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PEP talk

*Awareness of, and access to
post-exposure prophylaxis among
Gay & Bisexual men in the UK*

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Peter Weatherburn

Original Research Report

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As ever, our greatest debt is to the men who participated in the research by completing the *Gay Men's Sex Survey* (GMSS) in 2003 or 2005, or taking part in follow-up interviews in 2005. Without their willingness to honestly share their personal experiences, this research would not have been possible.

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1 PEP and its uses

This report presents the findings from a study investigating homosexually active men's awareness and access to post-exposure prophylaxis (PEP) following potential sexual exposure to HIV. The study consisted of two arms. In the first, identical questions on PEP were asked in the *Gay Men's Sex Survey* in 2003 and 2005 to examine population level and sub-group changes in awareness over a period where the public profile of PEP was increased. In the second part, men who had at least one experience of attempting to access PEP took part in detailed one-to-one interviews. This qualitative data offers a detailed insight into men's awareness of the treatment, what prompted them to seek help, their satisfaction with the clinical experience and follow-up, and their subsequent behavioural intentions and practices in relation to HIV risk.

The remainder of this chapter offers a brief introduction to PEP and its use, by reviewing existing academic research and commentary on PEP (mainly focussing on its use outside of the occupational setting). It also provides background information on developments relating to PEP following sexual exposure in the UK context. Chapter 2 presents the quantitative data, and Chapter 3 presents a thematic analysis of the information gained from the one-to-one interviews. In the final chapter, we present conclusions drawn from the findings of both arms of this investigation, as well as practical recommendations regarding meeting the PEP-related needs of individual men at risk of HIV exposure, and the needs of professionals working towards full implementation of the UK guidelines on PEP following sexual exposure to HIV.

1.1 INTRODUCTION TO PEP

The notion of using anti-retroviral therapies to prevent HIV sero-conversion emerged following on from laboratory and animal testing of the technology for its efficacy in various transmission settings (Tsai *et al.* 1998, Otten *et al.* 2000) and its highly effective use in the prevention of mother-to-child transmission. As scientific understanding of the pathogenesis of HIV has improved, it has been possible to hypothesise about the best uses of available anti-retroviral medications as post-exposure prophylaxis (PEP). Immediately following HIV exposure, there is an infection of dendritic cells at the site where exposure occurred. Those infected cells then travel to the nearest set of lymph nodes during the 24-48 hour period immediately following exposure. The theory behind the use of PEP is to halt the onward development and 'settlement' of HIV infected cells within the lymph system (and onward to a full systemic infection) by initiating anti-retroviral treatment during that brief window of time that is available before systemic infection takes place (Almeda *et al.* 2004). There is some variation in views on how long that initial window period is, with some protocols disallowing access to PEP where a patient presents more than 36 hours after exposure (Ende *et al.* 2006), while others allow for treatment up to 72 hours later (Centres for Disease Control and Prevention 2005, Fisher *et al.* 2006). All existing protocols recommend that treatment is maintained consistently for twenty eight days. Evidence from animal and human studies demonstrate that the sooner the PEP is initiated, the higher the likelihood of success (Tsai *et al.* 1998, Roland *et al.* 2005).

Protocols for the use of PEP following needle-stick injuries sustained by healthcare and emergency services staff in the occupational setting have been developed and implemented on a widespread basis (Rey *et al.* 2000). However, across the developed world (where access to anti-retroviral medication is relatively affordable and accessible), access to PEP following sexual exposures (sometimes referred to as PEPSE) has been much more sporadic, and it would still be difficult to argue that there is scientific or medical consensus on its use. France instituted national guidelines for PEP following sexual exposure in 1998, yet in other locations, guidelines were not introduced until 2001 (Australia), 2005 (United States) and 2006 (UK), and some countries (ie. Canada) remain

without national guidelines regarding exposures that are not occupational. While the debate about the scientific basis for the use of PEP following sexual exposure continues, existing national guidelines advance the notion that in the absence of randomised control trials, there is a strong enough biological argument on which to base an expectation of efficacy.

1.2 ACADEMIC AND PRACTITIONER DEBATES

In this section we briefly highlight some of the central issues arising from scientific and practical discourses about the use of PEP following sexual exposure as they relate to the themes arising from the research findings presented in subsequent chapters. More detailed reviews on these topics are also available elsewhere (Pinkerton *et al.* 2004, Almeda *et al.* 2004, Centers for Disease Control and Prevention 2005, Fisher *et al.* 2006).

The most frequently cited studies on PEP following sexual exposure took place in Brazil and the USA. In one Brazilian project, homosexually active men were given PEP supplies to commence immediately after sexual exposure (Schechter *et al.* 2002), whereas in the other, HIV outcomes for men who received PEP within the 72 hour period were compared to those who presented later (Schechter 2002). In both these studies, men who took PEP following potential sexual exposure to HIV were less likely to sero-convert than men who had not.

The other key project in this area is referred to as the San Francisco PEP Study, which explicitly did not set out to examine efficacy (as in the Brazilian work). Instead, articles emanating from the San Francisco study report on feasibility of accessing PEP among those at high risk of transmission (Kahn *et al.* 2001), cost effectiveness of treatment (Pinkerton *et al.* 2004) and subsequent behavioural impact (Martin *et al.* 2004). This collection of articles provide an underpinning for the development of an evidence base on the implementation of PEP following sexual exposure from the point of view of epidemic impact. They sustain strong arguments for the judicious use of PEP following occasions where it is either established or likely that the source patient is HIV infected.

Kahn *et al.* (2004) report that the use of PEP following sexual exposure is feasible and acceptable within communities where HIV is prevalent, and that in most instances, those seeking PEP described a lapse in their usually cautious sexual practices, rather than habitual high-risk behaviour. This latter finding is supported by a study undertaken in Australia which will be discussed in greater detail below (Körner *et al.* 2003, 2005).

One of the concerns raised by health practitioners has been the extent to which offering PEP following sexual exposure will increase the strain on service provision and already escalating treatment costs at a local level (Richens *et al.* 2005). Fisher (2005) responds directly to this concern by highlighting that cost arguments are not queried in relation to treatment following occupational exposures, despite much lower risks of transmission in these circumstances, and that modelling studies have demonstrated that PEP following sexual exposure is cost saving when appropriately administered. He refers here to the work of Pinkerton and colleagues (2004), who assessed cost effectiveness outcomes for 96 different metropolitan areas in the United States, recognising that local HIV prevalence rates would impact on the costs per transmission averted. They found that cost effectiveness increased with improved targeting of people involved in high-risk exposures, particularly those where the source was known to have HIV, and that PEP following receptive anal intercourse was cost effective in all metropolitan areas, regardless of whether the source was known to have HIV.

Another key issue that is raised in relation to PEP following sexual exposure is the extent to which it could contribute to a so-called 'optimistic bias' effect on sexual behaviour, to the extent that those who know about PEP might be more likely to engage in sexual behaviour that carries a high risk of HIV transmission as a direct result of that awareness.

We believe there is a distinct danger that the promotion of PEPSE could reinforce rising trends in sexual behaviour and might add to, rather than lessen, HIV transmission. (Richens, Edwards & Sadiq 2005: 190-191)

However, this claim is refuted by a range of research investigations which have demonstrated that this type of simplistic relationship between PEP awareness and risk behaviour does not exist. Quantitative research undertaken in the United States to address this question has used a range of methods. Results from a survey conducted among an opportunistic sample of Gay men in San Francisco (Waldo *et al.* 2000) indicated that knowing about PEP at all may have increased men's likelihood of engaging in unprotected anal intercourse (UAI), but that knowing that PEP was available locally did not – again, challenging notions of a straightforward relationship between knowledge and behaviour. Those analysing twelve month follow-up records from the San Francisco PEP Study noted that those with a high level of risk behaviour at baseline (before being prescribed PEP) were the most likely to gradually revert to prior behaviours, but that PEP access was not an independent influence on subsequent behaviour (Martin *et al.* 2004). The authors point out that this is not a surprising finding within a context where 41% of respondents reported a high risk of being exposed to HIV within the three months before their initial request for PEP. This chimes with other studies demonstrating that HIV high risk behaviour may neither increase nor decrease HIV infection among those who have taken PEP (Grulich *et al.* 2006). One randomised control trial that tested the effectiveness of standard versus enhanced risk reduction counselling for individuals on PEP (Roland *et al.* 2006) found that enhanced provision (five counselling sessions as opposed to two) was most effective for those with the highest baseline level of risk.

1.3 HEALTH PROFESSIONALS' AWARENESS AND PRESCRIPTION OF PEP FOLLOWING SEXUAL EXPOSURE

Research that explores knowledge, behaviour and attitudes relating to PEP following sexual exposure usually concentrates on the views of doctors. While being aware of the time-sensitivity of much of the work in this area, various research teams have sought to establish the extent to which doctors working variously in General Practice, Accident and Emergency departments, and other hospital settings were aware of PEP either for occupational exposures, non-occupational exposures, or both (the configuration of different national and regional health care systems will dictate the extent to which these different types of practitioners would encounter patients with concerns about HIV exposure). In most instances, it has been demonstrated that professionals' knowledge of PEP and its different applications is patchy at best. For example, in 1998 a postal survey of 273 junior doctors in two teaching hospitals in London, found that while the vast majority of respondents knew of the existence of PEP, just under one third did not know the recommended time period in which it should be administered (Chen *et al.* 2001). A study undertaken among GPs in Sydney, Australia in 2002 (Ooi *et al.* 2004) demonstrated that more than two thirds were aware of the use of PEP following occupational exposures, while only a third had heard of its use following sexual exposure.

It has been demonstrated that the introduction of national guidelines for the provision of PEP after non-occupational exposures contribute to the improvement of HIV specialists' attitudes towards prescribing treatment following voluntary sexual exposure (Laporte *et al.* 2002), yet this impact would not seem to be replicated in studies that focus on the practices of doctors in emergency department settings. Among an opportunistic sample of 600 Emergency practitioners (Merchant & Keshavarz 2003), 68% had administered PEP, with the vast majority of those cases relating to occupational exposure. A distinct difference was noted between the numbers of those reporting PEP following non-consensual sex (48%) and consensual sex (8%). This differential treatment might be bolstered in some settings by protocols to treat all penetrative sexual assault cases with PEP.

A further study conducted among Emergency Departments in New York State found that 65.3% of sexual assault exposures that presented in 2005 were treated with PEP, but that only 42.7% of so called 'voluntary exposures' were similarly treated (Ende *et al.* 2006). It would seem clear that attitudes about 'innocent' and 'guilty' victims of HIV exposure remain entrenched in discourses and policies pertaining to PEP at a professional level. As one commentator notes:

Most health care workers are empathetic to a colleague who sustained a work-related injury. This empathy, however, may not extend to an individual who has participated in a high-risk activity. Although physicians may not condone the behaviours exhibited by an individual with non-occupational exposures, they continue to have an obligation to act in the best interest of the patient. PEP should be considered as one of the therapies available to this population when they have an *isolated*, high-risk exposure to HIV.

(Spence 2003: 5)

Given the disproportionate concern surrounding community and occupational exposures to HIV it is not surprising that some doctors with both HIV specialist and emergency care backgrounds have a tendency to prescribe PEP when it is not warranted (Braitstein *et al.* 2002, Laporte *et al.* 2002, Patel *et al.* 2002).

1.4 HOMOSEXUALLY ACTIVE MEN'S AWARENESS AND EXPERIENCES OF PEP FOLLOWING SEXUAL EXPOSURE

In contrast to the existing literature on doctors and PEP following sexual exposure, there is comparatively little known about the PEP-related knowledge, attitudes and behaviours of individuals most at risk of HIV exposure. The work that does exist focuses on homosexually active men, which is unsurprising considering the epidemiological profiles of most countries where PEP is affordable and available.

Among populations of homosexually active men, awareness and access to PEP following sexual exposure is contingent on the existence of local and national protocols, and the extent to which community information campaigns have been successful. For instance, the small scale survey study by Waldo, Stall and Coates (2000), sampled Gay men in San Francisco community settings before and after a high profile PEP campaign in that city. Despite the limitations of a small sample size (n= 295 at Time 1, and n=234 at Time 2), the findings demonstrated that 58% were aware of the concept of PEP following sexual exposure at baseline, which increased to 70% following the intervention. This study was undertaken long before the implementation of national guidelines on PEP following sexual exposure in the United States. In contrast, a prospective cohort study of HIV negative homosexually active men, started in Sydney in 2001, found that men's awareness of PEP at the outset was 78.5%, which increased to 97.4% by the time of the fourth annual interview (Grulich *et al.* 2006). Guidelines recommending the use of PEP following non-occupational exposures were introduced in New South Wales in 1998, and across Australia in 2001.

A qualitative study also undertaken in Sydney offers significant insight into the narratives, motivations, experiences and reflections of men who have taken PEP following sexual exposure (Körner *et al.* 2003, 2005). As part of a wider study in New South Wales that aims to monitor the implementation of guidelines on PEP following sexual exposure in Australia in 2001, those who had received PEP were invited to take part in an interview arm, designed to establish the circumstances under which PEP was requested and the impact of prescribing PEP on behavioural intentions (Körner *et al.* 2003). Of the 84 respondents, a total of 77 were homosexually active men. One of the central findings of this work was that PEP was used as a means of reclaiming control over unusual situations that had resulted in unexpected exposure to HIV among individuals who tended to have a low baseline level of sexual risk.

One theme which runs like a leitmotif through all the issues raised in the interviews is that of control: control over sexual practices; control in the post-exposure period; control over decision making processes and disclosure; and taking control in the future.

(Körner *et al.* 2003:10)

Many of the men in this sample described sexual contexts and situations that were outside of their own norms, some had just broken up with long term partners, or they had sex at a house that wasn't their own, or they were dealing with stress in other areas of their lives. To this extent, potential HIV exposure came as a surprise to them, and accessing PEP was at least in part a means of restoring order. Men described feelings of shame and stupidity about the circumstances that led to their exposure, which posed a significant barrier to telling others about being on PEP.

PEP for sexual exposure involves much more than unprotected intercourse and a four-week course of anti-retroviral drugs. It entails admitting mistakes, failure, bad luck, losing control, disappointment for letting one's standards drop, acting in spite of one's better knowledge and dealing with emotions of anger and anxiety.

(Körner *et al.* 2003: 48)

Men in this study tended to feel that the experience had helped them to realise that HIV exposures don't only happen to others, that they too were vulnerable. Given that interviews were held within six months of men's exposure experiences, it was not possible to determine the longer term behavioural impact, but most expressed a desire to avoid HIV exposure in the future.

Nonetheless, it is also worth bearing in mind that a separate piece of quantitative research also undertaken in Sydney found that men who had been prescribed PEP continued to be at high risk of subsequent HIV infection (Grulich *et al.* 2006). Here, analysis demonstrated that during the course of their participation in an ongoing cohort study (started in 2001) men who had ever received PEP were 2.82 times more likely to become infected with HIV than men who had not received PEP.

1.5 PEP FOLLOWING SEXUAL EXPOSURE IN THE UK

In order to place this research report in its context, it is important to highlight a number of events before, during and after the data collection period. These include: the inclusion of PEP-related aims in *Making it Count* (Hickson *et al.* 2003a); the development and publication of a UK prescribing guideline for PEP following sexual exposure; and a CHAPS campaign (in England and Wales) to increase awareness of PEP among homosexually active men.

The *National Strategy for Sexual Health and HIV* (Department of Health 2001) does not mention post-exposure prophylaxis (PEP). Moreover, the Chief Medical Officers Expert Advisory Group on AIDS (EAGA) has stated that "it is aware that some physicians have prescribed PEP outside the occupational exposure context, on an individual case-by-case basis. However, due to lack of any evidence of efficacy, at present EAGA cannot recommend in favour of, or against its use." (Department of Health 2004, p 20).

The current edition of *Making it Count*, the CHAPS HIV prevention strategy, includes targets concerning PEP (Hickson *et al.* 2003a). For the first time in 2003 *Making it Count* included a population target of increasing the proportion of men who have sex with men (MSM) who are sexually exposed to HIV who take PEP within 72 hours of exposure. *Making it Count* also outlines a number of needs men who have been sexually exposed to HIV have related to accessing PEP, including:

- awareness of PEP;
- the existence of accessible, acceptable and effective PEP prescribing services;
- knowledge of and trust in local PEP services; and
- understanding of the potential and limitations of PEP.

Making it Count also outlines the needs men who access PEP have that are related to the successful completion of the course of drugs, including:

- knowledge of how the drugs work and the importance of completing the course to their efficacy;
- clinical monitoring for side-effects;
- space to talk over conflicting emotions about continuing taking the drugs versus the chance of becoming infected.

The research presented in this report concerns a number of these needs, starting with quantitative data about basic awareness of PEP's existence and actual attempts to access and take PEP. While the latter are not direct measures of the proportion of men exposed to HIV who take PEP, they are general indicators of progress in this measure. Qualitative information was also collected in order to gain a more detailed understanding of men's experiences relating to PEP. This has allowed us to gain considerable insight into the range and accessibility of PEP prescribing services, and the extent to which men who were prescribed PEP experienced clinical monitoring and support in terms of adherence, side effects, psychological impact and behaviour change.

In April 2004, the Clinical Effectiveness Group within the British Association for Sexual Health and HIV (BASHH) released for consultation a draft set of guidelines on the administration and prescription of PEP following sexual exposure to HIV. BASHH is a professional representative body for sexual health professionals in the UK, including those involved in the management of STIs and HIV. The draft guidelines included a review of data to support the use of risk assessment frameworks, recommendations on when PEP should and should not be considered, the possible impact on sexual behaviour, cost effectiveness and best practice service provision.

