

Managing uncertainty

***Risk and unprotected anal
intercourse among gay men who
do not know their HIV status***

Laurie Henderson
Peter Keogh
Peter Weatherburn
David Reid

Original Research Report

Acknowledgements

First we would like to thank the many respondents who gave their time and energy and who shared their intimate personal experiences with candour. Without their participation this research would not have been possible.

In addition, our gratitude goes to those agencies who assisted in the recruitment of the respondents especially Terrence Higgins Trust South, Terrence Higgins Trust Midlands (Birmingham Branch) and Yorkshire Mesmac. Their assistance in recruitment was invaluable.

Finally, thanks to Will Nutland, Ford Hickson and Michael Stephens who read and commented on drafts of this report.

This research was funded by the Terrence Higgins Trust as part of the Community HIV and AIDS Prevention Strategy (CHAPS), an HIV prevention initiative financed by the Department of Health.



© Sigma Research
Faculty of Humanities & Social Sciences
University of Portsmouth
Unit 64, Eurolink Business Centre
London SW2 1BZ
020 7737 6223
www.sigmaresearch.org.uk



Terrence Higgins Trust, London
52-54 Grays Inn Road
London WC1X 8JU
020 7831 0330
www.tht.org.uk

Published on behalf of the CHAPS Partnership by Sigma Research

ISBN: 1 872956 63 7

November 2001

Contents

1.	Introduction	2
1.1	Background	2
1.2	Methods	3
1.3	Sample demographics	4
2.	Ways of knowing HIV status	5
2.1	Contingent knowledge: chances are ...	5
2.1.1	Cumulative uncertainty: a numbers game	5
2.1.2	Critical uncertainty: about last night!	7
2.2	Categorical knowledge: a way of thinking	9
2.3	Discussion	11
3.	Implications of not knowing HIV status: HIV testing and health	12
3.1	The regular testers: like to know	13
3.2	Reluctant testers: other things scare me	14
3.3	Testing as a last resort	14
3.4	No cause to test	17
3.5	Discussion	18
4.	Implications of not knowing HIV status: managing sexual risk	19
4.1	During UAI	19
4.1.1	Early termination of UAI	19
4.1.2	Later termination of UAI	20
4.1.3	UAI to ejaculation	21
4.1.4	The protective imperative	22
4.2	UAI and the possibility of HIV transmission	22
4.3	Meanings attached to UAI	24
4.3.1	Negative meanings: loss of control, transgression of boundaries	24
4.3.2	Positive meanings – intimacy and affirmation	27
4.4	Risk and testing	27
4.4.1	Group one: testing as a result of risk	28
4.4.2	Group two: taking a test in order to engage in UAI	29
4.4.3	Group three: overwhelming disincentive to test	30
4.4.4	Group four: no perceived risk	31
4.5	Discussion	32
5.	Conclusions	34
	References	37

1 Introduction

1.1 BACKGROUND

In the United Kingdom, community HIV health promotion for gay men has moved through at least two distinct stages. Initially, gay men were encouraged to assume that, in the absence of an HIV diagnosis, they and / or their partner were infected, HIV was present in all instances of anal intercourse (AI) and transmission certain to occur. Condoms were therefore promoted for all instances of anal intercourse between men. Later, when it was shown that gay men were making decisions about not using condoms based on assessments of their own or their partner's HIV status (Hickson *et al.*, 1992; Kippax *et al.*, 1993), the relationship between condoms and HIV status changed. It was recognised that HIV was not present in all instances of anal intercourse, and transmission was therefore differentially likely to occur. Full knowledge of one's own and one's partner's HIV status became the pre-requisite for not using condoms. The question of testing for non-clinical purposes therefore became important.

While health promoters in the United Kingdom, have not been slow to recognise this shift, implementing interventions that operationalise (lack of) knowledge of HIV status has proved problematic. One of the reasons is that gay men and bisexual men in the United Kingdom have substantially lower rates of HIV testing especially in comparison to Australia (Van de Ven *et al.*, 2000) and the USA (Mayne *et al.*, 1999). Indeed, over the last four years or so the proportion of gay men and bisexual men who have never tested for HIV has remained remarkably stable at between 40.5% and 42.6% (Hickson *et al.*, 2001). This pattern of (not) testing has not been substantially affected either by the relative success of anti-HIV combination therapies or by a range of HIV health promotion campaigns urging men to ascertain their status.

Within this context, men who do not know their HIV status become particularly problematic. The first difficulty emerges with how 'not knowing' is defined. Much of the academic literature pertaining to the management of HIV risk makes a substantial assumption that men that have never tested for HIV cannot, by definition, know their HIV status. If we are guided by this assumption, we find it impossible to quantify the risk behaviour of this group since we cannot examine the sero-concordance of the unprotected anal intercourse (UAI) that they engage in. Assessing sero-concordancy of UAI usually involves comparing the known status of a respondent with the assumed or known status of his UAI partners and this is not possible.

Closer examination of quantitative data throws some light on this question. In each of the last three years the *National Gay Men's Sex Survey* (GMSS) has asked all men *What do you believe your HIV status is currently?* and offered the following possible responses: *definitely HIV positive, probably HIV positive, couldn't say / don't know, probably HIV negative, or definitely HIV negative*. For a fuller explanation of the methods and results of these surveys see their full annual reports (Hickson *et al.*, 1999; Weatherburn *et al.*, 2000; Hickson *et al.*, 2001).

In GMSS 1999, 72.2% of men who had never tested reported they were definitely or probably negative against this measure (Weatherburn *et al.*, 2000). In GMSS 2000, this figure rose to 77.8% (Hickson *et al.*, 2001) of men who had never tested. Given that another small proportion (1.2% in 1999 and 3.9% in 2000) of men who had never tested reported they were definitely or probably positive, it is clear that more than three quarters of men who have never tested are able to make a judgement as to their HIV status.

These data also highlight that men who had previously tested for HIV can report that they currently are 'not sure' or 'don't know' their HIV status. In 1999, 9.6% (428 of 4477) of tested negative men reported not knowing their status as did 1.5% (7 of 458) of men who had tested positive. In 2000, 5.7% (279 of 4866) of tested negatives reported not knowing as did about 0.6% (3 of 532) of tested positive men. Overall then, between one sixth (16.1% in 1999) and one tenth (10.4% in 2000) of all gay and bisexual men report that they are currently 'not sure' or 'don't know' their current HIV status.

Hence knowledge of status is not necessarily dependent on testing, and men who report not knowing their HIV status are not coterminous with men who are untested. These findings cause more difficulties than they resolve. Our understanding of the risk behaviour of men in this group becomes even less clear.

As we are dealing with impressions or convictions as opposed to concrete knowledge, we are also dealing with degree. How strong is a man's conviction that he doesn't know his status? Is it strong enough for him to take HIV risks based on his (lack of) knowledge? We are also dealing with context. How does a man 'not know' his HIV status? What experiences, evidence or impressions is he using when he comes to this conclusion? Finally we are dealing with variability: does the state of not knowing one's status lead all men to similar decisions or similar strategies?

It is, therefore, hard for us to conceptualise how men can negotiate sexual risk or make plans for their future without some idea of their HIV status. During sex, what is the most important imperative with regard to HIV: protecting oneself from contracting HIV or from passing it on? In their day-to-day lives, do such men live with constant anxiety concerning the possibility of serious illness? How therefore, do we promote risk reduction strategies when the risk is mutable? How do we promote personal well-being when the men in our target group may, or may not have contracted a life threatening condition? In short, we are dealing with a complex question: what does it mean to **not** know something?

This report attempts to provide answers to this question to help target men in this group more effectively. We do this by breaking down our overall question (what does it mean to not know one's HIV status and what are the consequences of this lack of knowledge). First, we explore the types of knowledge upon which assessments of HIV status are based. That is, how do men (not) know their HIV status? Second, we examine the meanings attached to this knowledge. That is, how is this (lack of) knowledge regarding HIV status mobilised in relation to different imperatives (such as risk management and quality of life)? Finally we examine how this lack of knowledge effects sexual risk behaviour.

In the next section we present our methods and sample demographics. Chapter two examines the types of knowledge men take into account when they report not knowing their HIV status. Chapters three and four animate this knowledge by relating it to the different life imperatives. In chapter three, we deal with day-to-day well-being and quality of life. In chapter four, we assess sexual risk through an analysis of incidents of UAI. Finally, chapter five presents some general conclusions and recommendations.

1.2 METHODS

In order to investigate our central research questions more fully, thirty-four men were recruited employing two different methods. Firstly, fourteen respondents resident in London were recruited from a pre-existing panel of gay and bisexual men (Hickson, Hartley *et al.* 2001). They had all previously reported they *didn't know or couldn't say* what their current HIV status was. By letter we invited men who fitted these criteria to attend an in-depth interview at Sigma's offices. When potential respondents telephoned to book an interview, they were again asked the same question

regarding their current HIV status beliefs. Once it was clear that a respondent fitted the criteria that they *didn't know or couldn't say* what their current HIV status was, an interview time and date were set.

The remaining respondents were recruited by CHAPS partner agencies leafleting at community and scene venues in Brighton (8), Birmingham (8) and Leeds (4). These leaflets explained the interview criteria were that men *did not know* their current HIV status and asked those who qualified to call and arrange a confidential interview. All respondents were also offered £20.

In-depth, semi-structured interviews were conducted with all respondents. At interview, men were asked to discuss how they came to the conclusion that they did not know their HIV status and what meanings they attached to this (lack of) knowledge. In addition, men were asked to discuss critical incidents of sexual risk in their past. That is, they were encouraged to give examples of times they had engaged in sexual risk and reflect on what effects these incidents had on them or what meanings they attached to them.

Interviews lasted between 90 minutes and two hours and with the respondents' permission were audio-taped. Recordings were fully transcribed. A case-by-case analysis was conducted on transcripts in order to generate initial themes for a full thematic content analysis. Analysis was conducted by two researchers working independently. Several reflexive tests were conducted to ensure inter-rater reliability as well as internal coherence in the analysis of cases and overall coherence in terms of themes generated.

1.3 SAMPLE DEMOGRAPHICS

While they are somewhat older than large scale samples, the demographic profile of the 34 men recruited to the qualitative study is broadly similar to other studies of gay and bisexual men, recruited via community venues (Hickson *et al.*, 1999; Dodds & Mercey, 2000; Weatherburn *et al.*, 2000; Hickson *et al.*, 2001).

AGE			
Range:	23 – 55		
Mean age:	37 years		
ETHNICITY		EDUCATION	
White British	24	No qualifications	5
White European	3	'O'-levels or GCSEs	6
Mixed race	6	NVQ or Diploma	6
Indian	1	Degree or higher	17
HIV TESTING HISTORY AND STATUS		SEX LAST YEAR	
Untested	13	Unprotected anal intercourse	21
Last test negative	21	Protected anal intercourse	11
Last test positive	0	No anal intercourse	2

2 Ways of knowing HIV status

In this chapter, we look at the two common processes by which gay men come to articulate uncertainty about their HIV status. Both depend on the use and mobilisation of knowledge about oneself. One consists of a movement from a state of certainty to uncertainty. That is, men had, in the past, believed themselves to be uninfected (or for some, infected) and now had reason to doubt this certainty. Therefore, experience and knowledge changes belief.

The other process is characterised as a barrier between uncertainty and certainty regarding HIV status. This works in two ways. The first is where men doubt their status until they have incontrovertible evidence that they are either infected or uninfected: that is they test and receive a result. The second is where men are certain of their status in spite of evidence to suggest that they should doubt it. The latter process depends on a very specific and sometimes problematic relationship to diagnosis.

