIV status is deduced by their behaviour. The lack of insistence on a condom is assumed by a positive man to be a sign that the other is positive (“He must be positive or he wouldn’t let me do that”). A negative man makes the opposite assumption (“If he was positive he would protect me and use a condom”).

HIV positive men’s guess work may be very inaccurate, but is probably not *as* inaccurate as the attempts used by HIV negative men. HIV positive men know the ‘signs’ better.

They may also be less likely to think that the willingness of a partner to have unprotected sex indicates that they are seroconcordant with them. The 2002 UK Gay Men’s Sex Survey *Out and About* found that Of the participants whose most recent HIV test was negative, two-thirds (65.3 per cent) said they would expect an HIV-positive man to disclose his status before having sex. Even more men

who had never tested for HIV had the same expectation (77 per cent).

However, in contrast, only just over a third of HIV-positive men expected that a partner would disclose their HIV status.

This survey makes the false assumptions gay men make about other's status very clear. It also underlines the disincentive many HIV positive men have to disclose.

Forty-four per cent of HIV-negative or untested men said they would not want to have sex with the man who'd just disclosed his HIV status to them – and this rose to 56 per cent of men who had never had an HIV test.

Report authors Sigma Research comment: "Expectations that men with HIV will tell a prospective sexual partner their HIV status are still widespread. Over a third of men not tested [HIV] positive both expected a positive partner to disclose their status prior to sex and would not want to have sex with them if they did.

"In this climate, it is difficult to see what incentive men with HIV have for disclosing their status."

5. Safe spaces like the Internet, are being used by gay men with HIV as places in which to disclose and to negotiate HIV-reduction strategies

So gay men with HIV show evidence of *wanting* to avoid infecting others, but being scared to take the necessary steps to do so.

Are there any strategies HIV positive men *are* using to disclose?

Concern has been expressed in recent years that the huge increase in sexual encounters being arranged on the internet may be facilitating an upsurge in unprotected sex. This concern has been fuelled by the rise in the number of explicit 'barebacking' sites.

In a study (Bolding) by the same group of researchers as reference 13, four groups of gay men (internet chatroom users, London gym users, HIV positive men attending clinics, and HIV negative men attending for an HIV test) were asked about their patterns of unprotected sex and internet use.

HIV-positive men in the clinic and gym samples who used the internet to look for sex were significantly more likely to report unprotected anal sex with men of the same HIV status than other men ($p < 0.05$). And both HIV-positive and HIV-negative men who used the internet to find sex were more likely to report serodiscordant unprotected anal sex with a casual partner than other men ($p < 0.05$).

So far, this looks as if the internet is facilitating increased levels of unsafe sex.

But the investigators found that HIV positive internet users were also more likely to have *concordant* unprotected sex, i.e. to 'serosort'.

In all samples, HIV-positive men who looked for sex through the internet were significantly more likely ($p < 0.05$) to report concordant unprotected anal sex with a partner they met on-line rather than off-line. For example, 10 per cent of the HIV positive clinic sample reported concordant unprotected anal sex with a man they met on-line, and only four per cent said they had had concordant unprotected sex with a man met off-line.

What's more, the investigators found that amongst the HIV-positive clinic sample, men said that they were more likely to disclose their HIV status to men

met on-line (24 per cent) than men met off-line (14 per cent, $p < 0.001$).

They also found that the apparent causal link between internet use and *serodiscordant* unprotected sex was an artefact. When asked directly about *how they met* partners they subsequently had unprotected sex with, there was no evidence that gay men, whether HIV-positive, negative or untested, were more likely to meet partners for discordant unprotected anal sex on-line rather than off-line.

For example, among HIV-negative men in the internet sample, 10 per cent reported non-concordant unprotected anal sex with men met on-line only, 11 per cent with men met off-line only, and 6 per cent with men met on- and off-line. "In fact," note the investigators, "for HIV-negative men in the clinic and gym samples who looked for sex through the Internet, the reverse pattern was seen; they were more likely to report non-concordant unprotected anal sex with a casual partner met off-line."

In other words internet meets were more likely to result in unprotected sex which was concordant: serodiscordant unprotected sex was at least as, or more likely to occur during casual encounters or arise from meets in social venues like bars.

The investigators write: "What is new about this study is that we can establish whether the excess risk of HIV and sexually transmitted infections seen among gay men who looked for sex through the internet actually occurred with the men they met on-line.

"In our study, HIV-positive men who looked for sex through the internet were more likely to meet other HIV-positive men with whom they had (concordant) unprotected anal intercourse on-line rather than off-line."

They add: "Men who looked for sex through the internet were no more likely to meet their non-concordant unprotected anal intercourse partners on-line than off-line. This was seen for HIV-positive, HIV-negative and never-tested men alike."

The investigators suggest that the internet may provide a safe space for HIV-positive men to disclose their health status, 'thus facilitating "filtering" or "serosorting" of sexual partners'.

This is not the only study that suggests the internet is being used by HIV

positive men as a safe place in which to disclose and negotiate the level of sexual safety they want.

A study presented at the 2005 Retrovirus Conference (Chiasson) of users of 14 US-based gay websites found that 28.5 per cent of men had unprotected sex during their last encounter.

