

Prospective attitudes to HIV Pre-Exposure Prophylaxis (PrEP)

1. Introduction

The Sigma Panel is a community-based research project investigating HIV precautions among gay and bisexual men in England. It consists of 13 monthly internet surveys recording sexual behaviour and service use in the preceding month alongside a rolling programme of quantitative and qualitative insight questions. The aim is to generate formative and outcome evaluation data to improve sexual health promotion with gay and bisexual men across England.

Each month an Insight Blast provides swift feedback to health promoters on one or more of the ten HIV-related choices described in *Making it Count 4* (2011). This 6th Insight Blast focuses on prospective attitudes to HIV pre-exposure prophylaxis (PrEP), and uses both quantitative and qualitative data. To facilitate the development of research about and access to PrEP, Sigma Panel members (who did not have diagnosed HIV) were asked a series of questions in Month 5 (sent on 1st June 2011) to which 1259 men responded. To find out more about the Sigma Panel or other Insight Blasts go to <http://www.sigmapanel.org.uk>

The Sigma Panel 2011 consists of approximately 1500 men who are sexually attracted to other men. The Panel was predominantly recruited through gay dating websites and contains men with a wide range of sexual lifestyles. The box below describes the Panel in more detail.

Who are The Sigma Panel?

The following was offered to Panel Members at the beginning of the Month 1 survey.

All of you have told us that you are men aged 16 years or over, that you live in England, and that you are sexually attracted to at least some men.

You are living in almost all areas of the country, in cities, towns and rural areas. You share a variety of households: 40% of you live alone, and 27% live with a male partner, while others are living with friends, parents, female partners, children and a range of other people (and pets).

You represent a range of cultural and ethnic backgrounds in roughly the same proportions as the general population; 17% of you were not born in the UK and 14% grew up entirely outside the UK.

You also represent a range of educational backgrounds and current occupations, including sizable groups of men who are students, unemployed, on long-term sick leave or retired. You represent a wide range of incomes.

All of you are attracted to at least some men, and 41% are currently in a steady relationship with a man, about a quarter of which are in a Civil Partnership (or 11% of all Panel Members).

A fifth (20%) of you are also sexually attracted to at least some women, of which a quarter is in a steady relationship with a woman, most of whom are married (about 5% of all Panel members are married to women).

Sexuality plays a variety of roles in your lives, from being centrally important to being somewhat irrelevant to how you think about yourselves. Many of you think sexuality is important but it's not 'the be all and end all'. Other things that are important to how we think about ourselves include: being partners or husbands, family members and friends; being at particular stages of life, and in particular physical or mental health; our class background, education or occupation; our personalities and how we relate to other people.

Together you're expecting to be asked a wide range of questions as a member of the Panel, including your engagement in and opinions about personal relationships, well-being and what makes for a good life.

You'd like an opportunity to both tell us what you do but also how you think and feel about the choices available to you. Some men are hoping to gain some personal insight through taking part in the Panel.

2. The questions

Our Month 5 (June 2011) questions on PrEP were designed to elicit prospective acceptability of PrEP to MSM. Rather than an indication of likely uptake of PrEP the data may better be viewed of indicating the likely extent of community acceptability of the treatment, an important factor when seeking support for research trials and service developments. The questions were developed by Ford Hickson (Sigma Research at London School of Hygiene and Tropical Medicine) in collaboration with Sheena McCormack (Medical Research Council Clinical Trials Unit), Gus Cairns (editor of Nam's *HIV Treatment Update*) and Fabiola Martin (University of York Centre of Immunology and Infection).

The survey page was headed “**Would you take a pill BEFORE sex to reduce your risk of getting HIV?**” Men were first offered the following text:

Please read the following carefully.

Recent research suggests that an anti-HIV drug called Truvada taken EVERYDAY can significantly reduce the likelihood someone picks up HIV if they have unprotected intercourse with an HIV positive partner. Doctors in the UK are wondering if it might be appropriate to offer this drug to people at risk of picking up HIV.

The drug could be offered to HIV negative people attending an STI clinic who are at risk of acquiring HIV, including those who:

- *are diagnosed with an STI;*
- *and/or who have been involved in unprotected intercourse with multiple partners or with a partner may be HIV positive;*
- *and/or who have an HIV positive steady partner;*
- *and/or who keep experiencing condom breakages.*

People who get the drug would need to return to the clinic every three months to retest and to get another prescription.

Truvada is generally well tolerated but it may have some negative physical side-effects (most commonly dizziness, nausea, diarrhoea, fatigue and/or headaches).