Each of the above processes was characterised by a different type of knowledge. In the first case, knowledge is contingent. That is, past sexual behaviour may have put one at risk and thus potentially infected with HIV. In the latter case, knowledge is categorical: a test result proves once and for all that one is definitely infected or not.

2.1 CONTINGENT KNOWLEDGE: CHANCES ARE...

There are two ways in which men came to doubt their HIV status. The first we have called cumulative uncertainty, the second, we have called critical uncertainty.

2.1.1 *Cumulative uncertainty: a numbers game*

Under the term 'cumulative uncertainty', we group men who report a gradual or growing awareness that they can no longer be sure of their HIV status or have come to this conclusion on reflection. Here, men based their assessments on a number of factors as opposed to one isolated incident. Cumulative uncertainty was the most commonly reported experience amongst the men we interviewed. The significant factors in influencing men's perceptions of their own HIV status included the numbers of sexual partners they had; the amount of sex they perceived to be 'risky' with regard to HIV; the perceived HIV status of their partners; and the state of their overall health. Individual men used these factors together or in isolation and the emphasis varied between men.

It was most common to use cues from partners and sexual interactions to assess the likelihood of being infected (for example, the perceived HIV status of one's partner or the numbers of partners one has had). This assessment can take several forms and result in very different outcomes.

Some men simplified the process by thinking only of the number of sexual partners rather than the type of sex they had. More often, uncertainty about status was a consequence of the types of sex they had been having. Generally, those who had engaged in UAI were more likely to doubt their status.

"Since I moved to London I've had unprotected sex with maybe two or three people and [laugh] I mean it's two or three people but it only takes one and your chances are a lot higher than the first time. I've been fucked without a condom a few times and on one occasion the guy came inside me. So I'm kind of more nervous about that."

(age 23, receptive UAI with 1 casual last year, tested 3 years ago)

"[past UAI] makes me nervous but it's a numbers game isn't it? [...] Because I've had a lot of sexual partners, just basic shags.

Is it setting those numbers or the risks?

The odds and the risks, a gamble on what stakes you've got on. But I would say that the stakes have been very low for me just to have unsafe sex three times. It's all a gamble really isn't it? I mean who knows? If I have a test today I might be positive. If I have a test today I might be negative. I just don't know."

(age 27, receptive UAI with 2 casuals last year, tested 2 years ago)

Those men who always engaged in anal intercourse with a condom or did not engage in anal intercourse at all, were more likely to consider the relative HIV risk of oral sex and whether they had ever had someone ejaculate in their mouth.

"I have had sex with an awful lot of men. Well really I suppose since I've been back in Brighton it's just so easy to get sex here and so even if there's like a low risk with unprotected oral sex then by having sex with lots of different people and lots of different times then I know I'm pushing up the possibilities of catching HIV even if it's low risk."

(age 45, insertive UAI with 1 casual last year, tested 1 year ago)

Others placed more emphasis on the HIV status of sexual partners with whom they have had UAI. This involves reviewing their previous partners and the possibility they were HIV positive. Some relied on details such as relative youth, inexperience or being married and heterosexually identified to assess the likelihood that they were positive.

"I thought well all the lads that I've been with in the past have turned out to be straight. The chances are I was their one and only gay experience. So thinking about it logically, possibly it's a fallacy but thinking about it as logically as you can we were all low risk because we were all sexually inexperienced and because I am the only one out of the entire group... who has actually turned out to be gay."

(age 27, insertive UAI with 2 casuals last year, tested 18 months ago)

Some relied on a strong sense of trust that their regular sexual partners were being honest with them about past and current sexual behaviour outside the relationship. The following man had never had 'unsafe sex' until he met his current partner. As he did not know the HIV status of this partner he was no longer certain of his own status. He acknowledged that both he and his partner did not know their HIV status, but because he had not had any UAI with other men, he felt that the risk of infection was minimal.

"In the time until I met my [current] partner 4 years ago I didn't have what I would consider unsafe sex. Certainly not fucking without condoms, and not swallowing cum or getting it in my mouth. Because neither of us has had a test in the period that we've been together and from his reporting to me I believe that he's not had a test at all. There must be some risk there as neither of us have any proof of our status so there is a chance but I think a small chance that I may have it [HIV]."

(age 49, UAI with regular last year, tested 10 years ago)

Cumulative uncertainty works in complex ways. In this context, when men say that they are unsure of their HIV status, they are generally describing a process whereby the possibility of being uninfected competes with the opposing possibility of being infected. With cumulative uncertainty, the statement 'I am unsure about my HIV status' masks a constant re-appraisal or inner dialogue about the possibilities. That is, the individual does not settle for being unsure, but continually re-

assesses whether he might be infected and why he might not be. Therefore accounts of cumulative uncertainty will include reasons for concluding that one is not infected. For example, some men felt that they were likely to be HIV negative because over time they had enjoyed good health and had regularly used condoms for AI. Any previous sex they had which was perceived to be 'risky' in terms of HIV transmission occurred a long time ago.

"I've had protective sex really for so long that I feel I'm reasonably sure. I think I'm probably correct in saying that I am 100% safe. You know, if I was going to be ill there would have been signs and I would have noticed something now.

You said a long time ago, how many years ago?

Unprotected sex... Must be 15 years ago. I suppose I'm just this sort of person who is incredibly cautious."

(age 48, only PAI last year, never tested)

"I suppose the longer I've not known and been in good health I assume that I could be HIV negative but then you don't know the incubation period necessarily so you could say that I might have fucked somebody 6 or 7 years ago without a condom and still be in the incubation period so it's a case of the longer I stay healthy means I'm more likely to be HIV negative."

(age 36, receptive UAI with 1 casual last year, never tested)

Others balanced the relative risk of the sex they have taken with their own level of health to determine their status. For this man being free of any symptoms of HIV translated into a belief that he was HIV negative.

"I haven't been completely cautious and most of the guys I've slept with I haven't actually known that well. It's been pretty casual so it could be anybody. So I don't have long term relationships with them or that I really know them well. I mean a lot of the guys I know they are all on the scene and.. it's quite an active scene. There are a lot of people going around. Even though I'm unsure I think I'm negative because I don't see any symptoms so that's why I don't want to know, kind of why, not worry."

(age 29, receptive UAI with 1 casual last year, tested 2 years ago)

2.1.2 Critical uncertainty: about last night!

Critical uncertainty was the second most common way in which men came to doubt their HIV status. Critical uncertainty stands in marked contrast to cumulative uncertainty as it is characterised by a specific incident (usually sex) that worries the respondent. Some were having sex that was not as safe as they would have liked, primarily UAI, or had a 'mishap' that they worried might have involved HIV transmission. For some men the threat of HIV infection is so dominant in their thinking about casual sex that they experience physical (and emotional) difficulty in having sex that they considered to be risky.

Men tended to assess the relative risk of incidents of unsafe sex in various ways. In the following, case, the respondent debated the possibility that his partner was infected and decided that this was unlikely.

"How long had you known him when you fucked without a condom?

A few hours.

And he fucked you?

Yes.

And did he cum inside you?

Yes and actually I was shocked when he fucked me without a condom and I mentioned it. Well I didn't mention it actually, I just pulled a face, you know like a shocked face but actually I didn't really stop him I guess because he kept on doing it. I didn't see him putting a condom on or anything.

Did he seem concerned at all?

Not at all, he didn't, that was what concerned me the most. Since I didn't really know him and if he's not concerned at all about fucking people without condoms he might do it quite often. I mean the next day I felt worried really because actually I didn't know him at all. I had no idea [of his status] really. I think he was negative. I still believe that positive people normally say it up front."

(age 26, receptive UAI with 4 regulars & 1 casual last year, tested 3 months ago)

Conversely, the following respondent concluded that his partner was most likely to be infected. His distress was compounded by comments made by his sexual partner and his partner's willingness to engage in insertive UAI to orgasm.

"You were saying that you fucked with a casual without a condom?"

Yes. I was very distraught after that... immediately afterwards actually. Because he came. That's what makes the difference for me. That's what really scared me and I didn't feel very happy after that. I've been trying to forget about it actually because it upset me. I think I remember him saying something afterwards like, 'So how many other guys have cum up you tonight?' I didn't like it. I didn't feel very happy about that at all. [...] I didn't know he'd cum inside me and I wasn't sure so when he exactly came inside me I wasn't sure about that, I didn't know that. I didn't want him to come inside. So it's all this kind of picture of him and what he said which is why I had the feeling that he might be positive. It really upsets me thinking about that."

(age 34, receptive UAI with 1 regular & 1 casual last year, tested 5 years ago)

However, it was often impossible to divorce the anxiety attending critical uncertainty from other factors. The risks associated with HIV transmission were often embedded in a range of psychological, personal and interpersonal concerns which shaped how the individual experienced this anxiety. For example, in the following case, the respondent was in a long term relationship. His partner was married, considered himself bisexual and had told the respondent that he had not had sex with anyone except his wife. Based on this information, the respondent assumed his partner was HIV negative. They started by using condoms for anal intercourse and after a while stopped using them altogether. At that time this respondent felt he was "99% sure he was negative."

"I assumed that we were both negative. It just happened over a period of about 6 months. But as I say, I never really had a huge amount of anal sex and when I had I always used condoms. I was still pretty certain until after the relationship ended. Then I found out that he'd been sleeping with half of [city name] while he was sleeping with me which obviously put a different spin on things... still I don't think he would have risked anything. I can't say that though can I? I can't second judge someone else's sexual behaviour. I don't know. I wouldn't have thought that he would have done anything that would have put him or his wife at any risk because... The first big thing was finding all the emails from other people. I think in the space of about 5 weeks he'd been with about 7 men. I stopped having sex with him that day and then that was the end of the relationship. It was a purely monogamous relationship on my part. It was a verbal agreement to be monogamous and really on several occasions he was on the verge of leaving his wife. I wouldn't let him because I didn't want to split the family up. I assume if you have a relationship with someone it's monogamous and he knew my feelings were quite clear on it."

(age 33, only PAI last year, tested 4 years ago)

The following account is more complex as the UAI reflected both the respondent's ambivalence regarding whether or not he actually wanted to engage in it and brought to mind emotionally painful past sexual experiences. He also had major plans for his future.

"I had sex with this guy, this guy had sex with me, as I put it, and it was the same as when I was 20 and no foreplay with just sex straight away and it really hurt and he wanted just a little bit more and it just freaked me out. And when he finished he... During the night he tried to stick his penis up me and I don't know whether he went in or not but it freaked me out because he didn't have a condom on.

He started fucking you again without a condom?

Hmm.. and that freaked me out. It freaks me out now more than it did back then because I've got a lot to look forward to in life now. You know, I'm doing this drama course and soon, hopefully I will be on stage so I've got a lot to look forward to. I'm starting to think about my life now because I don't want to start my career and then in the early stages get sick. Working in the theatre means a lot to me and I just want to be sure. I don't know how I would handle it, seriously I don't. I'm not sure if he came in me or not. It just freaks me out. I've got a lot to look forward to and this would be a major thing to stop my goals in life, my ambition."

(age 27, receptive UAI with 2 casuals last year, never tested)

2.2 CATEGORICAL KNOWLEDGE: A WAY OF THINKING

We have already described a way of (not) knowing one's status based on a dynamic process whereby men assess their status over time with reference to their changing sexual risk or having had a critical incident of sexual behaviour that caused them concern. In marked contrast to this dynamic process is the static process of incorporating a rigid or unequivocal belief system.

