

In this chapter we draw on the views and experiences of gay and bisexual men who have had an HIV diagnosis and are living with HIV. These are already reported in detail across FAQ chapters but with a wide scope of findings and discussion in *this* chapter we provide an overview and point towards a number of significant areas where the needs of men living with HIV merit specific exploration. We begin with quotes from men below, and continue to represent what we have been told in the pages that follow.

I live with HIV now, I don't live for HIV. When you are given 48 hours to live and you survive it, you have to look forward.

(Gay, 45+, HIV positive)

I was just ill all the time. Kind of felt sick all the time and we did all sorts of tests, and I said I think you should test for HIV. This was my GP clinic. I don't know why they didn't suggest it. I think they were scared of approaching it. It's not like they didn't know I was a gay man.

(Gay, 45+, HIV positive)

It was just a regular check-up. It did come as a surprise. I was shocked and upset about it at first. I didn't play safe all the time but nobody highlighted to me how I could get it. I just got a 6 month check-up and I got a call and was told to come in and see them.

(Gay, 16-25, HIV positive)

It seems that there are a lot of guys out there prepared to have bareback sex without disclosing status, but if you tell your status then they run a mile. So I think that's pretty un-educated really.

(Gay, 36-45, HIV positive)

We did talk online and they said they were positive. It's definitely not on my profile that I am but it is a conversation you need to have and it's best to do it before you actually meet up.

(Gay, 36-45, HIV positive)

I only have anal sex with guys who are HIV+. I just don't feel comfortable having anal sex with guys who don't have it. It's just my mind-set. Never.

(Gay, 16-25, HIV positive)

It's not just psychological it's a physical thing. It's stressing in both ways... It's a chronic condition. I tend to try to separate that from my life. I try to pigeon hole. Obviously it's still a problem with on-going impact, if you sneeze you worry. But medicines do a pretty good job of controlling. My health is very good. It's actually something that I don't always have success in pigeon holing it.

(Gay, 45+, HIV positive)

They think it's a deadly disease, that you're a sleazy person if you have it.

(Gay, 26-35, HIV positive)

I think it's quite useful to have someone with insight into the particular issues of HIV. They're knowledgeable about the gay lifestyles and that's quite important... I've had some really good input and some terrible input as well, but mostly good. People who I see now are pretty damn good, dedicated to working with people with HIV.

(Gay, 45+, HIV positive)

My consultant is really good. The nurses at the clinic are really good they're very honest with me and I'm honest with them so it works well.

(Gay, 36-45, HIV positive)

Smile. Be non-judgemental. Be open about sex and sexual acts, talking about anal sex, and you know, gay sexual practices. Be sort of friendly. Be non-authoritarian and non-disapproving.

(Gay, 45+, HIV positive)

FAQ Scotland is part of a larger project that wants to prevent HIV infections in Scotland among gay and bisexual men; the project is called an HIV Needs Assessment, undertaken by NHS Greater Glasgow and Clyde and NHS Lothian. FAQ has included men who know their HIV status - negative or positive - and men who do not know their HIV status. While we frame the work in terms of HIV *prevention* FAQ is also interested, in the broadest sense, in the sexual health and wellbeing of *all* gay and bisexual men, whatever their HIV status. The intention is to make HIV and Sexual Health services the best they can be, so they can support *all* men to experience safe, happy and healthy sexual lives.

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. This chapter is unusual in that it is largely an overview and points towards more detailed findings elsewhere; however, when it comes to men living with HIV, FAQ poses these questions for practitioners.

- Do I know enough about the experience of living with HIV? Can I learn anything from those who are?
- In the consulting room, do I make space for individuals living with HIV to pause, reflect, and talk about how they feel?
- Do I know what support, advice, or information a man living with HIV wants and needs to be able to manage discussions about his status?
- Do I provide opportunities for the man living with HIV to talk about what a safe, happy, healthy sex life means to him?
- Does my service provide an appropriate balance between sexual health support and advice and HIV treatment and care?
- How do I feel about and respond to prejudicial views HIV negative/untested men express, and how men living with HIV experience them?
- Discussing HIV can make me reflect on my own experiences and needs if I am HIV positive or putting myself at risk: is support in place for me should I need it?

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FAQ PARTICIPANTS AND HIV STATUS

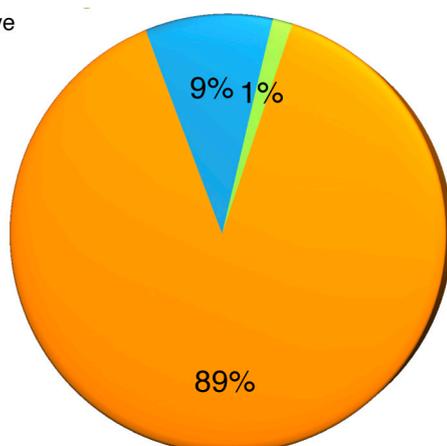
Men have taken part in FAQ in these ways:

- 136 men took part in **telephone interviews** over 2 phases of recruitment through 2013.
- The **Diary Room** was a broad based survey completed by 427 men in October and November 2012.
- The second phase was a number of thematic surveys that we called **Quickies**. There were 24 quickie surveys, which attracted a total of 2,423 responses. The surveys were available for men to complete from mid-June to mid-July 2013.

