

Positive Prevention for All

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Introduction

Good afternoon.

I'd like to thank the organisers for inviting me to address you today. I'm hoping to take this opportunity to make a contribution to debates about what is called positive prevention, working with or targeting people with diagnosed HIV for HIV/STI prevention, and also to introduce the fourth edition of *Making It Count*, the collaborative planning framework of the CHAPS Partnership for HIV prevention with men in England who have sex with men.

I've called my talk 'positive prevention for all' because the principles behind such work are the same as those for prevention work with all people.

The success a community or country achieves in responding to HIV depends on the extent of solidarity between those of us with HIV and those of us without it. If people with HIV are seen as the problem, a community will fail to respond effectively to HIV within it.

Why do HIV prevention?

'HIV prevention' can be considered a weasel phrase, a word or phrase that creates the impression of something specific and meaningful but which is actually vague and ambiguous.

There are two distinct groups of activities we label 'HIV prevention'.

In the first, we use the term to mean the precautionary actions of people who are at risk of passing or acquiring HIV. These actions might be avoiding sex, choosing non-penetrative sex, using a condom, or seeking post-exposure prophylaxis. We might maintain that only those with the opportunity to be involved in HIV transmission are able to engage in its prevention.

However, we also use the term to mean another and much wider class of activities, done by some people to or with other people, with the intention of influencing them such that they are less likely to be involved in HIV transmission.

We also call these activities 'HIV prevention', although they're so clearly different to the first group of activities that it is curious we use the same word for them.

When we talk about evidence for HIV prevention, it is crucial to distinguish which of these two kinds of prevention we mean.

We also need to clear why we are doing each type of activity. Just as patient education is central to adherence, appreciating the reasons for precautionary measures is key to their enactment.

What about the reasons for our engaging in their promotion?

It saves the country money

We should be wary of justifications for HIV prevention based solely on economics. The argument that we should do HIV prevention because it saves the country money, both sends the message that prevention is not worth spending money on for its own sake, and also encourages us to think the ultimate outcome is saving money rather than improving lives.

While I think programmatic HIV prevention education does save money in the long run, it should not be the justification for doing it. If it is the justification, we are in danger of endorsing methods that create more human misery than they alleviate through the infections they avert.

A strong focus on saving money, as with a strong focus on making money, encourages gaming, competition and deception. One of the things we might do in HIV prevention if our goal were to save money, might be to put less value on the misery we cause in the process. Just as we might be less concerned about the truth if we are writing to sell magazines rather than to educate a reader, HIV prevention driven by saving the NHS money will place different values on both the potential consequences of people's choices when they have sex, as well as the methods we might use to influence those choices.

Most of us are not engaged in HIV prevention because it saves the country money but because, we hope, it reduces misery. It therefore makes no sense to prevent HIV infections using methods that create other misery in the process.

Ensuring people live in fear and isolation, with sex lives that are surrounded by paranoia and distrust, might make sense if all we are trying to do is save money. It makes no sense if we are trying to improve people's lives.

Improve our sex lives

If an organisation's aim is to improve the quality of life of people with HIV, there are few things it could better focus on than improving their sex lives.

In the *What do you need?* survey, a larger proportion of people with HIV were unhappy about their sex life than about any other area of life. Along with anxiety and depression, self-confidence and sleep, sex was one of the four areas of life around which people experienced the most problems.

Now this might also be true for people without HIV - personal and sexual relationships can be a source of both intense joy and intense pain for all of us, as well as being the source of everyday pleasures or mundane dissatisfaction. However, there are good reasons (and plenty of evidence) for thinking sex is particularly problem strewn for people living with HIV.

A lot of these problems arise solely from the way HIV is depicted, regarded and talked about. The majority of problems we face around sex are problems of attitude rather than technique.

However, it is not, as the Bard says, thinking alone that makes things good or bad. Physical problems are also common challenges, including the impact of drugs.

People with HIV, like everyone else, have the right to the best sex with the least harm.

This includes harm to others as well as to ourselves.

While some potential harms arising from the sex lives of people with HIV have been so extensively rehearsed as to be obsessive, the meaning of a good sex life has been little explored and rarely measured.

For the past year I have been engaged in articulating the CHAPS Partnership's approach to HIV among men who have sex with men.

This has resulted in the fourth edition of the framework known as *Making It Count*, which last week was released for consultation.