However twice as many instances of unprotected sex happened after casual offline encounters that after internet meets.

And online meets were more likely to involve discussion of HIV status. More than half of the men who had met online had discussed their HIV status before sex as opposed to a third of partners who met offline.

The authors comment: “The large number of men on-line and the diversity of their risk and ways of meeting partners show that the Internet provides a unique opportunity for far-reaching behavioural interventions.”

An example: HIV STOPS WITH ME

It's important to emphasise that so far most of this use of the internet has been informal use by positive gay men making use of existing websites. In the UK so far HIV-specific websites have in the main been organisations' web 'shopwindows' and discussion boards like the UKC's Positive Voices, rather than ones specifically designed as prevention support for people with HIV. CHAPS almost entirely use print media and GMFA at present does not even have its own website.

It is however possible (though not necessarily more desirable than setting up the conditions for informal use) to set up a positive-prevention-centred site. We have already mentioned HIV STOPS WITH ME. This is a US social marketing campaign directed at people with HIV. It is largely web based but supported by magazine and poster advertising.

Set up by Better World Advertising (see www.socialmarketing.com), who also developed HIV IS NO PICNIC, it uses a combination of HIV 'role models' specifically



recruited because of their appearance and opinions, with other written contributions encouraged from site users. It was originally criticised for featuring unrealistically positive role models and having them take a heavily moralistic, 'just-do-it' line on safer sex.

However although HIV STOPS WITH ME is still a social marketing campaign and not a community-owned or contact site, its content is now much more representative of, and chosen by, the HIV positive community . It is now sponsored by HIV service organisations in nine US cities who select 'role models' autonomously and edit their input. Models now have a much broader range of opinion and experience when it comes to sex, relationships and disclosure. Better World Advertising now simply contribute the technical and marketing expertise.

This site's specific model is not necessarily recommended for the UK. In the US HIV is, at least to some degree, spread more generally around the population, rather than focused on two very different communities as it is in the UK. There are 20 times as many people with HIV to choose from and therefore a wider range of 'role models'.

And there is some evidence that, culturally, US populations are more responsive to influential 'thought leaders' in their own community. For instance, a successful campaign using popular gay-scene members as HIV prevention peer educators in four cities in the USA (Kelly) failed when the same concept was tried in Glasgow and London (Flowers, Elford 2001b).

It also lacks the real-time interactive component which is the most potentially powerful internet prevention tool.

However it at least is a start in attempting to use the real opinions and experiences of HIV positive people as a primary HIV prevention resource.

6. Some of the strategies gay men with HIV may adopt to avoid transmission may make them more vulnerable to other sexually transmitted infections, but sexual health education specifically directed at gay men with HIV is a neglected area

What do these 'safe cyberspaces' look like? Paradoxically, they may look like places where men deliberately seek out unprotected (and, some would therefore assume, unsafe) sex.

There are HIV-specific chatrooms and dating sites like www.positivepersonals.com, but most of the debate has been around the phenomenon of 'barebacking', which has spawned a huge internet industry of contact sites and erotica all of its own.

'Barebacking' originally signified a transgressive, eroticised adoption of unprotected sex by gay men as a rebellion against the norms of HIV prevention messages.

As well as involving the sexual charge of doing socially proscribed acts, it has also involved an eroticisation of HIV and HIV transmission themselves, with language terms evolving such as 'bugchaser' and 'giftgiver' for men who seek – or who *fantasise* about seeking – to respectively receive and transmit HIV.

These may be seen as attempts to conquer the extreme anxiety of AIDS by controlling it via eroticisation; similarly, sado-masochism may be seen as a way of controlling anxieties about humiliation and inadequacy. Or they can be seen as an extreme version of compensation for the all-pervasive shadow of HIV stigma – defiantly making 'cool' and sexy what is deemed by society to be most sinful and depraved.

Unsurprisingly 'barebacking' created a media furore, with documentary films like *The Gift* (Louise Hogarth, 2002) exploring this apparently self-destructive gay subculture. Prominent gay figures denounced barebacking as a manifestation of gay men's self-hatred: Playwright Harvey Fierstein said that "Many of our young men see infection as a right of passage, an inevitable coming of age," and AIDS activist Stephen Gendin, who had written articles supportive of barebacking, commented sadly before he died of AIDS at the age of 34 that "Maybe in my crusade to prove that life with HIV can be full, rich and meaningful, I forgot that being HIV negative is still the preferred way of life."

So that is what barebacking *was*: but what it *did* may have been a different thing. Because it involved a way whereby HIV positive men attempted to make the deeply unsexy (HIV and disease) sexy and thereby conquer their own internalised stigma, it seems to have become in part a *code* for “I’m HIV positive”, if for no other reason that the next question to a barebacker seeking sex in a chatroom is usually “are you poz?”