Between July and September 2004 the Terrence Higgins Trust ran a pilot multi-part education intervention about PEP targeting Gay men and Bisexual men, on behalf of the CHAPS partnership. The intervention was targeted at men resident in London and Brighton & Hove. It comprised four methods:

- Full-page colour adverts were displayed in the following local Gay community magazines and newspapers: *QX* (London), *G-Scene* (Brighton) and *3Sixty* (Brighton).
- An educational leaflet was produced and distributed hand-to-hand by outreach workers and in leaflet racks on the Gay scene in both London and Brighton & Hove. The leaflet was also inserted in the July issue of *QX* magazine in London.
- A variety of promotional materials reflecting the campaign imagery were designed for use during outreach sessions, both as ice-breakers and reference items for men to take away and keep. Included were fridge magnets, sticks of rock, small wallet sized (A8) information cards and quiz cards (A6) in question and answer format. Bar-staff were also offered t-shirts with the campaign imagery.
- An internet micro-site was established which carried the advert and leaflets as well as a self-administered risk assessment too. It also included a list of clinics known to prescribe PEP, a section for health professionals and some suggestions for community action in areas where PEP was not available. The website was promoted on all written materials and via banner adverts on www.Gaydar.co.uk

Evaluation of the intervention indicated it was acceptable to its target audience and effective at increasing awareness and knowledge of PEP (Weatherburn 2005).

In the summer of 2005 the same campaign was implemented across England and Wales. The same full-page colour adverts appeared in one weekly (*Boyz*) and five monthly (*G-Scene*, *Gay Times*, *Out North West*, *Midland Zone* and *Bent*) Gay media titles between June and August 2005. The educational leaflet was distributed nationally as were the promotional materials for use during

outreach. The internet micro-site was updated and additional investment in www.Gaydar.co.uk was purchased for its promotion.

It was not until February 2006 that the finalised version of the BASHH guidelines were published (Fisher *et al.* 2006), but in the interim it was expected that the draft document could function as a *de facto* framework to assist decision making on risk assessment and provision of PEP following sexual exposure. The text of the document did not change significantly from its draft form apart from some clarification on what constitutes high prevalence communities for the purposes of risk assessment. The published guidelines made it very clear that the provision of this new technology should be situated within the broader context of HIV prevention strategies and sexual health.

The writing committee feel it is crucial to consider PEPSE as only one strategy in preventing HIV infection and, as such, it should be considered as a last measure where conventional, and proven, methods of HIV prevention have failed.

(Fisher *et al.* 2006: 84)

In spite of the prior comments of the Chief Medical Officers Expert Advisory Group on AIDS (Department of Health 2004) the publication of these guidelines received direct support from the Chief Medical Officer. In April 2006, in a letter addressed to all Primary Care Trust Chief Executives and Directors of Strategic Health Authorities the Chief Medical Officer stated that:

I would therefore ask you to ensure that PEP is a part of the spectrum of sexual health services for your local populations.

(Donaldson 2006)

2 Changes in PEP awareness, seeking and using

2.1 METHODS

The *Gay Men's Sex Survey* (GMSS) is an annual, community-based, self-completion questionnaire generating data about HIV prevention risk behaviours and needs. Field work occurs from July to September each year. The survey changes each year, drawing on a stock of behavioural and needs indicators based on *Making it Count* (Hickson *et al.* 2003a). The survey is funded by the Terrence Higgins Trust as part of the CHAPS programme for England and Wales.

The survey is available to complete on-line and is promoted on two large commercial Gay web sites (*Gaydar* and *Gay.com*), and a large number of non-commercial Gay community web-sites. The survey is also available as an A6 booklet which is self-sealing and has a Freepost address for return to Sigma Research. These booklets are distributed by health promoters to men who have sex with men in a wide variety of settings during the course of their work. GMSS has occurred every year since 1997 – further details about the surveys can be found at www.sigmaresearch.org.uk/reports.html

In 2003, GMSS included a series of questions about PEP. Prior to the questions on PEP, respondents were presented with the following text:

PEP is a one month course of anti-HIV drugs. It attempts to stop HIV infection taking place after a person is exposed to the virus. It should be taken as soon as possible after exposure and probably within a few days. In a few UK hospitals PEP is available for those exposed to HIV through sex. In those hospitals whether you get PEP will depend on the likelihood that you have been exposed to HIV and your ability to cope with the side effects.

All respondents were then asked the following three questions:

- *Have you heard of Post-Exposure Prophylaxis (PEP)?*
- *Have you ever tried to get PEP?*
- *Have you ever taken PEP?*

In addition, men who did not have diagnosed HIV were also asked:

- *If you thought you had been exposed to HIV would you consider trying to get PEP?*

GMSS 2005 repeated the PEP questions from 2003. In 2004 the pilot CHAPS PEP campaign was targeted at men in London and Brighton and Hove. The intervention was rolled out nationally in mid-2005 (see section 1.5). GMSS 2003 predated any PEP-specific health promotion campaigns in the UK. GMSS 2005 occurred after the pilot implementation of the CHAPS PEP campaign targeting men resident in London and Brighton & Hove, and during the roll-out of the CHAPS PEP campaign across England and Wales.

This chapter examines changes in PEP awareness and access, and the extent to which changes were geographically confined and differential by the intervention target groups.

2.2 SAMPLES DESCRIPTION

The following table presents the demographic descriptions of the samples across the two surveys using nine variables: recruitment method; residence; age; ethnicity; annual income; HIV testing history; current male relationship status; female sexual partner in the last year; and number of male sexual partners in the last year. Differences in awareness, seeking and taking PEP are described across these nine variables in the remainder of this chapter.

Previous *Gay Men's Sex Surveys* have demonstrated that the following sub-groups of homosexually active men are more likely to be involved in sexual HIV exposure (Hickson *et al.* 1998, Hickson *et al.* 1999, Weatherburn *et al.* 2000, Hickson *et al.* 2001, Reid *et al.* 2002, Hickson *et al.* 2003b, Reid *et al.* 2004, Weatherburn *et al.* 2005).

Residence: men living in London and Brighton & Hove, where HIV prevalence is highest.

Age: men under 40. The average age of HIV diagnosis among MSM in the UK is about 36 years, so the average age of infection is some time before this.

Ethnicity: Black men, who are over-represented among homosexually active men with HIV in the UK and show higher levels of sexual risk behaviours.

Income: men with lower incomes show higher levels of sexual risk behaviours.

HIV testing history: Although men with diagnosed HIV are not expected to take PEP they are much more likely to be involved in sexual HIV exposure than uninfected men and are able to inform their sexual partners about PEP.

Female sexual partner in the last year: men who have sex with men only are over-represented among men with HIV and show higher levels of sexual risk behaviour.

Number of male sexual partners in the last year: men with higher numbers of male sexual partners are over-represented among men with HIV and show higher levels of sexual risk behaviours.

While we have also demonstrated that men with lower levels of formal education are both more likely to be involved in HIV exposure and more likely to have HIV, identical measures of education were not used in GMSS 2003 and 2005. However, there is a close correlation between income and educational level (Reid *et al.* 2004) and the income data provides some insight into the likely relationship of educational achievement to the PEP variables that follow.

In both years the internet accounted for three quarters of the sample with the booklet providing the other quarter. The proportion of men who had ever tested for HIV (55.9–56.5%) and the proportion who had tested HIV positive (6.3–6.5%) did not significantly vary over the two years.

Compared to GMSS 2003, the 2005 sample included slightly smaller proportions of respondents in Wales, Scotland, Northern Ireland, North England and South England, and slightly higher proportions in Mid & Eastern England and London. Also the 2005 GMSS sample was significantly older, more ethnically diverse, had higher incomes, were more likely to have a current regular male sexual partner and to have had fewer male sex partners in the last year but more likely to have had sex with a woman in the last year. These differences are outlined in the following table.

In the following sections we report the proportion of men who were aware of, had sought and who had taken PEP, and the proportions in each demographic group who had done so. Chi-square was used to examine univariate differences. Within each year, odds ratios were examined to look at differences across each of the nine demographic variables, adjusted for the other eight. Within each demographic group, odds ratios were examined across the two years, adjusted for the differences between the two samples. This ensures that the reported differences between 2003 and 2005 are not a function of differences across the samples.

UK sample description * = p<.01 (chi-squared) difference across the two years		2003	2005
total sample size		14551	16432
recruitment method (ns)	web	74.2 10801/14551	75.0 12325/16432
	booklet	25.8 3750/14551	25.0 4107/16432
	missing n	0	0
Residence * [nb. Booklets distributed in Scotland & N Ireland in 2003 but not 2005 due to funding changes] [nb. All cases missing Directorate of residence were known to live in the UK]	London	25.5 3434/13488	28.8 4350/15100
	South England	19.6 2649/13488	18.2 2744/15100
	Mid & Eastern England	19.5 2635/13488	20.1 3039/15100
	North England	20.9 2820/13488	20.0 3015/15100
	Wales	4.2 568/13488	3.9 584/15100
	Scotland	7.7 1042/13488	7.1 1067/15100
	N.Ireland	2.5 340/13488	2.0 301/15100
	missing n	1063	1332
Age * [nb. Large age missing in 2003 due to user input design error on internet version]	N	12 230	16 309
	mean	33.01	33.73
	standard deviation	11.45	11.82
	median	31.0	32.0
	range	14-90	14-89
	missing n	2321	123
Ethnicity *	White British	84.0 12177/14498	81.2 13252/16311
	White other	10.4 1506/14498	11.4 1867/16311
	Asian	2.0 294/14498	2.9 465/16311
	Black	1.6 239/14498	2.3 379/16311
	All other groups	1.9 282/14498	2.1 348/16311
	missing n	53	121

UK sample description * = p<.01 (chi-squared) difference across the two years		2003	2005
total sample size		14551	16432
Income *	<5k	10.8 1542/14311	10.4 1669/16104
	£5k – £14k	25.4 3633/14311	22.8 3668/16104
	£15k – 24k	29.0 4157/14311	27.7 4461/16104
	£25k – £34k	17.8 2546/14311	18.9 3040/16104
	£35k+	17.0 2433/14311	20.3 3266/16104
	missing n	240	328
HIV testing history (ns)	Never	44.1 6377/14468	43.5 7056/16218
	Last negative	49.6 7180/14468	49.9 8100/16218
	Positive	6.3 911/14468	6.5 1062/16218
	missing n	83	214
Current (male) relationship status *	Single	47.4 6758/14253	45.6 7379/16167
	Partnered	52.6 7495/14253	54.4 8788/16167
	missing n	298	265
Any female sexual partners in the last year *	No	89.3 12989/14551	86.7 14249/16431
	Yes	10.7 1562/14551	13.3 2182/16431
	missing n	0	0
Number of male sexual partners in the last year *	none	6.2 880/14215	7.0 1135/16255
	one	17.9 2538/14215	19.0 3088/16255
	2, 3 or 4	28.1 3992/14215	27.6 4487/16255
	5 to 12	23.6 3352/14215	22.9 3730/16255
	13 to 29	13.0 1842/14215	12.5 2027/16255
	30+	11.3 1611/14215	11.0 1788/16255
	missing n	336	177

2.3 POTENTIAL ACCEPTABILITY OF PEP

Before turning to the measures of awareness and uptake of PEP, we look briefly at its potential acceptability. In GMSS 2003, 97.4% (12862/13210) of respondents said they would consider taking PEP if they thought they had been sexually exposed to HIV. In 2005 this figure dropped to 95.9% (14172/14773). Adjusting for demographic differences in the samples, the odds ratio of saying yes in 2005 was 0.71 (95% confidence interval (CI), 0.60–0.83). This suggests a drop in the apparent acceptability of PEP. The educational campaign stressed the potential negative impact of taking PEP (eg. “It can cause severe side effects such as diarrhoea, nausea and prolonged headaches”), and this finding may reflect an increase in knowledge about this aspect of the intervention. However, the vast majority of Gay and Bisexual men would still consider PEP if they thought they needed it.

2.4 CHANGES IN AWARENESS OF PEP

Across the UK as a whole, in 2005 men were 2.4 times more likely to be aware of PEP than they were in 2003, an increase from 22.2% to 38.5%. Awareness of PEP significantly increased in every demographic sub-group. The following graphs show the proportion of men who had heard of PEP in each year across each demographic group. Increases were highest among men living in the South of England, men with large numbers of male sexual partners, those over 50 years of age, and those who had tested for HIV.

In 2003, men recruited using the booklet were 1.4 times more likely to be aware of PEP than men recruited via the internet. Between 2003 and 2005 the increase in awareness was similar in internet and booklet recruited samples and so the same difference in awareness by recruitment method pertained in 2005.

2.4.1 Residence and changes in PEP awareness

In 2003 awareness of PEP was highest among men in London and Brighton & Hove. Compared to men in London, awareness was significantly lower in all areas of the UK except Brighton and Hove.

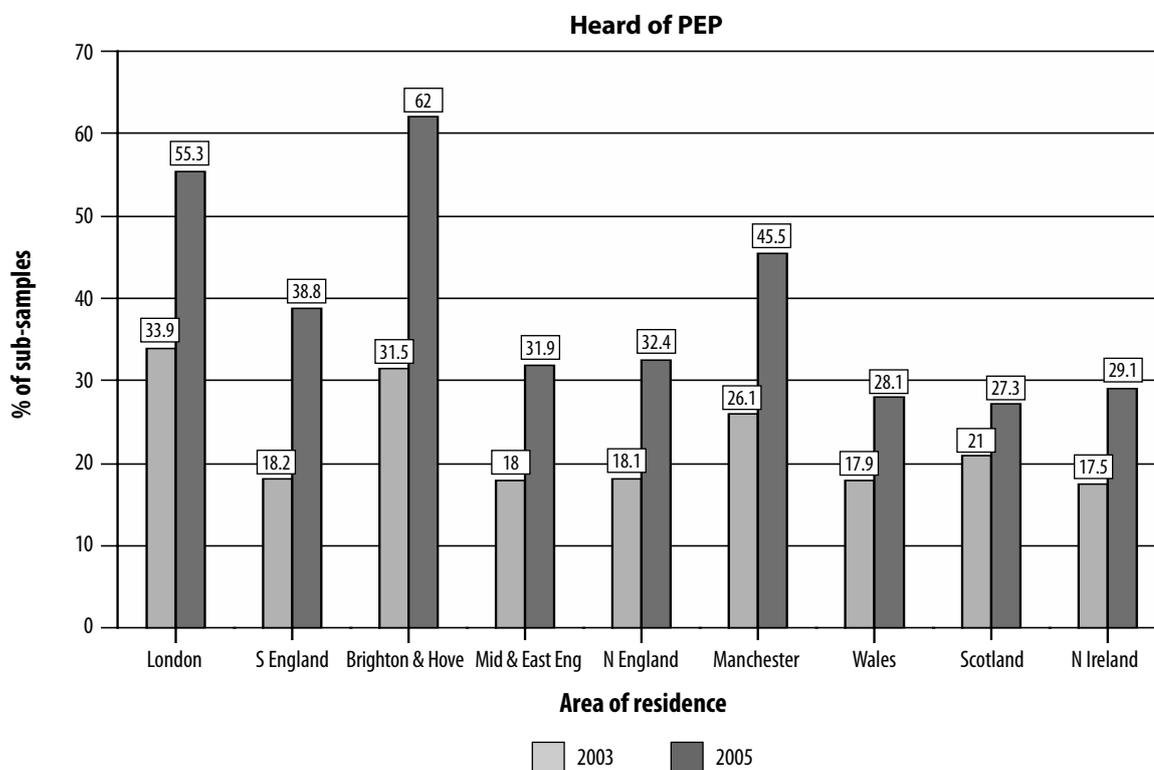


Figure 2.4.1: Increased awareness of PEP by area of residence, 2003-2005 (figures for South England include Brighton & Hove, and for North England include Manchester. Figures for men living in these two authorities are also shown separately).

By 2005 there had been a significant increase in awareness of PEP in all areas of the UK. The increase was greatest in London, South England and in particular Brighton & Hove. In 2005, a Gay man in Brighton & Hove was 3.4 times more likely to be aware of PEP than he was in 2003. The increase was most modest in Scotland which is outside the remit of the CHAPS programme. As a result of these changes, the difference in awareness of PEP between the South of England and the rest of the UK was greater in 2005 than it had been in 2003.

2.4.2 Age and changes in PEP awareness

In 2003, men under 20 were less likely to be aware of PEP than older age groups, awareness being highest among men in their 30 and 40s. By 2005 awareness of PEP had increased in all age groups with the largest increase among men in their 40s and the over 50s.

In 2005 men in their 30s and 40s were still most likely to be aware of PEP and the difference between them and men under 20 had increased.

Since men in the 30-50 age group are most likely to have knowingly engaged in sero-discordant UAI (see Reid *et al.* 2002, p.32), the need for PEP could be seen as highest here.

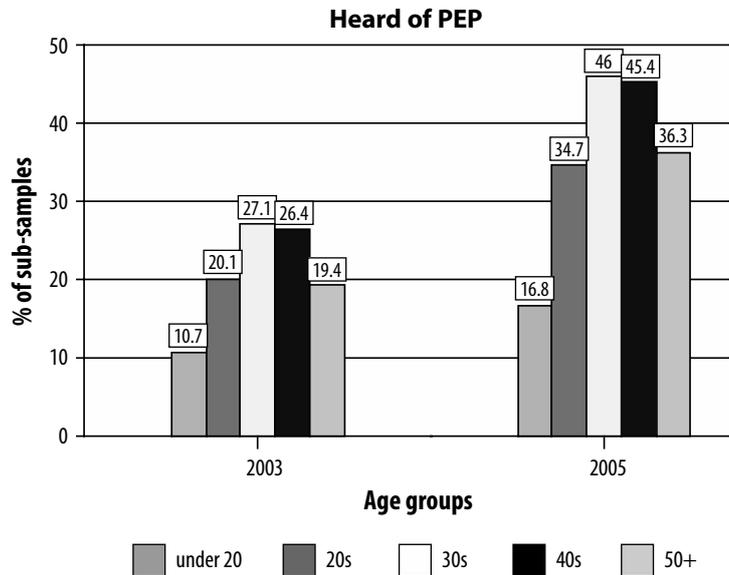


Figure 2.4.2: Increased awareness of PEP across age groups, 2003 - 2005.

