

This FAQ chapter presents the views and experiences of men in relation to PEP. We begin with quotes from men below, and continue to represent what we have been told in the pages that follow.

That should be good to know. I didn't know it was out there.

(Gay, 16-21, HIV negative)

I've heard of PEP but I haven't thought about it. I know it's at A&E or the clinic. Don't know if I'd use it.

(Gay, 26-35, HIV negative)

I had the worse experience of my whole entire life at A&E trying to get PEP. I'd never go back... The receptionist didn't know what I was even asking for.

(Gay, 36-45, HIV negative)

The medication was fine and I didn't have major problems taking it. Subsequent tests confirmed me to be HIV negative.

(Online respondent)

I know that it doesn't affect everyone like me but the PEP was horrendous. Everything in the book.

(Gay, 36-45, HIV negative)

Did use condoms, then stopped, my partner is now HIV+ so we are using condoms again... I've heard about PEP but don't know what it is exactly. It was mentioned at my partner's diagnosis but from my understanding its only if there's exposure, so we just use condoms, we got minimal information really. Yes, the doctor mentioned it but we haven't sought out any other information.

(Gay, 26-35, HIV negative)

I have to say when I read about PEP, it's not very well publicised. I'd heard about it and I do know but it's not in the forefront of my mind.

(Gay, 45+, HIV negative)

FAQ Scotland is part of a larger project that wants to prevent HIV infections in Scotland among gay and bisexual men. The larger project is called an HIV Needs Assessment, undertaken by NHS Greater Glasgow and Clyde and NHS Lothian. For more about FAQ and other FAQ chapters go to [www.faqscotland.co.uk](http://www.faqscotland.co.uk)

## OVERVIEW

### What we learned from men about their experiences:

- Awareness of PEP among gay and bisexual men remains low.
- There is some confusion among men as to when an experience of condomless anal sex requires PEP as a response.
- When men know about PEP they might make their own assessment about whether condomless anal sex has been risky enough to consider its use.
- Men report poor experiences of attempting to access PEP via hospital based Accident and Emergency services.
- Some men can experience difficulties using PEP because of side effects.
- FAQ participants support further efforts to raise awareness of PEP.

### What the findings mean for HIV prevention and HIV/Sexual Health clinical services:

- Further work needs to be done to raise awareness of PEP.
- Education about PEP should support gay and bisexual men to understand when they should seek professional advice about the appropriateness of PEP.
- If men are advised to attend Accident and Emergency services for PEP then these services need to have appropriate knowledge, skills and attitudes toward providing this service.

### Reflective questions for practitioners

Throughout FAQ reporting, we ask individual practitioners, teams and services to read the detail of findings and then take time to reflect on important questions.

- What role should I play in raising awareness of PEP with individuals at risk of acquiring HIV?
- How does knowledge or use of PEP sit alongside other risk reduction work with the individual?
- Do I know enough about PEP, its recommended use and its management?
- What needs to be done with colleagues in Accident and Emergency services to improve the service they provide when it comes to accessing PEP?

More about the FAQ approach and project participants in the **About FAQ** chapter.

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Throughout the chapter, direct quotes from participating men appear **in blue**. When direct quotes are taken from an FAQ telephone interview it is possible to identify sexual orientation, age category and HIV status (actual or perceived); an internal interview code is also given. Quotes taken from online responses are labelled as such.

### INVOLVING PARTICIPANTS

We asked FAQ participants to consider awareness of, access to, and use of PEP. Men have done so via FAQ interviews, (with our first wave cohort of 118 men) we raised discussion of PEP when men described condomless anal sex, and in an FAQ online survey called **PEP** (completed by 46 men).

In both interviews and FAQ online, when it was necessary to explain what PEP is to men, we used the following:

- PEP is short for post-exposure prophylaxis. If you have been exposed to HIV it can help prevent you becoming HIV positive. It's a course of tablets that you need to take for 4 weeks after you have been exposed to HIV infection, for example after having unprotected anal sex with someone who is HIV positive. For it to work it needs to be started no more than 72 hours after the risk of HIV exposure, and is more likely to work if it is taken sooner. You can get PEP from a sexual health clinic or by going to a hospital A&E (Accident and Emergency).