In other words, it usually involved disclosure: disclosure not as an act of pure altruism or social responsibility, but disclosure in the service of sex, and therefore motivated much more powerfully than pure altruism could be. In a 2003 paper (Race) entitled “Re-evaluation of Risk among Gay Men”, Kane Race of the National Centre in HIV Social Research at the University of New South Wales comments:

“It is unknown at this stage whether barebacking has had a positive or negative effect on new HIV infections. While there are sporadic reports that some HIV-negative gay men make sense of some of the unprotected anal intercourse in which they engage in terms of barebacking, the phenomenon tends to be associated with HIV positive men. Thus, the effect may be to increase, rather than decrease, the degree of seroconcordance in the total number of sexual encounters. Barebacking may have the effect of partner sorting in a manner analogous to negotiated safety. Unlike HIV-negative men, HIV-positive men require only one HIV test to adequately ascertain their HIV status, thus this possible prevention ethic need not occur in the context of a regular relationship.”

An illustration of the paradoxes around disclosure and serosorting comes from the publicity surrounding a study of ‘Poz parties’ in New York (Clatts).

Researchers interviewed 115 men attending an HIV-positive-only sex party in New York. The primary reasons cited by the men for attending were “Not having to worry about disclosing my HIV status (35% citing this as their primary reason) and “I like having uninhibited or unrestricted sex’ (also 35%), with 14% citing ‘Not having to worry about infecting others’.

The majority of men indulged in unprotected anal sex: 59% receptive and 72% insertive. 47% and 50% respectively had receptive and insertive anal sex to ejaculation.

The men were on average relatively old (median 42) and relatively long-term

diagnosed (nearly 10 years), though the youngest attendee was 20 and the most recently infected had been so for two months. A third of men said they had had an STI other than HIV diagnosed in the past year.

In contrast to concerns that the use of recreational drugs was fuelling unprotected sex among gay men, only a small number (nine out of 86) used 'hard' drugs such as ecstasy, methamphetamine or ketamine, or sexual enhancers like *Viagra* or poppers.

Although the researchers acknowledged that the serosorting involved might be a public health benefit, they added that attendees had also had sex with status-unknown partners on other occasions.

They also cited the dangers of HIV superinfection, but as yet there is conflicting evidence as to exactly how often this happens or – more to the point – whether it often causes adverse clinical consequences.

Superinfection may turn out to be quite a frequent occurrence (see Smith 2004), but at present the cases that come to the attention of researchers do so *because* of adverse consequences, such as a person with wild type virus contracting resistant virus (see, for instance, Smith 2005). If superinfection is in fact common, one would also expect more evidence that it was damaging, though this evidence might be disguised as treatment failure attributed to other reasons.

However the choice of entitling the paper “An emerging HIV risk environment” may have been unfortunate in that it is easier to argue that on balance ‘poz parties’ are a risk environment for every STI *except* HIV. Media outlets, however, mainly picked up on the ‘HIV risk’ angle, with headlines such as “POZ parties may spread HIV superstrain” (Mitchell).

A similar controversy, though restricted to the HIV sector, arose in the UK around a London public-sex venue for gay men called Pigpitmen. This fortnightly sex club started off as an underground sex club in members’ homes, but soon moved to an established gay venue.

London had its own controversial example of an originally transgressive and ‘underground’ sex club which then came to be seen as a possible HIV prevention opportunity. Pigpitmen (see www.pigpitmen.com) started off as an ‘underground’ and almost exclusively ‘bareback’ sex club operating in people’s homes. It then became a commercial club venue operating weekly. Though it

has now closed, another positive-only night operates at a commercial sex venue in north London.

Pigpitmen had one unique feature, at least in London: it defined itself as a club for HIV positive men only, and applicants for membership were required to declare (though not to prove) that they had HIV. Someone attending a Pigpitmen club night was assured that all his fellow attendees were 'pre-disclosed' as HIV positive and that therefore whatever else was going to happen, he would not transmit HIV if he had unprotected sex.

This is not meant to imply that 'barebacking' is a better choice than maintaining safer sex. Like other harm reduction strategies, it is at best a good 'second best' to condom use. Its adoption may lay *individuals* open to HIV infection who were not before, while on a community level facilitating serosorting and making the *average* individual less likely to transmit HIV.

Furthermore, because barebacking has been a stigmatised subculture, those who adopt it may be those who adopt other subcultural and stigmatised behaviours that may also be HIV transmission risks. US researcher Perry Halkitis found that:

"Men who did identify themselves as barebackers were slightly younger. They were more likely to miss a dose of medication; report drug use (non-injection and injection); exhibit higher levels of sexual compulsivity and lower personal responsibility for safer sex; and report higher rates of unprotected insertive anal intercourse, unprotected receptive anal intercourse, and unprotected insertive oral intercourse with all partners, regardless of their HIV serostatus."

What this means, specifically in terms of HIV positive men, is that behaviour which facilitates serosorting also lays gay men with HIV open to a great many other health risks and in particular other STIs. In the paper cited as reference eight, the authors comment of the young gay men who were having unprotected sex primarily with other partners thought to be HIV positive that "These young men are putting themselves at significant risk for infection with an STD, which could have detrimental effects of their own disease progression."

And in the paper cited above (Elford 2001a), which found evidence of serosorting among London gym users, the authors comment of the HIV positive men that "Although seroconcordant UAI among positive men carries no risk of

HIV transmission to an uninfected person, it raises the possibility of reinfection and drug resistance for the men themselves.”...as well as the risk of STIs such as syphilis, LGV and hepatitis B and C.