Here, the state of not knowing one's HIV status was related to the meanings attached to an HIV diagnosis. For some, the possibility of being negative or positive was determined solely by the presence of an HIV test result rather than any assessment of their past sexual behaviour. For others, their certainty (or lack thereof) was based on beliefs about the actions and intentions of their sexual partners. Most commonly, the belief that partners will know if they are carrying the virus and will also disclose this information to them in any sexual encounter. Thus if there was no disclosure, they assumed their partners were negative and acted accordingly. Finally, a few held a belief that they were HIV positive in spite of repeated negative tests. In these cases the beliefs threatened to become a self-fulfilling prophecy.

Because categorical knowledge of status is based on inconsistent or epidemiologically unsound sets of beliefs, it can lead to unsound risk reduction strategies. In the following account of his sexual risk management strategy, it is implicit that the respondent considered himself negative, although when asked he stated that he was unsure of his status because he has never been tested. In other words, he acted as if he was negative and will continue to do so unless given a diagnosis. This belief also extended to his sexual partners. He believed all his regular and casual partners were negative unless he was told otherwise. He would always insist that his partner wear a condom during receptive AI (which was at odds with this belief that his partners were all negative) but would not use a condom if he was the insertive partner unless asked to do so. He did not feel that he had put himself at any risk of HIV through his sexual behaviour and thought that being the insertive partner in UAI protected him from infection.

"I believe my [HIV] status is negative but I couldn't say for definite because I've never had a test. For whatever reason or another I haven't considered myself to be at risk. I just didn't think there was a need to [take a test]...it wasn't something that was important enough to me for me to do. I can't think of anything I've done that has been risky. Because I consider myself

to be as close to negative as I am able to be without having a test.”
(age 26, insertive UAI with 3 casuals last year, never tested)

It was not uncommon for this reliance on diagnosis to indicate infection to be extended to sexual partners. Many men assumed their sexual partners were negative unless they disclosed that they were HIV positive (see also Weatherburn *et al.*, 2000).

“I’m sure he [sexual partner] is negative. Most people I know when they become positive they tell me. So I was with him all afternoon together and he never mentioned it so I thought he must be negative. That’s the kind of things people say first of all.”
(age 26, receptive UAI with 1 regular & 4 casuals last year, never tested)

The following account is from a man who had UAI with his five regular partners on an on-going basis as well as with a number of casual partners. With the exception of one partner who had disclosed his positive status, he was convinced that the other four were negative although he had never discussed HIV status with them. For this man, the question of HIV transmission was considered, but in an abstract, ethical manner. He did not ejaculate, not as a protective strategy, but in order to behave ethically. The presence of HIV did not seem to be a reality in his encounters, certainly with regulars. In addition, the possibility of his being infected was not a reality. That is, he was willing to accept the possibility of being infectious, but not of being infected.

“People I am having sex with without condoms are people who are married and are family people. I know they aren’t on the scene or anything like that so they are pretty reasonable risk. I sometimes don’t use a condom with the married men but I limit the risks to what I think are reasonable. I tend to make judgements and decisions and weigh up the risks but I never shoot [ejaculate] in them. If it’s somebody I don’t know then obviously I would use a condom every time but if it’s a married man who doesn’t go around at all then I won’t use one.”
(age 58, insertive UAI with 5 regulars & 5 casuals last year, never tested)

Others reported that they had always believed themselves to be positive even in the face of repeated negative results. This next account describes how some men believe they are HIV positive even prior to engaging in any HIV risk behaviours. This man described how he had thought he was HIV positive since he was young and first learned about HIV. Despite expressing a strong desire to use condoms for AI, most of his sex was receptive UAI with casual partners. He expressed a desire to change his sexual behaviour but believed he was powerless to do so. He tested frequently but did not change his behaviour. The only factor which he felt would affect his behaviour was if he were diagnosed positive.

“I was very young and I don’t know why but I always had the feeling that I had it [HIV] even before I had sexual relations. I am always worrying about my HIV status, always. I told you since the first time I heard about that I thought I had it so I really always have been worried about that. I really don’t understand my worry but I do. It’s something I have to change. Well unless it will change by itself. I think it’s my responsibility but it doesn’t happen I know. I feel responsible but I don’t act in a responsible way so I don’t know. I will be tested again and am talking about taking him [partner] to get checked but you know for me it doesn’t make sense after one month having sex without condoms and now stop having sex without condoms. For me... it’s too late for me.
Why is it too late?

Because I think one month is time enough if one of us has HIV. If one of us has, it’s too late not to have pass it. But if I get a positive [result] I think I will calm down a lot, of course, because I believe in my instincts as well. I think it will be constructive. It will be destructive for a while but I think it will be good. I think it will change my sexual behaviour.”

(age 24, receptive & insertive UAI with 1 regular & 10 casuals last year, tested 6 months ago)

2.3 DISCUSSION

This gradual move from certainty to uncertainty is not straightforward. There is never a stable static operative state of being unsure about one's status. That is, a man who is diagnosed positive for HIV will initially go through a period of trauma and generally settle into an altered sense of self which incorporates the state of being HIV positive (Keogh *et al.*, 1999). Likewise, a man who believes or knows himself to be negative will have as part of his on-going sense of self the fact that he is not infected. Men who reported not knowing their status did not have this 'fact' integrated into their sense of self. Rather, this state was characterised by a constant inner dialogue about the possibility of being infected versus the possibility of not being infected. This dialogue may take the form of a mild or nagging concern, a periodic sense of panic or an on-going state of personal crisis. The outcome of this dialogue (the answer to the question am I or am I not infected) varied according to a number of factors: the level of personal anxiety or concern, the evidence that the individual takes into account and the situation he was in. For example, when they were having sex, most men appeared to assume that they were not infected. However, in relation to life and health, this assumption was different.

In contrast to this, there was (a perhaps less functional) way of (not) knowing one's HIV status where actions are based on rigid, and often either inconsistent or epidemiologically incorrect sets of beliefs. What is of interest for our present purposes is to explore the relationship between the nature of these beliefs (these ways of not knowing) and the everyday lives of the men we interviewed. That is, what impact do these different forms of knowledge have on their sense of their health, well-being and sexual risk behaviour?

3 Implications of not knowing HIV status: HIV testing and health

Just as there are different ways of (not) knowing one's HIV status, such knowledge takes on different meanings when applied to different life imperatives. That is, an individual's perception of their own HIV status changes depending on which aspects of their lives they were considering. The biggest difference (for our purposes) emerged between the ways in which men talked about their HIV status in relation to their health and / or well-being and how they talked about it in relation to their sexual practices. In this chapter we examine these differences in relation to health and well-being. Chapter 4 examines the differences in relation to sexual practices.

Men tended to address their concerns about their health, well-being and their possible HIV status within the context of broader discussions about the personal desirability of HIV testing. That is, they discussed the personal implications of HIV testing and these discussions encompassed health in its broadest terms: physical, emotional, psychological and social. A wide spectrum of perspectives emerged ranging from those who saw testing as a positive way for them to monitor aspects of their health to those who saw testing as negative or detrimental to their psychological, emotional and physical health.

At one end of the spectrum were men who considered themselves to be 'regular testers'. This might mean they tested every six or three months or after any incident of sexual HIV risk. For these men, taking care of their health meant assuming responsibility for regular check-ups for STIs (including HIV). They felt strongly that the more knowledge they had about their physical health the better able they were to take care of themselves. In these cases knowledge gave power and control over one's health.

Other men were knowledgeable and optimistic about the value of early diagnosis and treatment of HIV and believed they 'should' have regular tests. However, unlike the first group, these men had an equally compelling fear of the negative consequences of a positive diagnosis. They had an equivocal attitude towards testing, and usually would only test if an incident occurred that overcame their fears regarding testing. They tended to regularly balance this fear with the belief that knowing their status could be of benefit to them.

At the other end of the spectrum were those who felt that they would not test until they were clearly symptomatic and could not diagnose their illness any other way. These men felt strongly that, although they were uncertain of their status, taking care of their health meant **not** knowing their HIV status. This was because they believed, often emphatically, that the consequences of a positive result on their health, well-being, sense of self and life expectancy would be overwhelmingly negative. Such men tended also to conflate HIV testing with a positive diagnosis. 'Ignorance is bliss' was paramount for these men.

Finally outside this spectrum is a group of men who did not see testing as personally problematic but felt no need to take one. This was because they believed that they had not taken any risks with regard to HIV. They were therefore making an assessment about their HIV status based on their past sexual history and their perceived (lack of) risk. For these men, uncertainty about their status was expressed in abstract terms. That is, they could not be sure about their status simply because they had either never had a test or had tested some time ago. What they lacked therefore, was a simple (and largely unimportant) diagnostic category.

What is important to note about these groups is that all attributed importance to whether or not they knew their HIV status. For the first group, such knowledge was a valuable tool for monitoring their health status and needs. For the second group, such knowledge became important only when they had sufficient reason to doubt their negative HIV status (as in cumulative uncertainty above). The third group saw such knowledge as highly problematic or even detrimental to their health. Men in the fourth group were different as they saw such knowledge in a very neutral way and attached the minimum of importance to it. The following describes these groups in more detail.

3.1 THE REGULAR TESTERS: LIKE TO KNOW

One of the distinguishing characteristics of men in this group is their belief that it was beneficial to know if they were positive at an early stage in order to avail themselves of early medical care and treatment. They tended to be optimistic about the likely success of anti-HIV treatments and could see few negative consequences to knowing their status. In addition, they were inclined to think of themselves as probably negative but felt that if they were positive they would want to know. Peace of mind was the recurring theme.

“Testing for HIV provides peace of mind. I think sooner or later you ought to know and I think it’s better to know in the early stage rather than let it be. I mean we have all had illness one way or another. I think it’s the sooner you know you are positive the sooner you have peace of mind and can sort out your life. I may go and make a mistake again but I can see that I’m alright, I’m healthy now and I have to get on with life. I think it is bad if you are going to have bad news but it’s going to be good to know you are positive because you are going to sort out what’s going on. Being in doubt you are thinking, ‘Oh dear, am I positive or negative?’ In the end you are going to have peace of mind. Maybe you can organise your life afterwards. Maybe point your life in the right direction if you are negative.”

(age 29, insertive UAI with 1 regular & 1 casual last year, tested 3 weeks ago)

“I’ve decided I like to know what’s going on in my body. Because I know that the sex I have is low risk when I do get a result then I’m quite reassured. I mean if I did get HIV I’d know when it began which I think is important. There was some kind of finding that said it was good to start combination therapy very early and then I would be able to do that. [...] [Last time I tested] was because I fucked someone without a condom and didn’t know his status. I wanted to find out whether I caught HIV on that occasion.”

(age 45, insertive UAI with 1 regular last year, tested 18 months ago)

Some thought it important to know their status not only to take care of their health but also to take responsibility for the sex they had with other men.

“In the case you are positive then you have to live with it and then you have to change your lifestyle, change the way you see your lifespan. I always normally do safe sex so that wouldn’t change but I would probably change from safe sex 98% of the time to safe sex 100% if I knew I was positive.”

(age 26, both receptive & insertive UAI with 1 regular and 4 casuals last year, tested 3 months ago)

3.2 RELUCTANT TESTERS: OTHER THINGS SCARE ME

Many men were aware of and believed in the benefits of early diagnosis and treatment, talked about why they thought it was a good idea to know one's status but were discouraged from testing by fear of a positive diagnosis. Often, they believed that they would not be able to cope with a positive diagnosis in a constructive manner and it would therefore be detrimental to their physical, emotional and psychological health. They lived with an on-going sense of ambivalence where their feelings and thoughts competed. For the most part, fear tipped the balance away from testing.

"What do you see as the benefits of testing for HIV?"

