

Nicola Douglas

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# I just get on with it...

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A study of the employment experiences of gay and bisexual men and black African men and women living with HIV in the UK

An original research report for NAT

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## Acknowledgements

This project would not have been possible without the generous and valuable contribution of a number of people. Many thanks to:

Those who assisted with the key informant study: Grant Chambers (DHIVERSE, Cambridge), Maro McNab, (Waverley Care), Chris Morley (George House Trust), Sue Murphy (Positive East).

Those who co-facilitated or assisted with co-ordination of the focus groups: Anthony Townsend (NAT) Juliet Reid & Anna Botha (Centre for African Families Positive Health), Eunice Sinyemu (HIV Scotland), Tarsisio Nyatsanza (Waverley Care), Colin Armstead & Chris Morley (George House Trust), Allan Anderson (Positively Women), Garry Brough (formerly Bloomsbury Patients Group).

Those who provided technical advice: Dr Salih Solomon, Oriel College, Oxford assisted with statistical analysis of online survey results. Maurice Hebert (NAT Volunteer) carried out desk research. Nia Roberts (University of Oxford) advised on literature searching and Anna Rambert (City University London) advised on ethical approval. Assured Transcription for transcription of focus group material.

Those who helped publicise the project: Tony Grew (Pink News), Living Well, Positive News and the numerous social, support and leisure groups for gay and bisexual men that we contacted.

Very special thanks to Qsoft, who generously donated their resources to host the online survey and Paul Trickey for technical advice, support (and infinite patience). Thanks also to Levi Strauss & Co who provided financial support.

Very special thanks to Eleanor Briggs (Senior Policy Officer, NAT) who commissioned the project and managed the research on behalf of NAT with such enthusiasm, patience and grace. Her contribution and hard work were invaluable. Many thanks also to Deborah Jack and the hard-working support staff at NAT who in their various capacities make NAT the fine organisation that it is.

The project also benefited hugely from the contribution of Professor Jonathan Elford (City University London) who supervised the research and donated his insight and expertise with such generosity (of time and spirit).

Final thanks go to those who provided feedback on the draft questionnaire, attended a focus groups or completed the questionnaire to advance understanding of the needs and experiences of people living with HIV.

Nicola Douglas

June 2009.

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## Background

NAT (National AIDS Trust) is a national policy and campaigning organisation seeking to halt the spread of HIV and to improve the quality of life of those affected. It has long been involved in activities related to HIV and employment, most notably as a partner in Ensuring Positive Futures, which saw a number of HIV charities working together to develop initiatives in this area. As a result of this work, NAT identified an information gap in relation to the experiences of people living with HIV who are in employment.

NAT commissioned an independent research project to investigate the employment experiences of two key groups of people living with HIV in the UK: gay and bisexual men and black African heterosexual men and women. The project was managed and conducted between May 2008 and June 2009 by Nicola Douglas and supervised by Professor Jonathan Elford, City University London. This report documents the research.

### Why Was The Research Needed?


Studies have identified some of the barriers to employment for people living with HIV (Weatherburn, Anderson et al. 2002; Doyal and Anderson 2003; Dodds, Keogh et al. 2004; Doyal, Anderson et al. 2005) and the perceptions of the general public about working with HIV positive people (National AIDS Trust 2008). However, in consultation with other HIV sector organisations, NAT identified that the employment experiences of people living with HIV was a relatively under-researched issue within the UK. One consequence is that little is known about how issues of HIV and employment may be experienced differently by the two key constituencies most affected by HIV in the UK: gay and bisexual men and black African heterosexual men and women.

A recent study conducted by Professor Elford and colleagues among London HIV clinic attendees showed that white gay men were more likely to be in employment than heterosexual black African men and women, with more part-time working reported among heterosexual black Africans. Black Africans were significantly more likely to report having insufficient income to meet their basic needs than gay men from minority ethnic groups and white gay men (Ibrahim, Anderson et al. 2008). When asked about disclosure of their HIV status, 21.6% of employed respondents had disclosed their HIV status to their employer, with white gay men reporting higher rates of disclosure to employers than heterosexual black African men and women and gay men from minority ethnic backgrounds (Elford, Ibrahim et al. 2008). Of those who reported experiencing any HIV-related discrimination, one-in-five had experienced this at work. Gay men were more likely to report discrimination at work than black Africans, although this may be accounted for by the fact that more gay men were employed (Elford, Ibrahim et al. 2008).

NAT therefore sought to commission a study that would gather primary data to identify how people living with HIV subjectively experience employment in order to contribute to the evidence-base available to those developing research, policy and practice in this area.

### Aims and Objectives

The primary aim of the study was to explore the employment experiences of two groups of people living with HIV in the UK: gay and bisexual men and black African heterosexual men and women. The objectives were:

- To conduct a review of the literature using Rapid Assessment methods (Butler, Deaton et al. 2005).
  - To obtain ethical approval for the proposed research via the Research Ethics Committee of City University London.
  - To gather expert opinion within HIV sector organisations regarding key research questions for exploration with groups of people living with HIV.
  - To design a focus group format and schedule to gather qualitative material to answer key research questions.
  - To conduct six focus groups, each of around 5-7 people living with HIV, to explore their experiences of employment.
  - To carry out an online survey of gay and bisexual men (both HIV positive and negative) using the social networking website, Gaydar to explore their experiences of employment.
  - To document findings in a written report.
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## Methods

In order to meet the proposed objectives, a mixed-method approach was used combining qualitative and quantitative techniques as follows.

### Literature Review

The most comprehensive method for identifying research evidence is the systematic review (Mulrow 1994). However, conducting a systematic review of sufficient quality and rigour typically takes 6-12 months. This was not feasible within the timescale and resources available to the project. Moreover, there were indications from knowledgeable sources that a dearth of research in this area would limit the scope for conducting a useful review. Therefore, a brief and focussed scoping exercise was carried out using modified Rapid Evidence Assessment techniques to identify relevant literature (Butler, Deaton et al. 2005). There are limitations with this method - it cannot be relied upon to provide a comprehensive review of the literature – however, it can provide a sufficient overview in a timely fashion within the resource constraints of a given project (Butler, Deaton et al. 2005). In addition, this method can provide a useful indication of the extent to which there is scope for a more comprehensive review.

The parameters of studies for inclusion in the assessment were as follows:

Studies conducted in Northern Europe, North America, Australia or New Zealand;

reported in English;

published since 1996;

with people living with HIV as research participants; and

which make reference to employment experiences in either the title or abstract.

Following consultation with a learning resources specialist, the following electronic bibliographic databases were searched in June 2008: Cinahl, Embase, Medline, Psychinfo, ASSIA, SSCI, Business Source Complete. The search terms used were: HIV and AIDS, work, employment. Excluded terms were: sex work, social work, group work, and workshop. Truncation was used so, for example, the term 'work' would also include the terms: worked, working, workers etc. Papers relating to the following were sifted out: occupational transmission of HIV, the needs and experiences of unemployed HIV positive people seeking to return to work, and the needs and experiences of those working in the 'illicit' economy (e.g. sex workers). The search strategy is outlined in Appendix 1.

### Ethical Considerations

The study conformed to the highest ethical standards and in accordance with the Statement of Ethical Practice for the British Sociological Association (British Sociological Association 2002). Ethical approval was sought and obtained from the Research Ethics Committee of City University London. In order to meet the ethical requirements, the following processes were observed.

Informed, written consent was obtained from all focus group participants (see Appendix 2). Participants were assured of confidentiality and anonymity, with only first names used (or pseudonyms if participants wished). Verbal non-disclosure agreements were made in all focus groups, and participants were advised of potential risks of disclosure by other participants. All involvement was entirely voluntary and participants were informed of their rights to withdraw from the study at any time without giving a reason and without consequence. All reasonable steps were taken to minimise any distress and participants were advised about methods for obtaining support from professional HIV organisations should distressing feelings emerge.

Online questionnaire participants were assured of the same rights to anonymity and confidentiality as focus group participants. They gave informed consent to participate in the study by electronic means as a pre-cursor to completing the questionnaire (see Appendix 3). No personal details (e.g. IP addresses) were obtained by which they could be identified.

All participants were advised that any complaints or comments about the conduct of the research should be submitted to City University London in the first instance. Participants were also advised as to where they can obtain a copy of the research report/summary.

The study also conformed to the requirements of the Data Protection Act 1998. Focus group transcripts were anonymised. All research materials (recordings and transcripts) were securely stored and only the primary researcher had access. Identifying data was stored separately from other material (e.g. focus group transcripts). All materials will be stored for three years after the completion of the study. Personal details will be destroyed one year after completion of the study. Electronic data is securely stored and password protected.

### Key Informant Consultation

Through discussion with research contract managers at NAT, six 'key informants' were identified. Patton identifies these as '...people who are particularly knowledgeable about the inquiry setting and articulate about their knowledge – people whose insights can prove particularly useful in helping an observer understand what is happening and why' (Patton 2002). Using a brief email questionnaire, we sought to gather structured feedback using open-ended questions to elicit information on the following:

The proposed content of the focus groups and the key research questions that the study should explore.

Whether any key topics had been omitted.

Any additional comments or suggestions.

Four of the six organisations approached were able to participate in the study and returned the information requested, which was used to inform the development of the focus group schedule. The results of this exercise were summarised in a briefing paper available upon request from NAT.

### Focus Groups

Focus groups are structured group interviews that typically involve individuals in discussion of a particular topic under the direction of a facilitator. The facilitator promotes interaction and ensures that

the discussion remains on the topic of interest (Stewart and Shamdasani 1990) . They are increasingly used for gathering rich qualitative material and utilising group dynamic processes to explore participants' knowledge and experiences (Kitzinger 1995; Morgan 1998). The use of focus group methods offered distinct advantages to this study in terms of effective use of resources and time. Moreover, advocates suggest the method can be useful: when investigating complex behaviour, beliefs and motivations; to understand more about diversity of opinion on a topic; when a 'friendly' and respectful research method is required (Morgan 1998). Focus groups can therefore allow qualitatively rich material to be obtained efficiently and effectively and encourage meaningful participation in a way that is accessible and respectful of the life-experiences and perspectives of those taking part.

There were three key phases to this aspect of the study:

Phase 1: Development of the focus group schedule

Phase 2: Recruitment of participants

Phase 3: Running the focus groups

Phase 1 – Developing the Focus Group Schedule

The development of the focus group schedule was originally informed by the literature review to identify key information gaps about HIV positive people's experiences in employment. This was further refined following the key informant phase of the work. Finally, research managers within NAT and group facilitators (see below) were asked to review the focus group schedule (see Appendix 4 for the schedules used).

Phase 2 – Focus Group Recruitment

Our objective was to conduct six focus groups: two with gay and bisexual men and four with heterosexual black Africans to include two single gender groups. However, despite repeated attempts, we were unable to recruit a sufficient number of HIV positive black African men for a viable single gender group. However, men participated in the mixed gender groups for Black Africans. We therefore ran five groups in total.

Due to the way in which gay communities and black African communities are differently structured and located in the UK, different approaches were necessary to reach the target groups. Expert consultation suggested that running the two groups for gay and bisexual men would be most useful and productive in two areas of the UK where there are large gay populations and a relatively high proportion of men living with HIV: London and Manchester were selected.

Recruitment for the gay men's groups used four main sources: 1) social/leisure/support groups for gay and bisexual men, 2) advertisements on websites/radio stations targeted at gay and bisexual men, 3) 'snowball' sampling, i.e. word-of-mouth recruitment via participants, and 4) support organisations for people living with HIV. Because gay community infrastructure is well developed in the UK with advanced use of IT (Bolding, Davis et al. 2004), an electronic flyer (see Appendix 5) was designed and distributed to a large number of social and support organisations in these two cities (London n=151 organisations, Manchester n=68 organisations). We also asked organisation co-ordinators to forward the email so it is likely that the recruitment flyer eventually reached many more organisations than those on our original list. Men responding to the flyer were provided with a detailed information sheet

and consent form and asked to confirm their eligibility (i.e. that they were gay or bisexual, living with HIV and in paid employment) (see Appendix 2). Upon confirmation, focus group details were forwarded to them.

In the event, the London men were recruited through diverse means as follows: online flyer distribution, flyer distribution at London LGBT Pride 2008, Gaydar radio advertisement, HIV support group and word-of-mouth. In Manchester, half of the group was made up of service users of George House Trust, which supported the project. The remainder of Manchester participants were recruited through websites (NAT or Gaydar) or word-of-mouth.

Due to immigration patterns and policies (particularly the policy of dispersal of asylum seekers) (National AIDS Trust 2008), it was important to involve black African men and women from different parts of the UK. We therefore conducted three focus groups in Luton, Glasgow and London. We initially perceived that it would be more effective to recruit black African men and women through HIV support groups than through social and other support organisations since community infrastructures for black African people in the UK are emerging but not yet well developed. However, we sought to use similar methods to those used to recruit gay and bisexual men in London and Manchester to test out this perception. We contacted 34 organisations providing leisure, social and community services to Africans in Glasgow. As predicted, this was not a successful strategy and instead we worked collaboratively with HIV organisations in the three locations to recruit men and women to the study.<sup>1</sup> All of the participants for the Luton, Glasgow and London women's groups were recruited through local HIV support organisations.

Our observation is that a combination of online and community organisation-based recruitment was necessary to obtain a mixed sample with sufficient numbers of people to take part. It is regrettable that we were unable to run a group especially for black African men and would advise that subsequent research might anticipate that greater effort will be needed to reach and involve black African men living with HIV.

### Phase 3 – Running the Groups

Each group ran for two hours and included a refreshment break. The aim was to create a relaxed and friendly atmosphere where participants could have some food and meet the facilitators and other participants before the exercises began. The exercises themselves were a series of guided discussions and workshop activities designed to enable participants to reflect on their experience and to share their insights with the group (see Appendix 4). A series of ground rules were agreed by the groups to ensure fair and respectful participation. With the exception of the 'social' time, the groups were electronically recorded with participants' consent and transcribed verbatim. Travel expenses up to £10 were reimbursed and an honorarium of £20 was given in the form of shopping vouchers.

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<sup>1</sup> The supporting organizations were: Centre for African Families Positive Health, HIV Scotland, Waverly Care, Positively Women, Living Well and Positive East.

As the researcher (a white British woman) did not share the primary characteristic of interest of the two target groups (i.e. gay or bisexual male sexual identity or black African ethnicity) it was felt important to include co-facilitators in each case who did. The role of the co-facilitators was to help set up the sessions, welcome participants and to take notes. Co-facilitators also gave extremely valuable insight into the content of the sessions during subsequent de-briefs. They were drawn from NAT, Waverly Care, HIV Scotland and the Centre for African Families Positive Health. We did not involve a co-facilitator in the session with black African women in London, because the group was relatively small and it was felt that the use of two facilitators might seem intimidating and 'unbalance' the group dynamics.

## Online Survey

In order to begin to quantify the insights gained from the focus groups we conducted an online survey of men using the gay social networking website Gaydar ([www.gaydar.co.uk](http://www.gaydar.co.uk)). Currently, there is no known commensurate facility from which a sample of black African people might be drawn and the costs of accessing a large sample of black Africans were prohibitive to conducting quantitative research within this project. There were two key phases to this work: questionnaire development/piloting and field work.

### Phase 1 – Questionnaire Development

A questionnaire was designed including a number of original questions and incorporating those from previously developed instruments. These were: the Workplace Employment Relations Survey 2004 (Department for Trade and Industry), the East London Project and Health, Sex and Steroids Survey 2008 (City University London), Gay Men's Sex Survey (Sigma Research). Ethnicity classifications were taken from the Office for National Statistics classification system. The draft questionnaire was piloted with a group of gay men who were asked to comment on question comprehension, acceptability and ordering. The final questionnaire was a 93 item instrument (with 40 questions completed only by HIV positive men). This aimed to explore respondents' demographic characteristics, their employment status, experiences and perceptions about work, experiences of workplace discrimination, awareness of legal protection and preferred sources of help and advice. We also sought to compare HIV positive and HIV negative respondents on selected key variables. The questionnaire is provided at Appendix 3.

### Phase 2: Fieldwork

The final version of the questionnaire was completed anonymously online by men who are registered users of Gaydar, excluding those who were ineligible (only men who were gay or bisexual, over 18 and in employment were included). Previous research has shown that survey samples can be obtained by this method that are similar in profile to homosexually active men from the National Survey of Sexual Attitudes and Lifestyles (the most comprehensive statistical profile available of gay and bisexual men in the UK) (Evans, Wiggins et al. 2007).

The questionnaire was available for completion on the site for 12 days (28/11/08 – 10/12/08). The opportunity to win one of five free three-month memberships of Gaydar was offered to men completing the questionnaire. Members of a Gaydar research panel (approximately 6000 users who are willing to participate in Gaydar research activities) were first sent a message about the questionnaire. A subsequent message was then sent to all of Gaydar's UK users to alert them to the questionnaire. We

estimated that a sample size of at least 500 HIV positive men would be needed to conduct a meaningful analysis.



## Analysis

Given that the study used multiple methods employing both quantitative and qualitative forms of inquiry, a mixed approach to analysis was required as follows.

### Literature Review

Studies that met the inclusion criteria ('hits') were identified. After duplicates and non-relevant papers were excluded, a total of 37 relevant papers were identified and downloaded to Endnote 10. The abstracts were then read carefully to identify potentially relevant themes by the researcher. Where highly relevant to the study papers were read in full.

### Focus Groups

Qualitative material was analysed using Braun and Clarke's approach to thematic analysis (Braun and Clarke 2006). This is a flexible and pragmatic six stage method for identifying, analysing and reporting thematic patterns in qualitative material. The stages include: transcription, familiarisation with the data, generation of initial codes, searching for themes, reviewing themes and generating thematic maps. NVivo 7 was used to manage the text.

### Online Survey

An Excel spreadsheet of questionnaire response data was generated by Qsoft (the owners of the Gaydar website). After data cleaning, STATA and SPSS were used to analyse the data. Pearson's chi-square tests were run to examine correlations at the 95% significance level.

We sought to include in the analysis reported here only respondents who were employed, over 18, living in the UK, who described themselves as gay or bisexual and who knew their HIV status according to their most recent HIV test. The following respondents were therefore excluded from the analysis:

- Those who stated they were under 18 or did not answer the question about their age.
- Those who did not live in the UK or did not answer the question about where they lived.
- Those who did not describe themselves as gay or bisexual.
- Those who were not employed.
- Those who did not answer the question about their HIV status.
- Those who reported that they did not collect their last HIV test result and therefore did not know their HIV status.

## Findings

### Literature Review

In the following, we present findings from the rapid assessment literature review (Butler, Deaton et al. 2005). It should be noted that this does not allow for a comprehensive review of the literature but provides an overview of some of the key themes emerging from significant papers.

It should also be noted that almost all of the papers identified originated in the US, with a few from Canada or Australia. There were almost no papers originating in Europe (with the notable exceptions of those by Dray-Spira, et al from France) and no relevant studies originating from the UK. Therefore, it is important to note that there are limitations in the transferability of findings, not least due to the different epidemiological profiles of HIV and the variation in healthcare and welfare systems. However, noting these limitations we have sought to highlight relevant issues.

Researchers agree that the advent of ART (Anti-Retroviral Therapy) has changed the experience of employment for people living with HIV irrevocably. Relatively quickly after the introduction of ART, researchers began to document the ways in which more effective treatment was transforming employment options for HIV positive people. ART significantly impacted upon the disease profile of HIV leading to markedly increased life-expectancy, reduction in illness and symptoms and improved physical capacity to work. Improvements in physical wellbeing also translated into increased motivation and intention to enter or remain in work (Ezzy, De Visser et al. 1998; Goldstone 2003; Goldman and Bao 2004; Bernell and Shinogle 2005). Significant decreases in workplace absenteeism were also observed (Leigh, Lubeck et al. 1997).

However, the improved profile was not universal and certain social and psychological vulnerabilities confounded the ability of certain groups of HIV positive people to enter or remain in work. Burns and colleagues identified the way in which factors of age, ethnic background, disease progression and mental and physical functioning predicted the extent to which individuals would be able to capitalise upon the benefits of ART to re-enter or remain in employment (Burns, Young et al. 2006; Burns, Young et al. 2007). DiClementi and colleagues similarly observed that a history of substance misuse disorders acted as barrier to employment (DiClementi, Ross et al. 2004). Boshnick found that 'career self-efficacy' (ability to make plans about employment and implement them) was reduced for women compared to men living with HIV. A French study also found that workplace participation was reduced for those with lower levels of education compared to their better educated counterparts (Dray-Spira, Gueguen et al. 2007).

For those HIV positive people able to remain in work, studies have identified employment as a significant factor in improved quality of life (Blalock, McDaniel et al. 2002; Worthington and Krentz 2005). Conyers found that participants who returned to employment following involvement in a return to work (RTW) programme reported improved financial status, a sense of having overcome the debilitation that an HIV diagnosis represented, increased independence, improved social interaction and improved subjective health status (Conyers 2004). Studies have also found health-related improvements on objective measures. Dray-Spira and colleagues found that permanent employment was more protective against the risk of hospitalisation than temporary employment (Dray-Spira, Gueguen et al. 2005). Van Gorp and colleagues reported lower levels of depression for participants in their study upon commencement of employment (van Gorp, Rabkin et al. 2007). Mwaria found that HIV

positive women working longer hours (or having young children to care for) were more likely to engage in health promoting behaviours, particularly desistance from harmful substance misuse (Mwaria 2008). Two papers by Braveman and colleagues also highlighted the importance of maintaining an identity as a 'worker' for the occupational competence of gay men with HIV (Braveman, Helfrich et al. 2003; Braveman, Kielhofner et al. 2006).

A small number of studies have examined the role of work in the lives of HIV positive people. Two qualitative studies identified the following as significant: efforts to maximise health and longevity of functioning, emotional and financial stability, providing a distraction, feeling productive and independent and having a sense of purpose. Work was therefore regarded as an important source of self-identity and self-esteem (Campbell 1999; McReynolds 2001). Maguire and colleagues proposed a comprehensive model for understanding the employment experiences of people living with HIV, theorising the linkages between community factors (e.g. access to benefits, childcare), health issues (e.g. physical symptoms, medication side-effects) and employment (e.g. skills, job scarcity). They further examine how this relates to individual internal factors such as response to stressors and adaptability. They suggest that their model can help develop understanding of the unique interactions relevant to the employment experiences of HIV positive people and that it may be of use in informing needs assessments and interventions aiming to support individuals to obtain positive employment outcomes (Maguire, McNally et al. 2008).