The result is that though HIV transmission may be avoided by ‘serosorters’, HIV positive gay men who have unprotected sex with other HIV positive men are at a risk of other STIs so high that, if the general or even the gay population at large was so affected, it would be treated as a public health emergency. The recent exponential increase in syphilis cases between 1998 and 2002 was largely concentrated in HIV positive gay men, and recent outbreaks of sexually-transmitted hepatitis C and of lymphogranuloma venereum (LGV) almost exclusively so.

Leaflets on LGV and hepatitis C issued by the Terrence Higgins Trust (see <http://tth.org.uk/gaymen/lgv>) do mention that “Most of the men infected so far [by LGV] have been HIV positive” and give as an example of someone at risk of sexually-transmitted hepatitis C a gay man into fisting who has sex exclusively with other men with HIV. However there was never an STI prevention campaign in the UK directed *specifically* at gay men with HIV until the UKC developed its ‘Knowledge is Power’ campaign which in part alerted HIV positive men to sexually-transmitted hepatitis C.

There is an interesting parallel here. Gay men are 50 times as likely as heterosexuals to catch HIV, but only a minority of HIV prevention funding is directed specifically at programmes for gay men. Gay men with HIV appear on present figures to be 50 times more likely to catch LGV than HIV negative gay men, but the fact that they are so disproportionately affected – and may be so because they are not seen as a target audience for STI prevention, and therefore safer-sex, messages – is not acknowledged by an HIV-specific campaign.

Similarly, The ‘Look What’s Back!’ syphilis campaign noted in one sentence that half the syphilis cases in London had been among gay men with HIV but does not go on to draw the conclusion that, as HIV positive men form no more than 12 per cent of the London gay population, this means that gay men with HIV are at least four times more likely to get it.

7: Unbiased education for HIV positive gay men about HIV transmission risk in different situations should form a core part of positive-led prevention.

Serosorting is not the only method people with HIV may use to attempt to make sure they do not pass on HIV. If they have unprotected sex with HIV negative partners, they may attempt with their partners to reduce the likelihood of infection negotiating types of sex seen to be less risky.

HIV status is not the only thing that can be disclosed by men attempting to minimise their HIV risk. Several recent studies have found that gay men are questioning each other about their HIV viral load in order to try and establish if they are infectious. “Are you undetectable?” is becoming as common a chatroom question as “are you poz?”

In a study from San Francisco (Goldhammer) 78 per cent of 507 gay men questioned were familiar with the term `viral load` and one third (111 of the total sample) had discussed viral load with a partner of a different HIV status during the previous year in order to make decisions about which sexual practices to engage in.

Of those who had discussed viral load, more than half estimated that they used viral load disclosure to guide sexual decision-making in at least 70 per cent of their sexual encounters.

In another study from Sydney (Van de Ven) researchers asked 119 men who were in an HIV-serodiscordant regular relationship about whether they used viral load as a basis for their decisions on condom use. Twice as many (39.4 per cent) reported unprotected anal intercourse when the partner’s HIV last viral load test was undetectable as when it was detectable (20.8 per cent).

Not every analysis of viral load and sexual risk taking supports this. Crepaz (2004) did a meta-analysis of studies published between 1998 and 2003 that found that, taken together, there was no evidence that taking HAART or having a reduced viral load lead to high risk sex among people with HIV. However gay men’s awareness of viral load and sophistication in taking it into account may be changing very rapidly and Nicole Crepaz may have failed to detect a relatively recent phenomenon.

It may also be a dangerous assumption. One study (Taylor) found that a minority (about 12%) of gay men had higher viral load in their semen than in their blood while another (Kalichman) found no correlation at all between viral load in blood and viral load in semen.

On the other hand, studies from Africa (Wawer) show a linear relationship between decreased viral load and decreased infectiousness, at least in heterosexuals. We simply don't know yet to what extent only having unprotected sex with people who are 'undetectable' is a strategy that will reduce or increase risk. But that's no reason not to tell gay men what the studies say.

Other strategies include positive men adopting the passive role in anal sex and negative men the active role, because the knowledge that receptive partners are more likely to be infected than insertive partners has become well known within the gay community (and has been supported in one case by a THT prevention campaign). There is consistent evidence from the Gay Men's Sex Surveys that this strategy is adopted by serodiscordant couples: HIV positive men, if they have serodiscordant unprotected sex, are more likely to be 'bottoms', and HIV negative men 'tops'.

Another strategy that has been the focus of a recent GMFA campaign (opposite) has been to withdraw before ejaculation. Here the evidence is somewhat muddy as another study found that 'dipping' (inserting the penis without ejaculation before putting on a condom) was a significant HIV infection risk.

What has been missing from any of these campaigns, however, has been *quantitative* information.

The poster opposite says that "If you are HIV positive you can still pass on HIV even with an undetectable viral load." Well, maybe: a minority (about 12 per cent) of gay men have higher viral loads in their semen and rectum than in their blood, but transmission by someone with an undetectable viral load has in fact yet to be demonstrated.

What HIV positive people want to know (and often ask) are the *exact* answers to questions like:



- How likely is it that I will infect someone if my plasma viral load is undetectable?
- How more likely am I to pass on HIV if I fuck, rather than get fucked?
- How likely is it that I could pass on HIV through oral sex?
- How much more infectious am I if I've recently been infected myself?
- How likely is it that I could get a second HIV infection ('superinfection') if I have unprotected sex with an HIV positive partner?