Better treatments and not finding out that you are positive by becoming ill. Finding out that you are positive when you might be feeling quite well. Being able to establish a link with a hospital, a clinic, getting to know your doctor. I mean for sound medical reasons. There is a whole range of various things but for that reason. But then you are not able to fantasise that you are going to live forever if you get a positive test and you have to decide who to tell if you get a positive test. The fact that it might be positive leads to a whole range of other associated things that scares me. There does appear to be good medical reasons for knowing you are positive earlier than there ever used to be. I suppose it's that a positive result doesn't have the same horror stigma, immediate association with close death that it used to have. It seems more, 'Yes you can have it and you can just carry on leading your life'. I haven't tested again because of fear - fear of being positive, fear of not knowing how I will react to that, fear of not knowing whether I will be able to just carry on with my life, fear that I might... I don't mean suicide, I mean carrying on with my job, my career, that kind of stuff. Will I be able to function? Will I be able to get up in the morning and carry on and work, psychologically not physically. Fear of the unknown I suppose. This is emotional fear not cognitive, logical stuff."

(age 34, receptive UAI with 1 regular & 1 casual last year, tested 4 years ago)

For others, the possibility of securing a mortgage or life insurance if they had a positive diagnosis (or even an HIV test) was weighed against the benefits of early treatment and being able to protect themselves and their partners' sexual health.

".. the consequences of an HIV test can sometimes be difficult in terms of insurance, in terms of mortgages. Having gone through house purchasing a couple of times in the last few years I've been aware of insurance based mortgage products requiring statements about not only HIV status but also having HIV tests."

(age 42, only PAI last year, never tested)

Men therefore had a range of both subjective and objective concerns regarding the HIV test. Although they were aware of the benefits of an HIV test, be they related to personal health or future risk reduction strategies, their concerns overshadowed these possible benefits.

3.3 TESTING AS A LAST RESORT

Some men reported that they would never take an HIV test, unless it was the only way to diagnose an illness. For a number of reasons, they did not see any benefit in knowing their status. The following respondent reported two concerns. The first was the damaging effect of a positive diagnosis on his family. The second was a fatalistic conviction that as we are all going to die anyway, there is little reason to ponder on the cause of our death.

"I don't want to upset my family by turning around to them and saying, 'Look Mum, Dad, I've got this,' and them being upset and everything. I don't want that to happen. I'll die more likely in a car crash. I can't really see any benefit of having a test. You are either going to have it or not and what you don't know can't really harm you. I know it sounds ignorant but that's my answer to that question. [...] I might be sticking my head in the sand but at the end of the day it won't change me in the future with my sexual appetite. That has been strong since I was 13. I just don't see the point of testing."

(age 27, receptive UAI with 2 casuals last year, tested 2 years ago)

Others believed that as long as they felt healthy and showed no obvious symptoms of HIV infection, there was no point in knowing whether or not they were positive. The psychological cost of a positive diagnosis was considered too high, in the sense that, rather than focussing the respondent on achieving his life goals, the self-interrogation and self-blame which accompanied a positive diagnosis would be personally destructive. These men would therefore prefer to live what they perceive to be a fuller, more fulfilled life by assuming they were HIV negative.

"The knowledge of having this life threatening condition hanging over you. It would just change the whole perspective on life. I mean people say, 'If you are diagnosed with cancer and you suddenly want to get everything done that you've ever promised to do,' but I think I'm doing that anyway. I just don't see the point. And I think I'd spend half of that time thinking and going back over so many sexual encounters and thinking, 'Where did it all go wrong?' and guilt associations and all sorts of other things. I would spend too much time analysing and kicking myself for it. There are benefits, but to me not knowing my status as long as I'm healthy means I can make assumptions about myself. I'd rather be in ignorance for the cost of coming out positive."

(age 36, receptive UAI with 1 casual last year, never tested)

Other men feared the social consequences of diagnosis and potential for stigma and discrimination to the extent that they would rather not know. For the following respondent, disclosure was a major concern that outweighed any benefits of early detection and treatment.

"I now think even if I was positive I actually wouldn't want to know. I'd almost prefer not to know. [...] If I were to be faced with being HIV positive it would be an immense amount of issues, family, work, colleagues, friends, neighbours, people I go out with, people you meet casually, you are frightened of telling anybody. Of course the flip-side of that is the benefit of testing is that you can get treatment earlier. But then that is balanced by the fact that you have to deal with it if you are positive. That would be all negative and terribly depressing."

(age 29, receptive UAI with 1 casual last year, tested 2 years ago)

Others had more extreme fears around social stigma. For example, this respondent felt that a positive diagnosis would compel him to segregate himself socially and it was clear that the very thought of being positive was psychologically overwhelming for him.

"I don't think that testing would be in my own best interests because at least then I don't have to start worrying about whether I'm going to die or have to take combination drugs. The thought is terrible that I might get it because if I do have it what would happen at work? I'd probably lose me job. I'd certainly lose friends at work. I'd have to be segregated I suppose. I feel like I'd just have to disappear somewhere. I can't imagine what it would be like. I think if I was positive I actually wouldn't want to know. I'd almost prefer not to know."

(age 29, receptive UAI with 1 casual last year, tested 2 years ago)

For other men, there was a direct relationship between their psychological state, how they interacted socially with the world around them and their physical health. The following two examples are informative. In the first case, the potential psychological consequences of a positive diagnosis were assumed to be so acute as to endanger his general health. The respondent was not assuming that he did not have HIV, but was actively engaging with the possibility that he might already be infected. That is, if his immune system was already compromised, depression would compromise it further.

“Psychologically I would become, or emotionally I would become depressed and therefore I think I would become more susceptible to being ill because my immune system as I view it would go down because I wouldn’t be so healthy emotionally and psychologically. [...] So to me it’s better not to know while I feel healthy.”

(age 50, UAI with 1 regular last year, tested 18 months ago)

The following is an example of a related concern where the knowledge that one is HIV positive has both a social labelling effect and a psychological effect where the ‘sick role’ will be taken on, internalised and in effect, become a self-fulfilling prophecy. This was allied with a rejection of the current thinking that treatments and medical care of HIV have improved to the degree where it is useful to know ones’ status. Although a diagnosis might have increased the quantity of life, it is also likely to have decreased its quality.

“The possibility of starting combination therapy, the possibility of my life being labelled because I’ve seen too many patients being labelled and often they’ve said afterwards, ‘Oh I wish I didn’t have this test because I’ve now got this title and I don’t like it’. I suppose what I’m thinking is ignorance is bliss. I don’t think the treatments are what they are made out to be. I think the quality of life for those individuals, not all of them, but a great number that I see and that I know of is not good and it’s a question of quality versus quantity. That’s a personal opinion. I’ve got mates who have tested positive, gone on combo. therapy and have become so bloody ill, really sick. When I said I don’t see the new treatments as a benefit, I don’t think they would be a benefit for me. You meet patients who come into hospital, have a chest X-ray and you can see the cancer on the chest X-ray and they are told they have lung cancer and they are dead in two days. Now what killed them? The cancer or the thought of having it?”

(age 42, insertive UAI with 2 casuals last year, never tested)

Even though these men rejected the idea of having an HIV test, they almost universally said that they would test for HIV if they started to manifest physical symptoms which they could not attribute to any other condition:

“I think if I became unhealthy and there were indications that it may be HIV related then I think I would go for a test possibly because I think I could then use other medical services or systems to support myself. That’s if I was positive.”

(age 50, insertive UAI with 1 regular last year, tested 13 years ago)

In conclusion, the reasons men reported not wanting to test were manifold and operated on a range of different levels. Some men had a relatively straightforward lack of faith in the efficacy of new treatments. Others feared the imperative of having to disclose their HIV status to loved ones or partners. Others reported concerns about the discrimination, social stigma or labelling attached to a positive diagnosis. Finally, some feared the harmful psychological and physical effects of a positive diagnosis. Often it was an amalgam of these concerns which acted as a strong deterrent to testing for HIV.

It is vital to note that these men were not in denial about their HIV status. They were willing and able to actively engage with the possibility that they might already have had HIV. However, for a range of reasons, they were unwilling to have it diagnosed. That said, they were not merely waiting for symptoms to show, since most believe themselves to be uninfected. Instead, they were engaged in a sometimes distressing ambivalence regarding their own possible HIV status.

3.4 NO CAUSE TO TEST

Some men saw little need to have an HIV test because they were confident that the sex they had was unlikely to have resulted in HIV exposure or transmission. They were not remotely concerned that they might have HIV and therefore saw no benefit to testing. Most of these stated that they would have a test if they engaged in sex which they felt may have exposed them to HIV. Similar to others already described, they were also knowledgeable about possible benefits of early treatment and took this into consideration.

“A long time ago when I was more promiscuous and I didn’t use protective sex I might have thought about testing. But now I’ve thought to myself, ‘you’ve gone all these years, you are very healthy’, and you know, I suppose really it’s something I’ve just put out of my mind. I keep telling myself it’s unnecessary. I think that’s the reason. As long as I take precautions, I don’t feel that I need to take a test. I mean maybe if I did get drunk and did anything really stupid then I think probably I would. I think anybody who has any unprotected sex should. I have had protected sex for so many years I just got this feeling that if there were any symptoms then I would have noticed. I suppose I’ve convinced myself that everything is fine, and I do everything in my power not to catch anything - so the chances are slim, they really are slim.”

(age 48, only PAI last year, never tested)

This group tended to include more consistent condom users, or men who did not engage in anal intercourse. However, it also included men that engaged in UAI in circumstances that they considered posed no threat of HIV exposure. It was not the absence of any objective risk of exposure or infection that defined the group, but a confidence in decisions they have made in regard to the sex. For most of these men, HIV testing was not an issue for them since they were fairly certain of their status.

I am pretty sure [of my status] because I haven’t had any really bad unsafe sex [...] Like screwing around indiscriminately or having lots of unsafe sex.

You said that you had fucked without a condom with one regular partner in the last year. Do you know his status?

Yes, he is my most recent ex-boyfriend and both of us had our test 14 months ago at the same time and I have had unsafe sex with him this year again.

So the last time you had unsafe sex with him did you know what his HIV status was or were you unsure?

I was unsure but I trust him ... I know him very well so I know he hasn’t had unsafe sex with anybody else because I see him very, very regularly [...]

So how long have you been fucking without a condom on a regular basis?

Only since knowing him.

What do you think your status was the first time you fucked without a condom?

I knew that I was HIV negative because I hadn’t had any unsafe sex.

So you’d never actually had unprotected anal intercourse before with anyone.

Correct.

And why did you think he knew his status was negative?

I don’t think he was somebody that screwed around. He hadn’t had a sexual relationship like that, like we were having.

(age 37, UAI with 1 regular partner, tested 14 months ago)

3.5 DISCUSSION

We have seen from this analysis that men who did not know their HIV status expressed an enormous diversity of attitudes towards the possibility of finding out. Some would have preferred to know while others would not. For some, the possibility of a test was a manageable concern, for others, it generated enormous anxiety. However, it is clear that those men for whom not knowing their HIV status was problematic were in the minority. For the 'regular testers', an HIV test was one tool amongst many for managing the risks associated with being sexually active. On the other hand, the majority of those who would test only as a last resort, had compelling reasons not to do so (concerns about social stigma as well as psychological or physical damage). Amongst these, there were men who tested when they were sufficiently concerned about their past risk behaviour.

We see also that in relation to health and well-being the question of whether or not one had a positive HIV status became most animated. That is, the ambivalence men experience was based on competing possibilities in their lives: whether one carried the virus or not. The majority of men did not lead their day-to-day lives with the on-going thought that they may be HIV positive. The sheer gravity of this possibility was too great to be a constant concern. Rather, periodic testing, or a decision not to test were strategies developed in order to deal with the possibility of being positive. This question, of course generated anxiety. For the regular tester, this anxiety was around the time of the test. For the men who were unsure because of their specific sexual behaviour, this anxiety was associated with those memories. For men who preferred not to test, the anxiety regarding one's possible HIV status was experienced and yet rejected.