**FINDINGS**

Via interviews and online, men discussed PEP from a number of perspectives, covering men’s knowledge of PEP, accessing PEP, using PEP (or deciding not to) and how awareness of PEP should be raised.

**Knowledge of PEP**

When discussing recent episodes of condomless anal sex with FAQ interviewees, we raised the issue of PEP, allowing us to ascertain whether men are aware of PEP and how it is used. Generally FAQ interviewees have been unaware of PEP.

That should be good to know. I didn’t know it was out there.

(Gay, 16-21, HIV negative, I1/031)

I got positive because a condom burst, it was a year ago. I didn’t know about PEP. In all fairness the person didn’t know he had it.

(Gay, 26-35, HIV positive, I1/016)

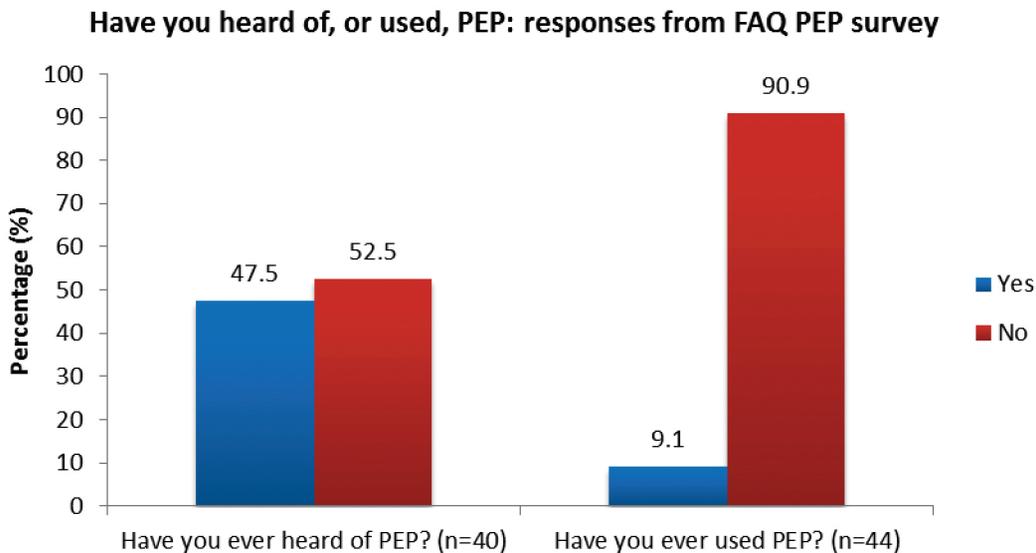
Did you talk about using condoms? Yes. I asked him what he wanted to do and he said he didn’t want to use them, that he never does. And I just gave into it... (After some discussion about PEP and an explanation of its use) Really? I’ve never heard of that. Thank you for that.

(Gay, 45+, HIV negative, I1/040)

Did you talk about using PEP? Is that like a screening for Gonorrhoea and HIV, going to the GUM clinic? No, I didn’t know about that.

(Gay, 42, HIV negative, I1/071)

Men responding to the FAQ online **PEP** survey were also asked these questions: *Have you heard of PEP (before you opened this page)? Have you ever used PEP?*



While some FAQ interviewees have no awareness of PEP, others have some, perhaps acquired recently, maybe from a clinic after an episode of risk, however these contributions continue to evidence poor awareness.

A couple of other times he fucked me but I don't think he ever came inside me. I didn't know what PEP was at the time. Now I do know what it is though.

(Gay, 45+, HIV negative, I1/098)

No, we didn't use them [condoms]. I trust him. I know him fairly well, I know he's tested and I do too so there's a level of trust, none of us are riddled. Did you ever think about using PEP after having anal without a condom? No didn't use it. I think I've heard of it, but it doesn't sound pleasant.

(Gay, 16-25, HIV negative, I1/115)

I didn't actually know what it was then. After that I wasn't very well and I was terrified basically, so I eventually went to a clinic and they told me about PEP but this was 2 or 3 weeks later.