Studies have also identified factors of concern to HIV positive people in maintaining their employment. Vetter and Donnelly's review of the literature on the major medical, psychological and psychosocial issues related to living long-term with HIV, identified the following as concerns: the physical demands of work, uncertainty about disease progression, feared loss of medical benefits to cover treatment costs (more relevant in the US), concerns about accommodations (or reasonable adjustments) in the workplace and fear of stigmatisation and discrimination (Vetter and Donnelly 2006). Baker examined factors related to job satisfaction among HIV positive participants, proposing a 'biopsychosocial' model examining the inter-relationships between physical health, psychological adjustment and work support/environment. Perceived supervisor support and workplace discrimination were significant factors predicting level of satisfaction (Baker 2005). Studies have also identified the importance of a gay-affirming organisational culture within the workplace for HIV positive gay men and the preferences of HIV positive people for confidentiality and non-discrimination policies as the most highly prioritised human resource issues (Brackmann 2003; Fulford and Rothman 2007). One interesting study examined the needs of a group of HIV positive women working in HIV service organisations. Personal stresses (e.g. the demands of caring for children and partners who may also be HIV positive) and the stresses of working in hard-pressed HIV service organisations offered significant challenges and contradictions (Poindexter 2006).

A further issue of interest has been the issue of disclosure of HIV positive status at work. Dray-Spira and colleagues reported that 70.1% of respondents in their study had not disclosed their HIV status at work (Dray-Spira, Lert et al. 2007). Reasons for non (or limited) disclosure were identified in a paper by Fesko as a preference for privacy, perceptions about the nature of the work environment and fear of possible consequences. Conversely, disclosure was related to the desire to explain work-related choices upon recruitment, accounting for changes in workplace performance and to ask for accommodations (reasonable adjustments) (Fesko 2001). In Simoni and colleagues' study of disclosure among HIV positive gay men, 35% had disclosed to their employer. Factors associated with disclosure were: being European American, having been diagnosed for more than 4 years, having had HIV-related symptoms, being open about their sexuality at work, and having a gay or bisexual

employer. Fears about a negative response to disclosure were not generally borne out in the experiences of men who had disclosed (Simoni, Mason et al. 1997).

Related to the issue of disclosure, the issue of HIV-related discrimination has also received some attention. Ortloff compared perceptions of discrimination among people living with HIV in healthcare versus employment, finding that gay men living with HIV perceived greater levels of discrimination in employment (Ortloff 1996). Dray-Spira and colleagues found reported rates of HIV-related discrimination at work of 11.9% and 9.2% among respondents recruited from HIV clinics in two regions of France (Dray-Spira, Lert et al. 2003). A subsequent study found that discrimination was significantly associated with job loss among those in their sample with the lowest educational attainment. The authors conclude that HIV discrimination at work may operate in a socially differentiated manner, i.e. by increasing workplace inequalities (Dray-Spira, Gueguen et al. 2008).

Studies have also examined factors associated with withdrawal from the labour market among people living with HIV. Research has identified that psychosocial problems (e.g. stress, depression, anxiety) were more explanatory than physical health-related reasons (Ezzy, de Visser et al. 1999; Vitry-Henry, Penalba et al. 1999). Dray-Spira and colleagues reported that the following factors were associated with job loss among their sample within a 2.5 year follow up: female gender, non-permanent job, poor accommodation, adverse virological indicators, chronic co-morbidity and hospitalisation in the preceding six months. They conclude that the risk of job loss is higher among women and people experiencing adverse socio-economic conditions (Dray-Spira, Persoz et al. 2006).

In the UK, the Disability Discrimination Act 2005 (DDA) is designed to protect people living with HIV from workplace discrimination. However, this rapid review identified no British studies examining its use to combat HIV-related discrimination in the workplace. Conyers and colleagues examined data from a large US database (the Equal Employment Opportunity Commission's Integrated Mission System), which documents complaints registered in relation to the American's with Disabilities Act 1990. They sought to document the rate of HIV-related employment complaints filed and contrast this with cases brought by Americans with all other physical, sensory, or neurological impairments. The most significant issue of complaint for both groups was being discharged from employment, which the HIV positive complainants reported to a higher degree (37% vs. 30%). Complainants in HIV-related cases were more likely to be male, with an ethnic minority background, aged 25-44, in white collar jobs and to work for businesses with 15 to 100 employees. A higher proportion of the HIV-related allegations were found to have merit by the Commission (32% vs. 22%) (Conyers, Boomer et al. 2005). Slack examined the extent to which informal organisational behaviour can interfere with policy intentions to outlaw discriminatory practice. He concluded that perceptions about the individual employee as co-operative or a 'trouble-maker', manager attitudes and the prioritisation of the profit motive above other concerns were significant barriers (Slack 2001).

The DDA is also the legislation that enshrines a legal right for disabled people, including those living with HIV, to ask for reasonable adjustments at work. Again, no UK studies were found reporting on this. However, one French study found that overall, 8.5% of their sample had obtained workplace adjustments and this increased to 22.1% among those who had disclosed their HIV status to a superior. The most frequently reported adjustments were alleviation of work demands (54.9%), changing to another position (37.4%), or part-time hours (16.2%) (Dray-Spira, Lert et al. 2007).

We were also interested in the nature of services and interventions made available to people living with HIV to support their employment. At the literature sifting stage, a number of studies were identified that examined the impact and nature of RTW services. However, our focus was on the needs of people in

employment. Vetter and Donnelly's review primarily concentrates on RTW programmes but notes the importance of post-employment access to counselling and services and further research on the needs of asymptomatic individuals, ethnically diverse groups and female populations (Vetter and Donnelly 2006). Werth and colleagues examined the role that counselling psychology might play in supporting HIV positive people with employment issues. They note a significant lack of research on interventions but highlight the potential role of social support (particularly from within the LGBT community for gay men) and initiatives to enhance 'career efficacy', designed to enable participants to overcome barriers regarding employment with a realistic understanding of the issues that people living with HIV face. Supporting clients to make complaints about discriminatory practice where experienced was also cited (Werth, Borges et al. 2008).

## Conclusions

Overall, on the basis of this rapid literature review, we can tentatively conclude that there has been a dearth of research examining the employment experiences of HIV positive people in employment, particularly in the UK. Findings from other countries may also have limited transferability to the UK context. However, we can identify some key themes emerging from the literature. Firstly, that the effectiveness of medical intervention has a profound effect on the ability of HIV positive people to work. However, employment opportunities are likely to be mediated by individual demographic factors and health and socio-economic inequalities. Understanding the interrelationships between individual and structural factors is necessary to give a full account of the employment experiences of people living with HIV. This means also paying attention to what HIV positive people themselves have to say about their concerns. However, in general terms, being employed translates to better quality of life outcomes for HIV positive people, and employment has a central and significant meaning for their self-concept. Issues of disclosure and discrimination remain central concerns but there is a lack of UK evidence about whether and how HIV positive people are using the legal remedies available to them through the DDA to combat discriminatory treatment. While research has investigated how HIV positive people can be supported into work, there is little to guide policy makers as to the experiences and needs of HIV positive people when in work. In the following chapters, we present original findings from a UK-based study examining these issues.

## Focus Groups

### Sample Description

In total five focus groups were run, involving 38 participants: 13 females and 25 males. The sample was evenly divided between participants in the gay or bisexual men's groups and those in the black African groups. Table 1 details the location and number of participants in each group.

Table 1: Focus Group Location and Participant Numbers

| Location   | Eligibility                 | No of Participants | Male | Female |
|------------|-----------------------------|--------------------|------|--------|
| Luton      | Black African men and women | 10                 | 4    | 6      |
| Manchester | Gay and bisexual men        | 10                 | 10   | 0      |
| London     | Gay and bisexual men        | 9                  | 9    | 0      |
| Glasgow    | Black African men and women | 5                  | 2    | 3      |

|        |                     |    |    |    |
|--------|---------------------|----|----|----|
| London | Black African women | 4  | 0  | 4  |
| Total  |                     | 38 | 25 | 13 |

Participants were asked to complete a brief questionnaire (see Appendix 6) to gather demographic data and in order to describe the focus group sample. They ranged in age from 26 to 55. The modal (most frequently reported) age was 46 (n=5).

All of the gay or bisexual men were white (n=19) and born in the UK, with the exception of two men who were born in Australia. All of the participants in the black African groups described themselves as black African, except one participant who described themselves as 'black other'. The following countries of origin were reported by participants in the black African groups: Zimbabwe, Zambia, Malawi, Burundi, Nigeria and Uganda.

Most participants were working full-time (n=29) and nine were working part-time.<sup>2</sup> When asked to classify their job, the results were as follows: Professional (n=16), Managerial & Technical (n=7), Skilled Non-Manual (n=1), Skilled Manual (n=8), Partly Skilled (n=3) Unskilled (n=1). Participants were also asked to report their highest educational qualification. The results were as follows: post graduate (n=11), degree or equivalent (n=9), higher education (n=7), GCE A Level or equivalent (n=6), GCSEs equivalent (n=3), other (n=1).

Table 2 presents data on other variables. It shows the range for each response and where appropriate, the average or modal (most common) response. It indicates that there was some variation in income but the largest proportion reported an income of between £10,000 and £19,999. This is lower than the national average (£26,020) but this is likely to be accounted for by the part-time workers within the group (Office for National Statistics 2008). Most had only had one employer in the last three years and the most commonly reported working pattern was a 40-hour week. There was some significant variation on when participants had begun their employment with their current employer, ranging from 1983 to 2008. There was also wide variation on when participants had been diagnosed with HIV, ranging from 1986 to 2008; however, the most common response was to report diagnosis in either 2001 or 2002. Ten participants had not started ART. Of those who had, the most common responses were to report starting ART in 2007 or 2008. Reporting of sick days and clinic attendance was 'skewed' by two individuals who had experienced significant periods of illness lasting some months requiring hospitalisation. In each case, the largest proportion of participants reported that they had had no days off sick, no sickness days related to HIV and no days absent for HIV clinic attendance.

Table 2: Focus Group Participants – Questionnaire Data

| Variable                  | Range                  | Modal Value              | Average |
|---------------------------|------------------------|--------------------------|---------|
| Income                    | £9,999 or < - £60,000+ | £10,000 – £19,999 (n=10) |         |
| Employers In Last 3 Years | 1-6                    | 1 (n=20)                 |         |

<sup>2</sup>Where figures do not sum to total number of participants (n=38), this is due to missing data.

|  |                          |                                    |         |
|--|--------------------------|------------------------------------|---------|
| Contracted No of Hours   | 8-44 hours               | 40 (n=11)                          |         |
| Year of Current Employment   | 1983 - 2008              | 2008 (n=8)                         |         |
| Year of diagnosis with HIV   | 1986 - 2008              | 2001 (n=5) 2002 (n=5) <sup>a</sup> |         |
| Year of starting ART   | 1995 – 2008 <sup>b</sup> | 2007 (n=5) 2008 (n=5) <sup>c</sup> |         |
| Sickness Days  | 0-183                    | 0 (n=12)                           | 22 days |
| HIV Sickness Days  | 0-183                    | 0 (n=24)                           | 19 days |
| HIV Clinic Days  | 0-120                    | 0 (n=16)                           | 7 days  |
| a – There were two modal values.<br>b – 10 participants had not started ART<br>c – There were two modal values |                          |                                    |         |

We can conclude that we were able to recruit a diverse group of people to take part in the focus groups, with a good representation of both gay and bisexual men and black Africans, as well as part-time workers versus full-time workers. Most regarded themselves as in professional, technical or skilled non-manual jobs but manual workers were well represented. Over half were educated to degree level or above.

There were lower numbers of black African men relative to women, but we were able to include men in both of the mixed sex groups for black Africans. It is regrettable that all of the gay or bisexual men were white, and the qualitative employment experiences of gay and bisexual men from black and minority ethnic backgrounds remains an issue for further study. There was a fairly even distribution as to when participants had been diagnosed with HIV; however, starting treatment fairly recently (within the last two years) was a common feature of the sample. Overall, we can be confident that the qualitative findings represent a relatively diverse range of opinion and experience within the two target groups of interest.

### Key Themes

The focus groups were positive and constructive generating a wide range of issues for discussion. Here we have chosen to focus upon a limited number of key themes to illuminate the dominant concerns and experiences that participants reported.

### Diagnosis

We were keen to explore whether and how being HIV positive impacted upon participants' employment. It was readily apparent that where there was an impact; there were two key 'flash-points': initial diagnosis and when starting or changing medication. Participants understood that the meaning of an HIV positive diagnosis had changed significantly over time with the advent of effective medical treatment but those who had been diagnosed before the availability of ART recalled their experience of coming to terms with diagnosis.

*Initially, it was very hard to consider going to work because I didn't know anybody that was positive in 1986, and of course that diagnosis then was that you were dead in two years probably, so I was really grappling with not just 'oh well it's a chronic illness'; I thought actually I'm going to be dead by 30, that's what I was thinking, you know. So it was a slightly different thought process than I think I would have today. (Gay and Bisexual Men's Group, London)*

Although it was recognised that the development of ART had dramatically improved the life-expectancy and working capacity of people living with HIV, the impact of initial diagnosis was still generally one of shock, disorientation and emotional upheaval.

*It has changed a lot. At first it feels like a shock, what is happening? You go through a period whereby later on you accept it...I don't feel anything any more, but the first few months was like oh no, how do [other] people feel, how dreadful! (African Men and Women's Group, Glasgow)*

*Even just to get your head round it. You've got to accept it yourself. As well as the being poorly, being ill I didn't know anything about HIV, I thought that's it, I'm dying. (Gay and Bisexual Men's Group, Manchester)*

Most participants reported that the emotional upheaval caused by diagnosis was lessened over time as they learned more about the condition and adjusted. However, the period of initial diagnosis sometimes caused difficulties at work. Anxiety and depression, absent-mindedness, lack of concentration and motivation were reported, leading a small number to question the role of employment in their lives.

*I think you're so consumed with the diagnosis that you kind of drift your way through work for a while... I think you do have a period of putting the job on hold as you go through the motions. (Gay and Bisexual Men's Group, London)*

*Well the first time I informed HR I basically told them to stuff it, I didn't want it. I was just newly diagnosed and I was unhappy, I was angry with the world and so I told her well I don't want your job, I don't want your 48 hours a week any more, I don't need it, you can have it. (African Women's Group, London)*

Interestingly, though this was not universally the case. One black African woman explained that for her, the process of coming to the UK, taking care of her family, finding housing and employment put such demands upon her that being diagnosed took a less central place in her life. Some of the gay and bisexual men also explained that they compartmentalised their lives as a coping mechanism so that work could become a kind of refuge; a place where they could concentrate on the demands of the working day and be distracted from the emotional turmoil.

*I've always had other things to think about. When I first came into this country there were issues with immigration and issues with not having a job, and you know, just loads of other issues so my HIV diagnosis slipped right to the bottom, and to be honest, I never got the chance to sit there and worry about it. There were so many other things that were much more important, oh you know, accommodation and just a whole load of things. (African Women's Group, London)*

*I've got a job to do and I've got to meet targets and so on and so forth. My personal life is completely different, I've got that time to think about it but having that kind of balance there for work that's allowed me to keep some perspective on things, so it's helped me. But it isn't denial. It's just my life; I have to work to pay bills, as everyone does, so it's been a good thing really. (Gay and Bisexual Men's Group, Manchester)*

In a small number of cases, participants had sought a brief absence from work to enable them to cope with their feelings but this was not the predominant pattern. Generally, participants had sought to carry on as usual, albeit recognising with hindsight that some impact on their work for the period of

adjustment was inevitable. Ultimately, pragmatic concerns such as the need to earn a living, meet professional obligations and maintain a job or career had to be accommodated.

*Yes, I think it throws up everything in your life of course but the one thing you have to do is to keep going to work. (Gay and Bisexual Men's Group, London)*

Not all of the participants had begun taking ART and of those who had, not all experienced side-effects. However, those who had experienced problems explained that while side-effects were often short-term in nature, they could be seriously disruptive when starting treatment or when treatment regimes were changed. Participants described the effects of disrupted sleeping patterns and fatigue and how they coped with side-effects that were considered more socially embarrassing such as skin rashes and diarrhoea. Flexibility on the part of employers and being able to be frank about the problems with understanding colleagues was an obvious help.

*When I first started medication, I had to apologise in the meetings saying that that I may need to run for the toilet and sometimes I'd just had the need to go to the toilet just there and then and have to just leave the meeting and go away but that's eased up now quite a lot. (Gay and Bisexual Men's Group, Manchester)*

*I remember once having a conversation with my boss who was giving me some work. I actually said to him I need to go now and I left the room, he was in mid-sentence...I just said 'I can't wait' and I left him there, and when I came back he said 'are you all right'?...It depends on your boss. Mine was a very inquisitive kind of guy, he'd ask you is the medication okay and how does it work and you tell him 'oh it gives me a bloody bad tummy-ache'; you know, it depends really on the circumstances, each person's completely different. (African Women's Group, London)*

## Ongoing Impact

Clearly, initial diagnosis was a difficult time but the groups also discussed ongoing consequences for working life. Ongoing physical consequences tended to be fatigue and a decrease in physical strength, often perceived to be a medication side-effect. This was particularly noticed by the men who were doing demanding physical labour but was observed also by those in professional jobs.

*I'm actually contemplating changing my career because the lifting of heavy [objects], the oil drums, tyres and this and that, I think it's getting too much for my body...I'm actually thinking of a change at the moment, something that is lighter. (African Men and Women's Group, Luton)*

*I could do eighteen, nineteen hours, this that and the other, gym afterwards, I could do loads but now with all the medication I just haven't got the energy that I used to have, and it's not age. I don't know about you lot but I'm more tired. (Gay and Bisexual Men's Group, Manchester)*

In the black African women's group particularly, there was some discussion about the ongoing emotional impact of living with HIV. One woman reported a constant awareness of being HIV positive and a hyper-vigilance about protecting her health. Another woman noticed a loss of confidence about her performance.

*It doesn't go away, the thought that you have it and HIV's not going to go away, so it stays in your mind. It's not just the thinking, it's the doing part as well...sometimes you go into a café or something and look around you and like [you're thinking] this doesn't look too clean so you're always consciously thinking of your health all the time so that's not good. (African Women's Group)*

*I think what the HIV makes you feel sometimes, I don't know whether it's just me or with other people, it's probably a judgment of me about myself because I feel sometimes inadequate, I could be doing more. (African Women's Group)*

In some cases, participants questioned their working lives in the light of these challenges and made choices about limiting the stresses and demands of work. In some instances, they chose part-time work, changed employer to one that they perceived as more accommodating or did not seek advancement that they anticipated would add stress and pressure

*My last job prior to this one I was vice-president of [detail removed] corporation. I needed to get back into the UK and I saw myself as a chief exec, and, you know, you go through all sorts of emotional shit on diagnosis. As that has settled down, I have made a conscious decision that is not what I want to do. I don't want to put myself up there. Actually, I don't think I could deal with that amount of work, my boss works too hard... I don't think that I have the physical stamina to do that job so, yes, I have made that decision, the level I'm at is fine. (Gay and Bisexual Men's Group, London)*

In some cases, living with HIV made participants more risk averse in that they were unwilling to pursue employment changes if their current situation was one that facilitated easier management of HIV. Employers who demonstrated adherence to employment protection procedures, had personnel in place who were knowledgeable about HIV and could offer flexibility to accommodate living with HIV commanded considerable loyalty on the part of participants.

*Before I was diagnosed I was seriously thinking about moving on and trying to get redundancy and trying to get another job...but in actual fact it's quite a safe environment. You can find the right job for you, that works for you and you know all the policies are there and there's someone somewhere who knows the answers to all the questions that you're likely to have, and they're quite accommodating... I know that if I needed anything like that there wouldn't be a problem. So as far as I'm concerned I'm sticking there like glue, like a limpet. (Gay and Bisexual Men's Group, Manchester)*

There were further considerations around practical issues. Overseas travel in particular could be a problematic issue since participants perceived that certain countries required disclosure of HIV status in visa applications or banned HIV positive people from entering the country. They were concerned that they might be searched and HIV medication found in their possession if they failed to disclose. Participants also faced a dilemma in relation to travel insurance fearing that failure to disclose their HIV status might invalidate any travel insurance arranged through their employer.

*The only other kind of adjustment I've had to make is that, because of the travel ban I can't go to the States and so I've had to make excuses as to why I don't go to our office in the States. Fortunately that's about to be lifted and so I'll be able to take*

*that responsibility up but nobody's even ever mentioned it, I think they just think I don't like flying. (Gay and Bisexual Men's Group, London)*

*I've got a lot of students who go on field trips like all over the world like to Africa and different parts of Asia, and I'm expected to go with them, like a few times a year like, to sort of supervise them and for this coming academic year nobody's mentioned anything to me about the rota of field trips...I've disclosed to my managers. They don't really know what to do and they don't know how to approach me about it...I hate flying anyway so I'm not actually that bothered but, you know, I think that they're a bit concerned as to how to go forward with it. (Gay and Bisexual Men's Group, Manchester)*

However, it is important to emphasise that for most participants ongoing consequences were few, particularly if their health was maintained, there had been no treatment side effects, or these had passed, and there was sufficient flexibility in their working lives to accommodate occasional clinic visits.

*I'm used to the medication I'm taking, so I find that I actually take less time off sick than people who are actually not HIV positive. So for me at the moment it doesn't really have an impact on my work and even with my hospital appointments, I find that it doesn't really have an impact on my work. (African Men and Women's Group, Glasgow)*

*I just don't feel it's relevant to my work. My line manager knows, she knows when I'm not there where'll I'll be and that I do the job to the best of my ability and it doesn't affect my work at all. (Gay and Bisexual Men's Group, Manchester)*

## **Disclosure**

To a large degree, the subject that most extensively occupied group discussions was the issue of whether and how to disclose one's HIV positive status at work. Participants were asked about whether they chose to disclose their HIV status at the point of initial application: it is the practice of many employers in the UK to ask about long-term health conditions or disability in job application forms. The stated motivation for this is generally to assess fitness for employment and so that any reasonable adjustments required under the DDA can be made.