In the next section, we explore the roles that these different forms of knowledge about, and attitudes towards, HIV status play in sexual behaviour. That is, how do men who report not knowing their HIV status manage the sexual risks associated with HIV?

4 Implications of not knowing HIV status: managing sexual risk

Of particular interest to HIV health promoters is the question of how men who do not know their HIV status manage the sexual risks associated with UAI. That is, whether such men can ever engage in UAI with a certainty that HIV transmission will not occur. To investigate risk, we asked respondents about their engagement in UAI in the year prior to interview. In total, twenty-one men had done so. We elicited detailed narratives about the incidents of UAI where men were asked to recall their feelings and thoughts *during* UAI, how they felt afterwards and the longer term meanings they attached to it. The results of this analysis are presented in four parts. The first concerns men's thoughts during UAI. The second deals with their assessments on the possible outcome of the UAI (that is, what factors mediated their assessments of risk). The third examines the larger symbolic meanings that UAI held for men. Finally, we look at the relationship between HIV testing and UAI. That is, whether or not having tested for HIV influences men's sexual behaviour (and *vice versa*).

4.1 DURING UAI

We examined both the circumstances in which UAI occurred and men's recall of their feelings while they were engaging in UAI. Accounts were divided into three types. First, there was momentary UAI where penetration occurred, but was quickly terminated. Second, were accounts of full UAI but without ejaculation. Finally, we recount cases where UAI continued to ejaculation.

4.1.1 Early termination of UAI

By far the most common account was where UAI was momentary, that is, it was terminated immediately after penetration. In all but one account, the respondent was insertive. The narrative usually began as one of pleasure and enjoyment. This respondent described his feelings on initial insertion of his penis into an anonymous partner.

"It was warm, it was close, it was... It was just really close. It was just so pleasant. It sounds terrible doesn't it but [...] He was enjoying it [laugh]. He was enjoying it, I was enjoying it. It was really nice actually."

(age 42, insertive UAI with 2 casuals last year, never tested)

However, this enjoyment was tempered by concerns about HIV risk which competed with sexual enjoyment. These concerns usually led to the rapid termination of UAI.

"... I was only up there for about two minutes and then pulled out.

Why was that?

Because it suddenly occurred to me that I was getting quite carried away with the whole thing and I was enjoying myself thoroughly, it was good, and suddenly I thought, 'Hang on, hang on, put the brakes on a bit, be sensible!'"

(age 27, insertive UAI with 2 casuals last year, tested 18 months ago)

This was also the case in the single account of receptive UAI. In the following case, the respondent was asleep after having sex with a casual partner.

“... I sort of woke up and I was feeling a bit aroused and I started caressing and he started caressing me and he started waking up increasingly and then he was being up against me and he just shoved his penis in the side of me and I don't know whether he went in or not. I felt it going in but I think it was just half way, not all the way.

So what did you do?

I moved away.

And did he say anything?

Yes he said, 'Don't worry I don't have any diseases' ... that's reassuring!"

(age 27, receptive UAI with 2 regulars last year, never tested)

In a minority of cases, the narrative was described differently in terms of emotional or physical dysfunction. This respondent described how he felt depressed leading up to an incident of UAI at a cruising ground.

“That particular night I was not okay in myself. I'd gone through a lot of trauma so I was depressed so I went out and it was just unfortunate that things moved along quite quickly and not long after I entered him I suddenly realised what I was doing and it freaked me out for a while afterwards. There was no ejaculation or anything, it hadn't got that far, but it still freaked me out that it could have gone on [...]

Did you have a condom on you?

No. It just happened so far which is what I suppose scared me more that it could have happened so at least... I suppose at least it didn't go all the way but...

What made you stop?

The realisation of what I was doing. I just went soft and that was it and before I knew what was happening I was pulling my trousers up and going.”

(age 35, insertive UAI with 1 casual, never tested)

In these cases therefore, the pleasure of UAI was mixed with a consciousness of HIV risk which led to UAI being terminated early on, either through withdrawal or loss of erection.

4.1.2 Later termination of UAI

In the second type of account UAI continued for longer. As before, these accounts were marked by an awareness of HIV risk and the 'necessity' to use a condom, and the presence of a range of risk reduction strategies. Our first account involves problems with initial penetration. That is, the loss of concentration associated with both putting on a condom and penetrating a partner caused some men to lose their erections.

“Were you concerned at the time about not using a condom ...?”

At the beginning yes. I thought, 'Well we'll do this for a few seconds, a minute and then we stop'. But then it didn't happen.”

(age 26, receptive UAI with 1 regular and 4 casuals last year, tested 3 years ago)

Thus, men decided to engage in momentary UAI to increase the pleasure or gain a 'better' erection, but withdrew to put a condom on before ejaculation. In other cases, either the respondent or his partner attempted to wear a condom, but removed it, for similar reasons.

“It's just a lot easier to put condoms on and they can't go on or they can't get it up and all sorts of things and then you just think, 'Oh sod it. Try again in a minute', but you take it off by that time and you want to shag and he's got it up so just do it.”

(age 27, insertive UAI with 2 casuals last year, tested 2 years ago)

By contrast, some accounts involved a choice not to use condoms but instead to withdraw before ejaculation as a risk reduction strategy (*coitus interruptus*). Here, a respondent who practised receptive withdrawal with a partner whom he thought might be HIV positive described their first sexual encounter.

"...I know exactly what goes through my mind if I'm having unsafe sex with somebody in that specific situation. There's the thought that he might be positive or he might be negative so I will make sure he doesn't cum inside me. I think that's kind of..."

Do you remember thinking that?

I do remember thinking that yes, 'As long as he doesn't cum inside me it will be alright!'"

(age 34, receptive UAI with 1 regular and 1 casual, tested 4 years ago)

In all of these cases, there was invariably an intention to use a condom, even if one was not used. Therefore, men were aware of the HIV risk as they engaged in UAI and took steps to reduce it (short duration of UAI, withdrawal, no ejaculation etc.).

4.1.3 UAI to ejaculation

In accounts where ejaculation occurred, men tended to respond in a range of ways. The following cases are contrasted. In the first case, the respondent met his partner in a cruising area where he witnessed him engaging in multiple receptive UAI. His partner attempted to do so with him also. Instead, he took his partner home. When the respondent experienced difficulties with penetrating his partner, his partner removed the condom and they continued.

"What were you thinking at the time?

Well I was worried because of the risk involved.

How did you feel about not using a condom before you had sex with him?

I wanted to avoid that situation.

It sounds like you had gone to quite a few lengths to avoid that.

Yes.

How did you feel about it afterwards?

I was annoyed that it happened. I was annoyed that I'd let it happen. I felt really frustrated that it had happened, that I hadn't ensured it didn't turn out that way and I was worried.

Worried about what?

About that I might have picked up something, HIV or something."

(age 30, insertive UAI with 1 casual last year, tested 8 months ago)

In contrast to this, another respondent reported engaging in insertive UAI with a partner in a cubicle in a sex club.

"So how was that?

Brilliant. I mean this was even better because I came inside him.

Were you concerned at that time? Was it going through your head what you were doing?

Absolutely, definitely, but it was just so good and I just didn't want to stop. Fickle [laugh]. But it was good, it was brilliant. He was enjoying it again, I was enjoying it [...]

After you finished what happened? Did you talk at all?

No.

Did you think about it later?

Yes again. I thought about it later and I've wanked about it since, you know, the joy of it.

The fantasy of it?

Yes and I've also thought about what was his status and he doesn't know what mine is and I came inside him and risk and that kind of thing. But then it just goes. Like when you go cottaging you feel guilty until you get home and then it's gone. You are beating yourself up all the way home from the cottage to the house thinking, 'Oh God you dirty little bugger', and then you get in and it's all forgotten."

(age 42, insertive UAI with 2 casuals last year, never tested)

4.1.4 The protective imperative

Men clearly displayed a range of attitudes, emotions and reactions to having engaged in UAI. In addition, UAI occurred in a range of contexts for a range of reasons. However, there were two common factors to all of the accounts of UAI. First, the respondent was aware of the immediate HIV exposure and transmission risk. Second, the imperative was to protect oneself. That is, even though men may have doubted that they were HIV negative, during sex, they acted as if they were. They perceived the risk of becoming infected. Therefore, accounts of UAI tended to be characterised as mistakes or aberrations. UAI was either terminated, occurred in spite of the intention to use condoms, or *coitus interruptus* was used as a risk reduction strategy. In those rare occasions where ejaculation occurred, respondents displayed attitudes ranging from great remorse and worry to exhilaration and excitement. There was no sense in which the occasion of UAI was 'normal' or planned (especially with casual partners).

4.2 UAI AND THE POSSIBILITY OF HIV TRANSMISSION

Men who had engaged in UAI were asked to discuss the possibility that HIV had been transmitted during the encounter. When men considered HIV transmission, the concern that animated much of their thinking was that they might have become infected. Noticeable here, was the assumption that all risk in UAI was a risk to the self.

"If I'm willing to fuck without a condom in effect you are entering into an open contract that you are both willing to do it. And if you are going to fuck someone without a condom you have got to be aware even in the back of your mind the risks that they might be positive, you might contract HIV from them."

(age 27, insertive UAI with 2 casuals last year, tested 18 months ago)

However, risk was mediated by a number of factors: that is, men engaged in risk reduction strategies. The first factor was knowledge of a partner. For some, this meant assessing either before or after the encounter the likelihood that the partner was infected. This might have been based on physical characteristics.

"The first guy, did you think at all what his status was? Did you sort of size him up at all?"

No, no, not at all, definitely not.

Did you do that later?

Yes.

And what did you think?

Did he look thin? What were his hips like when I was fucking him?

Really?

Yes because you can gauge somebody's body weight by their hips [...] so yes that kind of thing [...]

That post assessment what was the result of that?

He looked okay. It's stupid but he looked okay."

(age 42, insertive UAI with 2 casuals, never tested)

However, assessments of a partner's sero-status might also have been based on sexual behaviour.

"What did you think his status was?

I thought he might be positive.

Why did you think that?

Because he was fucking without a condom."

(age 34, receptive UAI with 1 regular and 1 casual, tested 4 years ago)

In addition, the level of social familiarity or emotional intimacy between partners was important. Here, knowledge mediated a perception of risk:

"How did you feel about it after you had [UAI]?"

Well I didn't think of that so I didn't feel very bothered about it. It was about three hours after. But you see I know him very well and I know he is not very promiscuous and he was negative since the last time he was tested so ..."

(age 26, receptive UAI with 1 regular & 4 casuals last year, never tested)

However, familiarity with risk itself (in addition to familiarity with a partner) also lessened its impact.

"Does your perception of your HIV status change at all after fucking without condoms?"

Sometimes yes I sort of worry about it for a few days and then forget about it.

I mean it sounds like with this one partner it's a very common occurrence to fuck without a condom so it's likely to happen again.

Yes.

Do you worry about that as well, with this partner? Do you worry for a few days and then...

No. Well it's not so much because we've done it so many times.

So you worry less and less.

Yes.

What would you say is your greatest fear about fucking without a condom?

Well it's just getting it [HIV] obviously."

(age 29, receptive UAI with 1 casual last year, tested 2 years ago)

Finally, whether or not ejaculation occurred mediated risk perception. For many, this was of more importance than whether a condom was worn.

"I kind of got my head into a way of thinking if there is loads and loads of lube which will kill off bits of pre cum [...] You know, sex without a condom... It's okay as long as somebody doesn't cum and it's almost safe sex, well probably safe sex but ...

Lower risk?

Yes in my mind I think it is lower but I don't know whether that's true or not. It must be vaguely true but I don't know."