Making It Count 4 explores a number of choices that men who have sex with men face and will continue to face. The framework proposes that how we all react to these choices collectively determines our HIV incidence. Rather than seeing the HIV infections that occur as the outcome of a small group of 'others', different to ourselves that need finding and fixing, it describes incidence as arising from very widespread and diverse risks being taken by the majority of the population.

The first six choices *Making It Count* explores are as follows:

1. Testing for and treating STIs before our next sex partner (or not)
2. Declining, deferring or dating potential new sex partners (or having sex at the first opportunity)
3. Telling sex partners about our HIV and STI diagnoses (or not)
4. Monogamy (or sexually open relationship)
5. Non-penetrative sex (or anal intercourse)
6. Condoms (or bareback)

For each of the choices, *Making It Count* outlines a set of associated needs that allow people to make the best choice for themselves and their partners.

The needs are broadly divided into those concerned with Motivation and those concerned with Power. What do we want to do? What are we able to do?

I'd like to briefly consider the first four of these choices and highlight some of the issues they raise for men with diagnosed HIV infection.

The first two choices are wound around each other, in that they are about the events of having new sexual partners and having STI screens.

The first choice is available to all of us all the time, unless perhaps when we are having sex. It is whether or not we choose to **test and if necessary treat for STIs before our next sex partner.**

Perhaps the minimum contribution we can make to sexual risk while still having new sexual partners is to have two sexual partners on the trot without testing for STIs in-between them. Even if we engage in non-penetrative sex with both, there is still the possibility of transferring an STI from one to the other. If we engage in penetrative sex that probability increases, and if we do not use a condom it increases again. But non-penetrative sex with multiple partners is not risk free: the probability we have still not picked up and now passing on an STI gets smaller with each new partner. It's getting smaller faster if we have anal intercourse with each one and faster again if we're not using condoms.

For people with HIV on meds, STI's may be the single biggest contributor to increased HIV infectivity, and consequently STI testing and treatment may be the next most important behaviour suppressing infectivity after taking meds.

How many partners is it OK to have before there is a need for an STI screen? We seem to prefer suggesting arbitrary time-periods rather than approach this question.

One of the benefits of undetectable viral load might be being able to have unprotected intercourse without concern for onward infection. However, this is also the activity most

likely to result in an STI which might mean a viral rebound. Which means our uninfected state, if that is what it is, is only as good as the number of men we've had UAI with since our last STI test.

It's been a slow development for HIV care providers to be able to meet the clinical sexual health needs of people with diagnosed HIV infection. For a long time, an assumption prevailed that people with diagnosed HIV should not even be having sex, therefore why would you need to test them for STIs. Addressing these needs acknowledges that people with HIV have sex. Diagnosing and treating STIs acknowledges that people with HIV sometimes have sex which places themselves, and therefore their sexual partners, at risk of STI and HIV transmission.

This has always been a difficult area and is increasingly challenging when the law is hanging over people who risk passing on infectious agents during sex.

The Swiss Statement on HIV infectivity was concerned only with vaginal intercourse in couples with mixed HIV status, where the positive partner has undetectable viral load and is free of other STIs. We need to avoid their claim being reduced to the question of whether or not undetectable means uninfected.

A more important question might be how many sex partners can we have, in particular how many sex partners can we have unprotected intercourse with, and still be confident we are STI free? This question is not peculiar to those of us with HIV.

The 2nd choice occurs when we are faced with the opportunity for sex with a new partner: do we decline, defer or date him or do we have sex with him at the first opportunity?

The profile of the rate at which we acquire new sexual partners is key to HIV and STI dynamics among us. This continues to be a controversial and difficult statement to make in gay communities.

The emergence of HIV provided the sex averse in general and the homophobes in particular with a powerful stick with which to beat us.

Our response to the claim that all gay sex is bad has been to claim that all gay sex is good, and that more gay sex partners is better.

There is often a confusion here between sex and sex partners. The need to be sex positive is often read as a requirement to pretend having many sexual partners is entirely unproblematic. Of course it is not. Especially if we consistently choose not to have STI screen between partners.

However, among gay men generally as well as gay men with HIV in particular, one of the most common reasons for being unhappy with our sex lives is that we would like more sex partners. How useful then, is it to simply tell gay communities (or any other communities for that matter) to reduce our number of sex partners?