More about how FAQ approached the work in the chapter **About FAQ**.

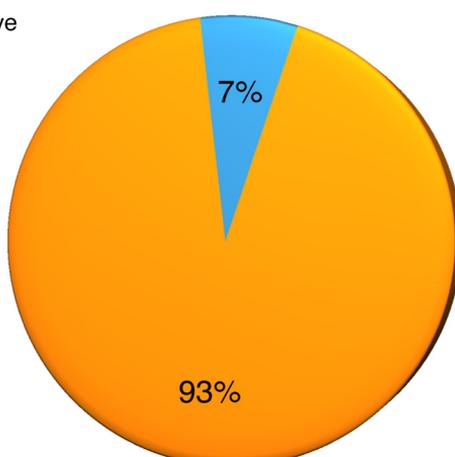
In terms of HIV status, 9% of men interviewed by telephone report their status as HIV positive.

- Negative/Think I'm Negative
- Positive/Think I'm Positive
- Did not disclose



Online, in the Diary Room and the Quickie Surveys an average of 7% of respondents report their status as HIV positive

- Negative/Think I'm Negative
- Positive/Think I'm Positive
- Did not disclose



SIGNPOSTING TO OTHER FAQ FINDINGS WHERE THE NEEDS OF MEN LIVING WITH HIV MERIT SPECIFIC EXPLORATION

A full report on FAQ findings is available in a series of thematic chapters published at www.faqscotland.co.uk.

In *this* chapter we point towards a number of significant areas where the needs of **men living with HIV** merit specific exploration.

In the FAQ chapter **Bisexual Men** we raise a number of issues and explore them in more detail:

- Bisexual men are less likely to engage with sexual health services; they are less likely to test and know their HIV status.
- As younger men are also less likely to attend clinics, younger bisexual men may be particularly vulnerable to not accessing sexual health services and knowing their HIV status.

In the FAQ chapter **Drugs** we raise a number of issues and explore them in more detail:

- While our FAQ Drugs chapter draws on a small number of respondents, FAQ suggests that services should consider that older HIV positive men may be more likely to engage with multiple partners while using a mix of drugs/chems.
- The provision of individualised care for men living with HIV should provide an opportunity to discuss and plan risk reduction strategies that are particular and appropriate to the individual's circumstances, this may include their use of drugs/chems.

In the FAQ chapter **Feeling Down/Mental Health** we raise a number of issues and explore them in more detail:

- Some FAQ interviewees connect being HIV positive or having a partner who is HIV positive to mental health problems.
- Support for men living with HIV needs to consider the impact on their psychological wellbeing as a consequence of an HIV diagnosis, long-term life with HIV, the expectation of disclosure to sexual partners and the negative or discriminatory response this might get when they do.
- FAQ contributors who experience mental health problems report real isolation and a lack of support, alongside concerns that poor mental health impacts negatively on choices and experiences in personal and sexual relationships.
- FAQ interviewees living with HIV think counselling support should be available from a professional person who understands what it is like to live with HIV, even if the focus of support is not directly about HIV.
- The LGBT community needs to begin a dialogue about the meaning and importance of mental health, and it needs to take place while recognising and rejecting any stigma associated with mental health problems.

In the FAQ chapter **HIV Status/Talking about HIV** we raise a number of issues and explore them in more detail:

- FAQ participants paint a complex picture in terms of knowing about and talking about HIV status.
- It is not common to ask a direct question about the HIV status of another man. There is little evidence of men discussing HIV status of partners prior to anal sex.

- Men make assumptions about HIV status, yet tell us that knowing a partner's HIV status is an important component of sexual decision making.
- There is an expectation among HIV negative/untested/presumed negative men that HIV positive men would and should disclose their status in all sexual encounters.
- Across FAQ interviews and in online responses, men (who state they are HIV negative or presume so) often use the term 'clean' to describe HIV negative status.
- Men living with HIV take different approaches to sharing HIV status; some men unequivocally want to ensure partners make informed choices to have sex; others do not feel an obligation to share and use knowledge of low/undetectable viral load while maintaining a commitment to condom use as protective.
- FAQ interviewees express concern that younger men are less likely to enquire about HIV status (although our surveys suggest younger men are more likely to want this information) and less likely to consider condom use in the absence of such information. Some view this as young men perceiving HIV as a condition affecting only older men.
- Around half of FAQ online respondents agree with the statement: *I would not have sex with someone if he is HIV positive*. Many FAQ interviewees agree, others say knowledge of HIV positive status would only affect choices made about anal sex. Interviewees also acknowledge that they may already have had sex with an HIV positive man but were unaware of his status.
- An important aspect of men's attitudes towards sex with a man living with HIV is described as the need to be 'at ease' with HIV; while men understand that condom use is a barrier to transmission, worries it seems are founded in a less rational place.
- Across FAQ interviews men express a commitment to condom use for anal sex, recognising that this is the most important protective behaviour in terms of HIV risk. When it comes to sex with a partner who may be HIV positive, this is emphasised by men who adapt what might be a 'don't ask/don't tell/play safe' approach which depends on condom use every time.
- For some men, living with HIV means a preference or exclusivity for sex with other positive men.
- FAQ interviewees living with HIV talk about the impact of diagnosis on mental health and an increased sense of isolation; sex or relationships can feel out of reach.
- For some men, late diagnosis can have an immediate impact on physical wellbeing, with time needed for recovery.
- For some positive men sex now tends to be with other HIV positive men and/or includes a commitment to condom use or other protective strategies.
- HIV positive men see many HIV negative (or presumed negative) men as having no or little information, therefore making poorly informed choices about looking after themselves.
- Men living with HIV experience enduring stigma and discrimination from negative/untested men and risk rejection if they disclose to sexual partners. In the context of relationships with individual men, HIV prevention and HIV/Sexual Health clinical services need to give continued consideration to their role in education and prevention which tackles ignorance, discrimination, and stigma about HIV.