(age 34, receptive UAI with 1 regular & 1 casual last year, tested 4 years ago)

Often, some or all of these factors operated in tandem to mediate the level of perceived risk in a sexual encounter. This respondent talked of two incidents of receptive UAI, one with a long-term partner (whom he thought might be positive) without ejaculation, the other with a casual partner in a backroom where his partner ejaculated.

“How did you know that he [casual partner] came inside you?”

He told me because I asked him and he said he had and I could feel it.

Did he express any concern about not using condoms?

No, it's all this kind of picture of him and what he said which is why I had the feeling that he might be positive. His behaviour was of a positive man, or is it just someone who seems to have thought about it and not been concerned about it. [...] this was someone you had the feeling could be positive [...] it really upsets me thinking about that.

Why were you so upset?

Because I didn't want it to happen and I just felt ...

When you say you didn't want it to happen do you mean out of control or...

Not control, it just felt like I wasn't valuing myself at all and yet I've been fucking away frequently with this guy I'm seeing without condoms and it feels totally different.

Is it something to do with HIV risk?

I think someone not cumming makes a difference with the risk but not whether you know somebody or whether it's casual sex.

So it's this thing about not cumming inside you?

Yes. That's more important to me than whether it was casual sex or not somehow. I think why I felt bad about that thing on the [cruising area] is because I actually don't think I was in ... I didn't feel particularly good about myself that day and I think it really seemed to have reflected that somehow. I think that's why it upset me because it seemed to sort of reinforce perhaps how I was feeling that day.”

(age 34, receptive UAI with 1 regular & 1 casual last year, tested 4 years ago)

The perception of risk changes depending on the circumstances in which UAI occurred. Moreover, outcomes of risk were not always perceived as negative. That is, although the possibility of infection was a negative aspect of UAI, risk could also have resulted in enhanced sexual excitement, increased intimacy or a relationship. We examine those broader meanings and values attached to UAI in the next section.

4.3 MEANINGS ATTACHED TO UAI

UAI had a huge variety of meanings which mediated perceptions of fear or pleasure. Such meanings were associated with self-perception, personal agency or power within sexual relationships and expressions of intimacy or personal boundedness. Generally speaking, these meanings centred around a sense of personal integrity and the extent to which personal boundaries were breached. In some instances (for example, an unwelcome power imbalance or an unhappy relationship), transgressing personal boundaries was seen as negative. In others (a happy, intimate relationship), such transgressions brought rewards. Although the meanings we discuss here did not relate directly to HIV risk, they were what animated the sense of risk. That is, emotions attached to HIV risk lost much of their meaning without this context.

4.3.1 Negative meanings: loss of control, transgression of boundaries

The most commonly expressed emotion connected with UAI was regret at losing control or transgressing personal boundaries, often within the context of momentary or terminated UAI (see section 4.1). The following respondent did not feel he had risked infection, but was concerned about the meanings of his actions.

“[My greatest fear about UAI] would be taking away the certainty of control. At the moment I'm in control. If now I had unprotected sex I wouldn't be in control and I'd be worrying totally.

So it's about loss of control?”

Yes more than anything.

What does that mean for you?

For me it would mean everything. I'm on my own now as such so the only person at the moment that is really going to be concerned about my life is me and if I'm not concerned about it then why should others ..."

(age 35, insertive UAI with 1 casual last year, never tested)

For others, it was the fear that once they had engaged in UAI, they would be tempted to repeat the experience.

"[That experience of UAI] means in a way that I have stopped doing anal to a degree or I've cut down dramatically and I'm a bit more careful now with oral so it does have an effect. So yes I can't say it's not had an effect because it has.

In terms of cutting down on anal sex is that because you are concerned about possibly infecting somebody else or is it because it could make you vulnerable to infection?

I've got to say both because 1) I can't pretend and 2) I can't pretend that they are negative. I don't even live near [cruising ground] so I had all that time going home to think about everything and it doesn't just go away when you sleep on it overnight. I could quite happily say I'm over all the issues now, thankfully. At least now I know that if I go to [cruising ground] I won't go into anal sex now because it's putting too much at risk for me.

Even with a condom?

Even with a condom now. That's taking too much of a risk. [...]

Is it difficult not to fuck when you are down there? Is it hard to resist?

For me now no. I've got that mental block there now."

(age 35, insertive UAI with 1 casual last year, never tested)

UAI was experienced as negative when men felt that it was inappropriate to their emotional engagement. This respondent talked positively about the passion and chemistry connected to UAI and had a romantic desire to "give himself completely" to a partner. However, he was concerned about the appropriateness of his desires, that is, about having sex when he wanted affection.

"The thing is I put too much love or feelings into... Even to share with somebody I have to feel something. I kiss and it's like a kind of a commitment even if it's for a one night stand or things like that. You are giving yourself to the person and sometimes you feel like, 'Come on let's give yourself'.

Alright, 'give all of myself'?

Yes but sometimes I think that's the wrong way to think [...] I always want to have some link with the person. It's like not upsetting sex, it's like there has to be a bit of feeling, there has to be a bit of sharing. I think that's what makes me vulnerable. Maybe I should be a bit more cold but I don't want to be... Okay, 'let's give all of me because what is that person going to think'. I think I have to be more cold and that's why maybe I am determined to have something really close with somebody. It's good to stop being a fool. Sometimes you go for sex when you are looking for something else, maybe you are interested in affection ...

(age 29, insertive UAI with 1 regular & 1 casual last year, tested 3 months ago)

Intimacy and power also mediated another respondent's experience of UAI with his ex-partner. During the relationship, they had an agreement regarding 'negotiated safety'. Since parting, they engaged in occasional sex which sometimes resulted in UAI. He was almost certain that his own status was negative and was asked to categorise his ex-partner.

“Two questions we ask usually! In the last year, have you had sex with a man whose HIV status you knew was negative and in the last year have you had unprotected anal intercourse with a man whose HIV status you didn’t know? Which would you put him into?”

No I’d put him into the category that I’ve had unsafe sex with that man but I knew his HIV status was negative.”

(age 37, insertive UAI with 1 regular last year, tested 1 year ago)

UAI was ‘unsafe’, not because of HIV, but because of the feelings it provoked. The same respondent felt that he engaged in UAI because of his partner’s power over him.

“How did I feel? I felt I would have liked to use a condom but I also wanted to take his feelings into consideration and when he says those words I think I just switch off then [finger click] and I just do as he says. No I don’t just do what he says, I just become very weak. I become very weak and I need somebody to come around, like I said, and slap me across the face and say, ‘Look you need to do this’. So basically before we were lying in bed I need like somebody standing at my bedroom door and I need to be assertive and told, ‘Right, go in there and put a condom on and do safe sex’. But nobody was there to like give me a jolt and I was very weak. It’s the weakness I suppose with that individual I know his HIV status, I know his history, I know his background.”

(age 37, insertive UAI with 1 regular, tested 1 year ago)

Such lack of power was also associated with sexual domination scenes. This respondent was receptive for UAI during a ‘rough’ sex session, but felt that it was inappropriate to request his partner use a condom. He also felt uncomfortable about speaking to his partner about the matter afterwards, not because he feared that his partner was positive (he had come to the conclusion that this was not the case), but because of his partner’s possible reaction.

“I would have liked [him to wear a condom] but I didn’t want to push the issue.

Why didn’t you want to push the issue?

I think I probably did want to but I don’t know the guy very well. That’s a stupid excuse but ... I’m not really sure. I think if I’d known him a bit better I would have probably pushed it a bit more and said, ‘Look use one’. I mean he was a kind of a nice guy but not nice during sex, kind of thing, if you get what I mean [...]

Was it up to him to decide to use condoms or not?

No I think I probably could have now, thinking about it.

But at the time it was quite difficult to.

Yes it was just kind of hard to him to get one.

What do you think would have happened if you had?

I think if he had one he would have used one.

How did you feel about it afterwards?

Pretty pissed off at myself.

Why was that?

Just because I didn’t know what my status was from before and it just adds another sort of doubt to it all [...]

Did you talk about the fact that you fucked without condoms afterwards?

No.

Why not?

I was too nervous.

How do you mean?

Not so much what he would say about his status but just generally nervous about how he

would take it, talking about it. I mean okay it was something that affected both of us. You didn't know how he would respond to that or whether he'd want to talk about it. Yes I'd only known him for a couple of months or so."
(age 23, receptive UAI with 1 casual last year, tested 3 years ago)

4.3.2 Positive meanings – intimacy and affirmation

Some men associated UAI with positive or pleasurable thoughts, usually concerning emotional intimacy. The following respondent talked of his long term (sexually open) relationship. He occasionally engaged in UAI with this partner when neither was sexually active outside of the relationship. UAI was therefore associated with intimacy rather than risk.

"Like if I see him and he says, 'I was with so and so last week', or I say, 'I was with so and so', it might encourage one or both of us to use condoms. It sounds really weird. Whereas if we hadn't been with anybody else we won't bother with condoms.

Do you talk about it or is it just ...

We don't talk about disease."

(age 29, receptive UAI with 1 casual last year, tested 2 years ago)

This respondent reported that his regular partner was possibly positive because of his age and sexual history.

"Sometimes I think he is [positive] and sometimes I think he isn't and I don't really care.

Why is that?

Because it's good and I want to be with him.

When you say it's good you mean life in general with him or sex with him?

Yes, life with him, sex with him. Yes I'm very happy.

Did you think about HIV at all on Sunday when you were having sex with him?

It's kind of there in the back of my mind.

What do you mean?

You know, I think about it for a tiny split second before the actual fucking and perhaps sometimes afterwards.

What do you think?

That I'm making a decision to do this, I'm making a decision to have unsafe sex now."

(age 34, receptive UAI with 1 regular & 1 casual last year, tested 4 years ago)

Therefore, the enjoyment and intimacy associated with UAI with this particular partner was weighed against the possible risk.

4.4 RISK AND TESTING

In chapter three, we investigated how attitudes towards and experiences of HIV testing influenced men in their assessments of their own possible HIV status. We saw that some men reported not knowing their HIV status in spite of having tested negative in the past. Others had significant disincentives to test. The absence of a test result allied with some previous risk behaviour led them to conclude that they could not judge themselves to be negative and yet were unsure whether or not they were positive. We also learnt that considerations of quality of life (am I infected? will I get ill?) informed men's testing practice far more than intentions to use a test result to reduce risk (testing to engage in negotiated safety, for example). We therefore found that the test *per se* had little connection with notions of future HIV risk.

In contrast, quantitative research has found clear relationships between HIV testing and HIV risk (Elford *et al.*, 2001; Leaity *et al.*, 2000). That is, men who repeatedly test negative engage in elevated levels of HIV risk. The same research interprets this risk as a result of repeatedly testing negative. That is, men who test negative repeatedly, develop a sense of immunity to HIV and consequently continue to engage in risk. We were therefore prompted to investigate this relationship amongst a sample of men who had reported not knowing their HIV status in spite of one or more negative HIV tests.

Twenty-one of our respondents (62%) had tested for HIV. A similar number had engaged in UAI in the previous year (22 or 65%). We also found that the group who had tested and the group who had engaged in UAI were almost coterminous: that is, only four men who had engaged in UAI had never tested for HIV.

In order to explore this relationship further, we categorised the accounts given by the twenty-two men who had engaged in UAI by the levels of risk taken (basing this categorisation on duration of UAI, whether or not ejaculation occurred, etc). We conducted a secondary analysis on these transcripts, concentrating specifically on their accounts of UAI and their attitudes towards testing. Instead of looking for overall themes, we looked for internal consistency within accounts. We categorised men into groups depending on the relationship between the UAI they engaged in and the HIV tests they had taken in the past. The contexts within which these men engaged in UAI varied as did the length of time since their last test (one had tested as recently as three weeks ago, another as long as 13 years ago). However, our analysis gave rise to four different types of relationship between HIV risk and testing. We present the results of this analysis below.