Some employees had joined their employer prior to learning of their HIV positive status and so any disclosure had to come later. However, the process of being asked to disclose their HIV status, even if only indirectly in the form of questions about disability or long-term health conditions, was almost universally detested by participants. Various strategies were employed for dealing with the issue, from choosing not to disclose to simply not applying for jobs where this was required.

*I'll be honest, I lie. I lie and I'll tell you the reason why I lie is because physically at the moment I feel perfectly well and if I'm in a job that doesn't require me to reveal my status, I won't. I'm a great believer that it's my choice to tell as and when. As long as I feel I'm not putting anybody in danger, I don't see why I need to. (African Women's Group, London)*

*I was going to apply for a different department and saw the form and thought sod that, I'm not, because I think it specifically asked [about HIV] and I thought no I'm not. (Gay and Bisexual Men's Group, Manchester)*

When asked what participants found objectionable about these sorts of questions on application forms, the obvious answer was that they had little faith that disclosures would not be used to discriminate against them. Participants felt that if a disclosure was going to be made, this should be done face-to-face, with someone within the organisation with whom they had a relationship of trust.

*I wouldn't disclose on the form because of discrimination so I would rather get the job and then see someone and then disclose. (African Men and Women's Group, Luton)*

*I think usually after you have created a relationship with your employer, you feel free to express whatever you want to express. You close the door, you tell him 'I'm going to tell you something that is confidential' and what you say here stays here. (African Men and Women's Group, Luton)*

However, whether done at the point of application or later, the issue of whether or not to disclose to their employers was one that each participant had to consider. In some cases, disclosure was an occupational requirement as a result of the sort of work participants were engaged in. In other instances, disclosures had been made soon after diagnosis, when participants were newly assimilating the news. Such disclosures could then be regretted and others appreciated being advised to think through the issue very carefully.

*There was a very short window of time between my diagnosis of HIV and being told that I had to go onto meds. I think along with that you get a lot of anxiety and a whole range of emotions...I actually blurted out, well I spoke to my HR manager in confidence, but I also confided in someone I thought was a friend as well as a colleague, and which turned out to kind of, you know, bite me on the bum so to speak...I think when you're in a panic situation like that you don't really think rationally. (Gay and Bisexual Men's Group, London)*

*I was diagnosed and I remember my counsellor, this health social worker who I saw to tell me my result, she said have you thought about who you're going to tell? And she said, just think hard and fast, it's entirely your decision of course but once you tell someone you can't untell them. (Gay and Bisexual Men's Group, London)*

It was common for participants to undertake a very careful type of cost-benefit analysis as to whether to disclose their HIV status at work. A wide range of factors motivated participants to disclose. In a minority of cases, participants had had extended periods of sickness which they felt they had to account for with colleagues, or were experiencing temporary negative affects on their work performance that needed to be explained.

*I was quite open about it in the end because people were saying, you know, where have you been? You know, you'd sort of fallen off the edge of the planet, and I thought about it for some time and I decided the way I would describe it was I just simply said my immune system had crashed... they pieced it together, they worked out from what I was saying that I was HIV [positive]. (Gay and Bisexual Men's Group, London)*

*I think it did affect my decision. It justified why, you know, the level of my performance was going down, because obviously it becomes noticeable, you don't concentrate as much; you've got so many other things on your mind. If you're on medication for instance you're trying to remember to take your medication, there's so many other things...for me it was, you know, fine,*

*the reason I'm constantly late or the reason my work's not up to scratch is because I have this and this is what's causing it. (African Women's Group, London)*

More commonly, disclosure facilitated the management of HIV at work with the minimum of disruption. It enabled participants to ask for flexibility or time off to attend occasional HIV clinic appointments and meant that they did not have to be disingenuous about their condition and how they were managing it.

*And then you explain to him [the employer] so that in the near future if anything happens, you're in position and you've already protected yourself by at least letting him know in advance that in the event that a,b,c happens, you say, 'Remember the other day I told you, I might not be able to make the time because of a, b, c.' (African Men and Women's Group, Luton)*

*It's easier to not have to lie about something and in terms of medication the best time for me to take my medication if I want a lie-in at the weekends means I have to have my medication at work. (Gay and Bisexual Men's Group, London)*

For others, an influencing factor might also be described as political, in the sense that they believed that the disclosure of their HIV status at work might have positive social benefits in supporting other colleagues who were struggling with decisions about whether to take an HIV test or a recent diagnosis, raising awareness about HIV among managers and colleagues and helping to challenge the stigma and misconceptions that can surround living with HIV.

*When I first got diagnosed there were issues around meeting people and the whole rejection thing and I thought if they found out they'd run a mile, so it wasn't just about my work it was my personal life as well. If I was out personally, I made a decision quite early on that I was going to be out there [at work]. I think it was almost like a bit of a political thing, I saw it as why shouldn't I? Why should I have to hide my status as a part of my life? (Gay and Bisexual Men's Group, Manchester)*

*Yes, I would love them to know because the way they take an HIV [positive] person, it's really ... when you go somewhere and people they talk about HIV, they think an HIV [positive] person is somebody who is really sick and can't do anything... So I want to tell people that I'm HIV [positive] but sometimes, as I say, you know, I just hold it. (African Men and Women's Group, Glasgow)*

There was a wide range of mediating factors that influenced participants' choices about disclosure. These can be summarised as their perception of their reputation at work, i.e. was the person well-regarded with a good work record, how long had the person been in their job and how secure was it, what type environment did they work in, could they trust that the disclosure would remain private and could they cope with a 'worst-case-scenario' if negative consequences followed?

*I had a reputation as a good worker, as a good colleague, as a good friend, as an open person, open about being gay, so this was just another little facet of who [I] was really. I had that sort of relationship with people... I didn't go to my managers I went to colleagues that I trusted but you know, in the nature of human beings, the minute you tell one person it will, with the best will in the world, get out. So for me it was a decision to not only be open but to accept that it will get around and I have to be confident about that.. (Gay and Bisexual Men's Group, London)*

*I think it was a case of using my own judgment and I think it's necessary to tell someone who is your line manager and especially if you feel that you can trust them, I think you have to use your own judgment in that situation. And I've got nothing to lose, if I had a problem with it it's only part time [work] so it's disposable to me. (Gay and Bisexual Men's Group, London)*

A particularly strong factor was participants' perceptions about the nature of their workplace. Participants came from a very wide range of occupational backgrounds with significant diversity in their working environments. However, there was a shared perception (not always borne out by experience) that certain environments, particularly those in the public sector, were more favourable ones in which to be open about one's HIV positive status. In some cases, participants had been attracted to these types of employers for that reason.

*Previously [I] worked at a very heterosexual IT environment, very macho American environment and I probably never would have done it there, but the civil service is the most right-on employer that you can find. It has to enforce every policy that the government chooses to put in place...you name it, we have a policy and a support group for it, so if you can't do it there you can't do it anywhere. (Gay and Bisexual Men's Group, London)*

*That's why I've ended up in the NHS because I think of it as being more stable. Being a hospital probably I expected them to be more understanding. I would have chosen to go to the private sector and get paid loads of money but I felt it wouldn't suit me in that sense. (African Women's Group, London)*

Having made careful considerations about the costs and benefits of disclosure, a sizable number of participants ultimately chose not to disclose. Again there were a range of factors that influenced their decision. In many cases, participants felt that their HIV status was a private matter and saw no need to disclose. One participant questioned the assumption that disclosure was inherently useful or necessary, and others described managing living with HIV in ways that did not require it.

*I'm not sure that disclosure or non-disclosure are either correct. Surely it's a matter for the individual in individual circumstances. So I just have a little bit of an issue I think with the notion that we should be moving towards disclosure in some journey of self-discovery, I don't actually think that's the case. (Gay and Bisexual Men's Group, London)*

*Unless I fall ill, then I might probably have to reveal but at the moment I've managed. So far since I've started working, juggling my appointments using my leave and all that. It has been fine. I've not also taken any days off because of illness which I think is a good thing. (African Women's Group, London)*

Those who chose not to disclose generally gave the most obvious reason; to avoid discrimination. Again, the decision whether or not to disclose was often informed by perceptions about the type of working environment. Environments that were perceived as tough, highly political, competitive, macho or homophobic were regarded as ones where disclosure was unwise, since discrimination was thought likely to follow. Indeed, in some instances superiors or human resources staff advised participants against any further disclosure. There were also certain occupations where disclosure was thought particularly unwise: healthcare, teaching, personal care work and work involving food preparation were most commonly cited. The underlying assumption appeared to be that learning that a worker in these

environments was HIV positive might raise misplaced fears amongst others about occupational exposure, since bodily contact or contact with food was involved.

*One overriding reason why I've chosen not to tell anybody is that I work in a very macho environment, I'm at a very senior level, and despite the fact that we have still on our books...an anti-HIV discrimination policy, I know that I wouldn't keep my job. (Gay and Bisexual Men's Group, London)*

*Especially the food industry, in some cases they would want, say in the bakeries, say in the abattoirs, say in the maybe the fruit and veg. I think if you're dealing with say cutting vegetables or something like that they would ask, they would want that disclosure... They might take it positively, they might take it negatively...In management we'll say maybe 50% understand, 50% might not understand. (African Men and Women's Group, Glasgow)*

A striking difference in the accounts was the fact of access to a person within the organisation that they genuinely trusted. Those who had disclosed often had a manager or other individual that they had a good relationship with and who they were confident would manage the information carefully. This was lacking in the accounts of those who did not disclose who were highly fearful about what a reaction to their disclosure would be. These contrasting accounts from two black African women illustrate the difference.

*I obviously got to know my boss on a personal level. He had his own issues and we talked to each other about them... We often went to a coffee shop across the road and I said 'we need to have a coffee' and he said to me 'oh gosh, this doesn't sound good' and I said 'no, it's fine we just need to have a coffee' and then I sort of told him over coffee. (African Women's Group, London)*

*Before I disclose my status, I would want to know what they would use that information for and how confidential would that be. And if they can promise me and say this is not going to affect my job, my well-being and things like that, then I would do that... some people might use that as a weapon to sack you or to punish you or to discriminate [against] you. So we need to be a bit careful, we need to disclose when we find it fit to disclose. (African Men and Women's Group, Glasgow)*

Those who remained in work without disclosing their HIV status faced certain problems in obtaining time off to attend occasional clinic appointments and explaining the medication they took. In many cases, participants organised their lives so that clinic appointments and medication were managed outside of work hours. In other cases, participants had sufficient existing flexibility to accommodate clinic visits, or they gave some other reason for needing to be absent.

*If I have a late appointment, I just work a few hours during the day, so like I'll do one hour extra the day before and then take it off that next day, go to my appointment and the following day then I may do an extra hour there so that I do 16 hours in a week. So that's how I work it. So long as they get 16 hours in the week, that's it. (African Women's Group, London).*

*I've got a kidney problem. Always when I say I go for an appointment or I wait for the appointment, they know that I've got that problem, the kidney problem, so I just have to say to them it's the kidney. (African Men and Women's Group, Glasgow)*

However, participants recognised that these strategies either required a flexible working environment or placed a burden of subterfuge. Those with sufficient flexibility tended to be professional and 'white-collar' workers who had a greater degree of autonomy in the management of their work. Those in more manual occupations found greater difficulty in obtaining this type of flexibility. There was a perception within one group that this affected black African people to a greater degree, particularly those who were more recently arrived in the UK and who were more likely to be engaged in less secure forms of employment.

*I get away with it partly because of my position. Nobody would dare ask me where I'm going. So they don't and actually I think they're quite relieved when I'm not in the office so I don't get questioned about it. The boss doesn't complain but I don't offer excuses, I just turn up an hour late on a Thursday morning every two months, and that's it. (Gay and Bisexual Men's Group, London)*

*What I actually noticed is most of us African people, initially when we started working here, we've always worked under agencies. The amount of time you are allowed for a break is exactly the same, it's standard, so if you come with any you know 'reasonable adjustments' or excuses, you find you don't have much room to manoeuvre. (African Men and Women's Group, Luton)*

Although the decision not to disclose at work brought a certain amount of protection from HIV related discrimination, it could also be a stressful strategy that caused some difficulties. Participants in this situation described wanting to challenge HIV-related stigma but feeling unable to withstand the discrimination that they perceived might follow.

*It's stressful, mentally; first and foremost, for me personally, it's stressful mentally because you know there is this whole stigma. Like for me at work, a couple of times you're watching TV with the residents and programmes of HIV and AIDS come on and the comments that people pass, it's like excuse me, what world do you live in! It's just the attitudes that people bring that are mentally draining. (African Men and Women's Group, Luton)*

*I must say it's the first thing in my life I felt I have had to hide, and I feel really guilty about that...I feel like I shouldn't need to [hide] but it's like everything everybody's said here in some form or other, it's that, like, rejection. (Gay and Bisexual Men's Group, Manchester)*

## **Discrimination**

Clearly, the fear of discrimination in the workplace was a fundamental factor in whether or not participants chose to disclose their HIV status at work. As noted, participants looked carefully at their work environments and made assessments as to whether the environment was one where they could be confident that discrimination would be unlikely to follow. Some participants had to accommodate misguided efforts to protect them from discrimination by colleagues in ways that were less than helpful. Managers or others could make assumptions that participants would be subjected to discrimination, which would in turn leave participants fearful and anxious.

*My boss decided that obviously because I take showers at work, no-one else would probably take a shower if they knew that I was HIV [positive]. 'Well I'm not using that toilet, he uses that', you know, so, we don't mention HIV. (Gay and Bisexual Men's Group, Manchester)*

*I went into the university's occupational health and I went to see the doctor and I told him before I told anybody...His reaction was phhhw!, writing it down. And then he said right, you don't want to tell anybody, don't tell your manager, he said, because of the nature of it. And the thing is, if I didn't know anything more about it I would have been shitting myself. But I just thought no, I'm actually, I'm going to tell my manager, and when I told her about his reaction she was like, really shocked because he should have been there to support me and actually he just put the fear of God in me. (Gay and Bisexual Men's Group, Manchester)*

A further difficulty was that participants also felt that it was often difficult to specifically define discrimination as HIV-related since the perpetrators would act in ways that would avoid them being called to account for their actions. Subtle forms of exclusion, ridicule or unequal treatment led participants to suspect that the behaviour was due to HIV discrimination but this could not always be confirmed.

*It's quite difficult to pinpoint. Obviously people tend to be very careful you know how they do things, so you wouldn't really know whether it's really down to that [HIV] or it's something else. It's really kind of borderline because they don't want to get done for it, so you haven't got any solid proof it's down to that. (African Women's Group, London)*

*I don't think things are that cut and dried at all most of the time, because I think that the world that we live in, people are more calculated about the way that they discriminate now and I think that to cover their own backs they would discriminate in a way that you weren't able to say that was because of X, Y and Z. (Gay and Bisexual Men's Group, Manchester)*

However, in other cases there were accounts where the discrimination experienced or observed was more solidly linked to HIV status in the minds of participants. This could be on the part of employers or in one case a professional body regulating registration for a particular occupation.

*It was a friend of mine. At that time I didn't think he was HIV positive and he didn't know I was HIV positive. Another friend of his found out he was HIV positive and went to management because he was asking for time off like for his appointments...but he hadn't told management why he needed the time off. Somebody else went and passed it on...when he was sacked, the excuse that they gave him why they sacked him was the lamest excuse anybody could come up with and I mean it was all because of discrimination. (African Men and Women's Group, Glasgow)*

*The [detail removed] Council...believed that my HIV status called into question my fitness to practice and that took eight months to investigate. And they have lost an employment tribunal in exactly the same situation...They told me that it was perfectly standard procedure, it had nothing to do with my HIV status and that it applied to everybody who made a health declaration. But obviously, I spoke to colleagues who made health declarations and none of them had the same issue. (Gay and Bisexual Men's Group, London)*

It was also important to recognise that participants' identities were multi-faceted and that being HIV positive was just one aspect of who they were. In both the gay and bisexual men's groups and black African groups, there was agreement that if they were to experience discrimination at work, this would more likely be for reasons of their more 'visible' identities as gay or bisexual men or black people. Obviously, the gay and bisexual men could choose whether to be open about their sexuality and most were, without experiencing anti-gay discrimination. There was a perception that social attitudes about sexual diversity had changed significantly and that for most of the gay and bisexual men, their sexual identity was unremarkable in the workplace.

*I think it depends on people's attitudes towards HIV or homosexuality. I mean I said before that I worked with dinosaurs, like older people to be politically correct, but my sexual orientation is not an issue, I've never been the brunt of any jokes and I've not experienced any kind of discrimination at all and I'm openly gay, have been since I was 17. (Gay and Bisexual Men's Group, Manchester)*

However, this was not universally the case. A small number of gay and bisexual men perceived that their work environment was such that it was advisable not to be open about their sexual identity. Others reported that they had been open about their sexual identity and experienced discrimination as a result.

*It is a very macho environment, a lot of ex-military people, including myself, work there. It is a homophobic environment... The only person that actually knows that I'm gay, actually that's not right, there are two, the HR manager and the CEO. My boss, the Chief Exec, doesn't want me to tell people...because he knows that would make my situation untenable. (Gay and Bisexual Men's Group, London)*

*I've just been bullied continuously. She [manager] was just doing checks on my work where she wasn't doing checks on anyone else, trying to find fault with what I was doing in order to end my probation and I went to the top manager about it, and the union as well and got transferred to a different team. (Gay and Bisexual Men's Group, London)*

The issue of discrimination based on ethnic identity arose in the groups with black Africans. Universally, participants in these groups reported that they had experienced treatment in the work place that they construed as racist. Primarily, this appeared to be related to forms of unequal treatment, but could also be related to ignorant or insensitive remarks.

*I have been in my organisation for about two years. During the summer holidays, some of the staff they go with the clients and kids to holiday [in] different places. But myself, so far for the past two years I was the only one, the only black woman in that organisation, all of them are whites, I've never been asked, but my team members have been going for their holidays and they like it, but they'll never ask me. (African Men and Women's Group, Glasgow)*

*Yes you get a lot of those questions. Oh God some of them! 'Oh, can you use a knife and fork, where did you learn how to use a knife and fork?' and you're thinking, you know, what sort of a question is that! But yeah, you come across it all the time. (African Women's Group, London)*

Given this context, the men and women in the black African groups appeared to perceive themselves as already disadvantaged in the labour market to some degree. For some, holding an identity as a

black person and a former immigrant meant that publicly claiming an identity as HIV positive was simply too great a risk, so that the best strategy to avoid discrimination was non-disclosure.

*I see that I'm disadvantaged already. They can't pronounce my name; I can't give them another weapon to fight me with! So, sorry, there is no need for them to know. Because as I'm applying for the job, I'm thinking I'm well enough to do the job as anybody else so the HIV doesn't come into it at that point. (African Women's Group, London)*

*Being from an ethnic background, being black, is one thing; to being from [an] ethnic background and can't communicate, that's another thing. Being from an ethnic minority and being black and having HIV, that's another problem. (African Men and Women's Group, Glasgow)*

## Reactions to Disclosure

Discussions about HIV related discrimination and the fear of it gave participants opportunities to talk about the reaction that their disclosures of HIV positive status had elicited in actuality. Some participants reflected upon the fact that what they had anticipated would be a difficult, fraught and potentially risky act turned out in practice to be something of an anti-climax. In most cases, where participants had chosen the nature and timing of the disclosure, the response received had been positive and the feared rejection and discrimination did not occur.

*I think you kind of have in your head what it will be like and how people will react and when you actually do it it's just such a big let down and nobody reacts. It's like anything isn't it, you build it up and you build it up into something that is, that is just this beast that is never, ever going to materialise. (Gay and Bisexual Men's Group, Manchester)*

*In the end people were quiet about it and they didn't go talking to other people about it and it was treated with respect...because it was open and it answered the questions, it paved the way for an acceptance that has actually proved fruitful. (Gay and Bisexual Men's Group, London)*

## Employment Protection and Reasonable Adjustments

The key piece of legislation that protects HIV positive people from discrimination in the workplace is the DDA, 2005. In simple terms, this amended the earlier 1995 Act so that people living with HIV enjoyed the protections of the Act from the moment of diagnosis. Among other provisions, they are entitled to ask their employers for 'reasonable adjustments'. These are changes made to the workplace or role that allow people to continue to do their job taking into account their disability or long-term health condition, in this case HIV. We were keen to explore with participants their level of awareness of the Act, whether they had asked for reasonable adjustments and what their employers' response had been.

We gave each person a leaflet about the DDA produced by NAT (Positively Employed) and a brief explanation about it. In the sessions we then asked for a show of hands as to how many people had heard of the Act and its main provisions. In both of the gay and bisexual men's groups, all the men said they had heard of it and understood its protections for HIV positive people. However, reaction in the groups for black Africans was more mixed; fewer participants were aware of the Act and seemed less confident in their understanding of its provisions. Of those who were aware of it, those in the black

African groups also seemed to have less confidence that it would protect them from discrimination in practice.

*I'm kind of aware but maybe I just don't take it too seriously in the sense that the practical side is when you go there, you tell them [that you need a reasonable adjustment], it's 50/50 when they say yes and they say no. So, whether it's there or not, it doesn't make me feel any more comfortable. (African Women's Group, London)*

Some participants were also disappointed that their employers were not more knowledgeable about the DDA. In some cases, employers were thought to have no knowledge at all about it or failed to understand that it offered protection for HIV positive people.

*Speaking to some of the services that we provide and, you know, people that work in other departments, the DDA applies to people in wheelchairs, it doesn't apply to people like us, because we don't have that obvious disability that you can see. (Gay and Bisexual Men's Group, Manchester)*

In other instances, participants reported blatant disregard for its provisions or implementation in ways that caused participants to feel angry, humiliated and undermined. Clumsy handling of a request for reasonable adjustment could significantly damage a participants' relationship with their employer.