There has been a reluctance to give numerical rather than general answers to these questions. This reluctance is in some ways understandable, as there are no precise scientific answers to many of these questions. But there is generally a 'ballpark' of possibilities to choose from. For instance, estimates for the proportion of sexually-transmitted HIV that gets passed on via oral sex vary from zero to 8 per cent, depending on the study, with most producing a range of from two to five per cent.

An HIV poster devised by a prevention agency can say, "Take it from us, transmission via oral sex is not a high risk but it does happen." But this is completely to ignore an individual's right to determine the degree of risk *they* are happy at exposing their partners to. Different people may consider an oral sex transmission rate of (say) three per cent of infections to be low risk or to be surprisingly high risk, and have the right to the figures so they can make decisions themselves.

In the case of oral sex both positive and negative gay men can make sense of these figures. But in the case of something like viral load, HIV positive people on treatment have the lived experience of waiting to see if their drugs are working, undergoing the anxious discussions with doctors about salvage regimens if they are not, and may understand concepts like log measurements. Many are already 'expert patients' and are in a position to explain to partners what the risks are. Many others have a right to that expertise.

Terje Anderson in the speech quoted above (Anderson) puts it this way:

"We have the right to accurate information to make decisions on sexual safety. We need figures on the frequency of superinfection, of the impact of viral load on transmission, of the risk of specific sexual activities, of

the effectiveness of condoms, of the risk of non-HIV infections and of post-exposure prophylaxis options for partners. We are experts on our lives and our needs. We feel like we're not being trusted with the information we need because we are 'going to make the wrong choice'."

The fear behind providing precise figures for transmission risks is partly a rational one based on the fact that information about risks may change. For instance, the advice that "It's safer to fuck than be fucked" (directed at HIV negative gay men in one campaign by the THT) now has to be tempered by findings from African studies that show an equal rate of heterosexual transmission from women to men as from men to women, and by the finding of extremely high viral loads in rectal secretions. But Knowledge is Power, to quote the title of a hepatitis awareness campaign directed at HIV positive gay men by the UKC. To believe that HIV positive people will only use information about transmission risks as post-hoc justification of unsafe sex is not only to distrust them, but flies in the face of the evidence that they use this information constructively.

8. Training and peer support to help HIV positive men to disclose to sexual partners should also form a core part of positive-led prevention

So one component of positive-led prevention is that people have knowledge of risk that is as accurate as possible – given the limitations of what science knows.

The other necessary component is that either condom use is maintained *or* some kind of mutually-agreed level of risk is negotiated (or both – for instance, a serodiscordant couple could agree to use condoms when the positive man is the active partner but not when he's the passive one. In order for this to happen, there has to be disclosure of HIV status.

There has been a great lack of programmes to help people with HIV to disclose. With *lack* of disclosure or at least intentional concealment of HIV status now deemed a criminal offence if it leads to transmission, enabling people with HIV to disclose has assumed a new urgency. At present some lawyers believe that a prosecution for transmission is possible if disclosure does not happen even if there is an attempt at condom use.

However, as in the “Why won't he Tell?” campaign above, the emphasis has mainly been on informing HIV negative men that positive men do *not* always disclose. The background reading to this campaign gives a long list of reasons why a man with HIV may not disclose his status. This is just an extract; all in all, 33 possible reasons are given for non-disclosure.

- I don't want him to reject me.
- I'm sure he's guessed that I'm positive.
- I don't trust him with that kind of information.
- It's not the right situation to tell him.
- I'm not planning on fucking so there's no need to say.
- I don't want to be pitied.
- I want to have hot sex, not talk about my health.

Although it is entirely valid to lower negative gay men's expectations of disclosure, as we said above, this spreads a subtly disempowering message to HIV positive men. Where are the reasons *for* disclosure?

There are good reasons for HIV positive people to be careful about when, how and to whom they disclose HIV status. Consequences of disclosure may range from sexual rejection to social ostracism to assault to job loss to, in a few occasions, murder.

However HIV prevention agencies may have fought shy of encouraging people with HIV to disclose because they are worried about being seen to promote it as a moral obligation, and that this will be counterproductive.

This ignores the fact that one of the most profoundly negative aspects of living with HIV is the feeling of being socially isolated and marginalised. HIV positive people (of all genders and sexualities) may especially feel unacceptable or 'damaged goods' when it comes to achieving fulfilling sexual relationships. A person's HIV status is a hugely important part of their experience and may be at times felt to be the most important single thing that sets them apart as a person.

Without encouraging disclosure, how can we help people with HIV to 'normalise' themselves? To rejoin the rest of human society? To learn how to weather the inevitable rejections and judgements that will come their way? To develop relationships that involve honesty and mutual caring?

Where is there an emphasis on the *benefits* of disclosure? Not just on the fact that by doing so you may avoid legal liability for transmission, but on disclosure as a self-empowering act? It seems extraordinary that a political movement (gay pride) founded on 'coming out' and on rejecting homosexuality as something to be ashamed of has not developed a model of 'positive pride' and the personal growth benefits that follow learning to successfully disclose HIV status.