4.4.1 Group one: testing as a result of risk

The vast majority of men had tested for HIV because they had engaged in UAI. Indeed, twelve accounts concerned the specific incident of UAI described at interview. Most of these men doubted their hitherto negative status because of a single incident of risk (see section 3.1). All were either regular testers or had an equivocal attitude towards testing (see sections 3.2). Therefore, unlike those who test as a last resort (see section 3.3), they did not perceive an overwhelming obstacle to testing. The contexts of UAI varied (for some men it had been momentary or terminated insertive UAI, for others, it had been receptive UAI to ejaculation with a casual partner). All men had a clear perception of the risk they had engaged in and felt they might have been exposed to HIV.

“... when I’ve had my HIV tests and they have been negative I’ve always felt very confident that I’ve been negative even though I’ve been sucking and doing a whole load of other forms of sex but the minute I fuck without a condom I move into the ‘status unknown’ territory.”
(age 34, receptive UAI with 1 regular & 1 casual, tested 4 years ago)

What differed was the context within which men tested. Some men were regular testers, but the test following an incident of UAI had a greater anxiety attached to it. This respondent has his regular “MOT” (six monthly sexual health check which includes an HIV test). However, his last test was different.

*“Oh I was quite afraid because I had sex in Amsterdam with a boy, unsafe sex and I didn’t know him at all. I didn’t know anything about him so I was a bit tense of getting it.
Because you thought there was a chance of getting it [HIV] ...
From that time, yes.”*
(age 26, receptive UAI with 1 regular & 4 casuals, tested 3 months ago)

Thus, the common discourse of testing regularly as a ‘check-up’ is belied. Not all tests are equal: some carry with them the real possibility of a positive result.

Other men tested solely as a result of UAI, taking window periods into account and generally testing more than once, so that 're-establishing' their negative status was a lengthy process. Having recently received his own negative HIV test result, this man talked of his response to his ex-partner's positive diagnosis.

"Actually I'd been for a test just the week before but I've got to wait two weeks now to find out about firstly my result and then go back later. [...] Then it was, 'Well I can't see how I got it. The only way I could have got it is through swallowing, that's it, that's it'.

So when did you test after that?

It would be about 6 months.

Six months after that relationship?

Yes and it was negative. I mean for a while I never knew about the window period of three months or so [...]

Were you confident at that stage after you tested negative?

No. I plan to have another test in the coming week just for peace of mind."

(age 41, receptive UAI with 1 regular last year, tested 2 years ago)

Finally, some men were contemplating having a test at the time of the interview. That is, they were coming to the realisation (sometimes within the course of the interview) that they had taken a real risk. This might be through a process of rationalising or putting their concerns in context.

"If you had a test what do you think your status would be?

Well sometimes I think it will be negative and then other days I'm convinced it's positive. I guess the sex I've had has been unsafe so ... I don't know, it's very possible, it's not an irrational fear that I might be positive. It's not like these kind of people who think because they've had a wank or snogged some guy and then heard he was positive and think, 'Oh my God I'm going to be positive'. You know, I've been fucked without a condom and the guy came inside me and he was a guy who was very likely ... I don't know who it is, it was casual sex, but there's a high chance that he was positive and therefore that's very risky sex so that's not an irrational fear to think that I might be positive ... Maybe I should go and have a test."

(age 34, receptive UAI with 1 regular & 1 casual last year, tested 4 years ago)

4.4.2 Group two: taking a test in order to engage in UAI

Some men tested in order to facilitate engaging in UAI with a regular partner (that is, within negotiated safety agreements). It is interesting that despite the amount of attention given to negotiated safety by health promoters, this was the smallest group (only two men reported this). However, their cases are different.

The first respondent had engaged in UAI with a former long-term partner with whom he had a negotiated safety arrangement. This involved both partners testing simultaneously. Even though both had been sexually active with others since the separation, he was almost certain that he and his ex-partner were still negative.

"So the last time you had unsafe sex with him did you know what his HIV status was or were you unsure?

I was unsure but I trust him that he himself... I know him very well so I know he hasn't had unsafe sex with anybody else because I see him very, very regularly.

Has there ever been times when you've been absolutely sure what your HIV status is?

Yes just after I've had a test.

Other times you are not sure?

Other times I suppose you could say I'm not sure because I can't give you a guarantee I'm not HIV. I've really got to go and have a test this afternoon and then come back and tell you.

When does it change? How long after you've had a test or why does that change?

I think it's mental. It's your own history. I know that the sex I've had, even though I have had unsafe sex, I know the person I have had unsafe sex with is also in the same category as I am – HIV negative – and I trust him explicitly that he hasn't had any unsafe sex with a man who is HIV positive.

Why do you?

Because I just do. He's not a person that goes screwing around. I've known him for two years and I see him regularly [...] I sort of know his whereabouts, what's he doing, where's he going and blah, blah."

(age 37, insertive UAI with 1 regular last year, tested 1 year ago)

The second respondent used a negative test result from the distant past together with a discussion of sexual histories to reach a negotiated safety arrangement with his partner which was not based on recent testing.

"What about the sex you've had with this partner? Have you felt at all that you should test?"

No. From early days we fucked with condoms and then about 6 months after meeting and fucking with condoms we felt that we'd been honest enough with each about our past histories and that we would be conducting a monogamous relationship such that ...

You were saying that you are reasonably confident that your partner has a similar status to yourself that is probably negative.

Yes. Also the whole thing is taken on trust which is why I still use the word probably negative. I mean I'm assuming two things in that. One is that my one test at the time was correct and that nothing in the intervening years in terms of very low risk sex has changed that status and I'm assuming that he's telling the truth about his sexual history.

Which is.?

Is one partner with whom he fucked with condoms."

(age 49, UAI with 1 regular last year, tested 10 years ago)

For the men in groups one and two the relationship between HIV risk and HIV testing was, for the most part straightforward. The majority tested as a result of having taken a risk. A small minority tested in order to engage in UAI. We might describe the men in these groups as having a dynamic causal relationship between HIV risk and HIV testing. The test was used precisely as a diagnostic tool. This is not to say that there was not considerable anxiety attached to an HIV test but such anxiety was not sufficient to prevent them from testing. The five men in the remaining two groups were markedly different. These men were either too fearful to test (even though they were aware of the possibility of being infected) or they simply did not believe that their sexual behaviour had put them at risk for HIV. Of the four men in our sample who had both engaged in UAI in the previous year and were untested, three came from groups 3 and 4.

4.4.3 Group three: overwhelming disincentive to test

Like men in Group 1 (section 4.4.1), the levels of risk engaged in by men in this group varied. However, all felt an overwhelming disincentive to test, reporting that they would only do so if they were to become symptomatic (see section 3.3).

"What I do know is all the negative consequences of testing with regard to insurance and pensions and those kinds of things.

Anything else?

Mortgages and all that kind of stuff. I'm also a father. I'd feel that I'd have to be making decisions about whether I'd tell my daughter and that for me is a very difficult, it's a huge burden to deal with. So to me it's better not to know while I feel healthy. I think if I became unhealthy and there were indications that it may be HIV related then I think I would go for a test. As long as I am healthy, I just don't want to know [my HIV status] because of the negative psychological and emotional effect it could have upon me [...] the cost of that knowledge is too high."

(age 50, insertive UAI with 1 regular partner, tested 13 years ago)

Their fear of testing was associated with a recognition of the risks they had taken (and the possibility that they might be positive).

"Because I've had quite a lot of sexual partners between that time, well they weren't partners, just basic shags. [...] It's just reminded me now that your chances might be running low of being negative and basically that's just another risk on your insurance quote, as it were. The odds are running out [...] I mean there have been times in the past where I've been worried because I've been having a lot of sexual activity but I don't feel like [testing] because I am too frightened that I might be positive."

(age 29, receptive UAI with 1 casual last year, tested 2 years ago)

It was also associated with lack of belief in the efficacy of treatments or the attachment of particularly negative meanings to a positive diagnosis.

"How about the improvements in treatments?"

I don't think I agree with you, I don't think they have improved, I know I don't and I think the quality of life for those individuals, not all of them, but a great number that I see and that I know of is not good and it's quality versus quantity. That's a personal opinion [...].

Any other negative consequences to testing?

Yes, the label, the stigmatisation. You see in my line of work if I am HIV positive I must inform my employer.

What would that mean?

That would mean they would have to ... Very kind aren't they - employers? They would have to do a needs assessment on me as a practising nurse working in the field where you are involved in invasive treatments and that could mean bloody anything, then they have to remove you from that setting you see. That's a negative thing for me in my line of work. Also our professional body tells us if we are aware of practitioner who is HIV positive and hasn't informed the authority then you have to inform on them."

(age 42, insertive UAI with 2 casuals last year, never tested)

Two of the three men in this group have been tested in the past. However, all these tests were more than two years ago.

4.4.4 Group four: no perceived risk

The final group contained only two men. These men did not perceive that they had taken any risk for HIV, in spite of the fact that both had regularly engaged in UAI with a range of partners. Both might be described as practising risk reduction strategies. For one, this consisted of being the insertive partner during UAI.

"Because I don't consider it my business to keep other people safe when I'm insertive. It's up to them to keep themselves safe. I keep myself safe [by insisting on condoms if receptive] because I have the respect for myself to do that but I'm not a policeman am I? I'm not going to

tell them what to do. If they want to run the risk [of not using condoms] or make the decision to let me do it to them without, it's their conscious decision, they're doing it knowing that they're doing it. The reason why I am not worried [about infecting my partner] was because my knowledge of my status was strong enough to know that he wasn't going to catch it from me."
(age 26, insertive UAI with 3 casuals last year, never tested)

The other engaged in UAI only with men who are married or did not have a gay identity who, he reasoned, were unlikely to be infected.

"He'd never been fucked before. He'd been fucked once when he was 14 years old and that was the only time. He's 99% safe and married. I know he doesn't go with anyone else. He might go with somebody else for oral sex but never anal and that's very rare. I'm happy with not using a condom because I know I'm not going to shoot in him and I know that by the struggle he has to take it that he hasn't been having any anal sex. I'm quite sure of that because it takes a few goes to get it in him, a few complaints and few squeals and lots of bravery. [...] If it's somebody I know the history of and I've known him for some time. I know that they are married, family people who don't stray, as far as I know. They've got to be somebody I know quite well and know their history and background and stuff."
(age 58, insertive UAI with 5 regular & 5 casual partners, never tested)

Both of these men fit into the 'no need to test category' (see section 3.4) and both remain untested. We might therefore describe men in groups three and four as seeing little or no relationship between HIV risk and HIV testing. That is, they either do not perceive a risk, or, if they do, the anxiety attached to an HIV test proves too great a disincentive.

4.5 DISCUSSION

Men who report not knowing their HIV status can tell us much about the contexts and meanings attached to sexual risk. The variety of contexts within which sexual HIV risk occurred and the variety of ways in which men characterised their risk was enormous. For some men, HIV risk consisted of momentary insertive UAI with a regular partner; for others, full UAI to ejaculation with casual partners. However, only a small number of men consider their sexual behaviour to carry a high probability of HIV exposure and transmission.

However, there are certain factors which connect all the men in our sample. With very few exceptions, UAI was perceived as intrinsically risky. Risk was generally perceived during and after the sexual act. However, this risk is distinctive in that it is primarily considered as a risk to the self. It would be reasonable to assert that, during sex, the vast majority of men who profess not to know their status are acting under the assumption that they are currently not infected. The imperative which informs any risk reduction or risk elimination strategies is to protect themselves from HIV infection rather than their sexual partner.