2.4.3 Ethnicity and changes in PEP awareness

In 2003 awareness of PEP was higher among the White other group relative to White British men. It was not significantly different across other ethnic groups.

By 2005 awareness of PEP had increased in all five ethnic groups. The increase was most modest among Asian men who have previously been shown to be least likely to recognise mass media interventions targeted at Gay men. The result was the same ethnic group difference in awareness in 2005: men of White other ethnicities were most likely to be aware of PEP.

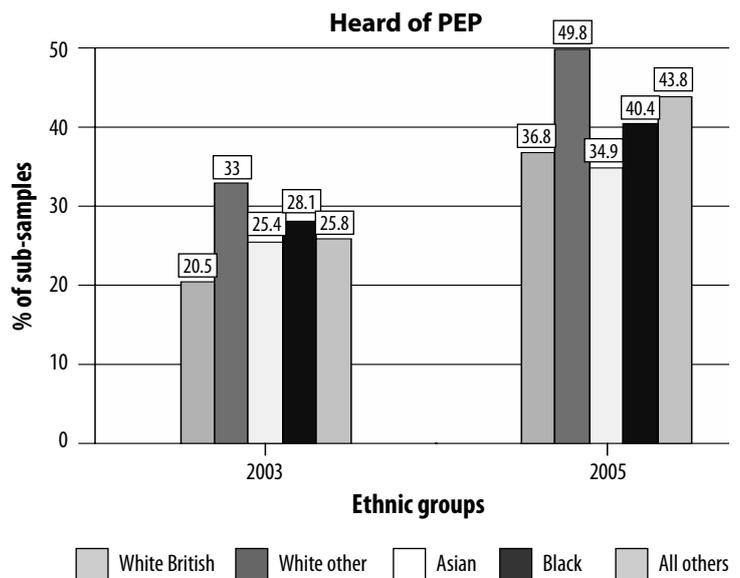


Figure 2.4.3: Increased awareness of PEP across ethnic groups, 2003 - 2005.

2.4.4 Income and changes in PEP awareness

In 2003 awareness of PEP was incrementally higher with increasing income; men who had an income of over £35000 were 2.0 times as likely to be aware of PEP than were men with an income of under £5000.

By 2005 awareness of PEP had increased in all five income groups but with higher values for men with higher incomes. Consequently in 2005, men with an income of £35000 or more were 2.5 times more likely to be aware of PEP than those with an income of less than £5000.

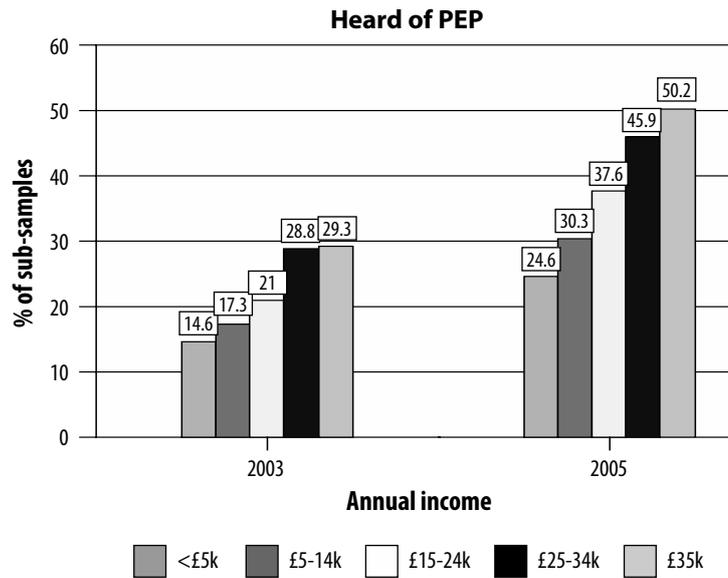


Figure 2.4.4: Increased awareness of PEP across income groups, 2003 - 2005.

2.4.5 HIV testing history and changes in PEP awareness

In 2003 diagnosed positive men were 4.0 times more likely to be aware of PEP than those whose last test was negative, and were 7.7 times more likely to be aware of PEP than those who had never tested.

By 2005 awareness of PEP had increased in all three HIV testing history groups but the rise was significantly greater among men who had tested (either positive or negative) for HIV than those who had never tested. Consequently in 2005, men who had tested positive were still 4.0 times more likely to be aware of PEP than men who had tested negative, but were now 10.0 times more likely to be aware of it than men who had never tested for HIV.

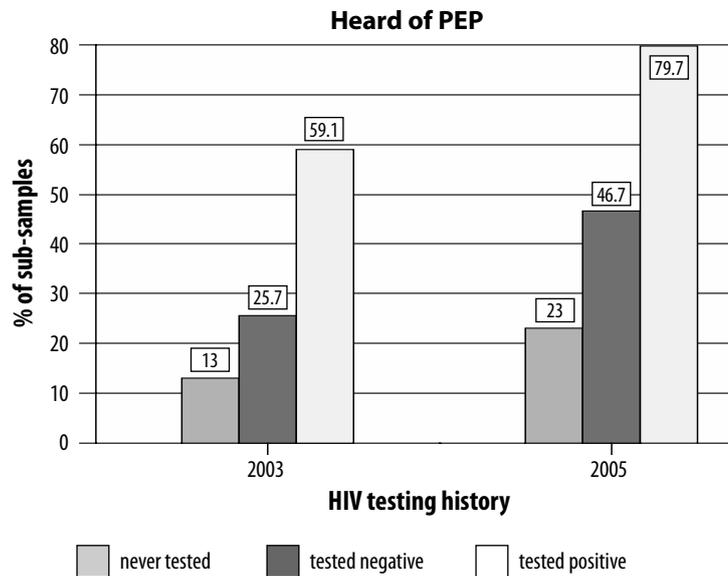


Figure 2.4.5: Increased awareness of PEP by HIV testing history, 2003 - 2005.

2.4.6 Female sex partners and changes in PEP awareness

In 2003 men who had sex with a woman in the preceding year were 0.7 times less likely to have heard of PEP than men who had no female sex partners.

By 2005, awareness of PEP had increased among both men with and without a female sex partner in the last year but the increase was greater among men without a female sex partner. In 2005 the difference in PEP awareness between these two groups was even greater: men with a female sex partner were now 0.4 times less likely to be aware of PEP as men without a female sex partner.

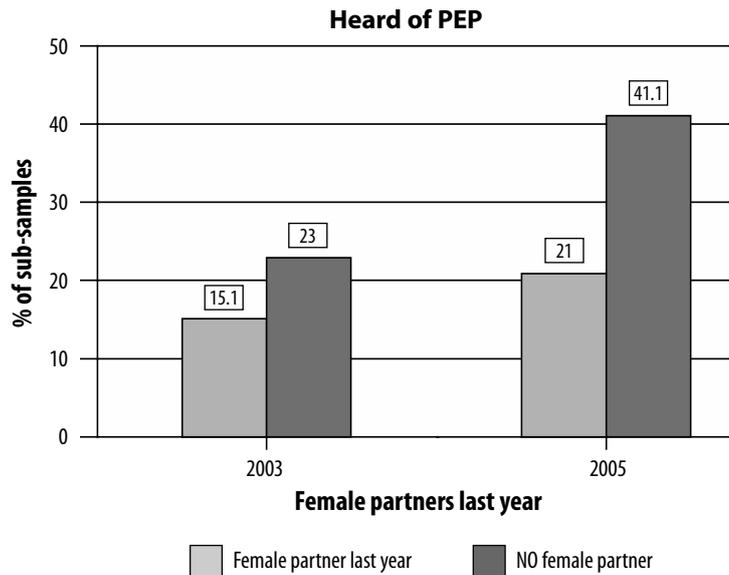


Figure 2.4.6: Increased awareness of PEP by having any female partners in the last year, 2003 - 2005.

2.4.7 Number of male sex partners and changes in PEP awareness

In 2003 awareness of PEP was higher among men with increasing numbers of male sex partners in the last year. Men who had thirty or more partners were 2.6 times more likely to be aware of PEP than men who had no male partners.

Between 2003 and 2005 the increase in awareness of PEP was greatest among men with more male partners. Consequently in 2005, the difference in awareness of PEP between men with few and those with many partners was greater than it had been in 2003. Men who had thirty or more partners were 3.6 times more likely to be aware of PEP than men who had no male partners.

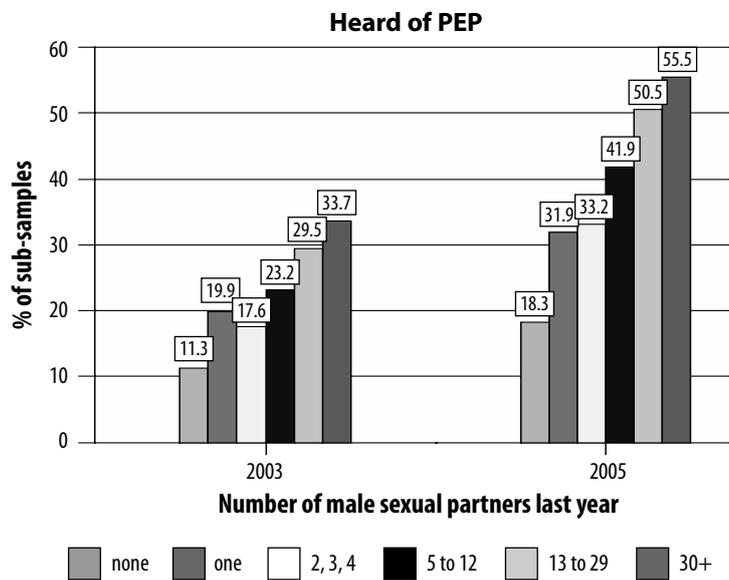


Figure 2.4.7: Increased awareness of PEP by volume of male sexual partners in the last year, 2003 - 2005.

2.5 CHANGES IN PEP SEEKING

Across the UK as a whole, in 2005 men were 1.4 times more likely to have ever sought PEP than they were in 2003, an increase from 1.0% of all men to 1.4%. The small absolute number of men seeking PEP means we found fewer group differences that were statistically significant but the proportion of men seeking PEP did not decline in any demographic sub-group. There were statistically significant increases in PEP seeking among: men in their 30s; White British men; men with an income over £35,000; men whose last HIV test was negative; men who did not have a female sex partner; and men who had fewer than 13 male sex partners. The following graphs illustrate the significant differences across each demographic group.

In 2003 ever having sought PEP was significantly higher among men recruited using the booklet compared to those recruited using the internet. A greater increase in PEP seeking among men recruited on the internet meant this difference was not significant in 2005.

2.5.1 Residence and changes in PEP seeking

In 2003, having sought PEP was significantly more common among London residents compared to elsewhere in England and in Scotland.

In 2005 the increase in PEP seeking was similar across all areas, so London still had a higher prevalence than elsewhere of men having ever sought PEP.

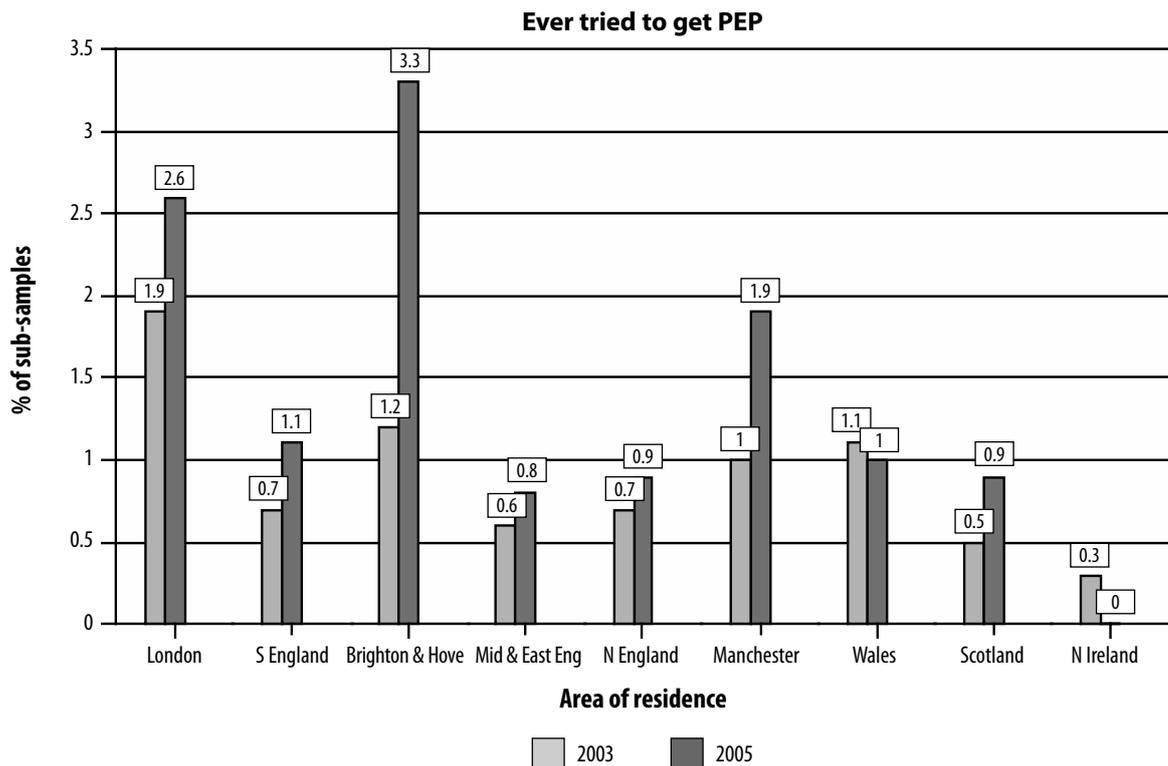


Figure 2.5.1: Increases in PEP seeking by area of residence, 2003-2005 (figures for South England include Brighton & Hove, and for North England include Manchester. Figures for men living in these two authorities are also shown separately).

2.5.2 Age and changes in PEP seeking

In 2003 men in their 20s were most likely to have sought PEP. Following increases among all age groups, in 2005 there was no significant difference across age.

2.5.3 Ethnicity and changes in PEP seeking

There were no significant differences in having sought PEP by ethnic groups in either 2003 or 2005.

2.5.4 Income and changes in PEP seeking

In 2003 there was no significant difference in having sought PEP by income. By 2005 we found a greater increase in PEP seeking among men in the highest income group, so that men with an income of more than £35000 were 2.5 times more likely to have sought PEP than those with an income of less than £5000.

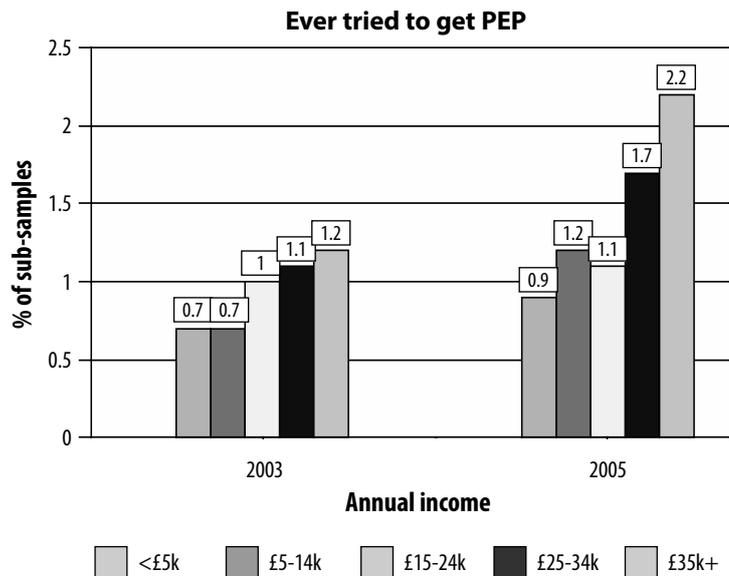


Figure 2.5.4: Increases in PEP seeking across income groups, 2003 - 2005.

2.5.5 HIV testing history and changes in PEP seeking

In 2003 men who had tested HIV positive were more likely to have ever sought PEP than men who had never tested for HIV.

By 2005 there had been a significant increase in PEP seeking only among men whose last test was HIV negative so that in 2005 positive men were still more likely to have sought than never tested men.

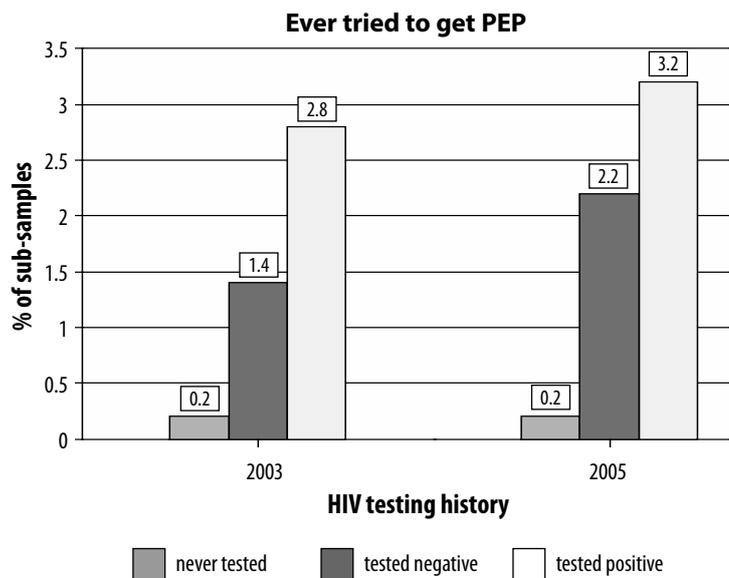


Figure 2.5.5: Increases in PEP seeking by HIV testing history, 2003 - 2005.

2.5.6 Female sex partners and changes in PEP seeking

There were no significant differences in having sought PEP by having or not having female sex partners in the last year either in 2003 or 2005.

2.5.7 Number of male sex partners and changes in PEP seeking

In 2003, men with 13 or more male sexual partners in the last year were more likely to have sought PEP than those with 12 or fewer. There was a greater increase in PEP seeking among men with fewer male partners. However, in 2005 men with larger numbers of partners were still more likely to have sought PEP.