We should remember that in the French study quoted above as reference 10, that although the vast majority of people with HIV who were in a long-term relationship had managed to disclose their status to their partner, 45 per cent of the sample were not in a relationship. This proportion of 'singles' is not that uncommon among gay men at large, but in this case we perhaps should be asking: how many of those singles were not in a relationship because they were terrified of disclosing their HIV status, and had received no help or advice on how to do so?

A note on criminalisation

Recent convictions of people with HIV for recklessly transmitting the virus to partners have given a new urgency to the debate on the importance of enabling HIV positive people to disclose more easily to partners. As the French study above suggests, most eventually manage it within the context of a long term relationship: but as the GMFA data equally suggests, only a minority do it in advance of sex.

In the appeal against Feston Konzani's conviction, the judges ruled that Konzani's partners could consent to sex (and its attendant usual risks such as STIs and pregnancy), but could not consent to the *risk* of HIV infection without knowledge that Konzani had it. They said Konzani:

'behaved recklessly on the basis that knowing that he was suffering from the HIV virus, and its consequences, and knowing the risks of its transmission to a sexual partner, he concealed his condition from the complainants, leaving them ignorant of it.'

And they comment that:

"If an individual who knows that he is suffering from the HIV virus conceals this stark fact from his sexual partner, the principle of her personal autonomy is not enhanced if he is exculpated when he recklessly transmits the HIV virus to her through consensual sexual intercourse. On any view, the concealment of this fact from her almost inevitably means that she is deceived. Her consent is not properly informed, and she cannot give an informed consent to something of which she is ignorant."

[R vs. Konzani, paragraphs 41 and 42]

As the law now stands, therefore, unprotected sex without HIV disclosure is not non-consensual sex as such, but it is sex without consent to the risk of a specific harm, namely HIV infection. It is therefore a form of violence.

Without a change in the law, there will be an increasing moral and social imperative on HIV support organisations to help HIV positive people avoid actions that run the risk of being judged as criminal.

9. Different people with HIV will need different levels of information and types of help with behaviour-change, which may at times seem contradictory

As we said above, the majority of gay men with HIV continue to maintain condom use and safer sex.

There are potential contradictions in any HIV prevention programme, including a positive-led one, between encouraging people to maintain condom use and encouraging them to adopt other harm-reduction behaviours if they don't.

Consistent condom users can interpret harm-reduction messages as ones that undermine their determination to continue to use condoms instead of rewarding it. This may be particularly keenly felt by HIV positive men, and positions can get quite polarised.

Take the GMFA 'Cum Outside' campaign mentioned above. This caused controversy when it appeared in Positive Nation (Flynn). While some saw it as an unexceptional harm-reduction message, others questioned its scientific validity, for reasons set out above, while others saw the message it gave out as simply wrong.

Promoter Spike Rhodes, who started Warriors, London's first club mainly for gay men with HIV, in the early 1990s, commented:

"I understand what GMFA are trying to do by acknowledging that barebacking is going on, but I think it is unacceptable behaviour not to use condoms.

"A previous GMFA campaign about HIV disclosure argued that it was OK not to disclose your HIV status. But not disclosing that you have HIV and then fucking without a condom, and hopefully withdrawing before coming, becomes a game of Russian roulette.

"I don't know anyone who can pull out before coming."

Carl Burnell of GMFA replied that they pre-tested the campaign to ensure men understood the message and that they didn't misinterpret the message as 'It's OK to have unprotected sex, as long as you cum outside.'

There is evidence that both condom use and harm-reduction behaviour like serosorting can reduce HIV transmission, but a responsible HIV prevention

agency must be aware of the contradictions that may be perceived between differing harm–reduction strategies, and of the perception that to promote one strategy may be seen as devaluing another.

An additional urgency to the need for clear thinking about how to portray these strategies had been injected into the debate by the criminalization of transmission. What happens if an HIV prevention agency gets sued by someone who became infected – as some inevitably will – while pursuing a harm–reduction strategy recommended by that agency?

Harm–reduction strategies need to be presented as a strategic network of choices which are genuine alternatives rather than mutually contradictory, and should not be capable of interpreted as encouraging rationalisations for taking sexual risks.

This dilemma has echoes in the far larger (and noisier) global debate about whether abstinence or monogamy should be the primary focus of HIV prevention work rather than condoms and other harm reduction methods such as needle exchange.

Opponents of condoms turn their relative success (at least 85–90% efficacy among consistent condom users, and 60% effectiveness at reducing HIV incidence among high–risk populations such as gay men) into evidence of failure ‘because only abstinence is 100% safe sex’.

However this is not to compare like with like, as ‘consistent abstainers’ are if anything less common than consistent condom users. And no study has ever showing a causal link between condom distribution, earlier sexual debut and/or greater numbers of partners.

Similarly, prevention campaigns that seek to reinforce and indeed validate non–condom based harm reduction measures among HIV positive people may be seen, in the absence of evidence that they work, as incitements to unsafe sex and increased HIV incidence.

Clearly, non–condom harm reduction strategies are likely to be riskier than condom use, for all sorts of reasons (partner deception: misinformation about viral load: superinfection: STI infection) and is important not to give the message that they are ‘as good as’ using condoms.