*When I first informed my boss that I was HIV [positive]...when I mentioned this he said really you should have informed me of this because if we had an accident or whatever. So fair point, I said, you understand my situation, I said well, I'm covered under the DDA. And that's when he came out with 'don't come with that crap here'. (Gay and Bisexual Men's Group, Manchester)*

*Participant: It's part of the reason I think my boss is an utter bitch. I asked for flexible working and they said no...when I told them that it's under the DDA - I have to go for regular hospital appointments roughly once a quarter - they said is there any proof about that? I'm actually having to provide receipts for my boss because she's asked for them to prove that I am going.*

*Facilitator: How does that make you feel, being asked?*

*Participant: Untrusted, hence why I'm seriously considering changing employer. (Gay and Bisexual Men's Group, Manchester)*

What was also important was that the adjustments offered were ones that were negotiated with participants and not imposed upon them. The fear that participants would lose control over their working situation could act as a powerful deterrent to asking for adjustments.

*I struggle sometimes and sometimes my boss has said a reasonable adjustment is you go part-time which, for me, would freak me out because, you know, financially it would be a nightmare. (Gay and Bisexual Men's Group, Manchester)*

However, these cases were more unusual, generally the reasonable adjustments that participants required fell into several categories that were apparently fairly easy to accommodate. Participants tended to need: flexibility to accommodate occasional clinic appointments, the ability to take medication at set times, understanding that starting new treatment regimes could lead to unpleasant side effects until adjustment had taken place and in some instances a change of role or workload to accommodate fatigue.

In many cases, participants had either made use of existing flexibility within their working patterns or employers had spontaneously made arrangements, without participants having to specifically ask for 'reasonable adjustments'. Cases where employers had been proactive in seeking to understand the experience of living with HIV and in working with participants to make helpful arrangements were particularly appreciated.

*I didn't use that term exactly but I just started to work a bit more flexibly and working from home, where, I mean I have my own office at work but a lot of people work open plan and they work 9 till 5. And now I sort of go in up until 10ish or whatever and leave early if I want to...work have been fantastic about that and I would consider that a reasonable adjustment under the terms of the Act. (Gay and Bisexual Men's Group, Manchester)*

*Well they've made adjustments with the work and the workload and like there's times when I think they've probably done their research and realised that fatigue is one of the things we go through and they've come to me and said right, if you're not feeling too good, just let us know and they don't push me, so they know some days I'm really good and I can get a lot of work done and there's no problem and some days it's not. (African Women's Group, London)*

However they came about, the availability of flexible arrangements to accommodate living with HIV were regarded as essential by participants in maintaining a working life. A number of the gay and bisexual men in particular felt able to be assertive if necessary in arguing for their right to this.

*Facilitator: Okay, if that flexibility were withdrawn what would it mean for your working life?*

*Participant: Well I wouldn't be able to do the job but the reality is that I'd just sue the asses off them. (Gay and Bisexual Men's Group, London)*

*I just knew that a) they would be compassionate and friendly and accommodating, but I also knew I was going to press the buttons on them. That if they were going to get difficult about it I kept the trump card and [would] say well, you know, I've been with you for an awful long time and you have an obligation nowadays to accommodate this illness, I'm doing my best. So, I felt quite comfortable in asserting my space but in the end I was pushing an open door. (Gay and Bisexual Men's Group, London)*

Importantly, however, this was an area where those who had felt able to disclose their HIV status at work were at a considerable advantage to those who had not. Non-disclosing participants were required to manage in ways that were not always advantageous to them. This might mean, for example, having to give up annual leave to attend clinic appointments or struggling to make arrangements without being able to explain why they were necessary. One woman had previously had HIV-related cancer and found herself having to make awkward arrangements with colleagues in order to attend for treatment.

*It was very, very difficult for me to get that time off. I ended up having to ask my work colleagues, to say look, I'm unable to come in on this day, could we swap so that I'll cover you if you'll cover me, that kind of thing and even now if I need anything, I work around with my work colleagues but I don't tell them why, I just say look can we swap shifts? (African Men and Women's Group, Luton)*

*I tried to actually go through our HR department to try to find out a way of dealing with it and the advice I got was, you should talk to your manager and it's up to your manager how he deals with it. In my case I haven't told my manager so how am I going to then tell him, look I need to attend this appointment a,b,c,d? So it wasn't really helpful at all. The last resort is to take it off my holiday which I find is really unfair. (African Women's Group, London)*

## **Getting Help and Advice**

In most cases, participants were managing their condition at work using a range of strategies; making careful assessments of their working environments and using various forms of information management to reduce the likelihood that they would encounter discrimination. For most, this appeared to be a successful approach. However, we were keen to explore with participants what options they felt were open to them if, despite these careful strategies, they were to experience HIV-related harassment or discrimination. We wanted to explore whether participants perceived that there were avenues of support, advice and information open to them about issues of HIV at work.

For some participants, there was simply no one they felt they would be able to approach for help. These participants tended to be in less secure, more 'blue-collar' jobs and were sceptical about whether workplace discrimination would be effectively dealt with.

*Facilitator: If you were experiencing discrimination, would there be anybody that you could talk to about it at work to get it stopped?*

*Participant: At work? I think, no..no, they can't help you, they'll still dis-, they're free always to discriminate [against] you so why tell them? (African Men and Women, Glasgow)*

Workplaces where there were thought to be few occupational policies in place regarding diversity issues and HIV in particular or where there was a lack of specialist human resources staff inspired lack of confidence among participants that HIV-related discrimination would be properly dealt with.

*I mean there might be forty, fifty people work at our place but there's no HR department. The sole purpose of [company name removed] is purely for profit, anything else really is a hindrance. So everything else is just dealt with on a whim. (Gay and Bisexual Men's Group, Manchester)*

However, this was not universally the case. Where participants understood that there were procedures and policies in place to deal with workplace discrimination, including that based on HIV or disability, most were confident that HIV-related discrimination would be properly dealt with. Participants tended to describe a fairly traditional 'chain of command' that operated in their workplace that they would use to address workplace grievances, including those related to HIV-related discrimination. In the first instance

the line manager and next-level manager would be approached. If this proved unsuccessful, human resources/personnel department and occupational health staff would then be approached where in place. Generally, participants had an expectation that line managers would be competent to take action should discrimination occur.

*If work knew about my status I'd feel fairly comfortable to think that something would be done about it, it would certainly be addressed to kind of stop the situation occurring, if a situation did occur. (Gay and Bisexual Men's Group, Manchester)*

*I'd have gone to the manager, who is expected to be open-minded about such things, so I expect her to deal with me when I come with such a problem. (African Men and Women's Group, Luton)*

However, using the 'chain of command' could be problematic if the participant had a difficult relationship or feared disclosing their HIV status to someone in the chain or did not trust that they would handle the matter competently or sympathetically.

*I wouldn't go to the head of department because he's a bastard anyway; I'd just go straight to the union or whatever. (Gay and Bisexual Men's Group, Manchester)*

We were interested to explore what other avenues of support and advice participants felt would be open to them if the 'chain of command' proved inaccessible or ineffective. One avenue mentioned by several participants was human resources/personnel units and occupational health departments. Some participants felt positive about approaching staff in these units or had positive experiences of doing so in practice. However, participants also discussed less than helpful responses. This might include making participants fearful about the consequences of others finding out their HIV status or insisting that participants had to follow the 'chain of command' when asking for reasonable adjustments, which meant disclosing to their manager whether they were comfortable to do so or not. Participants were especially angry about careless handling of personal health-related information that would, at worst disclose the persons' HIV status outright, or release enough information to raise difficult questions for participants with managers and colleagues.

*I was in with the [occupational health] doctor who did the assessment for less than five minutes, she said 'oh I've got diabetes' and we had a chat about chronic diseases and that was that. She ticked the box yes, capable of doing the job. (Gay and Bisexual Men's Group, London)*

*I've been to occupational health and I burnt myself because it was before I told the Headteacher and he specifically said to them that I didn't want them to contact the school...and then today I received an email that was addressed to the Administrator, not even to the Head...And the Head dealt with it quite well, he had to call in the Administrator and say well it's none of your business, you don't have to know and it's confidential and you are not to tell anybody and then warned her that if she did then she would face action. It was the fact that occupational health totally went against what I'd asked them to do. (Gay and Bisexual Men's Group, Manchester)*

We also asked about other forms of support and advice such as professional bodies and trade unions. Interestingly, those in the groups for black Africans appeared to show greater confidence in trade

unions as a potential source of support. However, participants in both the Gay and Bisexual Men's Groups and groups for black Africans clearly expressed the view that community-based HIV organisations were very important to them and a preferred source of information and advice concerning issues related to HIV and the workplace.

*It's helpful anyway when you've got your own union as well. Because they will help you and you know they will talk to who you're working with because they will be scared of doing such things to you when you're at work that you've got a union in there. They'll be there for you. So I would go to the union. (African Men and Women's Group, Luton)*

*The HR department is just absolutely incompetent, to be fair...so I don't have much confidence and faith in them. I'd much prefer to come to something like GHT [George House Trust] and get their advice and sort of impetus and see what they could do to help. (Gay and Bisexual Men's Group, Manchester)*

It was also the case that participants had employment-related needs beyond the fact of the living with HIV or any discrimination that they might face. As people managing often demanding jobs and making complex career decisions, they needed careers advice and information that was not simply confined to managing their condition at work. In this example, one of the women explains about feeling trapped in her career and wishing that there were other options available.

*To some extent I felt as though I've had a limited choice because immediately I graduated I started in housing as a short-term thing but I found it almost dictated everywhere I went because that's the experience you have, so they don't care about your economics degree, you know, you are a resettlement worker so you kind of end up being limited in that way. You're growing older, you're spending two or three years here, four years there, you know. You say well, can I not do something different? (African Women's Group, London)*

## **Positive Changes**

We also asked participants what positive changes could be made to facilitate their employment as HIV positive people. As noted, they regarded flexibility on the part of the employer as essential in enabling them to manage their HIV treatment, attend their clinic appointments and accommodate the demands that living with HIV could in some cases place upon them physically. They also needed to know that their employer had anti HIV-discrimination policies in place and staff who were equipped and willing to implement them if necessary. Beyond this, participants called for a greater general level of awareness about the realities of living with HIV. There was a consensus that public perceptions had not kept pace with the changes that ART had made possible for HIV positive people and that a better understanding would help to challenge the stigma that many saw as remaining, including in the workplace.

*I think the issue itself kind of needs a bit more visibility because I think there is a degree of mysticism about HIV itself in many workplaces...In the 80s you had the big tombstone adverts and then, you know, in the 90s you had Mark from Eastenders with HIV and that's the only visibility. I'm not really sure that there is a lot of attention drawn to HIV now. I know it's a lot more manageable now, you've got meds and it's not perceived as a life sentence or anything. (Gay and Bisexual Men's Group, London)*

Some participants therefore saw the value of workplace information and education campaigns that would dispel the misinformation that persisted about the condition and challenge discriminatory attitudes. They looked forward to a time when living with HIV would be normalised as a long-term, manageable condition and divested of the negative stereotypes and stigma that they perceived still surrounded it.

*The more employers and fellow employees are educated about HIV, that obviously makes them a bit more sympathetic, and you know, more acknowledging of the fact that, 'oh my colleague over there has to pop round the corner every so often because she's got tablets to take'. It would have a really big impact where I don't have to worry about someone seeing me knocking back my pills without raising an eyebrow. I think that for me would be one of the best things that can happen in the workplace. (African Women's Group, London)*

## Getting On With It

Despite the challenges, the participants in this study were making pragmatic arrangements to manage their condition and remain in employment, in many cases with support and flexibility provided by their employers. They expressed a quiet sense of pride that they had managed to face the significant life challenge that an HIV diagnosis represented and continue a productive working life: remaining in work was not only an economic necessity but a source of self-worth. There were different approaches and decisions made, particularly about disclosure. However, what they seemed to share was the conviction that living with HIV was only part of their life and did not entirely define who they were as people or as workers.

*In a funny kind of way I'm completely easy about it and I think the fact that I just go about my daily life in the same way as everybody else is probably a very good thing. (Gay and Bisexual Men's Group, London)*

*This [HIV] is what I have and yes it's a part of my life, but where I'm sitting, to say a small part of my life might be a bit, what's the word, insulting, because for other people it's a big part of their life but for me it's a part of my life but it doesn't rule my whole life. I just get on with it and I think that part of it has rubbed off onto everybody else that I've told and they've learned to deal with it in the same way. (African Women's Group, London)*

## Conclusions

Here we have presented qualitative material from a series of focus groups with gay and bisexual men and black African men and women in London, Manchester, Luton and Glasgow. As noted, we can be confident that we were able to include a range of professions and employment sectors across the two groups of interest. However, there remains scope to explore the employment experiences of gay and bisexual men from black and minority ethnic backgrounds.

While it is important not to overlook the differences, what is most striking about the findings are the points of similarity between the two groups. The experience of being a worker with a history of migration was an important distinction, as was the way in which discrimination functioned differently for the gay and bisexual white men and black African people in this study. However, there were many other ways in which the experiences and perceptions shared by participants in each group were paralleled.

Being diagnosed with a long-term condition such as HIV is necessarily a significant life-event. There were individuals within the groups who had been diagnosed many years ago when the prognosis was considerably more bleak than it is today with the introduction of ART. However, most participants were diagnosed after the introduction of ART. A clear theme was that diagnosis remained a time of shock and distress when participants needed an opportunity to adjust and come to terms with the information. This could have consequences for employment: some participants saw work as a 'haven' where they could be distracted by the demands and routine that it provided; others needed a short period of leave to come to terms with the maelstrom of emotions and decisions. However, the participants in these groups all returned to work and the automatic assumption that people living with HIV will by necessity give up work appears to be a thing of the past.

Where participants were able to disclose being diagnosed to their employers, relatively simple measures and a compassionate approach were helpful. It is important to emphasise that on the whole, participants in this study did adjust over time and continued their working lives.

Related to this is the issue of medication. Not everyone in the groups was taking ART, and not everyone began taking it upon diagnosis. However, the fact remains that for those taking it, ART is life-saving treatment and strict compliance with the recommended regime is essential. Often this required nothing more than being able to take medication at a regular time, sometimes with food; very simple accommodations facilitated this.

Not all participants taking ART experienced side-effects and those who did generally said that they often lasted for relatively short periods. However, employers needed to understand that beginning or changing a treatment regime could cause fatigue and other more socially embarrassing side effects such as skin rashes and severe diarrhoea. Again, an understanding approach and simple adjustments could help. Short-term changes to workload, working hours or tasks and/or short periods of working at home or facilitating easy access to toilet facilities were thought useful. Sensitivity and understanding on the part of colleagues and managers helped participants to cope until the side effects abated.

Most participants adjusted to the HIV diagnosis and the demands of ART (for those taking it) with little subsequent impact on their working life. However, others reviewed their employment and concluded that they wanted their working lives to be less stressful and demanding. In some cases they chose part-time work, did not pursue further progression or requested simple changes in order to accommodate living with a long-term health condition. In such cases, it was important for employers to respect the employees' wishes as far as practicable and to recognise that their needs may change over time along with their circumstances.

With the exception of certain medical professionals, disclosure of one's HIV status at work remains an entirely personal choice. As the findings showed, participants made very careful assessments of their workplaces and the costs and benefits of doing so. There were two key reasons why participants chose not to disclose: because they had no need to and/or because they feared HIV-related discrimination. Although the choice is a personal one, in order to request the 'reasonable adjustments' that HIV positive people are entitled to by the terms of the DDA 2005, a person must by necessity disclose a disability under the terms of the Act. In many cases, participants' jobs had sufficient flexibility to accommodate living with HIV and they saw no benefit to disclosure. However, if this was not the case, feeling unable to disclose could be problematic and these participants were disadvantaged as a result – having to use their annual leave or accumulating sickness absence to attend clinic appointments for example.

In 2008, with the protection of the DDA 2005, no HIV positive person should fear discrimination at work. So why did some respondents not feel protected? Either because they didn't know about the DDA 2005 or didn't trust that it would in fact protect them. The black African participants seemed especially vulnerable in this respect. Being black and an immigrant was felt to be disadvantageous enough where there was a threat of racism and xenophobia at work; declaring a further stigmatised identity by being open about one's HIV status was thought to be too much of a burden. These workers seemed more often to be in 'blue-collar' jobs with fewer opportunities to access information about their employment rights and how to enforce them. Interestingly, there seemed real scope for work with trade unions as a potentially trusted source to encourage them to bring the message to HIV positive workers that the DDA 2005 is there to protect them. Participants appeared to need to know not only about the provisions of the DDA 2005 itself but also how it is actually being used in practice to protect people from discrimination. There appeared to be a need to identify cases being brought and to highlight them as examples of anti-discrimination law in action.

Moreover, HIV community organisations were highly-regarded as the preferred source of information and advice for both the gay and bisexual men and black Africans. In a small number of instances, it appeared from participants' accounts that some employers were flouting the law by failing to respond to requests for reasonable adjustments. This would suggest that building capacity among HIV support organisations to enable HIV positive people to enforce their rights at work would be advantageous.

When participants did feel able to disclose their HIV status at work, this was often because they perceived that their workplace environment was a receptive one and there was a positive relationship with colleagues and/or a line manager. They expected their manager to know how to respond sensitively and appropriately and that the information would be handled in a professional manner. Above all, they wanted to be involved in decisions about onward disclosure and were angry when staff did not handle the information about their HIV status carefully. This has particular implications for the training of managers and other staff about how best to respond to a disclosure, including the need to involve and consult the person concerned where onward disclosure would be beneficial. In addition, the study suggested that participants needed a range of mechanisms by which they could disclose their HIV status and ask for reasonable adjustments if they needed them. Some participants simply did not trust their immediate line manager and inflexible insistence on using the 'chain of command' could be unhelpful. Interestingly, while there were unprofessional practices reported, respondents who had disclosed in a careful and considered way were generally met with a positive response. The concerns that they sometimes had in advance were often not realised in actuality. This is important to communicate to other HIV positive people who may be unnecessarily fearful.

However, it is important not to downplay the instances of discrimination that were reported. In some cases incidents appeared to be clearly and obviously linked to HIV status. However, it was important to note that discrimination as gay and bisexual men and as black people was also reported. This highlighted the multi-faceted nature of participants' identities and it is important to note that perpetrators of discrimination were rarely thought to operate in obvious ways that would provoke a disciplinary response. Participants perceived that HIV-related discrimination could be quite subtle and difficult to identify as purely HIV-related.

We asked participants what positive changes would make the most difference to them as HIV positive workers. As discussed, flexibility at work was crucial, but they also wanted a changed social environment at work. One the biggest barriers that still remained was stigmatising attitudes and outdated perceptions about living with HIV. In some instances perhaps, the fears that participants had that they would inevitably face discrimination were greater than experience demonstrated to be the

case. However, until such time as HIV positive people *feel* their workplaces to be accepting environments, such fears are understandable.

In conclusion, a clear overriding impression was left after conducting the focus groups with these men and women, whose backgrounds and working experiences were in reality often very different in spite of their shared HIV status. Overall, the impression left was that they and their employers (if aware of their HIV status) were simply 'getting on with it', finding flexible solutions to any challenges that living with HIV posed and getting the job done.

## Online Questionnaire Survey

### Eligibility

A total of 15,861 men responded to the online questionnaire. As noted, we sought to include in the analysis reported here only respondents who were employed, over 18, living in the UK, described themselves as gay or bisexual and who knew their HIV status according to their most recent HIV test (see the methods section of the report for details of exclusions). The majority of exclusions were due to non-disclosure of HIV status (n=4,274). The eligible sample was 8,369 respondents.

We asked respondents to report the result of their last HIV test and when the test was taken. Almost half of the sample had taken an HIV test in the last 12 months (48.3%) (see Table 3). Just over a fifth (1,830, 21.9%) reported that they were HIV positive (see Table 4).

Table 3: Date of Last HIV Test

|       |                      | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------|----------------------|-----------|---------|---------------|--------------------|
| Valid | Yes - Last 12 Months | 4042      | 48.3    | 48.3          | 48.3               |
|       | Yes - 1-2 Years      | 1598      | 19.1    | 19.1          | 67.4               |
|       | Yes - 2 Years Plus   | 2729      | 32.6    | 32.6          | 100.0              |
|       | Total                | 8369      | 100.0   | 100.0         |                    |

Table 4: Results of Last HIV Test

|       |              | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------|--------------|-----------|---------|---------------|--------------------|
| Valid | HIV Positive | 1830      | 21.9    | 21.9          | 21.9               |
|       | HIV Negative | 6539      | 78.1    | 78.1          | 100.0              |
|       | Total        | 8369      | 100.0   | 100.0         |                    |

### Comparing the Sample

An important question is how comparable are these respondents to gay and bisexual men in the UK more generally? There is currently no known random sample of homosexually active men in the UK with which we could compare. However, the National Surveys of Sexual Attitudes and Lifestyles (NATSAL) are stratified probability sample surveys of the general population resident in Britain (Mercer, Fenton et al. 2004). NATSAL is often referred to as presenting a good indicator of the size and demographic profile of homosexually active men in the UK (Macdonald, Dougan et al. 2004; Mercer, Fenton et al. 2004). We elected to conduct an online survey of Gaydar users since there is some indication that samples generated by this method are broadly comparable to NATSAL. Evans, et al, compared their self-selected online convenience sample to the NATSAL sample for homosexually active men aged 18-44 living in England, Wales and Scotland. They concluded that online samples can be recruited that are broadly similar to those from NATSAL in demographic terms (with some overestimation of sexual risk taking)(Evans, Wiggins et al. 2007).

The present study used a very similar method and source of recruitment to Evans, et al. However, our sample excludes those who were unemployed or solely students. In Table 5 we present data on demographic variables for respondents aged 18-44 living in England, Wales and Scotland alongside those reported by Evans, et al in their comparison with the NATSAL sample. It is important to note that even small variations in question wording can affect response so that the studies are not directly comparable and any conclusions can only be tentative.

The respondents for the present study appeared considerably more likely to have attained a degree or equivalent qualification. However, this is likely to be accounted for by the fact that we excluded the unemployed and those whose sole occupation was student. On the remaining variables (mean age, White ethnicity, occupational class, country of residence, living/working in an urban area, living in London and reported health status) the variation between the sample in this study and both Evans, et al and NATSAL are small – no more than ten percentage points in each case. With the caveats outlined, this would suggest that in important respects, our sample was broadly comparable to both the Evans sample and NATSAL.