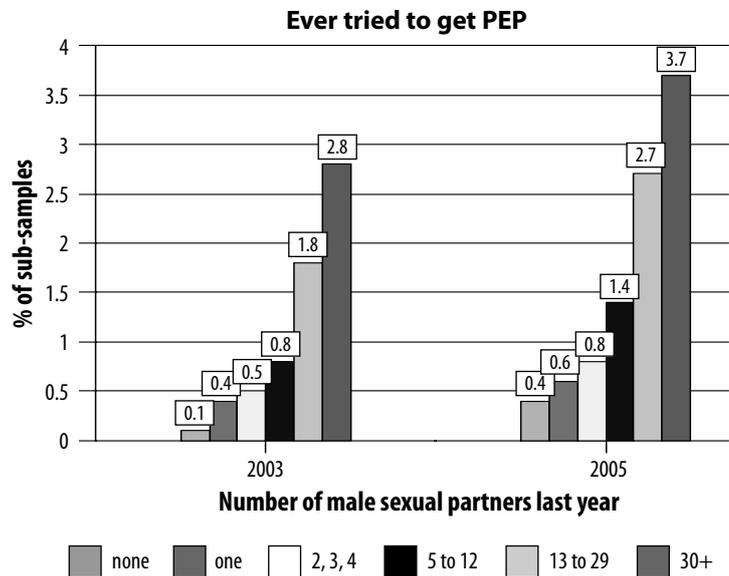


Figure 2.5.7: Increases in PEP seeking by volume of male sexual partners in the last year, 2003 - 2005.

2.6 CHANGES IN TAKING PEP

The following graphs show the proportion of men in each year and in each demographic sub-group who had ever taken PEP. The overall proportion of men who had ever taken PEP rose from 0.6% in 2003 to 1.2% in 2005, with an adjusted odds ratio for having taken PEP of 1.93 (95% CI 1.43-2.61). In no demographic sub-group did the proportion who had taken PEP decline between 2003 and 2005.

In 2003 having taken PEP was significantly more common in the booklet sample. The rise in having taken PEP was only significant in the web sample, but in 2005 the booklet sample was still more likely to have ever taken PEP.

2.6.1 Residence and changes in taking PEP

In 2003 ever having taken PEP was significantly less common in the rest of England than it was in London. There were significant increases in having taken PEP in London, South England and North England. In 2005 having taken PEP was still higher in London than elsewhere with the exception of Brighton and Hove.

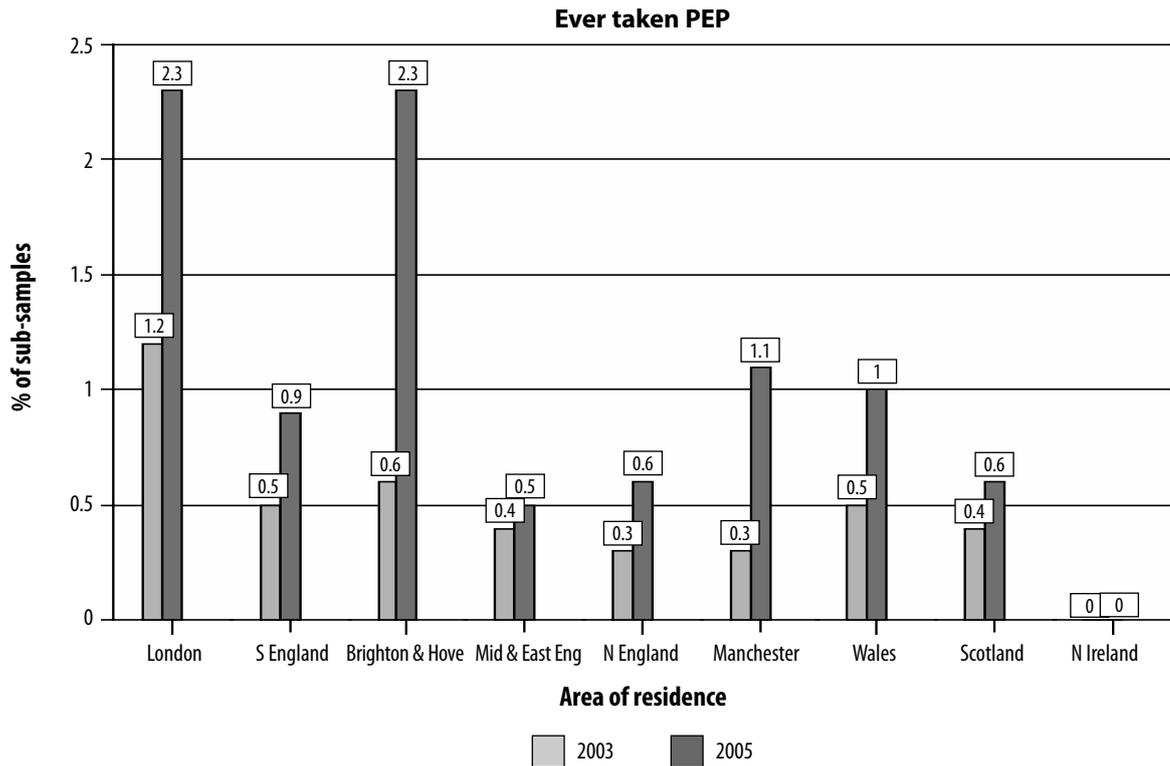


Figure 2.6.1: Increases in PEP taking by area of residence, 2003-2005 (figures for South England include Brighton & Hove, and for North England include Manchester. Figures for men living in these two authorities are also shown separately).

2.6.2 Age and changes in taking PEP

There was no statistically significant difference in PEP taking at different ages in either year. From 2003 to 2005 having taken PEP rose in all age groups, and the rise was significant among men in their 30s.

2.6.3 Ethnicity and changes in taking PEP

There was no statistically significant difference in PEP taking in different ethnic groups in either year. From 2003 to 2005 having taken PEP rose in all ethnic groups and the rise was significant among White British men and those in all other ethnic groups.

2.6.4 Income and changes in taking PEP

Men with higher incomes were more likely to have taken PEP and this difference increased from 2003 to 2005. The increase in PEP taking being greatest in the highest income bracket.

In 2005 men with an income of over £35000 were 2.6 times as likely to have taken PEP as those with an income of under £5000.

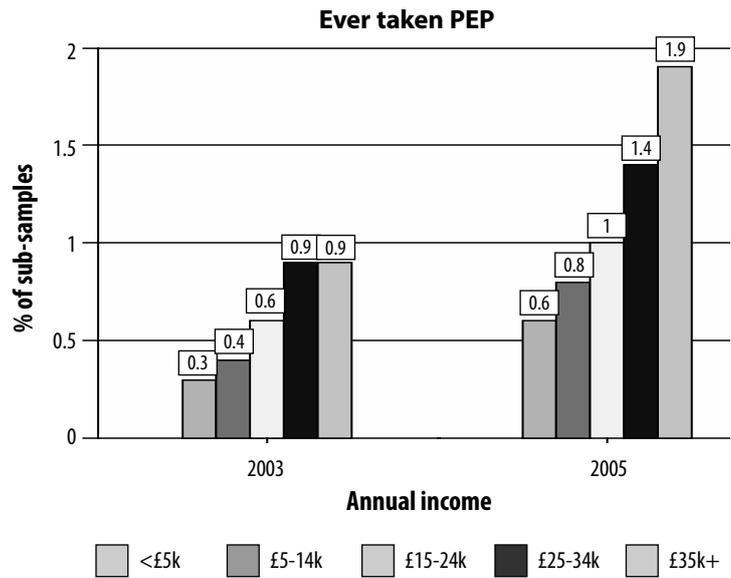


Figure 2.6.4: Increases in PEP taking across income groups, 2003 - 2005.

2.6.5 HIV testing history and changes in taking PEP

In 2003, men with diagnosed HIV were more likely to have taken PEP in the past than men whose last test was negative and those who had never tested.

To 2005 the increase in having taken PEP was greatest among men whose last test was negative, but less pronounced among diagnosed positive men. In 2005 men who had never tested were less likely to have taken PEP than were men who had tested, irrespective of the result.

Since all people who take PEP should have both pre- and post-PEP HIV tests, we should expect having taken PEP to rise

most among men whose last HIV test was negative, as observed. However, that the proportion of men who had tested HIV positive that had ever taken PEP was similar to the proportion among men whose last test was negative needs accounting for. It is clear that some men who take PEP subsequently go on to sero-convert to HIV.

PEP is by definition needed by the group of men at highest risk of HIV infection. Since prescribing PEP alone meets few HIV prevention needs other than the immediate biological need, having been prescribed PEP does not automatically place men in at lower risk in the future. It is likely men who have taken PEP in the past are still at significant risk from HIV and it should therefore not be surprising that some men go on to sero-convert to HIV.

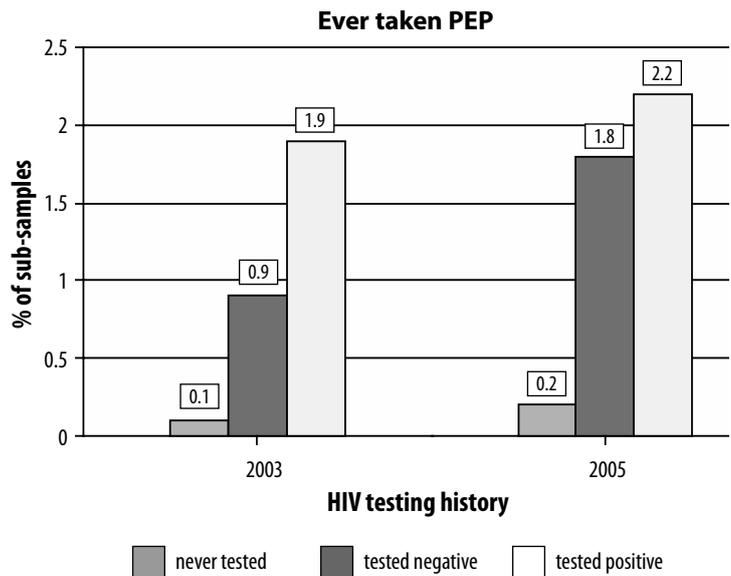


Figure 2.6.5: Increases in PEP taking by HIV testing history, 2003 - 2005.

2.6.6 Female sex partners and changes in taking PEP

In 2003 there was no statistically significant difference in PEP taking among men who had a female sex partner and those who did not. However, men who did not have a female sex partner in the last year remain more likely to have taken PEP.

2.6.7 Number of male sex partners and changes in taking PEP

In both years, men with higher numbers of partners were more likely to have taken PEP. In 2003 men with 13 or more partners in the last year were 3.6 times more likely to have taken PEP than men with fewer than 13 partners. Having taken PEP rose in all groups between 2003 and 2005.

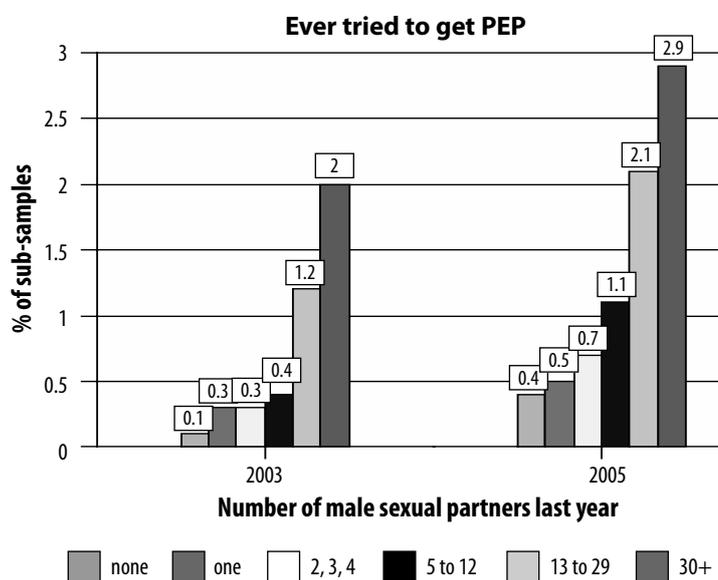


Figure 2.6.7: Increases in PEP taking by volume of male sexual partners in the last year, 2003 - 2005.

2.7 SUCCESSFUL PEP SEEKING

In 2003, 59.1% of all men that had ever sought PEP had ever taken it. There were no significant differences across demographic groups in men's rate of having taken PEP among those that had sought it.

Overall, between 2003 and 2005 the proportion of men who had ever sought PEP who had ever taken it rose significantly, from 59.1% to 73.9% ($X^2=9.572$, $df=1$, $p<.01$), suggesting an increase in access to PEP among those seeking it. Again demographic differences in taking PEP among those that had sought it were not the norm but there were two significant results. Among men that had ever sought PEP in 2005, those living in London (81.9%, $n=99/121$) or Wales (85.7%, $n=6/7$) were significantly more likely to have ever taken it than men living elsewhere. Also in 2005 men with higher incomes who had ever sought PEP were more likely to take have ever taken it: 63.3% ($n=38/60$) of those with an income of under £15000 who had sought PEP had taken it compared with 77.0% ($n=144/187$) of those with an income over £15000 ($X^2=4.379$, $df=1$, $p<.05$).

2.8 SUMMARY

In GMSS 2003, 97.4% of men said they would consider taking PEP if they thought they had been sexually exposed to HIV. In 2005 this figure dropped to 95.9%. This suggests a small drop in the apparent acceptability of PEP as an intervention. However, the vast majority of Gay and Bisexual men would still consider PEP if they thought they needed it.

In 2005, across the UK as a whole, men were 2.4 times more likely to be aware of PEP than they were in 2003, an increase from 22.2% to 38.5% among all men. While awareness of PEP significantly increased in every demographic sub-group, the increases were not uniform. They were most pronounced among men living in the South of England, men with large numbers of male sexual partners, those over 50 years of age, and those who had tested for HIV. The changes in awareness between 2003 and 2005 maintained differences across ethnic groups (with the White other group being most aware). They increased differences across area of residence (London and the South being most aware); age (men in their 30s and 40s being most aware); income (men with higher incomes being most aware); HIV testing history (positive men being most aware); gender of partners (exclusively homosexually active men being more aware); and number of male partners (men with more male partners being more aware).

While these disparities were usually in the direction of demographic sub-groups that are most likely to be involved in HIV exposure (London residents, men in their 30s, men with larger numbers of male partners) some were not. Until such time as awareness of the existence of PEP is universal it should also be most common among Black men and men with lower incomes (and hence less education).

Similarly ever having sought PEP rose from 1.0% of all men to 1.4% between 2003 and 2005.

The small absolute number who had ever sought PEP meant fewer group differences that were statistically significant but the proportion of men who had sought PEP did not decline in any sub-group. There were statistically significant increases in PEP seeking among: men in their 30s; White British men; men with an income over £35,000; men whose last HIV test was negative; men who did not have a female sex partner; and men who had fewer than 13 male sex partners.

In order to seek out PEP men must be aware of its existence but they also must have the confidence and skills to present for it. The changes in PEP seeking between 2003 and 2005 eliminated differences across age and maintained differences across: residence (being most common in London); HIV testing history (men who had tested being most likely to seek it); relationship status (men in relationships being more likely to seek); and number of male sexual partners (men with higher numbers of partners being more likely). It also created differences across income, with men with higher income now being more likely to seek PEP.

The overall proportion of men who had ever taken PEP rose from 0.6% in 2003 to 1.2% in 2005. In no demographic sub-group did the proportion who had taken PEP decline between 2003 and 2005. Overall, between 2003 and 2005 the proportion of men who had ever sought PEP who had ever taken it, rose from 59.1% to 73.9%, suggesting an increase in access to PEP among those men seeking it. Again demographic differences in getting PEP when it had been sought were not the norm but there were two significant results. Among men seeking PEP in 2005, those living in London and Wales were significantly more likely to have taken it than men living elsewhere. Also men with higher incomes who sought PEP were more likely to have taken it than men with lower incomes.

The recurrent problem of income (acting as a surrogate marker for education and class) is a major one to which we return in some detail in Chapter 4.

3 Seeking & getting PEP

3.1 METHODS AND SAMPLE

In this chapter, we describe in detail the experiences of thirty Gay men and Bisexual men who tried to access PEP following potential sexual exposure to HIV.

3.1.1 Methods

In 2005 men completing the online version of the *Gay Men's Sex Survey* who said they had ever tried to get PEP were invited to take part in a 30 minute telephone interview about their experiences. Telephone interviewing enabled men from a range of geographical locations to be interviewed at a time and place that suited them. Initial screening ensured that only those who had attempted to access PEP in the UK following a sexual (rather than occupational) exposure took part. Interviewing took place between August and December 2005. The interviews were undertaken by two researchers and were audio tape-recorded with consent. Detailed annotations were made of the recordings which were used for analytical coding (in the case of close-ended questions) and reflective thematic analysis (in the case of open ended responses). Analysis was conducted by two researchers working independently.

At interview, men were asked to describe their knowledge and awareness of PEP prior to the most recent time they sought help in relation to a potential sexual exposure incident, their experiences of seeking advice or information about accessing PEP and what happened when they tried to access PEP. Men were also asked about their satisfaction with the clinical process, who else they had told about their experience, and what affect they thought it had on future HIV-related risk. Those who were prescribed PEP were asked about follow-up care and side effects. Men who had tried to access PEP more than once were asked about their most recent experience first, and then asked for a brief account of the previous occasions when they had attempted to access PEP.

3.1.2 Sample

The majority of the men were in their 20s and 30s at the time of interview (the mean age was 32 and the range was from 18 to 48). Seventeen men were London residents, and the remainder lived in urban and non-urban settings in England (North West, Midlands, South West and South East) and Wales. Almost all men identified as White and most were British, though a quarter (n=7) were originally from North America, Australia or South Africa. One man was of unspecified mixed ethnicity. Most men (n=28) had remained in education after the age of 16 (the majority of these having done so for more than three years). The men were medium to high earners (two thirds earned more than £25000 a year, with over one quarter earning £40000 or more). The ethnicity, educational and income profiles of this sample are similar to the GMSS 2005 survey participants (see chapter 2) who had tried to access PEP.