(Gay, 45+, HIV negative, I1/013)

Although in a sero-discordant relationship, one interviewee also had low awareness of PEP or the role it could play for him.

Did use condoms, then stopped, my partner is now HIV+ so we are using condoms again. But since the diagnosis we rarely have sex. I've heard about PEP but don't know what it is exactly. It was mentioned at my partner's diagnosis but from my understanding its only if there's exposure, so we just use condoms, we got minimal information really. Yes, the doctor mentioned it but we haven't sought out any other information.

(Gay, 26-35, HIV negative, I1/022)

### Accessing PEP

Six men (3 FAQ interviewees and 3 respondents to our online PEP survey) shared experiences about accessing PEP. While one experience, accessing PEP via a sexual health service was straightforward and positive all other experiences point to difficulties, including staff ignorance of PEP, negative responses to an individual's request for treatment and discriminatory attitudes.

I used PEP about a year and a half ago. Went straight to Sandyford and they got me on it quickly.

(Gay, 45+, HIV negative, I1/114)

I got PEP at the sexual health clinic after a drunken unprotected sexual encounter in 2005. I'd never heard of it until I did some 'morning after' research on the internet. I wasn't offered it at the centre because the staff felt that the unprotected anal encounter was not as high risk as many - my sexual partner claimed he was HIV negative but I'd no way of proving this. However I was given PEP after specifically requesting it. I was actually made to feel like they were pandering to my anxiety.

(Online respondent)

I had the worse experience of my whole entire life at A&E trying to get PEP. I'd never go back. It was at the Royal Infirmary in Glasgow, I waited 4 hours before they saw me, reducing the chance of the PEP to work. I ended up quite angry, a nurse took me into the hallway where she asked me questions and took my blood pressure. I told her other people could hear our conversation. They made me feel really stupid, kept asking me if I knew if he was HIV+, four times. I kept saying he told me, so, I have to take that at face value. Then they were asking about his medication - I said I don't know. Then the doctor gave the same kind of treatment and argument. If it hadn't been for my friend I wouldn't have managed. I went to Sandyford after and they gave me information to make a complaint but I couldn't face it. I felt so ill on the PEP, exhausted, I didn't follow up. I'm not the only one who's been through this. It's how guys are treated I've been told. The receptionist didn't know what I was even asking for.

(Gay, 36-45, HIV negative, 11/017)

I got PEP from the A &E at Monklands. Was turned away from Wishaw General as they "didn't do that". Getting it was difficult as no one other than me seemed to know what PEP was and was used for, which was really frustrating. It took a long time and many separate, repetitive conversations to finally get it. Taking PEP was fine for me. Thankfully only mild side effects.

(Online respondent)

I tried to access PEP but after hours hospital GP had no idea about it, A & E had no idea about it, and the HIV hotline I called, a lady abruptly said I don't have HIV and to stop worrying about it.

(Online respondent)

Basically it tore, it was after he went to take it off and it was torn. He told me but I saw. I went for PEP. To the A&E because the clinic was closed in Edinburgh. It was okay but the doctor and nurses seemed a bit unpleasant. It came across that they thought I'd just not been bothered to use a condom. Kind of clipped short kind of communication. I think it was because of why I was there, just the way they responded to me, everything I said. I was unwelcome. Anyway, I just went to reception and just was clear with them about what happened. I waited for half an hour or so in one of the spaces that they close the curtain. They gave me enough pills to get to GUM and I went there. At GUM it was fine and they dealt with me quickly. The side effects weren't fun, mostly nausea, I completed the course.

(Gay, 16-25, HIV negative, 11/086)

### Using PEP

Nine men (5 FAQ interviewees and 4 online PEP survey respondents) shared experiences of taking PEP. As indicated above, the experience of using PEP varies for men; some report side effects as problematic.

The medication was fine and I didn't have major problems taking it. Subsequent tests confirmed me to be HIV negative.

(Online respondent)

I was going on holiday at the time, they told me the reaction might be bad but it was fine, no major side effects, just diarrhoea. They were okay at the hospital, got the impression that the doctor didn't know too much.