In the FAQ chapter **HIV Testing** we raise a number of issues and explore them in more detail:

- Some men living with HIV report that their first HIV test was point of diagnosis.
- Only half of FAQ interviewees have had an HIV test in the past 6 months. Around 1 in 5 of FAQ interviewees has not tested in the past year, or has never tested. Many men who report their HIV status as negative might more accurately describe their status as either *negative at last test*, or *unknown*.
- Men who have never tested may not yet engage in any way with a sexual health service. They may have concerns about doing this, so they may decline HIV testing or fear a positive result.

- In FAQ interviews and via FAQ online, men identify that HIV home testing and enhanced access to clinical services would encourage them to test more regularly.
- Information about testing should address men's concerns about doing so and promote the benefits of knowing HIV status.
- HIV/Sexual Health clinical services should engage with colleagues across the NHS to ensure that HIV testing is undertaken in other settings, including Primary Care, where this would benefit the patient.
- Services should consider how to extend access to home sampling/home testing and focus on responding to men's questions and concerns about how this works.

In the FAQ chapter **Oral Sex** we raise a number of issues and explore them in more detail:

- Men report that giving and receiving oral sex is part of most sexual encounters.
- In general, men consider oral sex as low risk for HIV transmission.
- Men (across all ages and sexual orientation) report that they generally do not and would not consider using condoms for oral sex.
- Men consider HIV risk increases in terms of oral sex with a partner who is HIV positive.

In the FAQ chapter **PEP** we raise a number of issues and explore them in more detail:

- Awareness of PEP among gay and bisexual men remains low.
- Confusion exists among men as to when an experience of condomless anal sex requires PEP as a response.
- Some men report poor experiences in terms of accessing PEP through hospital based Accident and Emergency services.

In the FAQ chapter **Relationships** we raise a number of issues and explore them in more detail:

- Many men see open relationships as a positive choice.
- Men living with HIV may see sex with friends as a means by which they can be open about their HIV status.
- Concurrent sexual partnerships are situations in which an individual has overlapping sexual relationships with more than one person. Concurrency is only an HIV risk if one or more of the individuals is HIV positive and has condomless anal sex with a partner.

In the FAQ chapter **Social Media and Apps** we raise a number of issues and explore them in more detail:

- The basic information provided in an online profile can be the only exchange of information men might have about HIV status or condom use; others will use chat/messaging to explore these issues further before any meeting is finalised.
- Rather than in a public profile, HIV positive men can use an online conversation to discuss status.
- Some FAQ interviewees report that social media/apps facilitate more openness about HIV status.
- Men make assumptions about HIV status and condom use according to the app men have a presence on. In particular, if a man has a profile on a site that has a focus on 'bareback' sex it will be assumed that condomless anal sex is what they want and/or they are HIV positive.
- In online environments HIV positive men can experience rejection, discrimination and stigma.

In the FAQ chapter **Visiting the Clinic** we raise a number of issues and explore them in more detail:

- FAQ interviewees living with HIV identify the opportunity to talk openly and frankly about sex and sexual health as a positive feature of some services; however they also recognise that a 'tick-box' experience can mean not enough time and care is taken to speak in detail about sex, relationships and sexual health.
- HIV positive men report that HIV/Sexual Health services should not assume that an HIV positive man has the information, knowledge or skills he needs to maintain a healthy approach to sex.
- While HIV positive men tell FAQ that HIV/Sexual Health services are good, they might also choose to limit the information they are willing to share, particularly when it comes to partner numbers or instances of condomless anal sex.
- HIV positive men identify the need for better integration across HIV treatment and care services and Sexual Health services when it comes to meeting their sexual health needs.
- HIV positive men report that they can still encounter negative attitudes towards their HIV status when engaging with other parts of the NHS.
- While practical arrangements and issues of access are important, what really defines a service and ensures that men return, is the relationship built between people.
- HIV positive men echo two key messages that emerge from talking with men of all ages, sexual orientation and HIV status. First, clinic staff should remember that men might be nervous or anxious, either when first approaching a service or when they attend with a worry about their sexual health. Second, men need clinic staff to be non-judgemental, respectful, informative, interested, friendly and professional.