Both this and the GMSS sample of men requesting PEP tended to be White with higher educational qualifications and incomes. Knowing about and actively seeking health interventions involves a range of personal, social and cultural characteristics which are often concentrated within White middle-class cultures (Wilkinson 1986, Kawachi *et al.* 1997, Hawe & Shiell 2000). Our samples therefore reflect a typical demographic profile of early adopters of new health technologies.

Where quotes from respondents are used in this chapter, they are contextualised by three pieces of information about the speaker. The age of the respondent is given, as well as the type of clinic where they sought help (A&E or GUM) and their area of residence at the time of the incident (which in some cases is not the same as the area where they sought PEP). These areas have been classified using the Standard Regions for England (North, South, Midlands & Eastern, London) and Wales.

3.1.3 When the potential risk incidents occurred

The table below describes when the possible exposure incident described in the interview occurred and the numbers of men for whom PEP was prescribed. We did not put a time limit on the recency of the potential exposure incident described in the interview.

Exposure incident	Number of respondents
within six months of interview	14 (of which 8 were prescribed PEP)
between 6 and 18 months prior to interview	10 (of which 8 were prescribed PEP)
between 18 months to 3 years prior to interview	2 (both were prescribed PEP)
more than three years prior to interview	4 (all of whom were prescribed PEP)

The majority of respondents (n=24) described a sexual risk incident that had occurred in the 18 months prior to interview, with nearly half (n=14) in the six months prior to interview. Of the twenty-four men describing an incident in the eighteen months prior to interview, sixteen were prescribed PEP. Of the six men who described receiving PEP more than 18 months prior to interview, all were given PEP.

In the remainder of this chapter, we first describe how men found out about PEP and how they realised they might need to take it. We move on to describe their experiences of presenting to clinics and the ways in which PEP was prescribed. We then describe taking PEP both in terms of physical symptoms and side effects and the broader impact on personal, social and sexual lives.

3.2 KNOWING ABOUT PEP, NEEDING PEP

In this section, we explore how and where the men derived their knowledge about PEP generally, what specific events or triggers made them decide that they may need to take PEP and how they went about seeking help.

3.2.1 Knowledge about PEP

The following table describes when men in the sample had first heard about PEP.

Heard of PEP ...	No. of men
in the 18 months prior to interview	16
between one and a half years and three years prior to interview	5
more than three years prior to interview	9

Of the sixteen men who had learned of PEP in the 18 months prior to interview, five had only heard of it after the risk incident described at interview. In some of these cases, friends and sexual partners told them about PEP. One man described an encounter where he did not understand his casual partner's attempt to disclose his HIV infection during unprotected sex. When their sero-discordancy became apparent, his partner told him about PEP. Others were told by the health professionals who they turned to for help following the exposure incident. Therefore, a significant minority did not know what PEP was or how it might have helped them at the point when they first realised they might have been at risk of HIV exposure.

The remaining eleven men who became aware of PEP in the 18 months prior to interview said they had heard of it through the Gay press, health promotion interventions, friends and health professionals.

When you read the press there was a lot of informative stuff about PEP at the time. I tend to look out for those things. There were three or four things, I think each of the major magazines had articles about it. The [CHAPS fire extinguisher] poster was one of the first things that informed me that PEP existed.

45 years old, GUM, London

Without prompting, three men recalled the CHAPS campaign about PEP, launched in the national Gay press as well as targeted local press in London and Brighton in April 2004.

The five men who had heard about PEP between 18 months and three years prior to interview also recalled Gay press coverage and health promotion materials (in the UK and/or other countries). Of these, two mentioned the CHAPS campaign unprompted and one said that he had discussed PEP with a health professional at some point in the past, but that the campaign had revitalised his awareness.

In the main, the nine men who had known about PEP for three or more years were health professionals or had volunteered in the HIV sector or had a long-term partner with HIV. One described being told about PEP by an HIV positive casual sexual partner after an exposure incident occurred. A total of five men knew about PEP because they had tried to access it on at least one previous occasion.

Knowledge about PEP was gained either at the point of need (after possible exposure), or through press advertising or through personal or professional networks. However, the decision to take action and seek help was not universally driven by prior knowledge of PEP. As we have said, some men were not aware of PEP until they sought advice in relation to a specific risk incident. For this reason, terminology such as 'seeking' PEP is not applicable to all men's experiences (as not all men were actively 'seeking' it).

3.2.2 Needing PEP

About a third of all respondents (n=9) said that they began considering PEP when they realised that a potential HIV exposure had occurred; either through condom failure or unplanned risk with a partner who was known or thought to have HIV. For these men, concern about the exposure event mobilised their prior knowledge and understanding of PEP. For instance, following a condom failure with his HIV positive partner, one man described how his concerns about the partner's high viral load contributed to his desire to get PEP.

My partner was only recently diagnosed, just after I met him. That was why I wanted to get PEP straight away, because I realised he would be highly infectious.

37 years old, GUM, London

Men tended to consider PEP when sexual incidents fell outside of the parameters they normally considered 'safe'. This occurred in cases where a partner's positive HIV status was known and where it was unknown. Where it was known, condom failure was often the trigger though one man considered PEP when he noticed his partner's precum on his own broken skin while also knowing that the partner's viral load was likely to be high. Where incidents occurred within relationships, sometimes men had to manage their positive partners' feelings about the process, and in some cases this meant time taken for discussion rather than seeking PEP immediately after sex.

In cases where a partner's HIV status was unknown, triggers often related to concerns about exposure to potentially infectious bodily fluids including ejaculate (usually, but not always in relation to condom failure) and blood. One man described his reaction to an incident of receptive oral sex in a London cruising area.

I have never swallowed spunk or anything, I have never taken it in my body. And that was the first time it had actually entered by body, in my eye. On that basis I felt it was significant. I started thinking about PEP within the hour. I think there is a higher risk than normal, because of where I was.

35 years old, GUM, London

Again we note the significance of men's own boundaries of 'safety' being breached in these PEP narratives. It was the recognition of circumstances that men defined as being outside of their comfort zone which tended to prompt action.

Roughly another third (n=11) became aware that their partner was HIV positive following sexual contact, either through disclosure from the partner (n=9) or from rumours (n=2). Disclosure from partners often followed condom failure and some men said that their partners had disclosed in order to encourage them to seek out PEP. Disclosure also occurred when regular partners received an HIV diagnosis within the days following a sexual exposure incident. In the following example, disclosure emerged after a condom failure in the first weeks of a new relationship.

He didn't say anything at first. I was saying, 'These things happen' and because he couldn't look at me, I realised he was really horrified. I worked it out very quickly myself by reading his reaction.

34 years old, GUM, Midlands & Eastern

Two men described 'finding out' about a casual sexual partner's HIV status from third parties as the trigger for their concern about exposure to HIV. One man who said that he had been drugged by a sexual partner was told by friends the next day that the same man had been known to have infected others. Another said that he was telling a friend about a sexual encounter with a particular individual, when the friend said: "Did you know he was HIV positive?". Although third party sources cannot be absolutely reliable, these respondents reacted to the revelations as though their sexual contacts' HIV positive status was a certainty.

For many (but not all) men, disclosure was the key event that compelled them to engage with the realities of the risk of exposure. Often, the sexual activity on its own was not sufficient to trigger a PEP-seeking response. Therefore additional information about a partner's HIV status often intensified concerns about risk of exposure.

The final group (roughly one-third) described some delay before considering PEP. In almost all of these cases, triggers such as condom failure or disclosure were absent. Instead, they spent some time alone or with friends reflecting on the sex they had before realising they may have been at risk. Often they described passionate, unrestrained, casual sex that they had enjoyed at the time, but which they later reflected upon with feelings of regret.

The revelation of, 'Oh my god, I've had unsafe sex with somebody I don't know. How ridiculous, how stupid!'

34 years old, GUM, London

Often, within the interview, the risk incident was described as a unique behaviour – not something they would normally do.

I went for a fumble in the park, if you like, and I don't know what happened. And I was sort of being the active partner which was really bizarre.

39 years old, A&E, London

A dawning discomfort and a growing concern that their partner may have been positive often motivated them to talk to friends and get advice from professionals. Again a consistent element in these accounts was men's identification of an 'exceptional' occurrence that led them to be concerned about the risk of exposure. Whether their concern arose immediately or on reflection; whether it concerned the sexual activity or the sexual partner – these were individuals, who, in the main, took a great degree of care to protect themselves from the risk of exposure to HIV. Therefore, once they had identified the sexual incident as 'out of the ordinary' because it might have carried risk, they were motivated to act. The finding that men who access PEP are seeking to reassert equilibrium following a temporary loss of control regarding HIV exposure risk, is supported by similar research undertaken in Australia (Körner *et al.* 2003, 2005).

3.2.3 Delaying seeking PEP

In some cases one or two days passed before a respondent attempted to access PEP or seek help. A range of other priorities could delay a telephone call or a visit to a clinic. A few men did not feel that they were at risk of exposure until they were made aware of a sexual contact's HIV status some time later – either from the sexual partner himself, through third parties, or in one case, after reading an updated positive profile on *Gaydar*. Four men had sex while away from home, and travelled back to their home city or town before accessing a clinic. A small number went to work for the day and then set about accessing PEP after work, while others waited until the effects of drink or drugs wore off first.

Despite some delays among a proportion of men, of the twenty-two men who were prescribed PEP, sixteen (two thirds) received their first dose within 24 hours of the exposure incident. Of these, five men received PEP within six hours or less. All five of these men accessed GU clinics and Accident and Emergency Departments in London, and their decision to seek PEP promptly played as much of a role in the speed of their access as the promptness with which they were subsequently processed in the clinical environment.

3.2.4 Seeking information: contacting a helpline

Most respondents went straight to an A&E, GUM or HIV clinic once they realised they needed help in connection with the risk incident. However, eight respondents contacted a helpline before seeking PEP. For all but one, this was their first time attempting to access PEP and they were looking either to confirm the existence of PEP, to find out about time limits and efficacy, or to find out where to go to access it.

Of these, three called NHS Direct. In all three cases, operators had not been aware of the existence of PEP (despite all three events occurring after the release of the draft BASHH guidelines). The first man called NHS Direct to ask about the recommended time-frame for receiving treatment, and was told to wait for a call-back, which came thirty minutes later.

I felt she shouldn't have had to go and talk to someone when the question was over timing. I did kind of think they should know the answers to that. It did seem a bit of a like, 'Oh no one ever asked that before.'

43 years old, A&E, North

It was suggested to another respondent that he should go to GUM the next day. The third man was told that PEP was not available on the NHS, and no further advice was offered.

The four respondents who contacted THT Direct with queries relating to PEP and the likelihood of exposure were satisfied with the expertise and support offered.

The THT helpline was very supportive of my emotional anxiety. They explained it in more depth. They might have mentioned a 24 hour time limit. He [the THT Direct operator] knew what he was talking about. His only doubt was whether it was a guarantee that you would always get PEP at A&E. I suppose it's very expensive.

39 years old, A&E, London

This misgiving about access may have been justified in view of some men's subsequent experience in clinics (see section 3.3 below).

One man contacted the National AIDS Helpline. He was unhappy with the advice that there was a very low risk of transmission if a sexual partner's cum had got into his eye, when the HIV status of the partner was unknown.

3.3 PRESENTING AT THE CLINIC

About half of the men acted on their concern about exposure by presenting at or telephoning A&E (n=14), and a similar proportion went directly to a GUM clinic (n=15). One individual went to see his GP first, but was referred to GUM that same day.

Twenty of the 30 clinical sites where men accessed help following sexual exposure incidents were in Greater London, although not all of these men were resident in London at the time. The remaining 10 locations tended to be close to where respondents lived at the time.

3.3.1 *The initial clinical experience: deflected, referred, determined*

Six men described being sent (or sending themselves) on from their first clinical access point. In some cases, such events entailed appropriate professional referrals to expert clinical units, while in others, individuals were forced to become self-advocates in the face of denial, hostility and ignorance on the part of clinical staff. The circumstances relating to each of these experiences are outlined below.

Deflected

- One individual rang an A&E department at his local non-urban hospital in the Midlands. He was told to go to a GUM in a few days, which is where he was ultimately prescribed PEP. This occurred approximately two years prior to the interview.
- One man was told by an A&E nurse in a city in the North West that he should talk to someone at a Brook Advisory Centre. He went there, but as it was a Sunday, Brook was closed and he returned to A&E. He was not given PEP despite reporting receptive UAI with a partner of unknown HIV status because no one at the A&E knew what PEP was. This occurred six months prior to the interview.

Referred

- One man living in the South East (not London) went to see his GP after a risk incident. The GP told him about PEP and arranged an appointment at GUM that afternoon, where he was prescribed PEP.
- A few months before the interview, one man contacted the A&E department at his local hospital in a city in the South West. He was processed through A&E and then sent directly up to the specialist infectious disease ward where his sexual partner received HIV clinical care. There he underwent a risk assessment and was prescribed PEP.

Determined (second tries)

- Following potential exposure to blood while engaging in insertive UAI with a man of unknown HIV status, one respondent was told at a central London A&E department that the low threshold of exposure meant they would not recommend PEP. He left with little confidence in their assessment. The next day he went to a major HIV treatment centre and was prescribed PEP. This occurred six months prior to interview.
- More than three years before the interview, one man attended an A&E department in London where clinical staff had not heard of PEP. The respondent insisted that they consult with a specialist, so they rang someone from a different hospital who advocated the administration of PEP. However, the pharmacy was closed, so the respondent was told to return the next day. When the respondent returned and presented his prescription, the pharmacist recognised that it had not been properly written, and referred the respondent on to the HIV ward in the same hospital, where he was immediately given a starter pack. The HIV consultant in that ward mentioned that he was on call the previous day and that the A&E department should have contacted him for a consultation at the time.

3.3.2 BASHH guidelines vs real life

In this section we assess the appropriateness of clinical care received by the men in this sample by applying the British Association for Sexual Health and HIV (BASHH) guidelines for the administration of PEP following sexual exposure (PEPSE) published earlier this year (Fisher *et al.* 2006). These guidelines were not officially endorsed when the incidents described in interviews occurred, however, as described previously, the draft version had been available for consultation among clinicians since April 2004 (a time-frame within which most of the men described their most recent attempt to access PEP).

The first three sections below provide a brief summary of the sexual exposure situations covered in the guidelines that would apply to men having sex with male partners (a high prevalence population) in the UK, and are presented separately according to treatment recommendation. The last section provides a summary of those scenarios outlined by respondents that were not covered in the guidelines. We have allocated all the accounts of risk supplied at interview to this structure. The middle column gives the number of men who fit into each category and the right hand column shows how many men in each of these categories did and did not ultimately receive PEP. Where men were initially refused or had to be persistent in order to obtain treatment this is specified.

BASHH: Situations where PEP is recommended.	Number	PEP given?
RECEPTIVE ANAL SEX with a partner who is DIAGNOSED HIV POSITIVE (ejaculation not specified)	9	7 yes 1 no at first clinic / yes at next 1 no
RECEPTIVE ANAL SEX with a partner of UNKNOWN HIV status (ejaculation not specified)	8	4 yes 1 initially given incorrect prescription (then corrected) 3 no
INSERTIVE ANAL SEX with a partner who is DIAGNOSED HIV POSITIVE	4	3 yes 1 no (he presented to the clinic 12 days after the exposure)
BASHH: Situations where prescription of PEP should be considered	Number	PEP given?
INSERTIVE ANAL SEX with a partner of UNKNOWN HIV status	5	3 yes 1 no at first clinic / yes at next 1 no
FELLATIO WITH EJACULATION with a partner who is DIAGNOSED HIV POSITIVE (modality not specified)	0	no respondents
FELLATIO WITH EJACULATION with a partner of UNKNOWN HIV STATUS (modality not specified)	0	no respondents
SPLASH OF SEMEN INTO EYE with a partner who is DIAGNOSED HIV POSITIVE	0	no respondents
Situations where prescription of PEP is not recommended	Number	PEP given?
FELLATIO WITHOUT EJACULATION with a partner who is DIAGNOSED HIV POSITIVE (modality not specified)	1	1 no
Situations described by respondents that are not addressed in current guidelines	Number	PEP given?
SPLASH OF SEMEN INTO EYE with a partner of unknown HIV STATUS	1	1 no
PRE-CUM from a partner who is DIAGNOSED HIV POSITIVE ON BROKEN SKIN	1	1 yes
BLOOD from a partner who is DIAGNOSED HIV POSITIVE IN MOUTH	1	1 yes

Of the 21 men who reported sexual exposure incidents for which current BASHH guidelines recommend administration of PEP, 16 received it. That means that five men who should have received PEP did not.

Of the 5 men who reported risk exposure incidents for which UK clinical guidelines recommend that PEP should be considered, 3 received it, 1 was assessed as a lower risk, 1 was not adequately assessed as emergency clinical staff were not aware of PEP.

Regardless of the post-hoc nature of this analysis (in that the formal publication of the guidelines occurred subsequent to data collection), all of these inappropriate refusals took place within 18 months prior to interview, and therefore followed the release of the BASHH draft guidelines and the CHAPS PEP awareness campaign. However, three quarters of men who should have been prescribed PEP did receive the medication in accordance with the guidelines.

There are important lessons to be learned from a closer examination of the five cases of inappropriate refusal. For this reason they are summarised below as a series of case studies.

Case #1: Person "A"

"A" had unprotected insertive and receptive anal intercourse with a casual partner of unknown HIV status during his first ever sauna experience. When he presented to his closest A&E department in a large city in the North West, he was told by a triage nurse that PEP did not exist. It did not appear that any doctor was consulted during his visit. "A" had first heard of PEP just one week earlier, when he was accessing GU services at that same hospital, and was very frustrated that his access was blocked, given that the health advisor who had told him about it had said to go to A&E if he thought he ever needed it. At the time of his last HIV test (two months after the incident) he was HIV negative.

