



FROM A POSITIVE PERSPECTIVE: KEY ISSUES FOR PEOPLE LIVING WITH HIV IN THE UK

December 2007



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1. Introduction

I am delighted to be able to introduce this report which is the outcome of a combined effort by HIV organisations across the country, and would not have been possible without the commitment and enthusiasm of the UK Coalition of People Living with HIV and AIDS (UKC) and their volunteers. The origins of this work go back to the *Changing Tomorrow* conference held in 2004, which the National AIDS Trust organised in partnership with UKC, Positively Woman and the National Long Term Survivors' Group. This event enabled over 250 people living with HIV (plwh) to come together to consider how to improve the skills of plwh in accessing and managing their health care, employment, education, legal and financial affairs and how to develop leadership and sustainable networks of support for plwh.

UKC wanted to build on the success of this conference and to develop the process further to ensure greater regional involvement in future events which brought plwh together. To this end, UKC co-ordinated a series of meetings, in partnership with local organisations, and were planning to organise a major two-day conference in September 2007.

Sadly the closure of UKC in July this year meant they were unable to complete this project. However, a significant amount of work had already been done, in partnership with organisations supporting plwh across the country, to identify areas of shared concern and issues to be explored at a national conference. UKC also published a questionnaire in *Positive Nation*, amongst other places, which had nearly 1,000 responses.

There was a commitment to ensure that all the time and effort put in by UKC staff and volunteers, organisations supporting plwh across the regions and focus group attendees, was put to good use. As a result, the National AIDS Trust have produced this report, analysing outcomes from regional focus groups/meetings and drawing on the UKC questionnaire, to identify what those involved in this process felt the key issues are for plwh in the UK. I would like to thank the Department of Health for their support which enabled us to allocate staff time to complete this project.

This report will be used as the basis of a smaller-scale one day conference to be held in London on 1 March 2008, bringing together representatives from all the regions who contributed. A small steering group of HIV organisations are taking this conference forward, with Positively Women leading on the event organisation. The National AIDS Trust will work with participants to record the outcomes from the conference and ensure these are reported back to all those involved in the process and to key policy formers and HIV stakeholders.

This report reflects the great collective will from plwh and organisations supporting them across the UK, to ensure the voices and concerns of those living with HIV are heard. I now look forward to the event on 1 March where we will have the opportunity to discuss how we can make sure that the Government and policy makers better understand these concerns and the role of plwh can have in both influencing them and holding them to account.

Deborah Jack
Chief Executive, National AIDS Trust

2. Executive summary

This report looks at key themes for plwh in the UK, as identified through the UKC regional focus groups/meetings and the UKC questionnaire. Full details of how UKC collected this information are provided in the next section and a summary of the questionnaire is given in section six. This executive summary provides an overview of the themes raised at the regional focus groups/meetings, with those themes raised most frequently detailed first.

All the regions raised concerns relating to the **NHS and healthcare services**. Issues highlighted under this heading include the need for better HIV education for healthcare workers, issues of confidentiality, involving plwh in the design of services, concerns about the danger of reduced funding for treatment, discrimination in healthcare settings and the variable quality of rural services.

Education was second most recurrent theme. People stressed the need for further prevention campaigns for the general public as well as messages to tackle stigma. This links to the next most frequently raised concern, **stigma and discrimination**, and the associated sense of isolation for many plwh.

Employment was highlighted as an important issue. The main concerns were about disclosing HIV status at work, explaining gaps in employment history, and combining a long term health condition with a career.

Poverty and housing featured frequently in the discussions, with concerns about the financial implications of not being well enough to work and also the question of confidentiality in shared housing. People also raised concerns about securing mortgages and insurance given their health condition.

Concerns about **disclosure** were raised. People voiced fears about the social consequences of disclosing their HIV status and the legal implications of not disclosing it.

This links to the next most frequently raised issue, **prosecution for the transmission of HIV**. Here people had fears that the move towards prosecuting people for the transmission of HIV will inhibit people from taking an HIV test and will increase stigma.

Concerns about cuts in **funding for voluntary sector support** for plwh came up, alongside recommendations for how these services could be improved.

Immigration issues, the fear of being deported to countries where it is not possible to access treatment, and the importance of making treatment available to all in the UK, were raised. The financial implications of not being able to work as an asylum seeker and the negative impact this has on mental and physical health were stressed.

Finally concerns over **international travel restrictions** and travel insurance were mentioned in several regions.

Section four provides a more detailed overview of these areas of concern as well as a list of other topics raised during the regional focus groups/meetings. Section five details which topics were raised in each region.