PLEASE NOTE THAT TRUVADA IS NOT YET LICENSED FOR PREVENTATIVE USE IN THE UK AND THEREFORE IS NOT CURRENTLY AVAILABLE

Panel Members were then asked the following series of nine questions [response sets in brackets].

Q1. *Had you already heard of the idea of taking a pill BEFORE sex in order to prevent HIV infection?* [No / Yes / Not sure]

Q2. *If you went to an STI clinic and were offered this drug, would you consider using it?* [No / Yes / Not sure]

Q3. *Why do you say that?* [open-ended]

Q4. <if Q2 is No or Not sure> *Do you think this drug should be available to others, even if you would not personally use it?* [No / Yes / Not sure]

Q5. <if Q4 is No or Yes] *Why do you say that?* [open-ended]

Q6. <if Q2 is Yes> *If they had the same protective effect, would you prefer to take a daily pill, or only one pill between 6 and 24 hours before sex, and a second pill 2 to 24 hours after sex?* [Daily pill / One pill 6-12 hours before sex and another pill 2-24 hours after sex / Not sure]

Q7. <if Q6 is other than Not sure> *Why do you say that?* [open-ended]

Q8.<if Q2 is Yes or Not sure> *The drug would not give people 100% protection against HIV. If taken as directed it could be expected to cut the risk of picking up HIV by at least 50%, and potentially up to 90%. If not taken as directed the drug would be less effective at preventing HIV. How would this effect your decision to use the drug?* [open-ended]

Q9. <if Q2 is Yes or Not sure> *If you used the drug, what impact do you think it might have on your sexual behaviour, including your use of condoms?* [open-ended]

3. Awareness and surface acceptability

The following table provides the overall quantitative results.

The Sigma Panel 2011 (Month 5 – June)	% of respondents (n)		
	No	Not sure	Yes
Q1. Had you already heard of the idea of taking a pill BEFORE sex in order to prevent HIV infection? (N=1252)	80.0 (1001)	3.1 (39)	16.9 (212)
Q2. If you went to an STI clinic and were offered this drug, would you consider using it? (N=1253)	17.4 (218)	30.3 (379)	52.4 (656)
Q4. Do you think this drug should be available to others, even if you would not personally use it? (N=592 men who said they would not use PrEP or were not sure if they would)	6.8 (40)	27.2 (161)	66.1 (391)
	Daily pill	Not sure	Before & after pills
Q6. If they had the same protective effect, would you prefer to take a daily pill, or only one pill between 6 and 24 hours before sex, and a second pill 2 to 24 hours after sex? (N=649 men who said they would consider using it)	54.9 (356)	17.7 (115)	27.4 (178)

Current awareness of PrEP as a concept is relatively low: 17% had heard of it.

Prospective acceptability is high: 52% would consider using it and only 3% overall thought it should not be available to others.

We found no differences in the proportion who would consider using PrEP by age, education, sexual identity, outness or household composition.

Men who had regular partners in the last month were least likely to consider using it (45.3%, 150/331), followed by those who had no sex in the last month (50.0%, 132/264). Those with casual partners only were more likely to consider using (54.9%, 140/255) while those with both regular and casual partners were most likely to consider using (57.7%, 224/388).

Interestingly, considering using PrEP use was no more common (55.0%) among the 20 panel members who had a regular sexual partner with diagnosed HIV.

Among those who said they would consider using PrEP, daily pills were thought preferable by twice as many men as before-and-after pills.

INSIGHT: Surface acceptability of PrEP among gay and bisexual men in England is high. There should be considerable community support for research and service developments addressing this treatment.

4. Reasons for considering or not the use of PrEP

When asked “*If you went to an STI clinic and were offered this drug, would you consider using it?*” (N=1253) over half of the respondents said ‘yes’ (52.4%, n=656), almost a third said ‘not sure’ (30.3%, n=379) and the remainder said ‘no’ (17.4%, n=218). Irrespective of their answer, men were asked the open-ended question “*Why do you say that?*”

4.1 Why I would not consider using PrEP (17.4% of respondents)

Of the 218 men who said they would not use PrEP, 203 responded to the open-ended question. “*Why do you say that?*” Reasons for not considering the use of PrEP revolve around the balance between the (perceived low) benefits and (perceived high) costs of doing so. The main reason for absence of perceived benefits was the absence of the risk that PrEP could reduce, either because men thought they had no sex with HIV infected men, or their sexual behaviour did not place them at risk if they did (or a combination of these two).