When we talk about risk, it is important to note that it can have positive as well as negative consequences. This ambivalence regarding the consequences of risk informed many men's risk assessments. That is, positive outcomes of UAI such as increased sexual excitement, increased intimacy etc. were often considered in addition to the negative outcome (infection with HIV). In addition, other factors reduced the risk. The most important of these was the notion of not ejaculating during UAI or *coitus interruptus*. In other cases, even when a condom was not used for anal intercourse, the intention to use it was always there (as in cases where men began AI with the intention of pausing to put on a condom, but did not). Therefore, even if the imperative of protection was not followed, it does not mean that men were not aware of it or were denying it.

In addition, one cannot meaningfully talk about UAI without the context of the larger symbolic meanings attached to it. These may be negative (such as a feeling that one has breached personal rules or boundaries) or positive (achieving a greater level of intimacy, complete abandon *etc.*). A finding that merits further discussion is the idea that although men often considered whether one instance of UAI had led to their infection, they also considered what an instance of UAI meant within the context of their feelings of more generalised risk. That is, although momentary insertion was unlikely to result in infection, men were often more concerned it might undermine their resolve to avoid UAI. What this tells us is that 'safer sex' is not a unitary concept which relies merely on the accretion of instances where condoms were used for HIV. Nor is it a once and for all decision. Rather, it is entirely dependent on context and meaning. UAI means different things to different people at different times. UAI also means more than merely an assessment of whether or not HIV exposure or transmission was likely to have occurred.

Finally, we have found that the group of men who do not know their status is not unitary, but fractured by the issue of HIV testing. The relationship between risk and testing for this group is for the most part functional and straightforward. Most men tested to find out whether or not they were infected during UAI. All attached considerable anxiety to a positive test result, and for the majority the question was not "Am I positive?"; but "Am I still negative?". We see therefore, that those men who have engaged in significant HIV risk and have tested, have done so in order to re-establish their negativity as a priority. They were in a state of transition. However, this was not in order for them to make more informed decisions about their HIV risk, but rather to put their minds at ease about their health and personal future. In short, it is clear that testing is almost universally related to personal well-being rather than future HIV risk. In contrast, for those who have not tested and have not taken any risk, the question of not knowing one's status is for the most part dormant or unanimated. That is, it does not play a large part in their day-to-day lives and where it might be supposed to play a part (during sex), it is generally replaced by an assumption of the self as negative and an imperative to protect oneself from infection.

5 Conclusions

It is perhaps ironic that in studying men who report a lack of knowledge (that is, do not know their HIV status), we learn so much about how such knowledge works. That is, what it means to 'know' ones HIV status and the effects of this knowledge on sexual behaviour and sexual risk.

We find, first of all, the mutable or contingent nature of knowledge. When a man is diagnosed with HIV, he generally experiences a period of trauma during which a new 'reality' is absorbed. For the majority of positive men, there is an incontrovertible knowledge that they have the virus within their bodies. Therefore saying one is HIV positive is an acceptance and assertion of a *fact*. Saying one is HIV negative is, generally speaking, an assertion of a certain *personal reality*: that is, an interpretation of one's world in a certain way, based on the available evidence (this may be through a test result and / or an assessment of past sexual risk). Most gay men will have questioned this interpretation at some stage and considered the possibility that they may be positive.

In contrast, men who report being unsure about their HIV status were stating a *lack of certainty*. That is, they were unable, for whatever reason to assert that they were negative, nor did they know that they are positive. They are therefore expressing a state of contingency or ambivalence. However, their 'knowledge' about their HIV status was animated by different imperatives: that is, there was not a stable operative state of being unsure about one's status. When men considered their life expectancy and health, they were generally engaged in a dialogue about the possibility of being HIV-infected versus the possibility of not being infected. By contrast, when they engaged in sexual risk, it was invariably from the perspective of one who is currently uninfected.

HIV prevention for gay men now tends to depend on two approaches. The first is ensuring that all men have basic information about sexual HIV transmission. The second is ensuring that all men can take informed decisions regarding their sexual risk based on their perceptions or knowledge of their own and their partner's HIV status. HIV testing is therefore increasingly recommended for gay men, not only as a clinical intervention (that is to reduce undiagnosed infection in order to increase the overall effectiveness of treatment programmes), but also as a behavioural or preventative intervention. The consultation draft of the English National Strategy for Sexual Health and HIV (Department of Health, 2001) sets specific targets for the uptake of HIV testing for gay men in order to facilitate clinical outcomes as well limiting further HIV transmission. Testing as a preventative strategy is assumed to work in two ways. Should the individual test positive, he can take measures to ensure that he does not pass on the virus to sexual partners. Should he test negative, he can both reflect on his past risk and make decisions about his future sexual behaviour based on a clear understanding of his own status in relation to that of his partner. Several assumptions inform the advocacy of HIV testing as an HIV prevention strategy. The findings detailed in this report allow us to comment on these and on the efficacy and limits of testing as an HIV prevention strategy.

The first assumption is that the knowledge generated by an HIV test result is clear and unequivocal and once tested negative, men can use this knowledge to make decisions concerning their sexual risk. Our findings indicate that such certainty is temporary at best. Over 60% of our sample who reported not knowing their HIV status had tested negative for HIV in the past. This may be due to a specific incident of risk, or concerns about being within a 'window period'. However more commonly, it was simply a recognition that many sexual acts confer some risk of HIV exposure and that cumulatively, there is a possibility of infection occurring as a result of a range of sexual activities. Put simply, a test result supplies only temporary certainty. What this report highlights is the difference between the diagnostic categorical 'knowledge' of HIV status produced by a test result and the

contingent mutable 'knowledge' of HIV status that most men who are not actually diagnosed HIV positive possess.

The second assumption underlying the promotion of HIV testing as a personal risk reduction strategy is that men cannot engage in risk reduction unless they have knowledge of their HIV status. Our study indicates that this is not the case. The vast majority of men who reported not knowing their HIV status engaged in limited risk (that is utilised risk reduction strategies) informed by a assumption that they were HIV negative. Their imperative during sex was protection from possible infection. Men therefore can engage in risk reduction strategies which do not involve having absolute certainty about their own or their partner's HIV status.

The third assumption is that gay men use the HIV test as more than a diagnostic tool. Such an assumption, we feel, over-emphasises the preventative potential of HIV testing and fails to recognise the most important meanings and values attached to testing by gay men. While repeat testers do engage in elevated levels of sexual HIV risk, it does not appear to be the case that they do so because the test result gives them feelings of personal invincibility or immunity to the virus. This interpretation over-emphasises the meaning of an HIV test. When we looked qualitatively at the relationship between testing negative and HIV risk, we found that the relationship was causal and for the most part one-directional. Men tested precisely because they had engaged in HIV risk rather than testing in order to convince themselves that they were immune. Moreover, only two of our testers had done so specifically to engage in negotiated safety arrangements. To put it simply, men who take risks test more because they have more reason to believe they might be positive. Testing is therefore used precisely as a diagnostic tool and not as an aid to risk reduction. The overriding question for men considering an HIV test is 'do I have HIV' rather than 'can I dispense with condoms when I engage in anal intercourse?'

We are not however, advocating that promoting HIV testing as a personal risk reduction strategy be abandoned. Rather we are questioning its appropriateness or possible effectiveness as a stand-alone measure. This is because, to advocate testing solely as a preventative strategy is to underestimate the various meanings that gay men attach to it as well as the imperatives they are responding to when they test. Moreover, we must think more critically about the nature of risk and risk-taking. Consider the meanings attached to finding out one's HIV status. Men in this study express a diversity of attitudes to testing ranging from concern to paralysing anxiety. Some use it as a tool for managing HIV risks while others will test only as a last resort. Our most important finding however, is that overwhelmingly, the HIV test is related primarily to health and well-being rather than future sexual risk. The question of whether or not one is positive, what one's life expectancy and health status is, are of overriding importance.

We must also consider the nature of risk as having positive as well as negative outcomes. Increased intimacy, a cemented relationship and increased enjoyment are all positive outcomes of not using condoms for anal intercourse. In addition, men risk more than possible infection. There are larger and more diffuse meanings attached to 'unsafe sex' such as those attached to personal or emotional boundaries. So the meaning of 'safer sex' is entirely contextual and the question of HIV infection interacts with other imperatives. It is perfectly possible for the HIV risk attached to an incident of UAI to be considered as negligible, but the other (negative or positive) outcomes to be considered momentous. Therefore, there is more to risk assessment than whether or not HIV transmission might have occurred.

When we take all of these factors into account, we are compelled to question the value of 'knowing' one's HIV status. This is because such 'knowledge' is contingent. Even when used merely as a diagnostic tool, a negative HIV test result can only give temporary certainty and considering the gravity of its potential outcome in terms of life, health and well-being, it is difficult to justify testing as an HIV prevention strategy. We end therefore with a single recommendation. In seeking to enable men who have not been diagnosed positive to develop dynamic personal risk reduction strategies, we might encourage them first to consider the contingent nature of their 'knowledge' regarding their HIV status and second to find ways of working with this contingency. Such an approach poses challenges to health promoters. However, we conclude that it is a more acceptable and potentially more effective strategy than encouraging men to seek certainty.

References

- Department of Health (2001) *The national strategy for sexual health and HIV – consultation draft*. London, Department of Health (0541-555 455).
- Dodds J and Mercey D (2000) *Monitoring high risk sexual behaviour amongst gay men in London, 1999*. London, Royal Free & University College Medical School (020-7380 9879).
- Elford, J, Leaity S, Lampe F, Wells H, Evans A, Miller R, Johnson M, Sherr L (2001) Incidence of HIV infection among gay men in a London HIV testing clinic 1997-1998. *AIDS 15(5)*: 650-653.
- Hickson FCI, Davies PM, Hunt AJ, Weatherburn P, McManus TJ, Coxon APM (1992) Maintenance of open gay relationships: Some strategies for protection against HIV. *AIDS Care, 4(4)*: 409-419.
- Hickson F, Weatherburn P, Reid D, Henderson L, Stephens M (1999) *Evidence for change: findings from the National Gay Men's Sex Survey 1998*. London, Sigma Research (020-7737 6223).
- Hickson F, Reid D, Weatherburn P, Stephens M, Brown D (2001) *Time for more: findings from the National Gay Men's Sex Survey 2000*. London, Sigma Research (020-7737 6223).
- Hickson F, Hartley M, Weatherburn P (2001) *London Counts: HIV prevention needs and interventions among gay and bisexual men in the sixteen London Health Authorities*. London, Sigma Research (020-7737 6223).
- Keogh P, Weatherburn P, Stephens M (1999) *Relative safety: risk and unprotected anal intercourse among gay men diagnosed with HIV*. London, Sigma Research (020-7737 6223).
- Kippax S, Crawford J, Davis M, Rodden P, Dowsett G (1993) Sustaining safer sex: a longitudinal study of homosexual men. *AIDS, 7*: 257-263.
- Leaity S, Sherr L, Wells H, Evans A, Miller R, Johnson M, Elford J (2000) Repeat HIV testing: high risk behaviour or risk reduction strategy? *AIDS 14(5)*: 457- 552.
- Mayne T, Weatherburn P, Hickson F, Hartley M (1999) *Sexual health and practices of gay, bisexual and homosexually active men in New York City*. New York, Gay Men's Health Crisis (00-1-212-367-1353).
- Van de Ven P, Prestage G, Knox S, Kippax S (2000) Gay men in Australia who do not have HIV test results. *International Journal of STD & AIDS, 11*: 456-460.
- 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*. London, Sigma Research (020-7737 6223).