However it is also not to present choices hierarchically (“use condoms, but if you

can't here's other things that might work") as this fails to validate choices such as serosorting which can if used correctly and with accurate knowledge be very effective.

A better option is to present them as a menu of possible choices, with attendant information about transmission risk. "These are the things you and your partner may do to reduce the likelihood of HIV transmission – and here are the success rates of each method, to enable you to make those choices."

This would more easily allow changes in sexual safety, as for instance if a couple decides to stop using condoms when and only when the HIV positive partner is 'undetectable'. The evidence that this helps is equivocal, but the emphasis should be on the word 'menu'; no agency should give gay men the idea that one particular strategy (other than condom use) *will* reduce risk, but should encourage gay men to combine strategies to maximise safety.

10. The long-term diagnosed with HIV are an untapped resource. Their experience of living with HIV and their accumulated knowledge could make them ideal peer supporters and mentors of the newly-diagnosed, and help them achieve strategies for safer sex.

We mentioned above although most studies show that people with HIV have more unprotected sex than HIV negative people, not all do.

A recent study of HIV positive patients in California (Diamond) found that those taking HIV medication actually had less unprotected sex than people not taking it.

Previous studies noted a temporal association between ARVs becoming available in the late 90s and unsafe sex starting to get more common, but did not prove that the people who were starting ARVs were the same ones as those using fewer condoms.

The study of 874 patients from six public HIV clinics in California has found that the 79% of them taking ARVs reported a third less unsafe sex than people off medication. Forty-six per cent of patients off medication reported at least one episode of unprotected sex in the previous three months compared with 31 per cent of those taking ARVs.

Maintaining safer sex was strongly associated with taking HIV medication properly. Twenty-eight per cent of patients who said they took more than 95% of their doses had unprotected sex compared with 41% of those who forgot more than one in 20 doses.

Those diagnosed for longer were less likely to have unprotected sex, which goes against an assumption that the long-term diagnosed might suffer from 'condom fatigue'.

The researchers suggested that patients who were responsible and health conscious enough to achieve optimal adherence might also be more likely to use condoms.

This allows a glimpse of an exciting possibility. Those taking HIV treatment may be the kind of people who also take fewer risks with their health. But the finding that *length of diagnosis* was also a predictor of a reduction in unsafe sex suggests that maintaining safety is a learned or self-taught behaviour. And if it

is learned, then it can be taught.

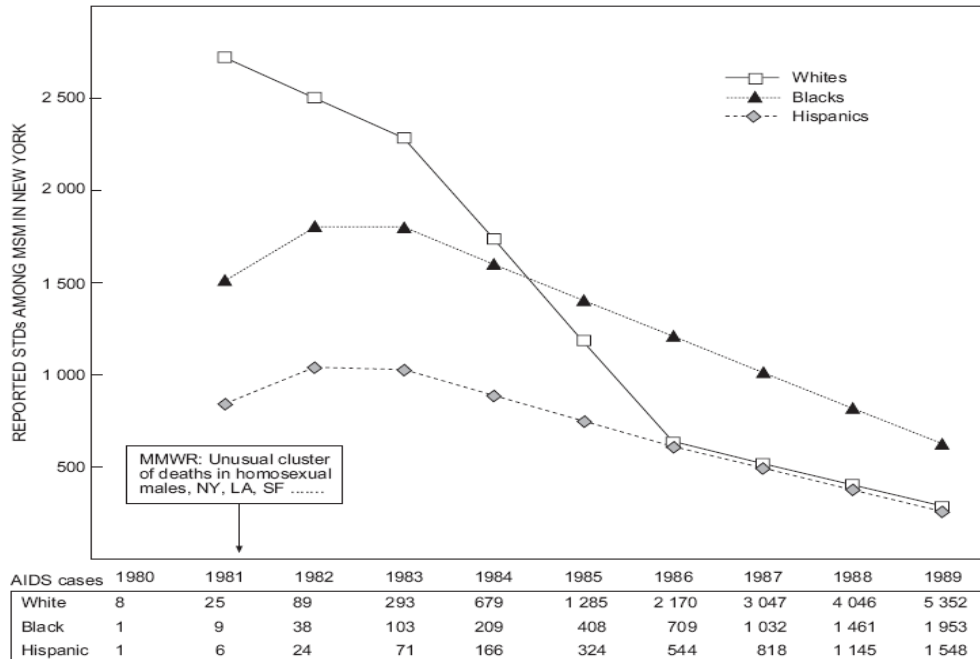
HIV diagnosis is a time of tremendous turmoil for virtually everyone who experiences it. While the fear of death may be less mordant than it used to be for those suddenly finding they have HIV, the fear of isolation and the sudden, radical uncertainty it puts people into about how to handle sex and relationships may make the experience more traumatic now, in the era of antiretrovirals, than it was before. One high-functioning gay professional told the author of this paper that his reaction to diagnosis was: “that’s it. I’ll never be happy again.” HIV diagnosis is an experience of tremendous loss and loneliness, and reactive depression and anxiety are perhaps the rule rather than the exception.

Surveys in the USA have shown that people who are depressed are more likely to have unsafe sex. In addition, the newly diagnosed do not usually have the body of scientific or ‘grapevine’ knowledge that the long-term diagnosed have about everything from viral load to how to handle rejection.