Table 5: Demographic Characteristics of All Respondents Aged 18-44 Living in England, Wales or Scotland Compared with Those of Homosexually Active Men in an Online Sample and a National Probability Study<sup>a</sup>

|  | Present Study<br>(n=6108) |         | (Evans, Wiggins et al.<br>2007)(n=2065) <sup>c</sup> |         | NATSAL<br>n=(117) <sup>b, c</sup> |         |
|--|---------------------------|---------|--|---------|-----------------------------------|---------|
|  | n                         | Percent | n  | Percent | N                                 | Percent |
| Mean Age                               | 33.3                      | 4%      | 29.4   | 7.6     | 31.9                              | 6.2     |
| Ethnic Group<br>– White                | 5567                      | 91.3    | 1955   | 95.6    | 108                               | 92.3    |
| Holds degree<br>or equivalent          | 4858                      | 79.6    | 898  | 43.6    | 51                                | 43.6    |
| Occupational<br>Class – non-<br>Manual | 4761                      | 78.5    | 1298   | 82.3    | 87                                | 80.0    |
| Country of<br>Residence -<br>England   | 5309                      | 86.9    | 1738   | 86.1    | 104                               | 89.7    |
| Country of<br>Residence –<br>Wales     | 194                       | 3.2     | 69   | 3.4     | 7                                 | 5.8     |
| Country of<br>Residence -<br>Scotland  | 605                       | 9.9     | 211  | 10.5    | 5                                 | 4.5     |
| Lives in Urban<br>Area <sup>d</sup>    | 5713                      | 93.8    | 1880   | 91.9    | 109                               | 93.7    |
| Lives in<br>London                     | 2096                      | 34.3    | 493  | 23.9    | 38                                | 32.3    |
| Country of<br>Birth<br>(UK\Ireland)    | 4852                      | 79.4    | 1874   | 89.9    | 98                                | 84.1    |
| Health<br>reported as                  | 3754                      | 80.8    | 1650   | 80.1    | 103                               | 88.5    |

|   |  |  |  |  |  |  |
|---|--|--|--|--|--|--|
| good  |  |  |  |  |  |  |
| <p>a The source of data for both of the comparative studies reported here is (Evans, Wiggins et al. 2007)</p> <p>b The subsample of 135 gay and bisexual men (18–44 years) that was identified for the comparison between Evans, et al and NATSAL was equivalent to an effective subsample of 117 men after adjusting for differing probabilities of selection and non-response.</p> <p>c Denominators vary slightly due to missing data for some variables.</p> <p>d For the present study, data is reported on whether respondents worked in an urban area.</p> |  |  |  |  |  |  |

We were also interested to identify to what extent the HIV positive men were comparable with a clinic-based sample of HIV positive gay and bisexual men. In Table 6 we present demographic data from London resident HIV positive respondents and all HIV positive respondents in this study alongside those from a study by Elford, et al, which recruited 758 HIV positive men from HIV treatment clinics in East London. Again, any conclusions must be tentative since the studies are not directly comparable. However, there was no difference in terms of average age and the differences in percentage points between the three samples on White ethnicity were small; less than five percentage points. The fact that a higher proportion of respondents in this study had completed higher education is likely to be accounted for by the exclusion of men from our sample who were unemployed or solely students. The difference between the whole sample of HIV positive men in this study and the London-resident men in terms of country of birth is most likely a reflection of the higher population of immigrants to London compared to the UK as a whole. Therefore we can conclude that the sample of HIV positive men in this study is relatively similar to the clinic-based sample recruited by Elford, et al acknowledging the impact of excluding men who were unemployed or students (see Table 6).

Table 6: Demographic Characteristics of the HIV Positive Sample Compared with Those of HIV Positive Gay and Bisexual Men in a Clinic-Based Sample

|  | Present Study – London Resident HIV Positive Respondents (n=738) |         | Present Study – All HIV Positive Respondents (Total n=1830) |         | (Elford, Ibrahim et al. 2007) (Total n=758) <sup>a</sup> |         |
|--|--|---------|---|---------|--|---------|
|  | n  | Percent | n   | Percent | N  | Percent |
| Mean Age (range)   | 39   | (20-68) | 39  | (18-69) | 39   | (18-72) |
| Ethnic Group – White   | 655  | 89.1    | 1697  | 93.0    | 646  | 85.0    |
| Higher Education   | 606  | 82.3    | 1370  | 75.0    | 514  | 68.8    |
| Country of Birth - UK  | 483  | 65.4    | 1459  | 79.7    | 506  | 71.8    |
| a Denominators vary slightly due to missing data for some variables. |  |         |   |         |  |         |

## The HIV Positive Sample

The majority of the HIV positive men in this study (n=1,830) were aged 30-39 (37.3%) and 40-49 (36.6%). Average age was 39, range: 18-69. The majority lived in England (1,656/1,830, 90.5%) and the most commonly reported city of residence was London (738/1,827, 40.4%)

Most described themselves as gay/homosexual (1,771/1,830, 96.8%) and identified as White British by ethnic group classification (1,412/1,824, 77.4%). Overall, 75.0% (1,370/1,826) were educated to degree level or above with the largest proportion attaining a university undergraduate qualification (857/1,826, 46.9%).

Over three-quarters (1,413/1,830, 77.2%), were working full-time, 16.4% (300/1,830) worked freelance and 8.9% (162/1,830) were working part-time.<sup>3</sup> A small number were also students (45/1,830, 2.5%). These men worked across the UK with the largest proportion working in London (644/1,544, 41.7 %). Most reported that they worked in a large city or a town (1,312/1,826, 71.9%). They were mostly employed on permanent contracts (1,534/1,827, 84.0%) in professional (591/1,816, 32.5%) and managerial/technical jobs (521/1,816, 28.7%). Almost three-quarters had had only one or two employers in the last five years (1,317/1,790, 73.6%).

The data showed that the gross annual (pre tax) salary was spread across the salary categories with the largest proportion in the £20,000-£29,999 bracket (506/1,815, 27.9%). The majority classified themselves as working in the private sector (1,130/1801, 62.7%) with a significant proportion in the public sector (532/1,801, 29.5%).

## HIV Positive and HIV Negative Men – Profiles Compared

As outlined above, we ascertained that the largest proportion of HIV positive men was: aged 30-49, lived in England and London, were white British, gay and educated to degree-level or above. Most were in full-time employment and worked in a large city or town. They tended to describe themselves as professional, the largest proportion had had only one or two employers in the last five years and earned within the £20,000-£29,999 annual salary bracket. Most worked in the private sector.

We were keen to identify whether the profile of HIV positive men differed significantly from the men who were HIV negative. Pearson's chi-square tests were run on the variables outlined in Table 7. Those highlighted in bold were found to be statistically significant at the typical 5% level used in hypothesis testing for which p. values are calculated.<sup>4</sup> (This corresponds with the 95% confidence interval within a range of values in which there is reasonable confidence that the true, but unknown, population value lies). Confidence intervals were not calculated here, and rather p.

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<sup>3</sup> The total figure exceeds 1830 due to respondents reporting more than one mode of working.

<sup>4</sup> Statistically significant results are highlighted in bold in the tables that follow.

values were used to assess whether there was a difference between the estimates under analysis.

From this exercise, we can conclude that the group of HIV positive men was on average slightly older than the HIV negative men (39 years vs. 37 years) and more likely to be: aged 30-49, report a gay sexual orientation, reside in England and London, be employed in a large city or town and work in the private sector. They were less likely to be white British, educated to degree level or above, and report a professional occupation.

However, the degree of difference between the two groups on variables where statistically significant differences were found was small; ten percentage points or less. The exception was to report being aged 30-49, where the degree of difference was more marked (14.6 percentage points).

Differences observed between the two groups on the following variables were not statistically significant: being employed full-time, having a permanent work contract, having only one or two employers in the last five years and earning an annual salary of £20,000-£29,999 (see

Table 7).

Table 7: Profile of HIV Positive and HIV Negative Respondents Compared on Demographic Variables

|   | HIV Positive    |         | HIV Negative    |         | P value |
|---|-----------------|---------|-----------------|---------|---------|
|   | n               | Percent | n               | Percent |         |
| Mean Age (Range)                                | 39              | (18-69) | 37              | (18-70) |         |
| Age (30-49)                                     | 1352/<br>1830   | 73.9    | 3879/<br>6539   | 59.3    | 0.000   |
| Ethnic Group – White British                    | 1,412/<br>1,824 | 77.4    | 5,100/<br>6,530 | 78.1    | 0.022   |
| Sexual Orientation – Gay or Homosexual          | 1,771/<br>1830  | 96.8    | 5,997/<br>6,539 | 91.7    | 0.000   |
| Country of Residence - England                  | 1,656/<br>1,830 | 90.5    | 5,508/<br>6,539 | 84.2    | 0.000   |
| City of Residence – London                      | 738/<br>1,827   | 40.4    | 1,959/<br>6,529 | 30.0    | 0.000   |
| Level of Education – Degree or above            | 1,370<br>/1,826 | 75.0    | 5,102/<br>6,532 | 78.1    | 0.015   |
| Location of employment – Large city/town        | 1,312/<br>1,826 | 71.9    | 4,148/<br>6,516 | 63.7    | 0.000   |
| Self-reported occupational class – Professional | 591/<br>1,816   | 32.5    | 2,277/<br>6,491 | 35.1    | 0.009   |
| Employment sector – Private                     | 1,130/<br>1,801 | 62.7    | 3,913/<br>6,405 | 61.1    | 0.011   |
| Number of Employers in Last Five Years – 1 or 2 | 1,317/<br>1,790 | 73.6    | 4,537/<br>6,351 | 71.4    | 0.075   |
| Employment Status - Full-time                   | 1,413/<br>1,830 | 77.2    | 5,028/<br>6,539 | 76.9    | 0.773   |

|                                     |                 |      |                 |      |       |
|-------------------------------------|-----------------|------|-----------------|------|-------|
| Contract Type – Permanent           | 1,534/<br>1,827 | 84.0 | 5,559/<br>6,621 | 83.7 | 0.174 |
| Annual salary - £20,000-<br>£29,999 | 506/<br>1,815   | 27.9 | 1,757/<br>6,441 | 27.3 | 0.056 |

### Experience at Work

We sought to explore the reported experiences of the HIV positive men in employment in more detail on a range of indicators as follows. On selected variables, we have also compared results with those for HIV negative men.

### Type of Employment

Respondents were asked to describe their job in two open-ended questions. Those with more than one job were asked to choose their main job (defined as the job that paid the most or took up the most time). In total, 1,821 main jobs were described by HIV positive respondents. These were grouped as outlined Table 8.<sup>5</sup> The types of jobs respondents did were varied with a wide range of professions and trades represented. The largest proportions were represented by those in the hospitality industries (9.8%), healthcare and medicine (8.8%) retail (6.7%), educational professions (6.5%), IT (6.1%) and financial services (5.6%).

Table 8: HIV Positive Respondents' Main Job Grouped by Industry

| Industry                                       | Frequency | Percent |
|--|-----------|---------|
| Advertising, Marketing & Public Relations (PR) | 52        | 2.8     |
| Administration (unspecified industries)        | 37        | 2.0     |
| Agriculture                                    | 3         | 0.2     |
| Animals: Care & Services                       | 6         | 0.3     |
| Art, Architecture and Design                   | 44        | 2.4     |
| Beauty Industry Services & Products            | 22        | 1.2     |
| Business: Corporate & Consulting               | 26        | 1.4     |
| Clergy, Church                                 | 3         | 0.2     |
| Clothing & Fashion                             | 9         | 0.5     |
| Commodities: Production, Purchasing, Trading   | 11        | 0.6     |
| Communications (Corporate, Telecom)            | 24        | 1.3     |
| Customer Service (unspecified industries)      | 31        | 1.7     |
| Data & Information Management                  | 23        | 1.3     |
| Domestic Services                              | 14        | 0.8     |

<sup>5</sup> Job categories were developed by reference to the Office for National Statistics categories used as the basis for the 2005 Labour Force Survey. Categories were expanded to more fully account for the jobs described. Further details available from the author.

|  |       |       |
|--|-------|-------|
| Education: Teachers, Educators, Academic Researchers, Librarians & Archivists                              | 119   | 6.5   |
| Entertainment & Performance Art Media, Film, TV + Theatre, Music, Dance, Drama                             | 63    | 3.5   |
| Environment & Conservation   | 3     | 0.2   |
| Financial Services: accountancy, auditing, banking, bookkeeping, credit                                    | 102   | 5.6   |
| Fitness & Sports   | 5     | 0.3   |
| Funeral Services   | 3     | 0.2   |
| Government Municipal Services (road works, postal service, police force, law enforcement, fire protection) | 31    | 1.7   |
| Government, Civil Service, Public Sector & Planning  | 55    | 3.0   |
| Health Care, Health Services, Medical products & Pharmaceuticals   | 160   | 8.8   |
| HIV Services   | 7     | 0.4   |
| Hospitality: Hotels, Restaurants, Pubs, Member-Clubs Catering, Events, Food Handling                       | 179   | 9.8   |
| HR: Human Resources, Recruiting, Health & Safety, and Resource Management                                  | 40    | 2.2   |
| Insurance & Actuarial  | 16    | 0.9   |
| IT, Computers & Electronics  | 111   | 6.1   |
| Landscaping & Horticulture   | 14    | 0.8   |
| Law  | 31    | 1.7   |
| Management, Consulting & Training (unspecified industries)   | 64    | 3.5   |
| Manufacturing, Factory, Warehouse  | 17    | 0.9   |
| Military & Defence (HM Forces)   | 3     | 0.2   |
| Non-profit & Charities   | 19    | 1.0   |
| Policy <sup>6</sup>  | 4     | 0.2   |
| Professional Trades  | 19    | 1.0   |
| Property: Construction, Development, Sales, Management, & Building Maintenance                             | 54    | 3.0   |
| Publishing, Printing, Editing, Journalism, Writing & Translating   | 26    | 1,4   |
| Purchasing   | 13    | 0.7   |
| Retail   | 122   | 6.7   |
| Science & Engineering  | 13    | 0.7   |
| Security & Surveillance  | 10    | 0.5   |
| Sex Industry   | 7     | 0.4   |
| Social Services & Community Care   | 96    | 5.3   |
| Transport, Travel & Tourism  | 107   | 5.9   |
| Utilities & Services   | 3     | 0.2   |
| Total  | 1,821 | 100.0 |

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<sup>6</sup> See also 'Government: Civil Service, Public Sector & Planning' for other policy positions occupied by government workers and civil servants.

## Number of Employers and Jobs

As an indicator of the stability of employment, we asked how many employers and jobs respondents had had in the last five years. Self-employed men were asked to include themselves as an employer. Most had had only one or two employers (73.6%) or jobs (64.0%) (see Table 9 and

Table 10).

Table 9: Number of Different Employers in the Last Five Years

|         |        | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|--------|-----------|---------|---------------|--------------------|
| Valid   | 1      | 814       | 44.5    | 45.5          | 45.5               |
|         | 2      | 503       | 27.5    | 28.1          | 73.6               |
|         | 3-5    | 402       | 22.0    | 22.5          | 96.0               |
|         | 6-10   | 61        | 3.3     | 3.4           | 99.4               |
|         | 11+    | 10        | .5      | .6            | 100.0              |
|         | Total  | 1790      | 97.8    | 100.0         |                    |
| Missing | System | 40        | 2.2     |               |                    |
| Total   |        | 1830      | 100.0   |               |                    |

Table 10: Number of Different Jobs in the Last Five Years

|         |        | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|--------|-----------|---------|---------------|--------------------|
| Valid   | 1      | 665       | 36.3    | 37.2          | 37.2               |
|         | 2      | 480       | 26.2    | 26.8          | 64.0               |
|         | 3      | 333       | 18.2    | 18.6          | 82.6               |
|         | 4      | 133       | 7.3     | 7.4           | 90.1               |
|         | 5+     | 178       | 9.7     | 9.9           | 100.0              |
|         | Total  | 1789      | 97.8    | 100.0         |                    |
| Missing | System | 41        | 2.2     |               |                    |
| Total   |        | 1830      | 100.0   |               |                    |

We have presented further detail on number of employers by HIV status to provide the range of responses reported (see The differences between the two groups were not statistically significant (p.=0.183).

Table 11). The differences between the two groups were not statistically significant (p.=0.183).

Table 11: Number of Employers in Previous Five Years by HIV Status

|              | 1     | 2     | 3-5   | 6-10 | 11+ | Total  |
|--------------|-------|-------|-------|------|-----|--------|
| HIV Positive | 814   | 503   | 402   | 61   | 10  | 1790   |
|              | 45.5% | 28.1% | 22.5% | 3.4% | .6% | 100.0% |
| HIV Negative | 2718  | 1819  | 1576  | 197  | 41  | 6351   |
|              | 42.8% | 28.6% | 24.8% | 3.1% | .6% | 100.0% |
| Total        | 3532  | 2322  | 1978  | 258  | 51  | 8141   |
|              | 43.4% | 28.5% | 24.3% | 3.2% | .6% | 100.0% |

### Job Satisfaction

Respondents were asked to specify their level of satisfaction with a range of aspects of working life using a Likert scale ranging from 'very satisfied' to 'very dissatisfied'. The aspects of working life examined included: scope for using initiative, sense of achievement, satisfaction with the work itself, amount of influence over work, job security, level of pay and access to training. Table 12 shows that in each case the majority of respondents were either 'very' or 'somewhat' satisfied with aspects of their work. Levels of satisfaction were highest with the amount of scope men felt they had for using their own initiative at work (81.8%) and their sense of achievement (78.6%). Dissatisfaction was highest in relation to amount of pay (24.2%), job security (18.5%) and training (18.0%) (see Table 12).

Table 12: Satisfaction with Aspects of Work

| Aspect of Work                 | Very/ Somewhat Satisfied |       | Neither |       | Very/ Somewhat Dissatisfied |       | Total Count |
|--------------------------------|--------------------------|-------|---------|-------|-----------------------------|-------|-------------|
|                                | Count                    | %     | Count   | %     | Count                       | %     |             |
| Scope for using own initiative | 1490                     | 81.8% | 196     | 10.8% | 136                         | 7.5%  | 1822        |
| Sense of achievement           | 1435                     | 78.6% | 221     | 12.1% | 169                         | 9.3%  | 1825        |
| Work itself                    | 1377                     | 75.7% | 266     | 14.6% | 176                         | 9.7%  | 1819        |
| Influence over your job        | 1283                     | 70.4% | 297     | 16.3% | 242                         | 13.3% | 1822        |
| Job security                   | 1062                     | 58.4% | 419     | 23.1% | 336                         | 18.5% | 1817        |
| Pay                            | 1035                     | 56.7% | 348     | 19.1% | 441                         | 24.2% | 1824        |
| Training                       | 983                      | 54.4% | 500     | 27.7% | 325                         | 18.0% | 1808        |

We sought to compare HIV positive and HIV negative respondents on two important dimensions of work satisfaction: satisfaction with their work itself and pay. We also examined whether there were differences in positive perceptions about their relationship with their manager. In each case, the differences between the two groups were not statistically significant (see Table 13).

Table 13: HIV Positive and HIV Negative Respondents Compared on Satisfaction with Aspects of Employment

|   | HIV Positive |         | HIV Negative |         | P value |
|---|--------------|---------|--------------|---------|---------|
|   | n            | Percent | n            | Percent |         |
| Level of job satisfaction - Measured by responding 'very' or 'somewhat' satisfied with work     | 1,377/1,819  | 75.7    | 4,853/6,468  | 75.0    | 0.599   |
| Level of satisfaction with pay - Measured by responding 'very' or 'somewhat' satisfied with pay | 1,035/1,824  | 56.7    | 3,599/6,462  | 55.7    | 0.728   |
| Relationship with manager - Measured by responding 'very good' or 'good'                        | 1,362/1,661  | 82.0    | 4,907/5,939  | 82.6    | 0.443   |

### Impact of HIV on Employment

The qualitative work and literature review suggested that the point of initial diagnosis is one that can have a particular impact upon the working life of HIV positive people. We asked respondents a series of questions about this. Table 14 shows that just under a third of respondents reported that their initial HIV diagnosis had no effect on their working life (30.8%). However, of those who reported an effect, the two most common responses were to feel stressed and anxious (42.3%) and to need to take some time off work (31.7%).

We also sought to explore whether participants felt that there was a current impact of living with HIV on their working life. Over half of the respondents said that that living with HIV had no current impact upon their working life (58.1%). Of those who reported a current impact, the most common responses were to report feeling very tired (19.8%) and feeling very stressed or anxious (13.4%).

Table 14: Reported Impact of HIV Diagnosis on Working Life

| Initial Diagnosis        | Yes   |       | Total | Currently               | Yes   |       | Total |
|--------------------------|-------|-------|-------|-------------------------|-------|-------|-------|
|                          | Count | %     | Count |                         | Count | %     | Count |
| No Impact                | 563   | 30.8% | 1830  | No Impact               | 1063  | 58.1% | 1830  |
| Stressed/Anxious         | 774   | 42.3% | 1830  | Very Tired              | 363   | 19.8% | 1830  |
| Took Time Off            | 581   | 31.7% | 1830  | Stressed/Anxious        | 245   | 13.4% | 1830  |
| Was Very Tired           | 516   | 28.2% | 1830  | Took Time Off           | 221   | 12.1% | 1830  |
| Was Less Confident       | 448   | 24.5% | 1830  | Less Confident          | 220   | 12.0% | 1830  |
| Was Less Productive      | 437   | 23.9% | 1830  | Experience Side Effects | 194   | 10.6% | 1830  |
| Was Less Able            | 270   | 14.8% | 1830  | Am Less Able            | 155   | 8.5%  | 1830  |
| Experienced Side Effects | 231   | 12.6% | 1830  | Less Productive         | 114   | 6.2%  | 1830  |
| Other                    | 133   | 7.3%  | 1830  | Other                   | 94    | 5.1%  | 1830  |

## Changes and Limitations

We were also interested in whether participants reported that living with HIV had caused them to change aspects of their working life. We asked about a range of indicators as listed in Table 15. Just over a third of respondents (36.7%, 651/1,776) indicated that they had made one or more of the changes listed; the remainder (63.3%, 1,125/1776) had made none. Table 15 shows that the most common changes that respondents reported were changes to hours worked (21.1%) and times worked (20.7%).