21 years old, A&E, North

Case #2: Person "B"

"B" received news that his regular partner had just been diagnosed with HIV when he was away from home. He had recently had sex with him. With the support of someone he knew, he decided to get to the nearest A&E department in the city that he happened to be visiting. The A&E nurse had not heard of PEP, and she checked with the hospital pharmacist who had also not heard of it. No doctor was consulted. The nurse told "B" that it probably wouldn't be of use anyhow, as he would have been exposed to his partner's HIV over a long period of time, and the nurse recommended that he test for HIV at a GUM as soon as he could.

"B" did not access the GUM clinic in that town at the time because it was out of hours, but when he returned home a few days later, he attended his local GUM for a test, as he and his partner were both registered there. Given that the window period for accessing PEP had expired by that point, it was not dispensed. The Health Advisor was knowledgeable about PEP, and informed "B" that only one of the two doctors at that clinic tended to dispense PEP, explaining that it was "just the way they practice medicine really". At that visit, "B" had an HIV test, and the result was negative. One month later "B" tested positive for HIV.

21 years old, A&E, Midlands & Eastern

Case #3: Person "C"

"C" was at a sauna after taking recreational drugs. He felt that his perceptions had been significantly altered and his judgement impaired by the drugs he had taken. He had receptive unprotected anal intercourse with at least six men, some of whom ejaculated inside him.

When he presented at A&E as he was coming down off his high, he was persuaded by clinical staff that the likelihood of sero-conversion was probably about 5%. "C" felt pressured to decide that the risks associated with PEP side effects outweighed the likelihood of sero-conversion, and that because the incident had happened 52 hours before he arrived, that the treatment would possibly be ineffective. "C" left the hospital without PEP and deeply regretted the entire experience, as he felt he had been persuaded to make the wrong decision.

29 years old, A&E, London

Case #4 Person "D"

"D" had sex with a man of unknown HIV status that he had sex with on a number of previous occasions. In this encounter, he engaged in receptive and insertive oral intercourse, protected receptive anal intercourse and unprotected insertive anal intercourse. Afterwards, he felt that he had been stupid for not having used a condom – he had never done that before.

I had a dawning realization a couple of hours afterwards, of...you stupid boy, you shouldn't have done that, and how daft I was, and then thinking, bollocks, that wasn't a good idea, and I had heard of PEP and I thought I would access it.

"D" called NHS Direct but they were not aware of PEP and told him to get in contact with GUM the following day. He rang the GUM clinic at the nearest town the next day and spoke to a Health Advisor. After explaining the situation, the Health Advisor apparently said (in "D's" words):

'...well, if such a thing existed we would have people queueing out the door for it. It is available for staff, so it isn't just available for people to turn up and have!'

"D" challenged the Health Advisor with information that he had read about PEP on the internet, but this was dismissed. He did not approach any other services until three months later when he went to a different GUM clinic for an HIV test because of his continuing concern about that incident. His most recent test was HIV negative.

32 years old, GUM, Midlands & Eastern

Case #5: Person "E"

"E" was having sex that included protected receptive anal intercourse with a casual partner. On more than one occasion the partner took the condom off and continued anal intercourse. "E" noticed and insisted that the partner put a condom on again, which he did, only for it to be taken off subsequently. "E" later calculated that he may have been exposed to unprotected sex for a total of 15 seconds throughout the encounter. The partner had told "E" he was HIV negative, but after the repeated condom removals, "E" did not trust the information the sexual partner had offered him. "E" presented at A&E in a city in the North West. He was told the risk of exposure was low, and that PEP was not necessary. "E" left the hospital feeling reassured, but later felt that they had been dismissive of his concerns and he regretted not having been prescribed PEP.

Their reasoning was, it can make you quite ill, and they only give it to, sort of, rape victims, or people who know they've had exposure to HIV. They said because I didn't know if he was HIV positive, they just refused to give it to me.

The incident took place just a month prior to interview, and "E" was going to wait two more months to take an HIV test.

20 years old, A&E, North

3.3.3 Appropriate refusals

In three other cases where PEP was not prescribed, it was clear that the appropriate clinical decision was made. For two men, the risk of exposure was too low to consider administering PEP. One had engaged in receptive and insertive unprotected oral sex with an HIV positive partner, but because the partner had not ejaculated, the risk was considered negligible. The other reported a splash of semen in his eye from a partner of unknown HIV status, and again this was judged to be low risk. The last of these three men was refused PEP because he was outside the recommended time-frame for administration of the medication. This respondent had been informed of his sexual partner's HIV positive status nearly two weeks following this exposure, which is when he tried to access help.

3.3.4 Warnings about side effects

The majority of those who were prescribed PEP recalled being warned about the common side effects of the medications that they were going to take. Most (19 of 22) were advised that they might experience diarrhoea and nausea while taking the medication, while about half were also advised that vomiting could result, and that they might experience fatigue during the treatment. Less than a quarter remembered any mention of potential liver damage before starting the medication, and only a few were advised about the possibility of skin rashes, hallucinations or dizziness.

In those situations where clinical staff took a significant amount of time to explain dosing and side effects on the first clinical visit, men expressed satisfaction with the experience.

**I was quite pleased, because [the doctor] did sort of sit with me for about three quarters of an hour, or an hour going through everything with me.
29 years old, GUM, London**

Although many also recalled discussions initiated by clinical staff about the importance of adhering to the regime, less than half said that they had been given advice on how to minimise side effects during their initial consultation. Some received a prescription on the same day for other medications to combat nausea and diarrhoea, and were told to take them as needed. Where it was offered, advice on dealing with side effects during the initial consultation was always confined to the use of other medications rather than dietary or complementary interventions.

While a few men commented that all of the advance information on side effects might dissuade those considering PEP, most felt that knowing all the possibilities in advance had consolidated their commitment to completing what could be an uncomfortable course of treatment.

**I thought, hmm, not much fun, but slightly better than getting HIV. It's worth it if it's only for a month.
30 years old, GUM, London**

Two men who had been on PEP previously mentioned that clinical staff did not review side effects in much detail because of their prior experience. Two others said that they did not feel safe in taking PEP before they started on the medication because of the lack of information about side effects. In one instance, a man felt he had been "fobbed off" by an A&E doctor with the manufacturer's highly medicalised drug leaflet.

**He said, 'Oh, if you need to know anything, there is a leaflet in there'. He said, 'What do you do for a living?'. I said, 'I am a teacher'. And he said, 'Oh well, I presume you can read'.
33 years old, A&E, London**

Another said he had been too overwhelmed with information to adequately absorb anything during the initial consultation, and he would have appreciated literature to take home and read.

Half the men who were prescribed PEP were given written information about PEP at their initial consultation, and all of these had attended either GUM clinics, or London A&E departments

attached to hospitals with large HIV clinics. Most who had received such information said that they had benefited from the opportunity to work through the materials at their own pace. One man who had not been offered any such literature was surprised to find out on the internet (once he was already on PEP) about the potential for organ damage due to the toxicity of the drugs he was taking. He was angry that the prescribing doctor had not made him aware of these issues.

3.3.5 Baseline HIV testing

Both the draft and published versions of the BASHH guidelines stipulate that a baseline HIV test result should be obtained as soon as possible in those cases where prescription of PEP is considered.

It is mandatory that individuals for whom PEPSE is provided to undertake an HIV test (with rapid result) prior to, or shortly after initiating therapy.

Fisher *et al.* (2006: 87)

This HIV test is required to rule out the possibility that the individual is already HIV infected, as provision of PEP in those circumstance could affect subsequent treatment options. Of the 22 men who were prescribed PEP, only four were rapid-tested for HIV in the clinical setting where they presented. Twelve others had an HIV test administered at the time they presented, but test results were obtained over a time that ranged from three days to two weeks later. One further man remained disconcerted that the result of the HIV test that was taken at an A&E department was never communicated to him, as all of his follow-up was conducted at GUM.

Five of the men who had taken PEP reported that no baseline HIV test was conducted at the time of their initial assessment, though two of these were tested the following day when they went to a specialist clinic. One other reported a delay of six days before the test was carried out. Two others said that an HIV test was not necessary at their initial assessment because they regularly tested (negative) for HIV. One respondent could not remember whether or not an HIV test was conducted or considered at all.

When respondents were asked to describe why they thought an HIV test might be considered at the time that they were presenting for PEP, most simply explained that it would be ineffective to take PEP if they were already HIV positive. However, a minority of men said that the reason for HIV testing at that stage had not been explained to them, nor had it always been absolutely clear at the point of drawing blood that an HIV test was going to be conducted on the sample.

3.3.6 Satisfaction with the initial assessment

We asked men to assess the degree to which they felt comfortable with the initial assessment of their case, and their satisfaction with the way their concerns were handled by healthcare staff. Receiving PEP treatment was not automatically equated with clinical success or satisfaction. Thirteen of the 22 men who were prescribed PEP reported that they were generally satisfied with the clinical process. These men felt reassured by those with specialist knowledge, and with a supportive, reassuring manner.

They were good, they spoke to me really properly. They treated me with respect even though I didn't feel like I deserved it. They were professional and they really knew what they were doing. It was really good.

34 years old, A&E, Wales

Confidence and satisfaction depended on individuals' assessments of their healthcare professionals' experience and expertise in dealing with PEP requests.

You put yourself into a good person's hands, and they hold your hand, and they walk you through the process. And at the end they shake your hand and say 'thank you very much, have a very good day'. That's how I run my practice and that's exactly how they ran me.

45 years old, GUM, London

Almost all of those who received PEP and were satisfied with their experience had accessed a GUM clinic in the first instance. Those who expressed satisfaction with their experience in A&E departments had attended hospitals with large specialist HIV care units.

Nine men who received PEP were dissatisfied with some aspect of the process. The most common reason for feeling unhappy was the experience of ignorance and hostility from healthcare providers and administrative staff.

If you ring up for information, you get a ward sister. And a lot of [A&E] ward sisters are not really aware about PEP, especially after sexual exposure. That is what I tried to explain to this nurse and she got really pissed off with me, because I was trying to tell her that it is available and you have got to access it via this mechanism, but she wouldn't have any of it.
40 years old, A&E, Midlands & Eastern

Basically they could have made the [GU] receptionist a bit more aware of what is going on. They are the front-line and the first people that anybody with an incident comes to see and if they don't know the treatment is available, she really didn't have a clue what I was talking about! I had to get stropky and demand to see a doctor.
39 years old, GUM, South

One respondent talked of the patronising attitude which his GU consultant displayed throughout the course of his treatment.

When I saw him last, I complained to him about having diarrhoea, my stomach was terrible with various other side effects. And he looked at me, only through the corner of his eye, and he said: 'Well you won't be doing that again, will you.'
48 years old, GUM, South

Some who presented to A&E were concerned that they were being treated by non-specialists who had little knowledge about HIV.

He didn't seem like he knew what he was doing, he had to keep going off and asking other people. If I had any questions he had to go and ask. It felt like he was kind of...I kind of got the impression that he would go and look it up in a book and then come back.
18 years old, A&E, London

Others described being rushed through their consultation, leaving the hospital feeling flooded with information and with no offer of support.

You know when someone gives you directions, they tell you really complex directions, and the minute you walk away, you think, what the fuck was that? I dunno what they said. It was kind of like that.
33 years old, A&E, London

Not being prescribed PEP was not uniformly regarded as an unsatisfactory outcome. Three of the eight men who did not get PEP were satisfied with the overall experience because they felt that their concerns were met with professionalism, and it was clearly explained to them that their low risk of exposure did not justify administration of PEP.

**On a scale of one to ten I would actually give them ten.
Is that because you saw a specialist?
Of course, yeah. I just felt really comfortable, and really relaxed and everything he was saying – he was actually quite understanding.**
36 years old, GUM, South

All the men whose PEP refusals were clinically inappropriate (see section 3.3.2) were dissatisfied with their experience. As one said:

To be honest I was quite annoyed after I came out, because they were quite dismissive. And basically told me to just not do it again, and there was basically nothing they could do.
20 years old, A&E, North

Another reacted with anger against the professionals whom he felt were purposefully withholding treatment that could protect him from infection.

And I was just really, really upset. I felt that they were holding back PEP for 'real' emergencies. God knows what a real emergency is!
29 years old, A&E, London

One respondent reported feeling partly responsible for his disappointing experience because he had not been able to give the A&E staff more concrete information about PEP and they had not heard of it. When asked if the staff did anything to find out about what treatment might have been available, he replied:

They might have done had I known it was called PEP and stuff and they might have been able to go away and find out what PEP is.
21 years old, A&E, North

One man who had subsequently been diagnosed with HIV described having low expectations of being able to get PEP. While he described the experience as "somewhat disappointing", he felt that this outcome was probably not unusual, and he didn't blame the individuals involved.

I had already read about difficulties getting hold of PEP anyway, so I wasn't necessarily expecting them to have heard of it or know of it... At the time I didn't really think anything of it. I thought, 'You know she's tried, there isn't a lot she can do', and I still think that now really.
21 years old, A&E, Midlands & Eastern

Men's satisfaction with their initial clinical experience was not necessarily outcome-based. Among those who described a satisfactory experience, what was valued above all else was the perception that their case was being assessed by someone with expert knowledge of HIV treatments, and they were treated with dignity and respect. When dissatisfaction was expressed, it was typically related to a sense that health providers' homophobia, embarrassment or clinical ignorance had interfered with appropriate assessment and professional conduct. It was also evident that a small number of the men who were more ambivalent about their negative experiences felt that they should not expect any better from the NHS. Those who took this approach regarded their experience as a typical outcome of an over-burdened institution, in which non-specialists could not be expected to assess and treat every case appropriately.

3.4 TAKING PEP

3.4.1 Follow-up care

Among those men who did take PEP, their pathways of care were influenced by where they had first been assessed. Those who had initially been seen at a GUM or HIV clinic were usually enrolled in a follow-up regime before they departed from that first visit. There were also a few men who indicated that A&E staff had made referrals for their ongoing care, making it clear that specialist care was a priority.

[It] was pretty much we'll give you the starter pack and you need to go to [named GUM] to talk to a consultant.
43 years old, A&E, North

The few A&E departments that provided clear guidance and referral pathways for respondents were located in hospitals with large specialist HIV clinics. Most individuals who attended A&E departments were given enough medication for a few days, and told to go to any GUM department

where medication for the entire course would be made available. Those without specific referrals (ie. booked appointments) were left to negotiate the overcrowded GUM system with no support. For instance, on the last day of his starter pack medication, one man attended the central London walk-in GUM service that was recommended by the A&E department. He was told he had arrived too late in the day for an appointment, and despite explaining the urgency of the situation with his medication, the receptionist sent him away. He crossed the city to another GUM that he had attended in the past, where he was provided with medication and follow-up care for the remainder of his treatment.

The clinical guidelines recommend that individuals presenting for PEP should be “referred and seen as early as possible by a clinician experienced in the management of anti-retroviral therapy” (Fisher *et al.* 2006: 87), regardless of whether PEP is offered or accepted. Referral processes described by the men taking part in this study varied enormously. Of the eight men who did not take PEP, none were given direct referrals to specialist support or advice – a few were simply told to go to GUM in three months for an HIV test. Of the ten men whose initial PEP prescription was issued by an A&E department, only three had a clear recollection of attending specialist care the following day. The most common experience was to seek GUM or HIV specialist support when the medication in the starter pack was running low, as advised when they left A&E. In the main, the twelve men who had been prescribed PEP by a specialist GUM or HIV clinic had been given follow-up appointments a few days to a week after their first visit.

Once a part of the specialist GUM system, most men were reassured by the confidence and expertise of the clinical and support staff who managed their ongoing treatment. Several said how helpful it was to be able to access treatment and counselling specialists during their routine weekly appointments.

I was rather depressed to be on PEP, as you can imagine, and they do help you with your positive thinking, and to stay on track, you know?

26 years old, GUM, Wales

In addition to being able to access support relating to their treatment at scheduled appointments, more than a third of those on PEP were offered more flexible means of support. Some were able to telephone their health advisor and counsellors at any time. Those who took this up described calling about side effects, missed doses, and general adherence support.

However, a third of the men who took PEP (n=8) described being offered no emotional or adherence support while they were on treatment. While some did not find this problematic, others felt that they had been left on their own by clinical staff who demonstrated little concern for either their overall well-being or the treatment outcome.

If anything, that's what kind of, I just felt was a bit of a let down with the whole thing, because I really felt that they were kind of lacking that ongoing support. There was no offer of, give us a ring, or anything like that. I felt very much, kind of alone, really.

34 years old, GUM, London

In the majority of cases, men described receiving prescriptions for only seven days' of medication at a time. This system ensured that those on PEP would be seen by the clinic on a weekly basis while they were on treatment, for the purposes of monitoring side-effects, taking bloods and checking on adherence and psychological issues. When men were given all of their medication at once, some reported not returning for follow-up care at all (due lack of interest, fear of needles, or discomfort with clinic attendance).

Most of those who attended follow-up care described undergoing systematic liver function testing, screening for other STIs and side-effects monitoring. Four men had their medications changed while they were taking PEP (two because of severe side effects, one because of new treatment information about the source, and one was told that he had been given 'the old kind of PEP' by the A&E department that he had originally attended).

3.4.2 Experiences of side effects

It is beyond the capacity of this study to offer a comprehensive report of treatment regimes or associated side effects. However, we make a brief comment on the ways that side effects impacted on men's lives.

While only a quarter of the men who were prescribed PEP (n=6) could clearly remember the names of the medications they had taken (the remainder having no or uncertain recall), all could remember their side-effects. Only three men reported no side effects. The side effects experienced by the remainder ranged in severity. Twelve reported a range of symptoms that typically included vomiting, nausea, diarrhoea and fatigue. A few of these felt seriously unwell while they remained on the medication. Some took time out from their responsibilities while others were unable to exercise or socialise much at all.