(Gay, 45+, HIV negative, 11/112)

Horrible made me ill. Terrible runs.

(Online respondent)

I couldn't finish it; the side effects were horrendous after 3 days. I called in and said I couldn't do it. I tested again and I was negative.

(Gay, 26-35, HIV negative, 11/018)

I know that it doesn't affect everyone like me but the PEP was horrendous. Everything in the book. It was disgusting, 28 days and 10 days I was a complete mess. I had known about it, about side effects, I took other pills for diarrhoea, headaches and sickness but it was still awful.

(Gay, 36-45, HIV negative, 11/017)

### Deciding not to use PEP

Men who know about PEP also tell us that after an episode of condomless anal sex they decide that PEP is not required because they assess the risk as low. Men also report, in the context of discussing PEP as an option, that they use other strategies to minimise risk (such as being a top). FAQ interviewees also share a view that HIV testing in itself is protective. The chapters entitled **HIV Status/Talking about HIV** and **HIV Testing** also address some of these issues.

Yes, he came inside me. No PEP. You can't really make that decision but I'd assessed him as low risk so I thought there was nothing to worry about. We'd had unprotected sex about a year before.

(Gay, 26-35, HIV negative, 12/005)

Did you use condoms? No, we didn't use them. Didn't talk about it. Got carried away on the poppers, we both felt guilty, not knowing each other, knew it was wrong, regretted it. Did you think about using PEP? Never thought about it, I was top.

(Gay, 36-45, HIV negative, 11/110)

So the first time it was assured we'd use condoms, the second time was in the middle of the night, but he didn't come inside me. Did you consider using PEP? No... I'd been recently tested, I'm fine. I don't believe he was positive.

(Gay, 26-35, HIV negative, 12/019)

I get tested every 6 months, if a condom came off I'd get tested within the month. I've heard of PEP but I haven't thought about it. I know it's at A&E or the clinic. Don't know if I'd use it. Someone I know did and it had bad side effects so I think from that point of view it might be difficult having time off work. If it was someone I knew was positive and the condom was problem then sure I'd use PEP, but if it was someone I knew I'd be less likely to. Depends how much I knew.

(Gay, 26-35, HIV negative, 11/023)

I didn't think about PEP when he was penetrating me, he wanted to go all the way and he said he was clean and had had himself checked. It is in the back of my mind but I'm not entirely worried about it.

(Gay, 26-35, HIV negative, I2/061)

Both of us came inside each other... Did you think about using PEP? Yes it thought about it but truthfully I don't actually know why not. Basically it was more like a case of well, nah I'll probably be fine and will just leave it but 2 weeks after I did go to Sandyford and have a regular check-up. It went fine, everything was clear. But they told me 2 weeks was enough to check for other STIs so I had to go back for another test, which I got the results yesterday which was all clear but they said it wasn't conclusive. They said they have better tests now that test for antibodies. But I still have to go back in another 3 weeks.

(Gay, 16-25, HIV negative, I1/082)

Inaccurate information may also influence men who decide not to use PEP. Being away from home and not knowing where or how to access a service can factor into a decision.

I actually did think of it but I was out of the window period for that occasion. That was a weekend in Germany and after I got back it was after that period it was too late. 48 hours. I didn't really think that in another country it would be possible.

(Bisexual, 26-35, HIV negative, I1/036)

### **Raising awareness of PEP**

In FAQ interviews and online, some men recognise that there has been some promotion of PEP, and that there should be more.

I have to say when I read about PEP, it's not very well publicised. I'd heard about it and I do know but it's not in the forefront of my mind.

(Gay, 45+, HIV negative, I2/081)

We also asked respondents to the FAQ PEP survey: *What do you think we should do to make sure more men hear about PEP and can get it?* 31 men offered a view. Most commonly men suggest advertising and promotion in gay commercial venues and publications (bars/clubs/magazines: 14 men) and in mainstream media (radio, TV soaps, Facebook: 8 men). Men also suggest promotion via gay apps/sites (Grindr, Gaydar etc. 5 men) and in saunas (3 men). Individual respondents mention using: GP surgeries, A&E Departments, Pharmacies, including information with condom packs and with safe sex promotional material.