Table 15: Reported Changes to Working Life as a Result of Living with HIV

|   | Yes   |       | Total |
|---|-------|-------|-------|
|   | Count | %     | Count |
| Number of hours worked                            | 372   | 21.1% | 1764  |
| Start/Finish Times                                | 361   | 20.7% | 1742  |
| Your Employer                                     | 270   | 15.5% | 1737  |
| Tasks/Responsibilities                            | 238   | 13.7% | 1737  |
| Employment Sector (public/private/not-for-profit) | 179   | 10.3% | 1736  |

We were also interested in limitations on their working life that respondents reported as a consequence of living with HIV. We asked about whether living with HIV had prevented respondents from seeking promotion or taking up occupational training and whether it had prevented respondents from travelling internationally for employment purposes or in seeking to take up a job with a new employer. Table 16 shows that the most frequent limitation respondents reported was in international travel (26.9%), closely followed by feeling unable to apply for a new job (24.4%).

Table 16: Reported Limitations to Working Life As A Result of Living with HIV

|                        | Yes   |       | Total |
|------------------------|-------|-------|-------|
|                        | Count | %     | Count |
| Travelling Overseas    | 470   | 26.9% | 1748  |
| Applying For A New Job | 429   | 24.4% | 1758  |
| Seeking Promotion      | 321   | 18.2% | 1764  |
| Taking Up Training     | 222   | 12.7% | 1747  |

## Health, Medical Treatment and Sickness Absence

Overall, 65.1% (1,191/1,830) of HIV positive respondents were taking ART. Almost all of these respondents were taking one (70.6%) or two (28.1%) doses per day (see Table 17). When asked whether they took their medication during working hours, less than a fifth (233/1,189, 19.6%) reported that they did so.

Table 17: Reported Daily ART Dosage

|  | Frequency | Percent | Valid Percent | Cumulative Percent |
|--|-----------|---------|---------------|--------------------|
|--|-----------|---------|---------------|--------------------|

|         |        |      |       |       |       |
|---------|--------|------|-------|-------|-------|
| Valid   | 1      | 837  | 45.7  | 70.6  | 70.6  |
|         | 2      | 333  | 18.2  | 28.1  | 98.7  |
|         | 3+     | 16   | .9    | 1.3   | 100.0 |
|         | Total  | 1186 | 64.8  | 100.0 |       |
| Missing | System | 644  | 35.2  |       |       |
| Total   |        | 1830 | 100.0 |       |       |

Respondents were asked to rate their physical and mental health over the preceding three months. Table 18 shows that 72.1% of HIV positive men rated their physical health as 'good', 'very good' or 'excellent' and over two thirds described their mental health as 'good' 'very good' or 'excellent' (67.7%). Few HIV positive respondents rated their mental or physical health as 'poor' (less than 10% in each case); although one-in-five rated their mental (22.7%) or physical health (20.4%) as 'fair'.

Table 18: HIV Positive Respondents' Rating of Their Physical and Mental Health in the Preceding Three Months

| Physical Health |           |           |         |               |                    | Mental Health |           |           |         |               |                    |
|-----------------|-----------|-----------|---------|---------------|--------------------|---------------|-----------|-----------|---------|---------------|--------------------|
|                 |           | Frequency | Percent | Valid Percent | Cumulative Percent |               |           | Frequency | Percent | Valid Percent | Cumulative Percent |
| Valid           | Excellent | 272       | 14.9    | 19.5          | 19.5               | Valid         | Excellent | 352       | 19.2    | 24.0          | 24.0               |
|                 | Very Good | 327       | 17.9    | 23.4          | 42.8               |               | Very Good | 283       | 15.5    | 19.3          | 43.3               |
|                 | Good      | 409       | 22.3    | 29.3          | 72.1               |               | Good      | 356       | 19.5    | 24.3          | 67.6               |
|                 | Fair      | 285       | 15.6    | 20.4          | 92.5               |               | Fair      | 333       | 18.2    | 22.7          | 90.3               |
|                 | Poor      | 105       | 5.7     | 7.5           | 100.0              |               | Poor      | 140       | 7.7     | 9.6           | 100.0              |
|                 | Total     | 1398      | 76.4    | 100.0         |                    |               | Total     | 1464      | 80.0    | 100.0         |                    |
| Missing         | System    | 432       | 23.6    |               |                    | Missing       | System    | 366       | 20.0    |               |                    |
| Total           |           | 1830      | 100.0   |               |                    | Total         |           | 1830      | 100.0   |               |                    |

We sought to identify whether there were any significant differences between the HIV positive and HIV negative respondents on perceptions about their health. The data showed that HIV positive men were less likely to rate their physical (72.1% vs. 82.5%) and mental health (67.7% vs. 78.1%) as 'excellent', 'very good' or 'good' compared with HIV negative men. We compared the average number of days leave taken for non-HIV related illness. The difference was not statistically significant (see Table 19).

Table 19: HIV Positive and HIV Negative Respondents Compared on Perceptions of Health and Sickness Leave

|                                  | HIV Positive |         | HIV Negative |         | P value |
|----------------------------------|--------------|---------|--------------|---------|---------|
|                                  | n            | Percent | n            | Percent |         |
| Perceived good physical health - | 1008/        | 72.1    | 4,140/       | 82.5    | 0.000   |

|   |           |      |             |      |       |
|---|-----------|------|-------------|------|-------|
| Measured as responding 'excellent' 'very good' or 'good' combined                                 | 1,398     |      | 5,019       |      |       |
| Perceived good mental health - Measured as responding 'excellent', 'very good' or 'good' combined | 991/1,464 | 67.7 | 4,109/5,263 | 78.1 | 0.000 |
| Mean days sickness leave in last 12 months (not HIV related)                                      | 8.3       | -    | 7.3         | -    | 0.096 |

HIV positive respondents were also asked how many days they had been absent from work due to illness related to HIV. Table 20 shows that 70.3% reported that they had not taken any days as sick leave for HIV-related illness while a further 13.9% had taken 1-7 days sick leave. Just over one-in-ten (11.5%) said they had had at least 14 days off work due HIV related illness.

Table 20: Reported Days Absent From Work in the last 12 Months Due to Symptoms Related to HIV or Treatment Side Effects

|         |            | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|------------|-----------|---------|---------------|--------------------|
| Valid   | 0 Days     | 1232      | 67.3    | 70.3          | 70.3               |
|         | 1-3 Days   | 114       | 6.2     | 6.5           | 76.8               |
|         | 4-7 Days   | 130       | 7.1     | 7.4           | 84.2               |
|         | 8-10 Days  | 64        | 3.5     | 3.7           | 87.9               |
|         | 11-13 Days | 11        | .6      | .6            | 88.5               |
|         | 14+ Days   | 201       | 11.0    | 11.5          | 100.0              |
|         | Total      | 1752      | 95.7    | 100.0         |                    |
| Missing | System     | 78        | 4.3     |               |                    |
| Total   |            | 1830      | 100.0   |               |                    |

Regular clinic attendance is a feature of living with HIV in order to monitor any progression of the condition and the effectiveness of ART. We therefore sought to explore how much time respondents had spent away from work to attend their HIV clinic in the last 12 months and how respondents were able to arrange to attend HIV clinic appointments during working hours. Table 21 shows that over a third of respondents (34.2%) had not taken any days off to attend their HIV clinic in the last 12 months. The next largest proportion had taken 1-3 days (30.3%).

Table 21: Reported Absence from Work in the Last 12 Months to Attend HIV Clinic Appointments

|       |            | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------|------------|-----------|---------|---------------|--------------------|
| Valid | 0 Days     | 454       | 24.8    | 34.2          | 34.2               |
|       | 1-3 Days   | 403       | 22.0    | 30.3          | 64.5               |
|       | 4-7 Days   | 319       | 17.4    | 24.0          | 88.6               |
|       | 8-10 Days  | 76        | 4.2     | 5.7           | 94.3               |
|       | 11-13 Days | 25        | 1.4     | 1.9           | 96.2               |

|         |          |      |       |       |       |
|---------|----------|------|-------|-------|-------|
|         | 14+ Days | 51   | 2.8   | 3.8   | 100.0 |
|         | Total    | 1328 | 72.6  | 100.0 |       |
| Missing | System   | 502  | 27.4  |       |       |
| Total   |          | 1830 | 100.0 |       |       |

Almost half of respondents used the existing flexibility within their current working arrangements to attend their appointments (45.7%). Only 5.1% used disability leave and 2.4% said they would be unable to take time off during working hours. A small proportion (8.7%) was using their annual leave entitlement to attend HIV clinic appointments (see

Table 22).

Table 22: Reported Arrangements for Attending HIV Clinic During Working Hours

|         |                                | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|--------------------------------|-----------|---------|---------------|--------------------|
| Valid   | Take flexitime/adjust my hours | 812       | 44.4    | 45.7          | 45.7               |
|         | Some other way                 | 367       | 20.1    | 20.7          | 66.4               |
|         | Use paid holiday               | 155       | 8.5     | 8.7           | 75.1               |
|         | Use special paid leave         | 141       | 7.7     | 7.9           | 83.1               |
|         | Go on leave without pay        | 104       | 5.7     | 5.9           | 88.9               |
|         | Disability related absence     | 90        | 4.9     | 5.1           | 94.0               |
|         | Take sick leave                | 65        | 3.6     | 3.7           | 97.6               |
|         | Couldn't take time off         | 42        | 2.3     | 2.4           | 100.0              |
|         | Total                          | 1776      | 97.0    | 100.0         |                    |
| Missing | System                         | 54        | 3.0     |               |                    |
| Total   |                                | 1830      | 100.0   |               |                    |

## Disclosure

As the qualitative phase of work showed, issues of disclosure at work can be extremely important to people living with HIV. We sought to explore how many respondents had disclosed their HIV status at work and to whom they had disclosed. In ease case, forty percent of respondents had disclosed their HIV status to colleagues (40.2%) or managers/supervisors (40.0%). Respondents were least likely to have disclosed to clients (6.8%) or customers (5.7%) (see Table 23).

Table 23: Reported Disclosure of HIV Status At Work<sup>(a)</sup>

| Disclosed to...                  | Disclosed |       | Not Disclosed |       | Not Applicable |       | Total<br>Count |
|----------------------------------|-----------|-------|---------------|-------|----------------|-------|----------------|
|                                  | Count     | %     | Count         | %     | Count          | %     |                |
| Colleagues, Co-workers           | 718       | 40.2% | 1016          | 57.0% | 50             | 2.8%  | 1784           |
| Supervisors, Managers            | 713       | 40.0% | 962           | 54.0% | 107            | 6.0%  | 1782           |
| Human Resources, Personnel staff | 477       | 27.0% | 1100          | 62.2% | 191            | 10.8% | 1768           |
| Occupational Health staff        | 448       | 25.4% | 1004          | 57.0% | 309            | 17.5% | 1761           |
| Clients                          | 121       | 6.8%  | 1395          | 78.7% | 256            | 14.4% | 1772           |
| Customers                        | 100       | 5.7%  | 1392          | 78.9% | 272            | 15.4% | 1764           |

a Respondents were asked if they had disclosed their HIV status to 'all' or 'some' or 'none' of the contacts listed here. All/some responses have been combined.

We were also interested to know respondents' perceptions as to how their disclosure had been received. Combining all responses, 1,046/1,702 (61.5%) respondents had disclosed their HIV positive status to one or more of the contacts listed in the questionnaire, as detailed in Table 23. Of these respondents, 956 answered the question as to how their disclosure had been received. Over three-quarters (77.2%) reported that the response had been 'very positive' or 'mostly positive'. Less than one in ten (6.0%) reported a negative response (see

Table 24).

Table 24: Reported Response to Disclosure of HIV Status at Work

| Very Positive | Mostly Positive | Neutral | Mostly Negative | Very Negative | Total  |
|---------------|-----------------|---------|-----------------|---------------|--------|
| 446           | 292             | 161     | 35              | 22            | 956    |
| 46.7%         | 30.5%           | 16.8%   | 3.7%            | 2.3%          | 100.0% |

We were interested to learn more about whether there were any significant differences between the men who had disclosed their HIV status to any of the workplace contacts listed in the questionnaire and those who had not (see Table 23 for the list). As noted, 1,046/1,702 (61.5%) respondents reported that they had disclosed and 656/1,702 (38.5%) had not. (The remaining 128 respondents were either missing cases or answered 'not applicable' in response to questions about disclosing their HIV status.) We therefore ran a series of Pearson's chi-square tests to examine whether there were significant differences between those who had and had not disclosed in relation to the variables in Table 25.

Respondents who worked in the public sector were more likely have disclosed than to have chosen not too (34.8% vs. 22.8% p. = 0.000). Respondents who disclosed were more likely to be taking ART (71.3% vs. 56.4%, p.= 0.000) and to do so in working hours (21.8% vs. 13.8% p.= 0.001). They were also more likely to perceive that their body was showing some physical sign of living with HIV (36.6% vs. 29.1%, p.= 0.002). Differences between the two groups on whether they worked for a large company (500+) were not statistically significant (see Table 25).

Table 25: Disclosure of HIV Status at Work – Respondents Compared on Key Variables

|                             | Had Disclosed |         | Had Not Disclosed |         | P value |
|-----------------------------|---------------|---------|-------------------|---------|---------|
|                             | n             | Percent | n                 | Percent |         |
| Employment Sector: Public   | 360/<br>1,033 | 34.8    | 147/664           | 22.8    | 0.000   |
| Taking ART                  | 746/<br>1,046 | 71.3    | 370/656           | 56.4    | 0.000   |
| Taking ART in Working Hours | 163/<br>746   | 21.8    | 51/370            | 13.8    | 0.001   |
| Showing bodily signs of HIV | 380/<br>1,046 | 36.6    | 191/656           | 29.1    | 0.002   |
| Employer has 500+ employees | 459/<br>1,035 | 44.3    | 226/646           | 41.2    | 0.180   |

We examined the reasons given by those who had not disclosed their HIV status at work (see Table 26). The most commonly cited reasons were that there was no need to disclose, since being HIV positive did not affect the respondent's work (65.4%), concerns that confidentiality about the issue would be breached (56.7%) and fear that poor treatment at work would follow (52.9%).

Table 26: Reasons for Non-Disclosure of HIV Status at Work

|  | Yes   |       | Total |
|--|-------|-------|-------|
|  | Count | %     | Count |
| No Need – It Doesn't Affect Work               | 429   | 65.4% | 656   |
| Concerned About Confidentiality Being Breached | 372   | 56.7% | 656   |
| Concerned About Poor Treatment                 | 347   | 52.9% | 656   |
| Not Applicable                                 | 23    | 3.5%  | 656   |
| Other  | 29    | 4.4%  | 656   |

### Pre-Employment Questionnaires

It is the practice of some employers to encourage applicants to disclose their HIV status (or status as a 'disabled person' for the purposes of the DDA) in pre-employment occupational health questionnaires. This may be done in order to monitor the number of disabled applicants or enable the applicant to request any reasonable adjustments as well as assess fitness for employment. However, as the qualitative findings showed, some HIV positive people fear that this will be used to discriminate against them in job application processes. We therefore sought to ascertain how respondents dealt with these questionnaires. Excluding respondents who were self employed and those who were not asked to complete any pre-employment occupational health questionnaires, 17.8% (218/1,222) of respondents reported that they were specifically asked about their HIV status on a pre-employment occupational health questionnaire for their current job. We asked whether respondents had disclosed their HIV status on the form. Almost a quarter (23.1%), were either HIV negative or unaware of their HIV status at the time. The remainder were evenly divided between those who did and did not disclose their HIV status on the form (38.4% in each case) (see Table 27). We also asked how respondents felt about being asked about their HIV status on

a pre-employment occupational health questionnaire. Almost three-quarters reported that it made them feel uncomfortable (71.6%) (see Table 28).

Table 27: Disclosure of HIV Status on Pre-employment Occupational Health Questionnaire

|         |                                   | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|-----------------------------------|-----------|---------|---------------|--------------------|
| Valid   | Yes                               | 83        | 38.1    | 38.4          | 38.4               |
|         | No                                | 83        | 38.1    | 38.4          | 76.9               |
|         | HIV Negative At The Time          | 43        | 19.7    | 19.9          | 96.8               |
|         | Unaware of HIV Status At The Time | 7         | 3.2     | 3.2           | 100.0              |
|         | Total                             | 216       | 99.1    | 100.0         |                    |
| Missing | System                            | 2         | .9      |               |                    |
| Total   |                                   | 218       | 100.0   |               |                    |

Table 28: Reported Feelings About Being Asked to Disclose HIV status in Pre-employment Occupational Health Questionnaire

|       |                    | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------|--------------------|-----------|---------|---------------|--------------------|
| Valid | Uncomfortable      | 156       | 71.6    | 71.6          | 71.6               |
|       | Comfortable        | 34        | 15.6    | 15.6          | 87.2               |
|       | No Strong Feelings | 28        | 12.8    | 12.8          | 100.0              |
|       | Total              | 218       | 100.0   | 100.0         |                    |

### Disclosure of Sexual Orientation

We have also presented the data on disclosure of sexual orientation and HIV status, which shows that a greater number of HIV positive men had disclosed their sexual orientation than had disclosed their HIV status. The response for both types of disclosures was generally positive (see Table 29 and Table 30).

Table 29: Disclosure of Sexual Orientation and HIV Status

|   | Yes   |       | No    |       | Total |
|---|-------|-------|-------|-------|-------|
|   | Count | %     | Count | %     | Count |
| Disclosed HIV status to one or more workplace contacts listed <sup>a</sup>      | 1046  | 61.5% | 656   | 38.5% | 1702  |
| Disclosed gay or bisexual to one or more workplace contacts listed <sup>a</sup> | 1581  | 91.7% | 143   | 8.3%  | 1724  |
| a. see Table 23 for the list of contacts.                                       |       |       |       |       |       |

Table 30: Reported Response to Disclosure of HIV Status and Sexual Orientation at Work Among HIV Positive Respondents

|  | Very Positive |       | Mostly Positive |       | Neutral |       | Mostly Negative |      | Very Negative |      | Total |
|--|---------------|-------|-----------------|-------|---------|-------|-----------------|------|---------------|------|-------|
|  | Count         | %     | Count           | %     | Count   | %     | Count           | %    | Count         | %    | Count |
| Disclosure of HIV positive status at work                | 449           | 44.5% | 300             | 29.7% | 174     | 17.2% | 50              | 5.0% | 37            | 3.7% | 1010  |
| Disclosure of gay or bisexual sexual orientation at work | 564           | 35.0% | 670             | 41.5% | 337     | 20.9% | 32              | 2.0% | 10            | .6%  | 1613  |

### HIV-related Discrimination

Given that over half of those who did not disclose their HIV status at work feared that poor treatment would follow, we were interested to explore respondents' reported experience of HIV-related discrimination. Respondents were asked whether they had experienced HIV-related discrimination in their current and previous jobs. Among the 1042 respondents who had disclosed their HIV status and reported their experience of HIV discrimination at work, 147 (14.1%) reported that they had experienced HIV discrimination in a previous job and 73 (7.0%) had experienced HIV discrimination in their current job. In each case, 8% of respondents were uncertain as to whether their experience was attributable to HIV-related discrimination (see Table 31).

Table 31: Experienced HIV-Related Discrimination in Previous or Current Job

|              | Yes   |       | No    |       | Don't Know |      | Total |
|--------------|-------|-------|-------|-------|------------|------|-------|
|              | Count | %     | Count | %     | Count      | %    | Count |
| Previous Job | 147   | 14.1% | 805   | 77.3% | 90         | 8.6% | 1042  |
| Current Job  | 73    | 7.0%  | 877   | 84.2% | 92         | 8.8% | 1042  |

We also asked respondents to describe the nature of the discrimination they had experienced in either a previous or current job. In each case, the two most commonly reported forms of discrimination were to perceive being treated differently/excluded (50.3% and 49.3% respectively) or to have their confidentiality breached in relation to information about their HIV status (52.4% and 42.5% respectively). 40.1% of respondents who has disclosed their HIV status and experienced HIV discrimination in a previous job believed they had lost their job as a result. A quarter (26.0%) to a third (33.3%) of respondents who had disclosed their HIV status experienced bullying in a current or previous job (see Table 32).

Table 32: Nature of HIV Discrimination Reported By Respondents Who Had Disclosed Their HIV Status

|                                   | Yes   |       | Total |                                   | Yes   |       | Total |
|-----------------------------------|-------|-------|-------|-----------------------------------|-------|-------|-------|
|                                   | Count | %     | Count |                                   | Count | %     | Count |
| Discrimination in Previous Job    | Count | %     | Count | Discrimination in Current Job     | Count | %     | Count |
| Confidentiality Was Breached      | 77    | 52.4% | 147   | Was Excluded, Treated Differently | 36    | 49.3% | 73    |
| Was Excluded, Treated Differently | 74    | 50.3% | 147   | Confidentiality Was Breached      | 31    | 42.5% | 73    |
| Lost My Job                       | 59    | 40.1% | 147   |                                   |       |       |       |

|                                   |    |       |     |                                   |    |       |    |
|-----------------------------------|----|-------|-----|-----------------------------------|----|-------|----|
| Was Bullied                       | 49 | 33.3% | 147 | Was Bullied                       | 19 | 26.0% | 73 |
| Didn't Get A Promotion I Deserved | 28 | 19.0% | 147 | Other                             | 16 | 21.9% | 73 |
| Other                             | 22 | 15.0% | 147 | Didn't Get A Promotion I Deserved | 14 | 19.2% | 73 |

We were interested to learn more about whether there were significant differences between the men who had disclosed their HIV status and experienced discrimination in their current job compared with those who had disclosed but had not experienced discrimination. Pearson's Chi-Square tests were run on the key variables outlined in Table 33.

Only one variable showed a statistically significant result: respondents who reported that they had disclosed their HIV status and experienced discrimination in their current job were more likely to perceive that their body was showing some physical sign that they were living with HIV (52.1% vs. 33.8%,  $p=0.002$ ). Differences between the two groups were not statically significant on whether they worked for large employers (500+), whether they worked in the private sector, whether they were taking ART or taking ART during working hours (see Table 33).