Those with persistent symptoms found the prescription of anti-nausea and anti-diarrhoea medication helpful. A few men received further clinical and counselling support in dealing with their side effects when they returned to their clinic for subsequent visits. The two men who had their medications changed because of side effects described fairly serious reactions (including a serious and painful rash, severe vomiting and hallucinations).

Some whose side effects were mild to moderate felt that clinical staff were perhaps over-emphasising the potential impact of being on treatment. However, none of those who experienced side-effects expressed any regret about their decision to take PEP. Most felt that the inconvenience had been worthwhile.

3.4.3 PEP adherence

All but one of the men prescribed PEP reported completing the full course of treatment. It is likely that this is a group who were highly motivated to complete their treatment. That is, as they had been proactive in seeking help and accessing PEP their reported completion rate should not surprise us.

Ten respondents reported imperfect adherence, but for most this consisted of one or two missed doses. Half of those who reported missed doses said that they had occurred toward the end of the treatment period. This was sometimes accompanied by a sense that it was less important to remain totally adherent in the latter stages of taking PEP. One man who had expressed his disappointment at the lack of adherence support said:

I actually stopped two days before I was due to complete because I was so ill, I thought I just couldn't take them any more. I was like: 'Ugh, I'm gonna die'. So I just stopped two days before I was going to finish I just stopped. And then I probably missed one or two during the course leading up to that, due to social kind of commitments.
34 years old, GUM, London

Another recognised that his mounting psychological turmoil about having to be on the medication was hampering his ability to take it on time, particularly in the latter stages.

In the beginning I was so paranoid about it I was anal about it. Towards the end, the last week and a half was difficult, I was at the point, I was delayed in taking it because I would sit there for half an hour to an hour staring at the bottle thinking 'I don't want to take these things anymore!'
29 years old, A&E, London

It was clear that there was a relationship between side effects and adherence, in that men who had fewer and less severe reactions to the medication found it easier to never miss doses.

3.5 SOCIAL, PERSONAL AND SEXUAL IMPACT OF PEP

We conclude with an examination of how taking PEP impacted on men's personal and social life as well as their sexual decision making.

3.5.1 Telling others about PEP

Those who were prescribed PEP were highly selective about telling others that they took it. Among those who did not receive PEP, very few had told others about their experience, apart from the friends or partners whom they had asked for advice following the exposure incident itself. There were a range of reasons given by men for not discussing either seeking or taking PEP.

For many, needing PEP was an indicator of having taken a risk, of having made a serious mistake. A number of men talked about how they had to confront their own sense of irresponsibility at the point when they realised they were in need of help. So it should not be surprising that some preferred not to have to rehearse that sensation by later explaining to others that they had needed PEP. As one man said:

I have a lot of middle-aged friends. They would think I was a moron if they knew I had done that and needed PEP.

45 years old, GUM, London

The majority of those who had taken PEP balanced their own support needs in social and work settings, with their desire for privacy about being involved in sex that risked HIV exposure. Many told a few friends, and a small number said they told everyone in their social network. Social support was certainly an important reason for telling others but frequently closest friends were the only members of an individual's social network who knew. Most of those who had regular sexual partners at the time of the incident told them about being on PEP and the incident that had precipitated it. In some cases of sero-discordant relationships, the sexual partners themselves were the source of the exposure and had supported respondents throughout the entire process. However, one man described falling out with his partner because he had sought PEP. He had been accused of being too quick to act out his concerns about exposure, and the partner had felt blameworthy as a result. Two men decided not to tell their long-term partners about being on PEP. One said that it would have been too difficult to manage within the context of their long distance relationship, and that nothing would be gained by disclosing. The other said that he could not risk the loss of the relationship, as acknowledging needing PEP would be an admission of infidelity.

It was very uncommon for men who had been on PEP to tell family members. One man who was living with his mother at the time decided to tell her that he was on PEP because he figured the medications would be too difficult to conceal. However, he managed the situation by telling her he had been exposed to a stranger's blood while helping out at an accident scene, rather than revealing that he was engaging in sex with men.

Only three men informed their GP about having been on PEP, and one of these had first gone to his GP for advice following the sexual exposure incident. Another man described telling his new GP about his experience after moving to a different city. In this instance, he was able to share this information with a health professional in a clinical setting, but no one else.

Men who took PEP demonstrated a variety of approaches to managing disclosure in work and educational settings. Nine of the men found that being on PEP did not interfere with any of their responsibilities, so there was no reason for colleagues to know. Most said that their personal health did not concern their employer.

A further nine men reported taking some time off from work or education due to side effects and / or follow-up appointments. With the exception of one man who worked in the HIV field they did not

feel that they could be honest with their employers, colleagues or course leaders about the reasons for their absences. Often they gave other alternative reasons for missing work (such as stress).

It is not really something you want to go around spreading to everyone.

34 years old, GUM, Midlands & Eastern

The remaining four men did tell their employers or co-workers about the situation despite not needing to take time off. These men described their disclosure as a preparatory measure, in case they were going to need time off, reduced work-load, or physical assistance. All were happy with their decision to disclose, despite the fact that their physical health did not deteriorate dramatically as a result of being on treatment. One respondent commented that some colleagues had been rather 'old-fashioned' and 'formal' in their response, but he felt that if the situation were to occur again, they would manage it more appropriately.

One respondent who had been inappropriately refused PEP said that the interview was the first time that he had told anyone at all about his experience. We must recognise that for some men, others' knowledge of them taking PEP, or even having sought it, is considered stigmatising.

3.5.2 Post PEP HIV testing

The majority of men who had taken PEP ensured that they undertook all of the recommended HIV tests following on from their exposure incident. Most reported a schedule that included antibody testing at the end of the treatment period, three and then six months later. Some men who had completed the treatment within a few months of the interview were anticipating attending their remaining tests. A few mentioned that rather than having appointments or being sent reminders for subsequent HIV tests, the treating clinic had simply advised them of a recommended testing schedule. Such an approach makes it impossible for retrospective efficacy studies to be carried out.

Six of those who had been prescribed PEP did not test at the recommended three and six month intervals (although two tested some time later). Men who did not follow-up with their HIV testing immediately after taking PEP tended to report a psychological need to 'move on' after taking the medication. They had felt traumatised by the experience of having to admit to health professionals that they had participated in sex that involved potential HIV exposure, and tended to interpret PEP as a 'punishment' for their behaviour. As a result, they preferred to try to forget about PEP as soon as possible.

Once it was over it was over I closed the door on that particular incident.

29 years old, A&E, London

One man made a very prescient observation about the ambivalence with which he regarded coming to the end of this treatment regime.

Towards the end of taking the medication I actually got quite nervous that it wasn't going to work. I thought, 'I can't wait until this stops', but then also, I didn't really want it to stop.

Because then you find out?

Exactly.

34 years old, GUM, Midlands & Eastern

There can be little doubt that for some, anxiety increased toward the end of the treatment regime. As we have seen, the 'moment of truth', symbolised by follow-up HIV testing, was sometimes too much to bear. Without support, a minority simply chose not to find out.

Of the thirty men who took part in this study, four were ultimately given an HIV positive diagnosis. The circumstances of one man's story (detailed in case study #2 in section 3.3.2) suggest his sero-conversion might have been avoided if he had been prescribed PEP when he sought it. Another man tested HIV positive three months after completing a course of PEP. He felt that the treatment

did not prevent his sero-conversion, but he still recommends PEP for others. The two remaining men with HIV attribute their infection to exposure that occurred after they completed PEP.

3.5.3 Impact on future risk

As outlined in Chapter 1, the extent to which the possibility of the provision of PEP following sexual exposure might impact on future sexual risk behaviours has generated a significant amount of academic and clinical debate.

None of the men in this sample reported that the experience of seeking or taking PEP had increased the extent to which they participated in activities that risked HIV exposure. Most described the risk as outside of their normal parameters of safety and acceptability and did not expect to risk exposing themselves to HIV again (although some said that they could not rule this out). Other men felt that their HIV-related risk awareness had been heightened or reinforced by their experience of seeking or being informed about PEP, even where they had been cautious in the past.

It's at the fore... at the front of my mind, I would always take precautions now. I mean, I was always very good before, but then I am just a lot more aware now. But it also makes me think, you know, people who are HIV positive and have to take medication such as this, just the hell they must be going through. Because, at least, you know, after a month that was it for me. So as well as, you know how it has affected my personal outlook on safe sex, I think it is also, you know, awareness of HIV more broadly.

34 years old, GUM, London

Quite a few men who described themselves as having had a somewhat cavalier approach to HIV risk before their experience with PEP, found that having to undergo assessment and medication had dramatically altered their attitudes.

It certainly opened my eyes to it. I mean the fact that I am gambling with my life, possibly, you know. No one wants to die prematurely. So it made me think, 'well hold on'. We all like to think we are immortal, but this kind of thing makes you realise that you are not. It is a bit of a wake-up call, really.

30 years old, GUM, London

Of the five men who had sought PEP on more than one occasion, none thought of PEP as an 'easy' way to manage exposure situations. Rather, PEP was regarded as a serious 'last resort'. Some of the incidents that led these men to seek PEP on more than one occasion included: condom failures with partners of known positive and unknown status; exposure of broken skin to the bodily fluids of a known HIV positive partner; mucosal exposure (via the eye) to semen of a partner of unknown HIV status; and exposure of unbroken skin (near but not in the anus) to semen of a partner of unknown HIV status. None of these are the types of exposure situations might be characterised as demonstrating systematic problems with managing risk.

If you do have an accident it doesn't have to be the end of anything. Accidents will happen, condoms will burst, whatever.

39 years old, GUM, South

Of the two men who sought PEP more than once as a result of separate incidents of receptive unprotected anal intercourse, one expressed a desire for support to change his behaviour while the other was certain that it would never happen again.

3.5.4 Spreading the word about PEP

It is worth noting the extent to which accessing PEP has prompted some men to educate others about the treatment. Six men had engaged in discussions with others about PEP because of their belief that more people needed to know about it, and because they felt it should not be regarded as a simple 'morning after' solution. A few had supported and advised friends and acquaintances

following a potential sexual exposure. Another said that while he did not feel comfortable telling his friends that he had needed PEP, he had purposefully started to introduce the topic among those in his social network.

One man talked of the ways in which men communicated with each other online about their experiences of being on PEP. He felt that this contributed to an overall increase in awareness and clarity about what treatment actually involved.

I think it's really important for people to realise, you know, we all shout about PEP and it's all very glossy. You know, the images THT put out with their fire extinguishers make it sound like an emergency thing, and you know, one squirt of the hose and it's all over. When it just fucking isn't. It isn't like that. And I spoke to quite a few guys that have actually had PEP and it's definitely had a massive impact on their sexual health risk taking as a result of it. I think they are more conscious and aware of... they are less likely to put themselves at risk.
40 years old, A&E, Midlands & Eastern

Some were critical of the way that the PEP message had been handled, embarking on their own promotion of PEP because they felt that not enough had been done by voluntary and statutory agencies to ensure that those at risk of HIV transmission knew about it.

I went on a sort of crusade after that, to let more people know about it, because I thought, 'well Christ, I am 29 years old, which isn't necessarily old, but I've been on the London Gay scene since I was about 13. I know a lot of people, and I've known a lot of things, and I thought I knew a lot about being a Gay man. I did not know about this.' And with hindsight, now, I've thought, 'Christ, the times that I could have recommended this to other people! How beneficial it would have been for them'. In many ways, although it was an experience to go through, it has – even now, even with one of my brand new friends, I basically took him down to the local clinic, and bang, he's on it at the moment. And even him, he didn't know anything about it. So although I have seen a lot more advertisements and things like that, I just don't think it's bold enough.
29 years old, GUM, London

3.6 SUMMARY & DISCUSSION

It's worth considering the means by which the men in our sample came to know about PEP. A third of the sample had heard about PEP through social and sexual networks and the remainder came to know about it through the (Gay) media. This suggests that knowledge of, and conversation about, PEP may be common in certain social or friendship groups. While the processes by which PEP-related information is diffused in such networks is not described here, it is important to recognise that social networks and health professionals have a key role to play in spreading PEP awareness, both before and after risk incidents occur.

The sexual incident that leads to men seeking PEP is described as an aberration from 'normal' sexual practice and the experience of taking PEP is usually an attempt to regain control over sexual risk. This finding has two implications. First, many of those who seek PEP are fully aware of the sexual risks they have taken and are prepared to act where HIV exposure may have occurred. They are not indiscriminate risk-takers. Second, they are using PEP as more than a clinical intervention. There is a broader symbolic meaning to seeking and taking PEP in which the individual takes responsibility and resumes control. This is important because the action of seeking PEP occurs at a time where men are forced to reflect on their sexual lives and their sexual risks. This may be the prime time to offer such men a more structured intervention to facilitate this reflection.

As we might expect, the experience of seeking PEP is influenced profoundly by the quality and receptiveness of both information and clinical services. The experiences recounted here illustrate a need to assess and if necessary, to improve information services about PEP. Some men relied on existing contacts (such as a positive partner or friend) to gain access to clinics but the majority

found that they needed significant personal resources, a capacity to advocate for themselves and a degree of persuasiveness to deal with frontline staff (nurses and receptionists) who were ignorant of PEP, or doctors who were either unaware of PEP or unwilling to prescribe it. Moreover, men found themselves having to negotiate complex treatment and prescribing pathways at moments where time was critical. The social capital that underpins this capacity is more common among better educated men or men with higher incomes or from certain professional backgrounds. It may not be an exaggeration to say that at present, whether or not you get PEP depends largely on who you are, where you live and who you know.

However, not all of the men's experiences of accessing PEP were negative or difficult. Some received an exemplary service from the start and for many, when they finally found a receptive service, they were reasonably satisfied. It is perhaps worth learning from these examples of good practice. A successful outcome is one where a man either receives PEP or not based on appropriate risk assessment, is treated at all times with respect, and is referred for ongoing support where necessary.

The experiences of the men in our sample show highly variable practice around initial assessment, HIV testing, information and support, after-care and follow-up. This impacted profoundly on the quality of men's experiences of taking PEP. What men valued most, both at follow-up and during initial assessment was that all staff in the clinical environment demonstrated professionalism, and that doctors had access to expertise and knowledge regarding PEP prescribing, side effects and adherence.

For some men, the social effects of taking PEP were significant. It is clear that there is a great deal of stigma attached to taking PEP. This has two causes. First men feel that their identity as responsible, self-reliant or prudent is compromised by having to take PEP. Second, talking about taking PEP mobilises knowledge about intimate sexual practices. In this sense, taking PEP was often seen as a personal or private matter. Like many areas where stigma is perceived, men reported balancing the need for social support and respite with the need to tell others about taking PEP. Men had a variety of ways to manage this tension. We recorded few difficulties in this respect. However, in view of the general resourcefulness of the men in the sample as well as their professional and social backgrounds, it is likely that they are able to manage such situations. It may be more difficult to manage information around taking PEP in different work or domestic environments or indeed where there are other social or personal co-factors (other health concerns, a chaotic lifestyle, or a shared household).

None of the men in our sample described PEP as an easy option and certainly none felt that the availability of PEP was likely to make them more likely to take risks in the future. Rather, for many, the experience of taking PEP was not something they would ever want to repeat. Therefore many spoke about how the experience might make them more careful in the future. However, in view of the proportions of men who sero-convert after taking PEP and those who have taken PEP on more than one occasion, it is clear that we need to know more about the sexual behaviours of men who take PEP (both before and after accessing treatment). Such investigations would contribute to the design of preventive interventions to be made available during and after men's experiences with PEP.

4 Conclusions and recommendations

We structure our conclusions and recommendations into two areas. First, who is seeking, accessing and taking PEP and second, the experiences of those who try to access PEP.

4.1 WHO KNOWS ABOUT, IS SEEKING AND GETS PEP?

Chapter 2 makes a distinction between awareness of PEP, ever having sought PEP and ever having taken PEP. As PEP is a relatively new technology or intervention, clear aims should be set with regard to awareness of PEP, seeking and receiving it.

As regards awareness, our aim should be that all homosexually active men are aware of PEP. The change data from 2003 to 2005, presented in Chapter 2, indicates that although awareness has increased overall, it is by no means at saturation and demographic differences are evident. With less than saturation awareness of PEP, an interim aim might be that men more likely to be involved in HIV exposure should be more likely to be aware of PEP. Overall this is the case, with the exception of Black men and men with lower income (White other men remain more aware of PEP while men with higher income are more likely to be aware of PEP than men with lower income). However, these differences should not distract from the overall aim which is to make PEP awareness universal. That is, we should be seeking awareness among all homosexually active men.

As regards availability of PEP, we should be aiming for a similar parity. That is, all men should have PEP equally available to them. The ways in which 'equally available' are defined is open to question. It is perhaps inevitable that a man in central London will always find PEP more easily available than a man in a small town or rural area. It might be more realistic to define a minimum availability that all men should expect – regardless of area of residence or other factors. The interventions needed to make this happen are likely to be structural and policy oriented.

As regards seeking and successfully getting PEP, our aim should be slightly different. On an individual level, our aim should be that any man who believes himself to be uninfected that is involved in possible HIV exposure seeks and gets PEP if he so wishes and if it is clinically appropriate. However, on a population level, we should expect the demographic profile of men who seek and get PEP to be similar to those most likely to be involved in exposure (that is, men under 40, men living in areas where HIV prevalence is highest, Black men, men with lower incomes, exclusively homosexually active men and men with higher numbers of male sexual partners). Here the match between those currently seeking and getting PEP and those who we would aim to do so is more complex. While men living in London, men who have tested and men with higher numbers of male partners are more likely to seek and take PEP, those with higher incomes are also more likely than those with lower incomes to seek and take PEP. Moreover, men with higher incomes who seek PEP are more likely to actually get it.