This raises the possibility that people with HIV can act as mentors for the newly diagnosed in a way that makes a positive difference to HIV incidence. In the developing world, where the lack of trained medical personnel has compelled it, organisations like the WHO are already recruiting large numbers of people living successfully with HIV on treatment to encourage the untested to test and the diagnosed to take treatment. They are also an important prevention resource.

The subcultural conversations happening in chatrooms, bars and sex-contact sites between gay men with and without HIV the world over are an example of the same process.

As the graph below shows (Low-Beer) risky sexual behaviour and STI incidence started declining in gay men almost as soon as awareness of AIDS became widespread in the community, before the discovery of HIV and the development of the HIV test and certainly before the birth of most organised HIV prevention programmes.



Could people with HIV these days act as peer supporters and educators of the newly diagnosed, and make a difference to HIV incidence? It's unlikely that interventions will ever have as dramatic effect as the one shown above, because most gay men now practice safe sex so the potential for risk reduction is smaller than it was in the early 1980s when most men did not use condoms. But it does suggest that there remains an untapped potential for 'grapevine knowledge'.

Gay men with HIV can also be mentors to HIV negative partners. They can teach the difference between real and perceived risk and how to read 'codes' that stand for positive status like self-identification as a barebacker.

One example of how they could be involved in HIV prevention is to address literature about post-exposure prophylaxis, not to the HIV negative, but to their HIV positive partners, and indeed the UKC has just commissioned a leaflet about PEP directed at HIV positive gay men.

These people already have the knowledge of HIV drugs and their side effects. They have an incentive due to criminalisation to disclose to partners that there has just been a transmission risk and that they should take PEP. And they know they have HIV, which means their negative partners are less likely to receive a sceptical reception from resource-pressed clinics that they have in fact been at risk and are justified in asking for this expensive intervention.

11. An HIV prevention programme led by visibly HIV-positive people themselves, reinforcing strategies that gay men with HIV *already use*, stands the best chance of helping people with HIV adopt and maintain HIV risk-reduction behaviour, in line with the social diffusion model of behaviour change.

There are a number of different models of how behaviour change happens among individuals confronted with a threat to health. One of the most persuasive is the social diffusion model. [Thanks to Keith Alcorn for permission to use the following four paragraphs from a section written by him in the *AIDS Reference Manual*].

Social diffusion theory states that innovations are diffused through social networks over time by well-established rules and that health-related behaviours are no exception.

A body of social theory called social diffusion theory has studied the diffusion of innovations in fields such agriculture, international development and marketing. More than 4,500 studies have been published on the diffusion of innovations.

Diffusion of innovations theory has been adopted for the study of the adoption of behaviour intended to avoid HIV infection. Diffusion theorists argue that a behaviour or innovation will be adopted if it is judged to have a high degree of utility, and if it is compatible with how individuals already think and act.

However, an innovation will only be considered if it is known about, and one of the major problems facing HIV educators is the difficulty of frank communication about HIV risk and how best to protect oneself and one's partners. The taboo status of much discussion about HIV makes it difficult for individuals to judge the utility of an innovation such as condom use, because frank discussion of condom use is impossible on television.

One of the few global success stories in reducing HIV incidence comes from Uganda, where HIV incidence went into a sharp decline in the late 1980s. It was accompanied, and probably caused, by an equally sharp reduction, unique among African countries at the time, in the average number of sexual partners people had.

This decline appears to be evidence that it was not merely the ending of war and

the restoring of civil order on the accession of President Yoweri Museveni in 1986, which would involve men returning from the army and militias to their families, which created this change in behaviour patterns.

According to Stoneburner and colleagues (Low-Beer) “Ugandans are relatively more likely to receive AIDS information through friendship and other personal networks than through mass media or other sources, and are significantly more likely to know of a friend or relative with AIDS. Social communication elements, as suggested by these kinds of indicators, may be necessary to bridge the motivational gap between AIDS prevention activities and behavior change sufficient to affect HIV incidence.”

In other words, Stoneburner is arguing that the social diffusion model in which there is (a) a wide personal acquaintance with HIV/AIDS in the population and (b) the encouragement and willingness to speak about it and pass knowledge on in informal social networks is the method that has worked to influence behaviour change, almost uniquely so far for an African country, in Uganda. The first is the inevitable consequence of a developing untreated epidemic: the second, however, can be influenced by political leadership and widespread awareness-raising work. Such work was, supporters say, initiated by Museveni when he started his AIDS awareness campaign in 1986, which included his famous ‘Zero Grazing’ policy, which urged monogamy on all Ugandans.

We hope we have gone some way in this paper to arguing that gay men with HIV form a separate ‘interest community’ that, relatively unsupported by standard programmes of HIV prevention, has been evolving its own methods and codes to attempt to reduce the frequency with which they pass on their infection. These methods may not look on the surface like standard ‘safe sex’ behaviour at all (though they may do), and there is a dearth of evidence showing if they are having an effect (though there is some).

Supporting gay men with HIV to be the educators of their own community in reducing HIV incidence is a promising new direction in HIV prevention, and should be supported with the funding appropriate to its potential importance.

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