Table 33: Respondents Who Had Disclosed Their HIV Status Compared on Key Variables by Experience of HIV-Related Discrimination in Current Job

|                             | Experienced Discrimination |         | Had Not Experienced Discrimination |         | P value |
|-----------------------------|----------------------------|---------|------------------------------------|---------|---------|
|                             | n                          | Percent | n                                  | Percent |         |
| Showing bodily signs of HIV | 38/73                      | 52.1    | 296/877                            | 33.8    | 0.002   |
| Employer has 500+ employees | 37/73                      | 50.7    | 373/868                            | 43.0    | 0.528   |
| Employment Sector: Private  | 35/71                      | 49.3    | 482/867                            | 55.6    | 0.307   |
| Taking ART                  | 50/73                      | 68.5    | 626/877                            | 71.4    | 0.601   |
| Taking ART in Working Hours | 13/50                      | 26.0    | 134/626                            | 21.4    | 0.449   |

As the number of men who had disclosed their HIV status at work and reported HIV discrimination in their current job was small, we repeated the analysis to include men who had disclosed their HIV status and experienced HIV-related discrimination in their current or previous employment, or both (i.e. had any experience of workplace HIV discrimination) (203/920, 22.1%).

We compared them on key variables to those who had disclosed their HIV status but reported no discrimination in their current or previous employment. Again, only one variable showed a statistically significant difference: respondents who had disclosed their HIV status at work and had experienced discrimination in either a current or previous job were more likely to perceive that their body showed some physical sign of HIV than men who had disclosed but had not experienced discrimination (51.7% vs. 30.8%,  $p=0.000$ ). None of the other variables tested showed a statistically significant difference (see Table 34).

Table 34: Respondents Who Had Disclosed Their HIV Status Compared on Key Variables by Experience of HIV-Related Discrimination in Current or Previous Job

|                             | Experienced Discrimination |         | Had Not Experienced Discrimination |         | P value |
|-----------------------------|----------------------------|---------|------------------------------------|---------|---------|
|                             | n                          | Percent | n                                  | Percent |         |
| Showing bodily signs of HIV | 105/203                    | 51.7    | 221/717                            | 30.8    | 0.000   |

|                             |         |      |         |      |       |
|-----------------------------|---------|------|---------|------|-------|
| Employer has 500+ employees | 80/203  | 39.4 | 320/709 | 45.1 | 0.318 |
| Employment Sector: Private  | 109/199 | 54.8 | 393/709 | 55.4 | 0.908 |
| Taking ART                  | 156/203 | 76.8 | 503.717 | 70.2 | 0.062 |
| Taking ART in Working Hours | 38/156  | 24.4 | 103/503 | 20.5 | 0.302 |

### Use of Grievance Procedures

As noted, 203 respondents had disclosed their HIV status at work and experienced discrimination in a current or previous job (there were 220 reports of discrimination as some individuals had experienced discrimination in both their current and previous job). We examined whether these respondents had used official complaint mechanisms or grievance procedures in relation to HIV-related discrimination. In total, 63/203 (32.3%) had done so. We also asked what the outcome of the complaint had been. Almost a third of complaints were not resolved to the satisfaction of respondents (30.2%). However, 20.6% of complaints were ongoing (see Table 35).

Table 35: Reported Outcome of Grievance Procedures Responding to HIV Discrimination Among Respondents Who Had Experienced Discrimination in a Current or Previous Job

|         |                     | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|---------------------|-----------|---------|---------------|--------------------|
| Valid   | Not Resolved        | 19        | 9.4     | 30.2          | 30.2               |
|         | Partially Resolved  | 17        | 8.4     | 27.0          | 57.1               |
|         | Completely Resolved | 14        | 6.9     | 22.2          | 79.4               |
|         | Complaint Ongoing   | 13        | 6.4     | 20.6          | 100.0              |
|         | Total               | 63        | 31.0    | 100.0         |                    |
| Missing | System              | 140       | 69.0    |               |                    |
| Total   |                     | 203       | 100.0   |               |                    |

### Getting Help and Advice – HIV Discrimination

Although only a small proportion of respondents had made an official complaint about HIV-related discrimination, we were keen to understand respondents' preferences as to where they would turn for help if they were to experience HIV-related discrimination at work. The most commonly preferred source of help was HIV support organisations (59.7%). Human Resources/Personnel departments (36.7%) and Managers/Supervisors (36.0%) were also commonly cited. Fewer than one-in-ten respondents (8.9%) felt that they would have no-one they could approach for help with HIV-related discrimination at work (see Table 36).

Table 36: Potential Sources Respondents Would Be Willing to Approach for Help Regarding HIV Discrimination at Work

| Potential Source of Help  | Yes   |       | Total |
|---------------------------|-------|-------|-------|
|                           | Count | %     | Count |
| HIV Support Organisation  | 1092  | 59.7% | 1830  |
| Human Resources/Personnel | 672   | 36.7% | 1830  |
| Supervisors, Managers     | 659   | 36.0% | 1830  |

|                                       |     |       |      |
|---------------------------------------|-----|-------|------|
| Trade Union, Professional Association | 515 | 28.1% | 1830 |
| Occupational Health, Counsellor       | 302 | 16.5% | 1830 |
| Colleagues, Co-workers                | 226 | 12.3% | 1830 |
| No One                                | 162 | 8.9%  | 1830 |
| Other                                 | 126 | 6.9%  | 1830 |
| Staff Network, Employees Group        | 93  | 5.1%  | 1830 |

### Disability Discrimination Act

The DDA 2005 was a landmark piece of legislation protecting HIV positive people from discrimination at work (and in other areas of life) from the point of diagnosis, also enabling them to ask for 'reasonable adjustments'. These are accommodations at work to enable people to continue with their employment, taking into account their condition or disability. We therefore sought to ascertain the level of awareness that the DDA offers legal protection to HIV positive people at work. Two-thirds of respondents (1,186/1,784, 66.5%) said that they were aware of this before completing the questionnaire. However, of these respondents, almost a third did not know that this entitled them to ask for 'reasonable adjustments' at work (30.1%) (see Table 37).

Table 37: Awareness of the Right to Ask For Reasonable Adjustments Among Respondents Aware of the DDAs Legal Protection of HIV Positive People at Work

|         |        | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|--------|-----------|---------|---------------|--------------------|
| Valid   | Yes    | 828       | 69.8    | 69.9          | 69.9               |
|         | No     | 357       | 30.1    | 30.1          | 100.0              |
|         | Total  | 1185      | 99.9    | 100.0         |                    |
| Missing | System | 1         | .1      |               |                    |
| Total   |        | 1186      | 100.0   |               |                    |

We sought to identify how many of those respondents who were aware of the DDA and the right to ask for reasonable adjustments, and who had also disclosed their HIV status at work (a prerequisite for making a request under the DDA) had asked for them. Excluding those who were self-employed (n=47), over a quarter of these respondents had asked for a reasonable adjustment (29.4%) (see Table 38). The most commonly requested adjustments were time off for clinic appointments (66.7%), a change in hours worked (51.9%) and a change to start/finish times (50.0%). (see Table 39).

Table 38: Request for Reasonable Adjustments

|       |       | Frequency | Percent | Valid Percent | Cumulative Percent |
|-------|-------|-----------|---------|---------------|--------------------|
| Valid | Yes   | 156       | 29.4    | 29.4          | 29.4               |
|       | No    | 375       | 70.6    | 70.6          | 100.0              |
|       | Total | 531       | 100.0   | 100.0         |                    |

Table 39: Reasonable Adjustments Requested

| Adjustment Requested             | Yes   |       | Total |
|----------------------------------|-------|-------|-------|
|                                  | Count | %     | Count |
| Time Off for Clinic Appointments | 104   | 66.7% | 156   |
| Change in Hours                  | 81    | 51.9% | 156   |
| Change Start/Finish Times        | 78    | 50.0% | 156   |
| Work At Home Occasionally        | 54    | 34.6% | 156   |
| Other                            | 22    | 14.1% | 156   |
| Change in Break Patterns         | 15    | 9.6%  | 156   |
| Work At Home All The Time        | 3     | 1.9%  | 156   |

We also sought to identify how employers had responded to the requests for reasonable adjustments among respondents who had disclosed their HIV status at work and were aware of the DDA/reasonable adjustments provisions. Overall, most requests among this group were fully or partially granted (89.0%). However, over one-in-ten requests were refused (see Table 40).

Table 40: Employers' Response to Request for Reasonable Adjustments

|         |                   | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|-------------------|-----------|---------|---------------|--------------------|
| Valid   | Fully Granted     | 105       | 67.3    | 67.7          | 67.7               |
|         | Partially Granted | 33        | 21.2    | 21.3          | 89.0               |
|         | Refused           | 17        | 10.9    | 11.0          | 100.0              |
|         | Total             | 155       | 99.4    | 100.0         |                    |
| Missing | System            | 1         | .6      |               |                    |
| Total   |                   | 156       | 100.0   |               |                    |

### Helpful Changes

We also asked about changes that employers could make that respondents would find helpful as HIV positive people. Perhaps unsurprisingly their response broadly reflected that for reasonable adjustments. As Table 41 shows, the adjustment that would be most helpful to the largest number of participants was for employers to allow time off for HIV clinic attendance (39.3%). Occasional working from home (22.2%) was also popular.

Table 41: Helpful Changes Employers Could Make

| Helpful Changes                  | Yes   |       | Total |
|----------------------------------|-------|-------|-------|
|                                  | Count | %     | Count |
| Time Off for Clinic Appointments | 719   | 39.3% | 1830  |
| Work At Home Occasionally        | 406   | 22.2% | 1830  |
| Change in Hours                  | 288   | 15.7% | 1830  |
| Change Start/Finish Times        | 272   | 14.9% | 1830  |

|                           |     |      |      |
|---------------------------|-----|------|------|
| Change in Break Patterns  | 126 | 6.9% | 1830 |
| Other                     | 125 | 6.8% | 1830 |
| Work At Home All The Time | 61  | 3.3% | 1830 |

### Advice and Information

We were keen to understand respondents' preferences as to where they would most like to obtain advice and information about issues of employment for HIV positive people. Respondents were given five options which they were asked to rank in order of preference. Here we report upon their first choice preferences. Overwhelmingly, respondents' first choice would be to obtain advice and information from HIV support organisations (69.3%) (see Table 42).

Table 42: Respondents' First Choice Preferences for Information and Advice About Employment and HIV

|         |   | Frequency | Percent | Valid Percent | Cumulative Percent |
|---------|---|-----------|---------|---------------|--------------------|
| Valid   | HIV Organisations                         | 1158      | 63.3    | 69.3          | 69.3               |
|         | Your Employer                             | 222       | 12.1    | 13.3          | 82.5               |
|         | Government Employment Services & Advisors | 204       | 11.1    | 12.2          | 94.7               |
|         | Trade Unions/Professional Associations    | 68        | 3.7     | 4.1           | 98.8               |
|         | Staff Network/Employees Group             | 20        | 1.1     | 1.2           | 100.0              |
|         | Total                                     | 1672      | 91.4    | 100.0         |                    |
| Missing | System                                    | 158       | 8.6     |               |                    |
| Total   |   | 1830      | 100.0   |               |                    |

### Impact of Employment Sector and Size of Employer

We were interested to explore whether employment sector and size of employer were important mediating factors in HIV positive men's experience of employment. We first compared HIV positive and HIV negative respondents in relation to employment sector (public, private, not-for-profit) and size of employer. The data shows that the trends for HIV positive and HIV negative men were the same: most worked in the private sector (62.7 vs. 61.1%,  $p=0.011$ ) and for employers with more than 500 employees (41.8% vs. 44.2%,  $p=0.082$ ) (see Table 43 and Table 44).

Table 43: HIV Status By Employment Sector

|              |       | Employment Sector |                |                       | Total  |
|--------------|-------|-------------------|----------------|-----------------------|--------|
|              |       | Public Sector     | Private Sector | Not-For-Profit Sector |        |
| HIV Positive | Count | 532               | 1130           | 139                   | 1801   |
|              | %     | 29.5%             | 62.7%          | 7.7%                  | 100.0% |
| HIV Negative | Count | 2088              | 3913           | 404                   | 6405   |
|              | %     | 32.6%             | 61.1%          | 6.3%                  | 100.0% |

|             |  |       |       |      |        |
|-------------|--|-------|-------|------|--------|
| Total Count |  | 2620  | 5043  | 543  | 8206   |
|             |  | 31.9% | 61.5% | 6.6% | 100.0% |

Table 44: HIV Status By Size of Employer

|              |       | Number of Employees |        |         |       | Total  |
|--------------|-------|---------------------|--------|---------|-------|--------|
|              |       | 1-10                | 11-100 | 101-500 | 500 + |        |
| HIV Positive | Count | 342                 | 415    | 296     | 755   | 1808   |
|              | %     | 18.9%               | 23.0%  | 16.4%   | 41.8% | 100.0% |
| HIV Negative | Count | 1156                | 1505   | 918     | 2833  | 6412   |
|              | %     | 18.0%               | 23.5%  | 14.3%   | 44.2% | 100.0% |
| Total Count  |       | 1498                | 1920   | 1214    | 3588  | 8220   |
|              |       | 18.2%               | 23.4%  | 14.8%   | 43.6% | 100.0% |

We also examined whether men who had disclosed their HIV positive status were more likely to work in any particular employment sector. In each group (those who had disclosed and those who had not), the majority worked in the private sector. However, men who had disclosed their HIV status were less likely to work in the private sector (55.5% vs. 72.5%) and more likely to work in the public sector (34.8% vs. 22.8%) or not-for-profit sector (9.7% v. 4.7%) than those who had not disclosed (see Table 45). The differences between the two groups was statistically significant ( $p = 0.000$ ).

Table 45: Disclosed HIV Positive Status By Employment Sector

|                   |       | Employment Sector |                |                       | Total  |
|-------------------|-------|-------------------|----------------|-----------------------|--------|
|                   |       | Public Sector     | Private Sector | Not-For-Profit Sector |        |
| Had Disclosed     | Count | 360               | 573            | 100                   | 1033   |
|                   | %     | 34.8%             | 55.5%          | 9.7%                  | 100.0% |
| Had Not Disclosed | Count | 147               | 467            | 30                    | 644    |
|                   | %     | 22.8%             | 72.5%          | 4.7%                  | 100.0% |
| Total Count       |       | 507               | 1040           | 130                   | 1677   |
|                   |       | 30.2%             | 62.0%          | 7.8%                  | 100.0% |

We were also interested to explore whether men who had disclosed their HIV positive status were more likely to work for larger or smaller employers. In each group (those who had disclosed and those who had not), the largest proportion worked for employers with more than 500 employees (44.3% vs. 41.2%) (see Table 46). The differences between the two groups was not found to be statistically significant ( $p = 0.180$ ).

Table 46: Disclosed HIV Positive Status By Size of Employer

|  |  | Number of Employees |        |         |      | Total |
|--|--|---------------------|--------|---------|------|-------|
|  |  | 1-10                | 11-100 | 101-500 | 500+ |       |
|  |  |                     |        |         |      |       |

|                   |       |       |       |       |       |        |
|-------------------|-------|-------|-------|-------|-------|--------|
| Had Disclosed     | Count | 189   | 228   | 159   | 459   | 1035   |
|                   | %     | 18.3% | 22.0% | 15.4% | 44.3% | 100.0% |
| Had Not Disclosed | Count | 104   | 161   | 115   | 266   | 646    |
|                   | %     | 16.1% | 24.9% | 17.8% | 41.2% | 100.0% |
| Total Count       |       | 293   | 389   | 274   | 725   | 1681   |
|                   |       | 17.4% | 23.1% | 16.3% | 43.1% | 100.0% |

We were also interested in whether respondents who had experienced HIV discrimination in their current job were more likely to work in any particular employment sector. In each case, the largest proportion of both groups (those who had and had not experienced HIV discrimination in their current job) worked in the private sector (49.3% vs. 55.6%) (see

Table 47). The differences between the two groups was not found to be statistically significant ( $p = 0.307$ ).

Table 47: Experienced Discrimination In a Current Job By Employment Sector

|                                    |       | Employment Sector |                |                       | Total  |
|------------------------------------|-------|-------------------|----------------|-----------------------|--------|
|                                    |       | Public Sector     | Private Sector | Not-For-Profit Sector |        |
| Experienced Discrimination         | Count | 31                | 35             | 5                     | 71     |
|                                    | %     | 43.7%             | 49.3%          | 7.0%                  | 100.0% |
| Had Not Experienced Discrimination | Count | 302               | 482            | 83                    | 867    |
|                                    | %     | 34.8%             | 55.6%          | 9.6%                  | 100.0% |
| Total Count                        |       | 333               | 517            | 88                    | 938    |
|                                    |       | 35.5%             | 55.1%          | 9.4%                  | 100.0% |

We also examined whether size of employer was a salient factor in having experienced HIV discrimination in a current job. The largest proportion of respondents in each group (those who had and had not experienced HIV discrimination in a current job) worked for employers with more than 500 employees (50.7% vs. 43.0%) (see Table 48). The differences between the two groups was not found to be statistically significant ( $p = 0.528$ ).

Table 48: Experienced HIV Discrimination In a Current Job By Size of Employer

|                                    |       | Number of Employees |        |         |       | Total  |
|------------------------------------|-------|---------------------|--------|---------|-------|--------|
|                                    |       | 1-10                | 11-100 | 101-500 | 500+  |        |
| Experienced Discrimination         | Count | 11                  | 13     | 12      | 37    | 73     |
|                                    | %     | 15.1%               | 17.8%  | 16.4%   | 50.7% | 100.0% |
| Had Not Experienced Discrimination | Count | 162                 | 199    | 134     | 373   | 868    |
|                                    | %     | 18.7%               | 22.9%  | 15.4%   | 43.0% | 100.0% |
| Total Count                        |       | 173                 | 212    | 146     | 410   | 941    |
|                                    | %     | 18.4%               | 22.5%  | 15.5%   | 43.6% | 100.0% |

Therefore, we can conclude that differences between the HIV positive and HIV negative men on which employment sector they worked in were slight, and differences between them regarding size of employer were not statistically significant. When we examined whether employment sector and size of employer were salient factors in disclosure of HIV positive status or experience discrimination in a current job, only one factor proved significant: men who had disclosed were more likely than men who had not to work in the public or not-for-profit sectors. Employment sector was not significantly associated with having experienced HIV discrimination in a current job. Size of employer made no significant difference as to whether men were likely to have disclosed their HIV positive status or experienced discrimination in a current job.

### Workplace Discrimination – Sexual Orientation and HIV

A primary aim of this study was to examine the experiences of HIV positive gay and bisexual men in employment. Above we reported on respondents' experience of HIV related discrimination. However, it was also important to examine sexual orientation as a potential source of workplace discrimination. Among those who had disclosed their sexual orientation, there was no statistically significant difference between the HIV positive and HIV negative respondents in relation to reporting anti-gay discrimination in a current job (7.1% vs. 8.0%,  $p=0.249$ ). A similar proportion of the HIV positive respondents had experienced HIV related discrimination in a current job (7.0%) (see Table 49).

Table 49: Discrimination in Current Job - Anti-Gay and HIV Related

|   | HIV Positive  |         | HIV Negative  |         | P value |
|---|---------------|---------|---------------|---------|---------|
|   | n             | Percent | n             | Percent |         |
| Reported experience of anti-gay discrimination in current job | 104/<br>1,464 | 7.1     | 414/<br>5,162 | 8.0     | 0.249   |
| Reported experience of HIV discrimination in current job      | 73/<br>1,042  | 7.0     | -             | -       | -       |

We were interested to examine whether there was any significant difference between HIV positive and HIV negative respondents who had disclosed their sexual orientation in their use of official complaints or grievance procedures to resolve anti-gay discrimination at work. The difference was not statistically significant. We have presented the data on the use of official complaints or grievance procedures among men who had experienced HIV discrimination, which shows that a greater proportion of the HIV positive men had used grievance procedures for HIV discrimination (32.3%) than for anti-gay discrimination (19.6%) (see Table 50).

Table 50: Use of Official Complaints/Grievance Procedures - Anti-Gay and HIV Related Discrimination

|  | HIV Positive |         | HIV Negative  |         | P value |
|--|--------------|---------|---------------|---------|---------|
|  | n            | Percent | n             | Percent |         |
| Reported use of grievance procedures regarding anti-gay discrimination | 96/490       | 19.6    | 355/<br>1,613 | 22.0    | 0.504   |
| Reported use of grievance  | 63/203       | 32.3    |               |         |         |

|   |  |  |  |  |  |
|---|--|--|--|--|--|
| procedures regarding HIV discrimination |  |  |  |  |  |
|---|--|--|--|--|--|

We sought to identify whether there were any differences between the HIV positive and HIV negative men on obtaining a successful outcome to their complaint of anti-gay discrimination at work (i.e. completely resolved). There was no difference. We have presented the data on successful outcome of official complaints regarding HIV discrimination, which shows a greater proportion of the HIV positive respondents reported a successful outcome for anti-gay discrimination (25.0%) than HIV discrimination (22.2%), but the percentage difference was small (2.8%) (see Table 51).

Table 51: Positive Outcome of Official Complaints/Grievance Procedures - Anti-Gay and HIV Related Discrimination

|   | HIV Positive |         | HIV Negative |         | P value |
|---|--------------|---------|--------------|---------|---------|
|   | n            | Percent | n            | Percent |         |
| Reported outcome of use of grievance procedures regarding anti-gay discrimination – Measured by reporting 'completely resolved' | 24/96        | 25.0    | 87/355       | 24.5    | 0.993   |
| Reported outcome of use of grievance procedures regarding HIV discrimination – Measured by reporting 'completely resolved'      | 14/63        | 22.2    | -            | -       | -       |

We were also interested in whether there was a difference between HIV positive and HIV negative men on their awareness of the Employment Equality [Sexual Orientation] Regulations 2003, which provides legal protection from anti-gay discrimination at work. The difference between the two groups was not significant. We have presented the data on awareness of the DDA among HIV positive men which shows that a greater proportion was aware of the Sexual Orientation Regulations (84.1%) than the DDA (66.5%) (see Table 52).