The importance of this finding cannot be underestimated because it points to overarching pre-existing social factors which threaten the success of PEP on a population level. Undoubtedly, clinical need will be the prime factor influencing PEP take-up (in the sense that all those who seek PEP have self-identified as needing an intervention of some kind). However, self-identification of need, awareness of PEP and capacity to seek out PEP will not be equally distributed across the population. Those taking up complex medical interventions are generally more likely to be from class and cultural backgrounds possessed of greater social capital, especially if seeking and obtaining

interventions depends to a large extent on self diagnosis, motivation to actively seek help and overcoming clinical and social barriers to obtaining help. To put it simply, men seeking and getting PEP are currently more likely to be White, middle class, better educated and higher earning and therefore do not fit the demographic profile of the group most likely to be involved in HIV exposure.

These findings are backed-up by the qualitative data which shows that often, requesting a highly specialised treatment (such as PEP) in a generic clinical setting (such as an A&E department), when such a request is likely to require a significant amount of explanation and description, demands a patient who is prepared to invert the traditional power relationship with his health care providers. To a certain extent this is also true when confronting ignorance about PEP among NHS reception staff.

When we regard the men who took part in qualitative research in these terms, we recognise their unique position at the forefront of PEP adoption and we are forced to conclude that it is unrealistic to expect that, with enough publicity, all men who are in need of PEP will already have the skills to access it. Interventions are therefore required to increase personal capacity (perhaps by increasing knowledge about rights to treatment or providing some form of advocacy service) while simultaneously working to remove the barriers to access encountered. Owing to a research design that did not recruit men directly from clinics where they had received PEP, this qualitative work brings with it the unique perspectives of men who were inappropriately denied PEP. Their experiences underscore the significant finding that simply knowing about PEP and going out to access it is not always enough to get it, even when it was clinically appropriate.

What this data highlights is that there is a need to ensure equitable access to PEP for those homosexually active men in greatest need. The CHAPS PEP campaign has successfully increased awareness and probably increased uptake among certain groups. However, the majority of media interventions appear to disproportionately benefit middle class men, who are also more likely to pick up the information from magazine articles and editorials that mass media adverts generate. This means that these interventions, while benefiting the entire population, actually increase inequalities in access to interventions, and can increase inequalities in HIV incidence across income, class and ethnicity. Ensuring all men benefit from emerging prevention interventions is a priority for all programmes and researchers.

Specific interventions also need to continually improve men's knowledge about PEP as well as their ability to access appropriate risk assessment and (where necessary) treatment. For instance, the men in this sample demonstrated that even where they knew about PEP in advance, not all were aware that treatment effectiveness was improved when PEP was started as soon as possible after exposure. Careful consideration needs to be given to how best to communicate the message that PEP is available within 72 hours of exposure while also emphasising that men should try to access it as soon as possible.

Thus, we might consider attending to the following in subsequent PEP interventions:

- the need to increase awareness of PEP further among Gay men generally;
- the need to increase the availability of PEP generally;
- the need for interventions to increase awareness (and uptake) of PEP among those homosexually active men more likely to be involved in exposure with less social capital (especially Black Gay men and men with lower formal education and income).

4.2 THE EXPERIENCE OF SEEKING AND TAKING PEP

Our findings on the experiences of accessing and taking PEP provide us with insights into the way that PEP is perceived and used. We can now make a distinction between PEP as a straightforward clinical intervention (assessment, testing, diagnosis and prescription) and PEP as it is experienced by the men who seek and take it (as an event with long-lasting emotional, psychological and social

significance). Attending to this latter conception of PEP allows us to envisage a range of social, psychological and interpersonal interventions that relate to taking PEP.

Our quantitative findings alert us to a need for a range of interventions which address the subsequent risk behaviour and support issues for those who present for PEP. As PEP is needed by men at highest risk of HIV infection, it should not surprise us that some of the men who take PEP subsequently go on to become infected with HIV (either through the failure of PEP or as a result of subsequent exposure). Men who have taken PEP in the past are still at significant risk from HIV and taking PEP alone may not reduce this risk (Grulich *et al.* 2006).

In itself, prescribing PEP cannot be seen as a long-term behavioural intervention. Such an expectation chimes too closely with the attitude demonstrated by the doctor who said to one respondent, 'Well, you won't be doing that again, will you?' and is hardly consistent with health promotion in the context of *Making it Count* (Hickson *et al.* 2003a). Instead, a more useful approach is to regard the event of seeking PEP as providing a unique opportunity where men may be open to reflecting about their sexual practices and risk reduction strategies and what might 'go wrong' during sexual negotiation. In our qualitative research, men described the moment of seeking PEP as a unique event in their sexual lives commonly characterised as the result of a temporary loss of control over sexual risk and a need to regain this control. This experience is echoed in research elsewhere (Körner *et al.* 2003, 2005). In short, this may be an appropriate opportunity to undertake tailored and sometimes in-depth interventions with men who are involved in exposure to HIV. As such, the clinical intervention's unforeseen effect (of restoring a feeling of control) might be augmented and significantly enhanced by a complementary intervention supporting those with behaviours that carry a high risk of HIV transmission (Roland *et al.* 2005).

The need for such an intervention becomes compelling when we consider that the population of PEP seekers are men who have been involved in possible HIV exposure. As PEP becomes more widely sought, it is likely that this population will increasingly approximate the population of men most likely to be involved in HIV exposure and sero-conversion. Moreover, health promoters have access to this group at a time when they are amenable to reflecting on their sexual practices. What this suggests is that PEP services should, wherever possible, refer clients to HIV prevention services that could meet their other HIV prevention needs perhaps via a tailored psycho-social intervention.

Allied to this need for interventions accompanying PEP assessment and prescription are a range of concerns about improving treatment protocols for PEP. The experiences of those taking PEP examined in the qualitative research indicate not only that there is patchy follow-up care and support, but also that baseline testing for HIV as well as three and six month follow-up tests are not consistent. Finally, there is little monitoring of men's sexual risk behaviour post-PEP nor any longer-term support. This is inappropriate because it impacts negatively on men's experiences of taking PEP and it precludes the possibility of developing proper follow-up protocols for this application of PEP.

Our qualitative investigation suggests shortfalls in the standards of services both from advice and information services as well as some A&E and GUM clinics. Interventions both to improve services and enable users to deal with their variable quality might include training and development for NHS staff about PEP – with a distinct component focussing on frontline and reception triage routines in such circumstances. In addition, advocacy with individual clinics about developing their own PEP treatment protocols and communicating these to clinical and non-clinical staff may be appropriate. Finally it may be important to provide information to homosexually active men, not only about what they can expect from providers, but also ways in which they can either demand PEP or enable providers who do not know about PEP to find out about it and administer it.

4.3 SERVICE RECOMMENDATIONS

4.3.1 Direct contact interventions for homosexually active men

Although we have highlighted differences in the demographic profiles of those who seek and receive PEP, it will be difficult to address them until we have reached a point of population saturation as regards awareness of PEP. We therefore recommend that in the short-term, interventions to increase PEP awareness should be prioritised over interventions to change the demographic profile of those who seek and receive PEP.

- Continued general PEP awareness campaigns for all homosexually active men are required. They should make it clear that the sooner PEP is sought after possible exposure, the better.
- Targeted PEP campaigns are required for men who are currently less likely to know about PEP.
- A range of information, support and psycho-social interventions are required for all men seeking PEP, including those who do not receive it.
- An information intervention enabling men seeking PEP to present to clinics more effectively and demand PEP if necessary (eg. information / activist cards).

4.3.2 Sector development interventions

The Chief Medical Officer has stressed that PEP should be a part “of the spectrum of sexual health services” in all Primary Care Trusts (Donaldson 2006). Uptake and implementation of this recommendation requires a variety of actions from a range of organisations including the Department of Health, Primary Care and other NHS Trusts, Strategic Health Authorities and voluntary and community organisations. These include:

- Develop and implement PEP information services and training protocols for all service providers (including A&E staff and NHS Direct). For example, some countries have implemented PEP helplines for medical staff who are unsure of protocols or prescribing criteria. Given the likely information needs among non-HIV specialist staff such an intervention could be considered for the UK.
- Monitor and seek to improve individual A&E and GUM clinics’ PEP protocols. Such protocols must attend to the way in which triage, reception and clinical staff handle those who seek assistance after a potential HIV exposure. Such protocols should also attend to the need for confidentiality, sensitivity, referral pathways, informed consent for HIV testing, and provision for HIV testing at three and six months following potential exposure.
- Work to ensure the development and/or implementation of appropriate follow-up protocols for those who present with a request for PEP, including direct referral pathways from A&E settings into specialist GUM and HIV care.
- Consideration should be given to the need for STI screening and counselling for those who do not receive PEP treatment.
- Adherence and related social support should be available for all those who receive PEP. These should be offered not only at the start of treatment but also towards the end, given that adherence can decline as individuals become either more anxious or less concerned about efficacy.
- Men who indicate a high level of pre-existing sexual risk behaviour should be referred to tailored behavioural interventions – either delivered by clinical psychology departments associated with the treating clinic, or by appropriate voluntary and community sector organisations.

References

- Almeda J, Casabona J, Simon B *et al.* (2004) Proposed recommendations for the management of HIV post-exposure prophylaxis after sexual, injecting drug or other exposures in Europe. *Eurosurveillance*, 9 (4-6): 35-40.
- Braitstein P, Chan K, Beardsell A *et al.* (2002) Prescribing practices in a population-based HIV postexposure prophylaxis program. *AIDS*, 16: 1067-1070.
- Centers for Disease Control and Prevention (2005) Antiretroviral postexposure prophylaxis after sexual, injection-drug use, or other nonoccupational exposure to HIV in the United States: recommendations from the U.S. Department of Health and Human Services. *Morbidity and Mortality Weekly Report*, 54 (No.RR-2): 1-16
- Chen M, Fox E, Rogers C (2001) Post-exposure prophylaxis for human Immunodeficiency virus: knowledge and experience of junior doctors. *Sexually Transmitted Infections*, 77: 444-445.
- Department of Health (2001) *The national strategy for sexual health and HIV*. Department of Health, London. www.dh.gov.uk/assetRoot/04/01/87/58/04018758.pdf
- Department of Health (2004) *HIV post-exposure prophylaxis: guidance from the UK Chief Medical Officers' Expert Advisory Group on AIDS*. Department of Health, London. www.dh.gov.uk/assetRoot/04/08/36/40/04083640.pdf
- Donaldson L (2006) *Improving the prevention and treatment of sexually transmitted infections (STIs), including HIV*. Letter to all Chief Executives of Primary Care Trusts and Strategic Health Authorities in England. Ref: 6352, April.
- Ende A, Beaudoin L, Sottolano D *et al.* (2006) Non-occupational postexposure prophylaxis (nPEP) in New York State Emergency Departments. *XVI International AIDS Conference*. Toronto, Canada. Poster TUPE0435.
- Fisher M, Benn P, Evans B *et al.* (2006) UK guidelines for the use of post-exposure prophylaxis for HIV following sexual exposure. *International Journal of STD & AIDS*, 17:81-92.
- Grulich A, Jin F, Poynten M *et al.* (2006) Non-occupational post exposure prophylaxis against HIV (NPEP) and subsequent HIV infection in homosexual men: data from the HIM cohort. *XVI International AIDS Conference*, Toronto, Canada. TUPE0434.
- Hawe P, Shiell A (2000) Social capital and health promotion: a review. *Social Science and Medicine*, 51 (6): 871-85.
- Hickson F, Reid D, Weatherburn P, Henderson L, Stephens M (1998) *Making data count: findings from the National Gay Men's Sex Survey 1997*. Terrence Higgins Trust, London.
- Hickson F, Weatherburn P, Reid D, Henderson L, Stephens M (1999) *Evidence for change: findings from the National Gay Men's Sex Survey 1998*. Sigma Research, London. www.sigmaresearch.org.uk/downloads/report99g.pdf
- Hickson F, Reid D, Weatherburn P, Stephens M, Brown D (2001) *Time for more: findings from the National Gay Men's Sex Survey 2000*. Sigma Research, London. www.sigmaresearch.org.uk/downloads/report01c.pdf
- Hickson F, Nutland W, Weatherburn P, Burnell C, Keogh M, Doyle T, Watson R, Gault A (2003a) *Making it Count: a collaborative planning framework to reduce the incidence of HIV infection during sex between men*. 3rd edition, Sigma Research, London. www.sigmaresearch.org.uk/downloads/report03e.pdf
- Hickson F, Reid D, Weatherburn P, Stephens M (2003b) *Out and about: findings from the United Kingdom Gay Men's Sex Survey 2002*. Sigma Research, London. www.sigmaresearch.org.uk/downloads/report03f.pdf
- Kawachi I, Kennedy BP, Lochner K, Prothrow-Stith D (1997) Social capital, income inequality and mortality. *American Journal of Public Health*, 87: 1491-1498.
- Kahn J, Martin J, Roland M *et al.* (2001) Feasibility of postexposure prophylaxis (PEP) against Human Immunodeficiency Virus infection after sexual or injection drug use exposure: the San Francisco PEP study. *The Journal of Infectious Diseases*, 183: 707-714.
- Körner H, Ellard J, Hendry O *et al.* (2003) *Taking Post-Exposure Prophylaxis: managing risks, reclaiming control*. National Centre in HIV Social Research, Sydney.
- Körner H, Hendry O, Kippax S (2005) It's not just condoms: social contexts of unsafe sex in gay men's narratives of post-exposure prophylaxis for HIV. *Health, Risk & Society*, 7 (1): 47-62.

- Laporte A, Jourdan N, Bouvet E *et al.* (2002) Post exposure prophylaxis after non-occupational HIV exposure: impact of recommendations on physicians' experiences and attitudes. *AIDS*, 16 (3): 397-405
- Martin J, Roland M, Neilands T *et al.* (2004) Use of postexposure prophylaxis against HIV infection following sexual exposure does not lead to increases in high-risk behavior. *AIDS*, 18 (5):787-792
- Merchant R, Keshavarz R (2003) HIV postexposure prophylaxis practices by US ED practitioners. *American Journal of Emergency Medicine*, 21 (4): 309-312.
- Ooi C, Dayan L, Yee L (2004) Knowledge of post exposure prophylaxis (PEP) for HIV among general practitioners in northern Sydney. *Sexually Transmitted Infections*, 80 (5): 420
- Otten R, Smith D, Adams D *et al.* (2000) Efficacy of postexposure prophylaxis after intravaginal exposure of pig-tailed macaques to a human-derived retrovirus (Human Immunodeficiency Virus Type 2). *Journal of Virology*, 74 (20): 9771-9775.
- Patel D, Gawthrop M, Snashall D, Madan I (2002) Out of hours management of occupational exposures to blood and body fluids in healthcare staff. *Occupational and Environmental Medicine*, 59: 415-418.
- Pinkerton S, Martin J, Roland M *et al.* (2004) Cost-effectiveness of HIV post exposure prophylaxis following sexual or injection drug exposure in 96 metropolitan areas in the United States. *AIDS*, 18 (15): 2065-2073.
- Reid D, Weatherburn P, Hickson F, Stephens M (2002) *Know the score: findings from the National Gay Men's Sex Survey, 2001*. Sigma Research, London.
www.sigmaresearch.org.uk/downloads/report02d.pdf
- Reid D, Weatherburn P, Hickson F, Stephens M, Hammond G (2004) *On the move: findings from the National Gay Men's Sex Survey, 2003*. Sigma Research, London.
www.sigmaresearch.org.uk/downloads/report04g.pdf
- Rey D, Den Diane M, Moatti J *et al.* (2000) Post-exposure prophylaxis after non occupational exposures to HIV: an overview of the policies implemented in 27 European countries. *AIDS Care*, 12 (6): 263-5.
- Richens J, Edwards S, Sadiq S (2005) Can the promotion of post-exposure prophylaxis following sexual exposure to HIV (PEPSE) cause harm? *Sexually Transmitted Infections*, 81: 190-191.
- Roland ME, Neilands TB, Krone MR *et al.* (2005) Seroconversion following nonoccupational postexposure prophylaxis against HIV. *Clinical Infectious Disease*, 41(10) 1507-13.
- Roland ME, Neilands, TB, Krone MR *et al.* (2006) A randomised trial of standard versus enhanced risk reduction counselling for individuals receiving post exposure prophylaxis following sexual exposures to HIV. *Thirteenth Conference on Retroviruses and Opportunistic Infections*, Denver, 2006. Poster #902.
- Schechter M (2002) Occupational and sexual PEP – benefit / risk? *VI International Conference on Drug Therapy in HIV Infection*, Glasgow, UK. Abstract PL 6.1.
- Schechter M, Iago R, Ismerio R *et al.* (2002) Acceptability, behavioural impact, and possible efficacy of post sexual exposure chemoprophylaxis (PEP) for HIV. *IX Conference on Retroviruses and Opportunistic Infections*, Seattle, Washington. Abstract 15.
- Spence J (2003) Should emergency departments offer post exposure prophylaxis for non-occupational exposure to HIV? *Canadian Journal of Emergency Medicine*, 5 (1):1-13.
- Tsai CC, Emau P, Follis KE *et al.* (1998) Effectiveness of post-inoculation PMPA treatment for prevention of persistent SIV infection depends critically on timing of initiation and duration of treatment. *Journal of Virology*, 72: 4265-4273.
- Waldo C, Stall R, Coates T (2000) Is offering post-exposure prevention for sexual exposures to HIV related to sexual risk behavior in gay men? *AIDS*, 14 (8): 1035-1039.
- Weatherburn P, Stephens M, Reid D, Hickson F, Henderson L, Brown D (2000) *Vital statistics: Findings from the National Gay Men's Sex Survey, 1999*. Sigma Research, London.
www.sigmaresearch.org.uk/downloads/report00b.pdf
- Weatherburn P, Reid D, Hickson F, Hammond G, Stephens M (2005) *Risk and reflexion: Findings from the National Gay Men's Sex Survey, 2004*. Sigma Research, London.
www.sigmaresearch.org.uk/downloads/report05c.pdf
- Weatherburn P (2005) Formative evaluation of the THT CHAPS PEP pilot campaign. Sigma Research, London.
- Wilkinson R (ed.) (1986) *Class and health: research and longitudinal data*. Tavistock, London.