A second absent benefit for these men was that of unprotected intercourse. Men stated that they preferred to use condoms, citing a number of reasons: they are more convenient than PrEP, they are more effective than PrEP, they protect against things other than HIV, and some men find UAI no more pleasurable than using a condom.

A third reason for judging PrEP to have limited benefits related to its perceived ineffectiveness both at preventing HIV but also its inability to prevent other risks associated with UAI. A fourth minority view of the absence of benefit of PrEP concerned disbelief in the casual relationship between HIV and AIDS.

As well as a lack of perceived benefit, men cited the potential costs of PrEP to be too high for them. Some men try to avoid drugs altogether and others do not like the idea of continuous prophylaxis, while others mentioned the unlicensed and experimental nature of the drug and its potential side-effects (some men had bad experiences of PEP and likened PrEP to this).

A different kind of cost to these physical impacts was the impact taking PrEP was thought to have on the kind of person you are. Some men see taking PrEP as indicating an irresponsible person, and that since they are a responsible person they could not be taking PrEP. Taking PrEP *in order to* take sexual risks conflicts with some men’s notions of themselves as responsible people.

INSIGHT: Many men envisage the only situation they would need PrEP in would be a situation they would never put themselves in – sero-discordant UAI. The utility of PrEP as a public health intervention for reducing HIV incidence depends on the proportion of exposures resulting in infections that are cognizant (men are aware of the risk involved in their practice) or naive (men are engaging in the practice only because they believe it is not a risk).

INSIGHT: Men overestimate the effectiveness of condoms, thereby reducing their perception of potential benefit of PrEP.

4.2 Why I'm not sure if I would consider using PrEP (30.3% of respondents)

Of the 379 men who said they were 'not sure' if they would consider using PrEP, 344 gave a response to *Why do you say that?* The content of men's reasons for saying 'not sure' were very similar to those for saying 'no' - too little benefit (absence of HIV infected sex partners and/or risk behaviour, insufficiently effective) and too much cost (side-effects and interactions, hassle of daily drug taking, increased risk taking)

Not feeling sufficiently informed to make a decision was (unsurprisingly) more common in the 'not sure' group, as was recognising circumstances might change. For example, some men thought they might use PrEP if they had an HIV positive partner. However at least one man with a current positive partner said he would not take it because he believes the risk is already very low, indicating that this intention will not always be carried through.

4.3 Why I would consider using PrEP (52.4% of respondents)

Of the 656 men who said 'yes', they would consider the use of PrEP, 586 gave a reason. Men would take PrEP because they do not want to get HIV. Several said they assume the drug will work (because they trust clinical STI services) and the side-effects would be tolerable.

These men recognised that all sex carries risk and that any reduction in risk (or increase in protection) is a good thing. They noted it is better to be safe than sorry (an insurance policy) and that PrEP could bring peace of mind and reduce worry (which is ruining the sexual lives of some men).

Men saw PrEP as having the potential to both reduce the harm associated with the sex they were having, and also to facilitate the sex they would like to have by reducing the risk associated with it.

Men with a wide range of behaviours saw PrEP as able to reduce risk in the sex they already had. This benefit was perceived by men who always used condoms, recognising condoms were not 100% precaution, particularly those who had multiple or known positive partners. It was also perceived as useful by men who recognised their behaviour as carrying a higher degree of risk. This included men who regularly engaged in UAI (or take ejaculate in their mouth) with positive or multiple partners, and those who did so only occasionally when they were not in control (intoxicated, submissive, assaulted). In this case men did not see PrEP as influencing their sexual behaviour but in reducing the risk associated with what already happened.

Other men saw PrEP as having the potential to enable them to have sex they want to have but do not have because it currently carries too much risk, including men who value unprotected anal intercourse and those who value taking ejaculate in their mouths. This includes men who do not trust condoms, or who lose an erection with a condom, or who are turned down by partners when

they insist on using a condom, or who would value unprotected intercourse with their HIV positive partner. These men anticipated that the protection afforded by PrEP would influence their sexual behaviour towards sex they preferred.

INSIGHT: The contexts and reasons for willingness to take PrEP will vary across sexual relationships and sexual acts; many men who do not meet the qualifying criteria for PrEP may seek it.

INSIGHT: PrEP can be expected to both reduce harm associated with current sexual behaviours but also to facilitate better sex for men who currently consider the risks as too high.