Some people *are* concerned that they have too many partners. In *What do you need* it was about 5% of those experiencing problems in their sex life compared with about 60% who had few or no sex partners and wanted more.

We need a population goal which is more nuanced than everyone having fewer partners. In *Making It Count* that goal is articulated as the relationship between the number of sexual partners and the number of STI screens. This allows for both an increase in sexual partners for some men and a reduction in harm among the population.

The **3rd choice is sharing our HIV and STI diagnoses with sex partners, or not.**

Obviously this choice has different potential consequences depending on if we have any infections and if so, which.

In terms of impact on HIV risk and other harms, I think this is the choice about which where everyone can be least confident of the outcomes. While some men prefer an 'always disclose' personal tactic, programmes to encourage blanket disclosure by all men could court harm. The outcomes of HIV/STI disclosure to sexual partners depends crucially on the status of the other partner. It may be that where disclosure occurs to discordant partners it reduces the level of sexual risk (and probably dissolves the sex) but where it occurs to presumed concordant partners it increase sexual risk behaviours. I underline 'presumed' here.

Depending on the harms we are talking about, disclosure is not the foregone better option. Depending on what kind of sex we are planning to have there may well be more to be gained from saying nothing.

Disclosure often opens up the potential for problems. The most salient and difficult problems around sex for people with HIV revolve around conflicting attitudes with sexual partners.

It is also important to note that disclosure faces in both directions. As well as choices about telling sex partners about infections before sex, there are also practical choices to make about telling former partners when we are diagnosed with an STI. Again, threats of the law stepping in may make such interventions less likely.

The **4th choice faces us if we have a regular sexual partner, and is whether or not with have sex with other people as well as our regular partner** – in other words whether we have monogamous or open relationships. A question posed on a gay chat forum recently asked whether an Open Relationship is an Open Grave? Not only does the question equate HIV with death at a time when HIV has never been less likely to kill us, it also assumes that the relationship needs protecting from the external threat of HIV, that HIV is out there rather than in here.

About half of the 30,000 gay men with diagnosed HIV are in relationships and about half of them are in relationships with men without HIV. That's a lot of magnetism. And a lot of sexual choices being made.

Men in sexually open relationships face a double STI risk because they are sharing their risks with their partner. They may also enjoy both the stability of a regular partner and the excitement of new partners. But not all of them. Monogamous relationships between magnetic couples and between same status couples have benefits that are nothing to do with infections and everything to do with good sex. The group of gay men least likely to be unhappy with their sex life are those with one on-going partner.

Although some people may try to deny us these choices, they will remain open to the vast majority of us.

It's common when the choices are made explicit like this for us to assume there must be a correct choice implied. We hear mention of any adverse consequences of something we wish to do as a lecture. We seek to blot out or minimise any potential costs on the horizon so as to better justify our choices. Gay men are not peculiar in being highly sensitive to criticism or disapproval of their sexual choices, but they are perhaps less tolerant of others doing so, often simply having no truck with the opinions of someone we think has judged us.

This makes it a challenge to raise awareness of what is at stake in the choices we are making and make us hesitate before sharing our opinions rather than our knowledge.

We must also be aware that people do not fall into the risky and the risk free.

- We can ask if your idea of the best sex is <<Unconfident about whether we already have gonorrhoea/syphilis, immediate sex with a new partner, Silent sex, and Open relationships>>
- Or whether it is when we are <<Confident of not having gonorrhoea/syphilis, actually No sex, deferred or dated sex, Discussed sex and Monogamous relationships>>.
- In practice lives tend not to fall like this. Instead we are faced with an on-going set of choices that each have the potential for both benefit and cost, utility and harm. We mix and match choices based on our changing circumstances, and the minutiae of our day-to-day lives. Increasing the quality of people choices is what positive prevention is about and positive prevention should be for all.

There are, of course, a number of other and crucial sexual choices facing us in addition to these four: for example, if we have sex whether or not we have intercourse; and if we have intercourse whether or not we use a condom, as well as choices around where ejaculate goes, and (if we do not have HIV) whether we use poppers and whether we seek PEP if we think we have been exposed.

But just as sexual problems are as often an issue of attitude rather than performance, so sexual solutions will I think be found in our relationships with each other, and our relationships to activities other than sex, as much as they will in being able to use a condom, or having access to PEP.

The consultation draft of *Making It Count 4* is available on the Sigma Research homepage and we're listening hard to what people are saying.

Thank you for your attention.

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