Table 52: Reported Prior Awareness of Legal Protections - Anti-Gay and HIV Related Discrimination

|  | HIV Positive |         | HIV Negative |         | P value |
|--|--------------|---------|--------------|---------|---------|
|  | n            | Percent | n            | Percent |         |
| Reported prior awareness of Sexual Orientation Regulations | 1482/1,762   | 84.1    | 5,562/6,484  | 85.8    | 0.078   |
| Reported prior awareness of the DDA.                       | 1,186/1,784  | 66.5    | -            | -       | -       |

## Conclusions

### **Profile of the Sample**

We compared respondents in this study (regardless of HIV status) with those from an earlier online study and national probability sample of homosexually active men on demographic variables. Acknowledging important caveats concerning direct comparability, the respondents in this study did not appear to be markedly different on demographic criteria. We also compared our subsample of HIV positive respondents to a sample of HIV positive gay and bisexual men recruited in a clinic based survey. Again, few important differences were evident. Using an online survey method, we were able to recruit a large sample of eligible respondents in order to conduct our analysis. While it is not possible to say that any sample of homosexually active men is 'representative', we can say that this sample compared favourably with others from reliable and robust studies reported elsewhere.

We were able to develop a profile of the HIV positive men in the study. They tended to be aged 30-49, lived in England and London, were white British, gay and educated to degree-level or above. Most were in full-time employment and worked in a large city or town. They tended to describe themselves as professional and the majority had had one or two employers in the last five years and earned within the £20,000-£29,999 annual salary bracket. Most worked in the private sector. We were able to compare the HIV positive men with the HIV negative men on demographic characteristics and found some significant differences on variables such as: age, ethnic group, sexual orientation, country and area of residence and employment, self-reported occupational class and employment sector. However, the degree of difference between the two groups was often no more than a few percentage points. There were no significant differences in whether respondents worked full-time, were permanently employed, had had only one or two employers in the last five years and annual salary. On the whole the two groups were quite similar in terms of demographic profile. Two variables where there was a greater degree of difference were age and city of residence. The fact that HIV positive men were more likely to be resident in England and London and to work in large city or town is probably a reflection of the concentration of HIV infection in London and other major cities (Health Protection Agency 2008). Similarly, the largest proportion of homosexually active men being seen for HIV care in the UK are aged 35-44, therefore we would expect HIV positive men to be concentrated in this group (Health Protection Agency 2008).

### **Stability of Employment**

We also presented data on the employment experience of HIV positive respondents on key variables. To our knowledge, this is the largest study of the subject in the UK and we have made some important new discoveries. Their employment was relatively stable with most in permanent contracts and with little movement between employers (most had had only one or two employers in the last five years). They were not significantly different from the HIV negative men in this respect. Their employment was widely dispersed across a range of professions and trades and while most worked in the private sector, a sizable minority (over a quarter) worked in the public sector. Hospitality, healthcare, retail, education, IT and financial services sectors were well represented.

## **Satisfaction With Work**

The average annual gross pay for males in the UK is £32,838 (Office for National Statistics 2008). The largest proportion of HIV positive men in this study were earning in the £20,000 - £29,999 bracket, which is below the national average, but in line with that of the HIV negative men who responded to the survey. This is perhaps reflected in respondents' assessment of their satisfaction at work. In each case, over half of respondents were satisfied with important aspects such as initiative over their work, sense of achievement and satisfaction with the work itself but were least satisfied with level of pay. When we compared HIV positive and HIV negative respondents on satisfaction with pay (and with their work itself), we found no significant difference. Both groups were also equally likely to report a positive relationship with their manager, suggesting that HIV positive men were no less well-integrated into their workplace according to these measures.

## **Impact of HIV Diagnosis on Work**

The qualitative findings suggested that the point of initial diagnosis can be a particularly difficult time for HIV positive people but that in most cases, after the initial shock and anxiety, adjustment takes place. We were interested to examine whether this was reflected in the responses of questionnaire respondents. A sizable proportion of respondents did report an impact on their working life upon initial diagnosis, mostly stress, anxiety and tiredness, with almost a third reporting that they needed some time off. These effects were considerably lessened when we asked respondents about current impact on working life. However, it was also important to note that almost a third of respondents said that their initial diagnosis had no impact on their working life, and this rose to over half in relation to current impact. Therefore, it cannot be assumed that all people living with HIV will react to initial diagnosis and the ongoing impact of living with HIV in the same way.

## **Changes to Working Life**

Only a third of respondents had made some change to their working life as a result of living with HIV, and of those who did, changes to hours worked and start/finish times were most common. However, this did not mean that there had been no other limitations. International travel had proved difficult for a quarter of respondents suggesting that travel restrictions remain a problem for a significant minority. A quarter of respondents also felt that HIV had stopped them from seeking a new job. As the qualitative work showed, HIV positive people could be reluctant to change employers and potentially jeopardise a secure employment situation that enabled them to accommodate living with HIV, and they expressed loyalty to employers who were supportive.

## **Health and Sickness Leave**

Overall, HIV positive respondents in this study were relatively unburdened by poor health. Less than 10% rated their mental or physical health as poor. Rates of reporting physical health as good were roughly similar to an online sample and national probability study that included homosexually active men (Evans, Wiggins et al. 2007). However, the HIV negative men in this study rated their physical and mental health more positively (around 10 percentage points difference in each case). Despite the differences in perception, there was no significant difference in the number of days sick leave HIV positive men took compared with HIV negative men for non-HIV related illness.

Over 70% of the HIV positive men had also taken no HIV-related sickness days in the last 12 months, and over a third had taken no leave in order to attend HIV clinic appointments. Respondents were often making use of existing flexibility in their jobs to attend appointments; only 3.7% used sick leave. The need for daily medication did not appear especially burdensome with almost all respondents taking their medication only once or twice a day and less than a fifth took it during working hours.

### **Disclosure**

In practice, over half of respondents had disclosed their HIV status to someone at work. Colleagues (40.2%) and managers/supervisors (40.0%) were mostly those disclosed to. This compares to disclosure rates of 41.4% to colleagues and 28.4% to employers in a sample of HIV positive gay clinic attendees in East London (Elford, Ibrahim et al. 2008). A greater number of HIV positive men had disclosed their sexual orientation (91.7%) than had disclosed their HIV status (61.5%), implying that there are still significant perceived barriers to HIV disclosure at work.

For over three-quarters of the men in this study, the response to the disclosure of their HIV status was generally positive: less than one in ten reported a negative response. We were interested to see whether there were any significant differences between the men who had disclosed their HIV status at work and those who had not. Working for a large employer (500+ employees) was not significant but those who were taking ART, taking ART in working hours and perceived that their body showed some physical sign of living with HIV were more likely to have disclosed. Those working in the private sector were less likely to have disclosed.

It is important to note that the decision to disclose one's HIV status at work is a highly personal one; participants in the focus groups explained how they made considered decisions after a careful assessment of the costs and benefits of doing so in their workplace. Among the questionnaire respondents, those who did not disclose most frequently reported that they simply saw no need to. However, fear of poor treatment or breaches of confidentiality were also significant concerns.

### **Pre-Employment Questionnaires**

We noted in the qualitative findings that pre-employment occupational health questionnaires and other pre-employment procedures that encourage applicants to disclose their HIV status (or disability under the DDA) can be problematic for HIV positive applicants, since they fear that the information will be used to discriminate against them. A small proportion (17.8%) was asked directly about their HIV status as part of such processes. The majority of these respondents reported that it made them feel uncomfortable to be asked about their HIV status in this way and just over a third chose not to disclose their HIV status.

### **HIV Discrimination**

Over a fifth of men (22.1%) who had disclosed their HIV status at work had experienced HIV discrimination in a current or previous job (the figures were 14.1% in a previous job and 7% in a current job). However, in each case an additional 8% were uncertain about whether poor treatment was related to HIV-discrimination. As the qualitative findings showed, perpetrators could be subtle in their techniques making it difficult to identify the precise motivation for the poor treatment. The most common forms of discrimination reported were being excluded/treated differently or having confidentiality about their HIV status breached. Around two-fifths of those

who had experienced HIV discrimination in a previous job believed they had lost their job as a result.

We examined whether there were any significant differences between those who had disclosed their HIV status and experienced discrimination and those who had disclosed but did not. Working for a large employer (500+ employees), working in the private sector, taking ART and taking it during working hours were not significant. Only one factor proved significant: respondents who perceived that their body showed some physical sign of living with HIV were considerably more likely to report HIV discrimination.

It was notable that of the 203 men who had experienced HIV-related discrimination in a current or previous job, only 63 had made a complaint or initiated grievance procedures. We do not know why many chose not to pursue redress in this way. It may be the case that matters were resolved by alternative means. However, given the way in which focus group participants talked about the importance of the management of information about their HIV status, it is a reasonable assumption that involvement in the procedure itself may be a disincentive. Although a number of complaints were ongoing, it is important to note that almost a third of complaints were not resolved to the satisfaction of the complainant. It was notable that when we asked respondents about where they would be most likely to turn for help if they did experience HIV discrimination at work, a clear preference was for HIV support organisations over and above those available in the workplace. Just over a quarter were prepared to turn to trade unions, who might traditionally be thought of as a source of support in addressing workplace discrimination.

### **Sexual Orientation Discrimination**

This study primarily focussed on issues of HIV but we also examined experience of discrimination related to sexual orientation. Overall, 7.1% of HIV positive men had experienced anti-gay discrimination in a current job and there was no statistically significant difference between them and the HIV negative men in this respect. The same proportion (7.0%) of HIV positive men had experienced HIV discrimination in a current job. There was no statistically significant difference between the HIV positive and HIV negative men on whether they had pursued grievance procedures at work for anti-gay discrimination, but a higher proportion had pursued grievance procedures for HIV discrimination than anti-gay discrimination. There was also no difference between the HIV negative and HIV positive men on whether they had obtained a successful outcome to their complaint for anti-gay discrimination. Levels of awareness of the legal protections available to people experiencing anti-gay discrimination at work (the Employment Equality [Sexual Orientation] Regulations, 2003) were high (over 80%) and there was no significant difference between the HIV positive and HIV negative men regarding this. Among the HIV positive men, the level of awareness of the Sexual Orientation regulations was higher than awareness of the DDAs protections for HIV positive people at work.

### **Awareness of the Disability Discrimination Act**

Only two-thirds of HIV positive respondents were aware of the DDA and its legal protection for HIV positive people at work before completing the survey and almost a third of these respondents did not know that this entitled them to ask for reasonable adjustments. Given that this is such an important provision for people living with HIV there would seem to be scope to increase knowledge still further. It is interesting to speculate how many of those respondents who were using annual leave or sick leave to attend their HIV clinic might instead have simply asked for the time off as a reasonable adjustment if they had known about their rights in this respect. It is also

notable that HIV positive respondents' level of awareness was lower in relation to the DDA compared with the Employment Equality [Sexual Orientation] Regulations 2003.

### **Reasonable Adjustments**

We sought to understand how many of those respondents who knew of the DDAs legal protection and the right to ask for reasonable adjustments had actually done so. Just over a quarter had sought some form of adjustment and most were either fully or partially granted. The majority of the changes that respondents needed were seemingly straightforward requiring little more than flexibility on the part of the employer (time off for clinic visits, flexible hours, occasional working at home). What was of concern was the small number of men who had seen their request for a reasonable adjustment refused. However, we do not know whether refused requests were in fact legitimate. When we asked about what workplace changes employers could make that respondents would find helpful, this reflected the requests for reasonable adjustments, so that time off for clinic appointments was most popular, followed by the option to work at home occasionally. Again, these appeared to be relatively simple requests to accommodate.

### **Getting Advice**

We also wanted to understand HIV positive respondent's preferences for where they would like to obtain advice and information about issues of HIV and employment. They had a strong preference to obtain such advice from HIV support organisations rather than sources at work or from trade unions or Government.



## Discussion

### Review of the Study

We gathered qualitative material from a series of focus groups with gay men and black African men and women in London, Manchester, Luton and Glasgow. As noted, we can be confident that we were able to include a range of professions and employment sectors across the two groups of interest. The groups led to important insights into the experience of living with HIV and maintaining working life.

We also gathered quantitative data via an online survey of gay and bisexual men and compared respondents in this study with those from an earlier online study and national probability sample of homosexually active men on demographic variables. Acknowledging important caveats concerning direct comparability, the respondents in this study did not appear to be markedly different on demographic criteria. We also compared our subsample of HIV positive respondents to a sample of HIV positive gay and bisexual men recruited in a clinic based survey. Again, few important differences were evident. This allows us to have confidence in the findings of the survey. We further compared the online sample of HIV positive and HIV negative respondents and presented data on the demographic profile of HIV positive respondents and their experience of employment.

However, there are some limitations to the study that must be acknowledged. The literature review conducted here was designed as a scoping study to assess the extent of research material available and to develop a sufficient overview to contribute to the development of the study. Systematic techniques were used for literature searching but this should not be confused with a full systematic review. Moreover, only sources of published material were searched and 'grey' literature was not included. However, the exercise achieved its objective of highlighting the important issues for further investigation and identified the apparent paucity of relevant UK research.

In relation to the focus groups, it is disappointing that we were not able to convene a specific group for black African men, although we were able to include them in the mixed sex groups. Similarly, none of the participants in the gay and bisexual men's groups were from black or minority ethnic backgrounds and these 'voices' will be important to include in future studies.

We also acknowledge that significant numbers of respondents to the online questionnaire did not know or did not disclose their HIV status and were excluded from the study. It should also be noted that the men taking part were a self-selecting sample and responded based on self-reported HIV status. Therefore, the findings should not be generalised to all gay men living with HIV in the UK or other groups such as heterosexual black Africans or those infected through injecting drug use. Other important limitations concern accessibility: by necessity, access to a computer, the internet and use of Gaydar were all required to take part in the survey. With the increasing growth of internet access and the fact that Gaydar is the most popular online forum for gay men, offering free membership, we would not expect these factors to be major barriers to participation in the survey but they may have deterred men who were less IT literate (Office for National Statistics 2008). However, as noted our sample compared favourably to that from a large national probability study and clinic recruited sample and provides an important insight into the employment experiences of a section of gay and bisexual men living in the UK.

Acknowledging these limitations, we conclude the aims of the study to have been met. To our knowledge, this study represents the most comprehensive research on the employment experiences of HIV positive gay and bisexual men and black African men and women in the UK and we have made some important new discoveries.

## Literature Review

The literature review highlighted how the introduction of ART changed the employment options of many people living with HIV forever, but that it was important to recognise that employment is also mediated by individual and social factors, including social inequalities so that the employment experiences of HIV positive people are not uniform. It further indicated that employment not only plays a crucial role for HIV positive people in economic terms but is strongly implicated in emotional well-being and social integration. Stigmatising attitudes and fears about discrimination remain important concerns for many HIV positive people at work and there is a lack of research about how measures designed to protect them (notably) the DDA are being used in practice.

## Focus Groups

The focus groups provided a rich insight into the experiences of the men and women who took part. The overall story that emerged was one of the initial shock and disorientation of diagnosis, giving way eventually to acceptance and the need to 'get on' with life, including the demands of work. Living with HIV was not without its ongoing effects. Some were physical, such as feeling fatigue to a greater degree and coping with the demands ART, which could often be dealt with by reasonable adjustments and understanding about the sometimes embarrassing side effects of starting or changing an ART regime. Others were psychological, leading some to re-evaluate their lives, including the place of work in it, concluding in some cases that a less demanding or stressful working life would be beneficial, while others decided that their working life should be as unaffected as possible. Where ART treatment was effective and health was maintained this was indeed possible, although there were in some cases practical barriers to do with international travel for example.

The issue that most exercised participants in the focus groups was that of disclosure. Generally, participants reported making a careful cost-benefit analysis: weighting up the benefits to be gained in easier management of their condition at work versus the possible risk of discrimination and exclusion. Factors such as their own reputation as a worker, the social environment of their workplace and the existence of protective human resources policies and competent staff were important considerations. When participants decided to disclose they wanted control over the process: a time and place of their choosing, to a person they trusted with the information handled sensitively and confidentially. They were deterred by pre-employment processes which requested disclosure and had little confidence that information gathered in this way would not be used to discriminate. They were made anxious and angry when others (colleagues, managers, and human resources staff) did not manage information about their HIV status appropriately.

The fear of HIV discrimination at work was very real for many of the participants in the study, although there was some indication among those who had disclosed that in practice disclosure was often responded to positively by those entrusted with the information. This did not mean that instances of discrimination were not recounted and it is important to note that perpetrators could reportedly be devious in their methods in order to avoid sanction. It was also important to

acknowledge that these participants had multi-faceted identities, including their sexual orientation or ethnic identity, which could also motivate discrimination.

Awareness of the DDA and its protections and entitlements was variable and some participants were disappointed at a perceived lack of awareness among their employers about the implications of the Act for HIV positive people. It was clear that those who were able to disclose their HIV status at work had a clear advantage in being able to ask for reasonable adjustments if needed. On the whole, adjustments requested were fairly straightforward and simple to accommodate, requiring little more than flexibility on the part of the employer. However, refusal or clumsy handling of requests had significantly soured perceptions about employers among participants who had experienced this. The traditional 'chain of command' line management structure could work well for handling disclosures and reasonable adjustment requests but other participants needed alternative ways to make their needs known and did not always have positive experiences of approaching human resource or occupational health professionals. Where there were significant problems participants often wanted to turn to external sources of advice, outside of this structure, with Trade Unions showing some popularity among the black African participants in particular. Overall, the group of men and women who took part were working flexibly to manage their condition at work and meet the demands of work placed upon them.

### Online Survey

The questionnaire findings reinforced much of the insight gained from conducting the focus groups. The men in this study worked across a range of sectors and professions and their employment appeared relatively stable. They were generally satisfied with most aspects of their work and positively rated their relationship with their managers. For a significant minority, HIV was felt to have no impact on working life at all but again, concerns about stress, anxiety and fatigue were reported, particularly following initial diagnosis.

A minority had made adjustments to working life as result of living with HIV but these were fairly straightforward changes to hours worked or start/finish times. Of more concern perhaps, were the quarter of respondents who had felt unable to seek a new job, perhaps denoting that HIV was limiting their career progression and economic prospects. The removal of barriers to international travel would also be helpful to over a quarter of respondents.

Any stereotypical assumptions that HIV positive workers will take excessive sick leave would be challenged by this study. The largest proportion took no sick leave related to HIV symptoms in the last year and time off for clinic attendance was also fairly minimal, and often accommodated by existing flexibility within respondents jobs. Overall, most rated their physical and mental health as good and the 'burden' of managing medication seemed fairly minimal with most taking only one or two doses per day.

Over half had also disclosed their HIV status at work and most who had done so reported a positive response. The differences identified between those who had disclosed and those who had not can perhaps be explained by respondents wanting to accommodate their 'hidden disability' becoming 'visible'. For example, we might speculate that needing to take ART and take it during working hours may have been seen to require explanation. Similarly, perhaps a perceived physical sign on the body that the person is living with HIV may also prompt disclosure. We might also speculate that those working in the private sector may perceive their working environments as less receptive and accommodating than those in the public sector and this would accord with the qualitative findings.

Again, those who did not disclose either perceived that there was no advantage to doing so or feared discrimination or breach of confidentiality. The majority of all respondents also reported feeling uncomfortable about pre-employment questionnaires that requested information about HIV status and only around 40% said that they had in fact disclosed, suggesting that such measures serve little purpose in practice. It was perhaps unsurprising, given the changing social attitudes that the gay and bisexual men in the focus groups described, that disclosure of sexual orientation was more common than HIV status.

Fear of discrimination was a commonly reported reason why respondents did not disclose. The proportions who reported HIV discrimination at work among those who had disclosed their HIV status were 7% (current job) and 22.1% (current or previous job). The forms of discrimination described were exclusion and differential treatment, although a small number felt that they had lost jobs in the past as a result of HIV discrimination. The perception that their body showed some physical sign of living with HIV was the only variable tested that proved to be correlated with experience of discrimination at work. Again, we might speculate that this is a function of the 'hidden disability' in some way becoming visible, allowing the person to become identifiable and thus vulnerable to discrimination.

Although the numbers were small it is potentially of some concern that only a third of those who had experienced HIV discrimination had made a complaint or brought a grievance procedure and that under a third of cases were satisfactorily resolved according to the perception of respondents. This is perhaps also related to the lack of awareness of the DDA, with a third of respondents being unaware of its legal protections for HIV positive people and almost a third of those who did know of its protections being unaware that it also entitled HIV positive people to ask for reasonable adjustments. Awareness of the Sexual Orientation regulations was considerably greater than awareness of the DDA. Where there was a need for further advice or information about responding to discrimination or workplace issues more broadly, respondents expressed a clear preference for community based organisations.

The extent to which adjustments had been sought was relatively small: just over a quarter of those who had disclosed and were aware of the DDA and its entitlements had asked for them. The adjustments requested were again relatively simple and required little more than flexibility on the part of the employer (e.g. time off for clinic appointments, flexible working). In the majority of cases these were granted. Of perhaps greater concern were the cases where adjustments had been refused. Future research might beneficially examine this issue further. Workplace changes that respondents regarded as potentially helpful also reflected the request for greater flexibility at work.


An important question was the extent to which the HIV positive respondents were significantly different from their HIV negative counterparts. On the whole differences were few. On demographic characteristics, even statistically significant differences were often only in the order of a few percentage points or explained by known facts about the profile of people living with HIV in the UK (e.g. age and geographical distribution). Their employment appeared no less stable according to number of employers and they were no less likely to have a good relationship with their manager or be satisfied with key aspects of work.

However, they were considerably less likely to report positive physical and mental health. We might perhaps reasonably assume that the knowledge that one is living with a long-term condition will be implicated in the difference in perception. Importantly, this did not translate into a greater average number of sick days taken for non-HIV related reasons and the majority of HIV positive respondents did not take any sickness leave due to HIV related illness.

## Concluding Remarks

Ultimately what conclusions can be drawn from this study? After more than twenty-five years as a society living with the fact of HIV, and four years after the amendment of the DDA to encompass HIV positive people, it is disheartening still to find anxiety amongst some taking part in this study about disclosing their HIV status at work. Fundamentally, the inability to disclose when they wished to prevented participants from asking for the relatively straightforward adjustments to which they were entitled to facilitate their employment. This is to the detriment of HIV positive people and their employers. Legally and morally there is no place for discrimination at work such as exclusion and bullying based HIV status, yet this study showed that such discrimination still exists, with apparent scope to improve the use of complaint mechanisms to obtain satisfactory redress.

However, it is important to emphasise that the overall picture being presented by the findings of this study is very much a positive one. They suggest that those who took part were significantly benefiting from the effective medical treatment now available and working flexibly with their employers to play their part in the UK workforce.



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