5. Reasons for thinking PrEP should or should not be made available

The 592 men who said they would not consider using PrEP, or were unsure if they would consider using it (47.7% of all respondents), were asked *Do you think this drug should be available to others, even if you would not personally use it?* Of those asked, 6.8% (n=40) said 'no' and 66.1% (n=391) said 'yes'. All were asked the open-ended question *Why do you say that?*

5.1 Why PrEP should not be made available

Of the 40 men who thought PrEP should not be made available, 37 gave a reason. Above we noted that some men saw UAI as an erotic and desirable behaviour that PrEP may make possible. Here, men saw it as stupid, irresponsible and risky and the main reason not to make PrEP available. Men who said PrEP should not be made available thought men should use condoms, or should not be promiscuous.

Some felt non-condom use is a social problem and equating condom use with PrEP questioned why men who could not 'be bothered' with condoms would not bother with PrEP. In addition, PrEP for HIV was recognised as not protecting against other STIs and increases in partner change and UAI accompanying PrEP would fuel other STIs.

The cost to the NHS was mentioned as a reason not to provide PrEP, especially in the context of sexual pleasure seeking. Several men pointed to the balance between the protection it brings and the risk it facilitates, and that a public health decision should be based on these parameters.

INSIGHT: Both those who welcome and those who will resist PrEP acknowledge it will increase UAI rates. It is the value they place on UAI that differs.

5.2 Why PrEP should be made available

Of the 391 men who said they thought PrEP should be made available to others (although they would not or were unsure if they would personally use it), 339 gave a reasons for their opinion.

Men who felt PrEP should be available to others (although they themselves might not use it) cited broadly similar benefits of PrEP as those who said they would use it – HIV is undesirable and, for whatever reason (ignorance, weak-will, foolishness, intoxication, lack of life-skills, sexual preference), many men have risky UAI. Any reduction in its risk should be welcomed. These men felt people should be given a choice of whether to use PrEP or not (rather than PrEP being withheld because they do not 'behave themselves'). These men (the majority) recognised that people's circumstances, values and capacities are different.

However, fewer men in this group suggested PrEP would allow other men to have sex they did not currently have.

Availability did not mean open-access and some men pointed out that PrEP would be particularly beneficial in certain contexts (positive partner, sex workers). Others suggested PrEP should be one of a range of interventions on offer.

Some pointed out the cost of a single HIV infection and that a PrEP programme for high-risk men may be cost-saving, while others suggested it should be available but that users should pay (or part pay) for it as this would increase its value to users.

INSIGHT: The reasons men would support PrEP being available are the same reasons as men would take it. Freedom to choose how to reduce risk is a strong value among MSM.

6. Reasons for dosing preferences

The 649 men who said they would consider using PrEP if offered it were asked: *If they had the same protective effect, would you prefer to take a daily pill, or only one pill between 6 and 24 hours before sex, and a second pill 2 to 24 hours after sex?*

Overall, 54.9% (n=356) said they would prefer a daily pill, and 27.4% (n=178) indicated a preference for before-and-after dosing. The remaining 17.7% (n=115) were not sure. Men who expressed a preference for one regime over the other were asked “*Why do you say that?*”

6.1 Reasons for preferring daily dosing

Of the 356 expressing a preference for daily dosing, 311 gave a reason for that preference. These men pointed out that sex is often spontaneous and when sex happens is unpredictable. A daily pill eliminates the need to know 6 hours in advance, to have to turn down an offer or to take a risk not having taken a pill. A daily pill is a routine or pattern which would develop into a habit and therefore easier than having to think about it. Some men suggested it go with their daily vitamin pill. Others likened it to oral contraceptive. Taking it every-day meant they would be less likely to forget to take it. Some men felt it would provide more protection because it would involve more drug in the body (building up greater resistance to HIV).

INSIGHT: Despite being more pills a daily dosing was seen as more convenient as well as being more likely to be used before sex.

6.2 Reasons for preferring before-and-after dosing

Of the 178 men who expressed a preference for before-and-after dosing, 154 gave a reason for that preference. These men also felt before-and-after dosing would be easier and more convenient. Some noted their lack of compliance with other daily regimens made it unlikely they could take a daily pill. Others already took a daily pill and did not want to add to it.

Frequency and planning of sexual encounters are central to the choice of daily or before-and-after. Men preferring before-and-after doses perceived themselves to have sex (or anal intercourse or unprotected anal intercourse) less frequently and with more planning and forewarning. They therefore felt that a daily pill would be overkill.

Some did not like the idea of taking pills all the time, feeling it would result in more side-effects or give the impression of greater protection than was in fact the case. Men noted that a before-and-after regimen would be cheaper. Pill burden could be reduced again if sex (or risk) did not happen, by not taking the second pill.

INSIGHT: Despite requiring more foresight and planning some men preferred the concept of before-and-after PrEP dosing rather than daily dosing.

7. Impact of extent of protection on intention to use

The 1035 men who at Q2 said they would consider using PrEP, or were unsure if they would use it, were asked the following: *The drug would not give people 100% protection against HIV. If taken as directed it could be expected to cut the risk of picking up HIV by at least 50%, and potentially up to 90%. If not taken as directed the drug would be less effective at preventing HIV. How would this effect your decision to use the drug?* Overall, 895 men responded to this question (568 who said they would use, and 327 who said they were unsure if they would use it).

Among those men that had previously said they were *unsure* if they would consider using PrEP, this additional information about likely efficacy (50-90%) usually undermined the possibility they would use the treatment. All had been uncertain anyway, and this additional information usually either made them less likely to want to use it, or even less certain what they might do. Some commented that they would expect it to be 100% effective (or very close) and compared PrEP adversely to the contraceptive pill and condoms which were widely perceived to be “99% effective”. Some men also felt less certain of whether they would be willing to take PrEP based in the additional information on the need for adherence - many felt they would need to know substantially more about adherence (and side-effects) before they decided if they would take it. A minority of men that had been unsure whether they would consider using PrEP were not adversely affected by the additional information on efficacy or adherence, and many of these stressed that they still felt it might make an additional contribution to their goal of avoiding HIV infection, especially if they found themselves in a sero-discordant relationship, or having a lot of new partners.

Among men that had previously said they would consider using PrEP, this additional information about likely efficacy did not usually change their mind. While many of the same issues were raised, most were not adversely affected by the additional information on efficacy or adherence, and very many stressed that they felt it might make an additional contribution to their goal of avoiding HIV. However, the vast majority asserted very clearly that they saw PrEP as additional protection, and that they would continue to use condoms to the same extent as they already did.

INSIGHT: The efficacy of PrEP will have an impact on its attractiveness and acceptability to gay and bisexual men, but men using PrEP as an additional precaution would still consider it even with lower efficacy.

8. Impact of use on sexual behaviour

Finally, the 1035 men who at Q2 said they would consider using PrEP, or were unsure if they would use it, were asked the following “*If you used the drug, what impact do you think it might have on your sexual behaviour, including your use of condoms?*” Overall, 906 men responded to this question.

The vast majority of all responses stated unequivocally that PrEP would have no impact on their sexual behaviour, especially in relation to condoms.

Almost a third of all men answered simply that PrEP would have no impact on their sexual behaviour. Many answered very simply (“no change”; “no difference”; “no effect”; “no impact”; “none at all”). However, not all these men were stating that they would continue to use condoms and lubricant consistently. Some expressly noted that using PrEP would not change their behaviour but might allow them to be more relaxed about not using condoms (or taking ejaculate in their mouths). Others noted no change to their behaviour but felt they might be more relaxed or confident or less anxious about the sex they have.

Another third of all responses inferred no change, but much more clearly stated that they would continue to use condoms, and/or maintain whatever other precautions they currently took. Many of these men noted that PrEP might reduce their anxiety (often concerning oral sex) and allow them to have better sex, but all noted that they would continue to use condoms for the anal intercourse. Some stressed the protective value of condoms for other STIs, but many simply could not imagine having unprotected anal intercourse.

The remaining responses accepted that PrEP would, or might, change their behaviour, specifically allowing them to have more unprotected anal intercourse and / or more partners. Many considered that it might make them “less responsible” or “more reckless”, but very few stated that it would make them entirely unconcerned about sexual risk. Many said they would still only have UAI with a regular partner, or someone they trusted not to have HIV. Others that they would still use condoms with men they knew to have HIV, or that they would have sex with men they knew to have HIV, but still not have anal intercourse. Some articulated a specific fear that it could or would make them less concerned about sexual safety, while many stressed it might change their behaviour but they hoped it would not.

Some specifically alluded to the efficacy of PrEP feeling a 90% effective treatment might impact their behaviour but 50% effective would not. Others stressed a desire to have a 100% effective treatment before it would have a significant effect on their sexual practice.

INSIGHT: The impact of PrEP on sexual behaviours will be very varied, with many men expecting to use it supplement their current precautions, and others expecting it to facilitate behaviours they currently consider too risky. The impact on sexual behaviour will be related to its perceived efficacy.

Suggested Citation: Sigma Research (2011) *The Sigma Panel Insight Blast 6: Prospective attitudes to HIV Pre-Exposure Prophylaxis (PrEP)*. London: Sigma Research. October 2011.