3. How key themes were identified

The 2004 conference, *Changing Tomorrow*, was hugely oversubscribed and some people found it difficult to travel to attend. In an attempt to ensure that more plwh would be able to contribute to the next conference and benefit from sharing experiences and concerns with other plwh, UKC designed a new regional approach.

From spring to early summer 2007 a team of UKC staff and volunteers worked with organisations supporting people living with HIV across the UK to set up local focus groups/meetings for plwh in the area. UKC volunteers received training and support during the project and the experience helped many go on to find paid employment. Some regions involved in this process organised regional conferences to draw together the findings from focus groups/meetings held in their region. In total 65 focus groups/meetings were held involving over 600 plwh. UKC provided each group with a briefing and guide questions in advance of the meetings, though this was not used by all the groups. This briefing is included at Annex A. A list of HIV organisations and support groups involved in the process is included at Annex B. It is thanks to the commitment and enthusiasm of UKC staff and volunteers, local organisations and focus group attendees, that the collection of information on such a large scale has been possible.

Sadly UKC ceased to operate in July 2007. However, by this stage most of the focus group work had been completed and UKC staff and volunteers were already in the early stages of analysing the data to identify areas of shared concern and issues to be explored further at a national conference. The National AIDS Trust were pleased to be able to continue this work and have studied the conclusions from the focus groups/meetings. The next section of this report details the key issues and themes from across the regions and section five has table which breaks down these themes by region.

The information gathering and analysis process to identify themes has not been perfect; it has given equal weight to each focus group, although some groups were larger than others, and informal feedback has indicated that on occasion some individuals dominated discussions. It is inevitably based on the views of those individuals involved in the process; these views may not be representative of the views of all plwh in each region. However, despite these imperfections, the analysis does provide a valuable indication of key issues for plwh in the UK.

To ensure that as many plwh as possible could contribute to the process, UKC also produced a questionnaire made available to people through *Positive Nation* and on the UKC website, amongst other places. There were almost 1,000 respondents to the questionnaire which covered a whole range of issues encountered by people living with HIV. Although the analysis was not completed, some findings from the questionnaire are detailed in section six of this report. A copy of the questionnaire can be found at Annex C.

4. Key themes emerging from the regional focus groups

It is striking that, though there were some regional variations, most of the focus groups/meetings highlighted the same issues, illustrating how these concerns resonate across the country. Whilst some regions used different language to describe these concerns, the underlying issues were similar. It has been necessary to apply a common vocabulary to the arising themes from the focus groups/meetings to enable us to analyse and compare the outcomes. These themes are presented below, with those raised most frequently across all individual focus groups/meetings presented first. There were some points raised that it has not been possible to discuss in detail in this summary report. However, to ensure that these topics are included, they have been listed under the 'other' heading at the end of this section.

Many of the focus groups/meetings began with a general discussion about how HIV has affected people's everyday lives and sense of self. Though nearly everyone said that their HIV diagnosis had changed their life, many people had a feeling of hope. There was a sense that new treatments were offering a 'second chance in life', particularly for those who had been diagnosed several years ago. Some people felt that since their diagnosis they have made more effort to look after themselves and subsequently felt healthier. However, others experienced difficulties with treatment and found managing adherence to their drug routine difficult. There were also concerns about lipodystrophy, wasting and other physical side effects. Some felt their condition put a strain on their mental health and personal relationships, whether with friends or family. There was a contrast between those who felt that their whole life was focused around HIV and those who felt they could manage it very effectively and it no longer dominated how they lived. Several groups wanted to ensure that plwh are not seen as victims but active people who can be happy and healthy and live fulfilling lives.

NHS and healthcare services

Issues related to the NHS and healthcare services were raised in every single focus group/meeting. A wide range of concerns (and sometimes positive comments) were discussed under this heading so the theme has been divided into sub headings.

- **Education for healthcare workers** The theme raised most frequently in this area – in fact the theme raised most frequently overall – was the need to develop the awareness and understanding of hospital staff and those working in primary care. There were repeated calls for more training for healthcare staff about the reality of living with HIV, from the hospital cleaners, to nurses, consultants, A&E staff, GPs and dentists. The need for better GP training was particularly stressed. There was a call from Scotland for HIV specialist practitioners to operate within GP surgeries until the overall education levels in primary care improve.
- **The issue of confidentiality** in healthcare settings was a recurring theme. In London and the North West this was a particular concern for those for whom English is a second language and who rely on interpreters. They felt that the confidentiality of their condition may be compromised when there are constantly changing interpreters, some of whom may have close links to the patients' community. There was also a concern about confidentiality in open plan waiting rooms where it is easy to identify those waiting for HIV services. Some

mentioned their fear that having their HIV status clearly visible on the GP's computer screen was a threat to their confidentiality. In Wales there was some trepidation about plans for a central medical record system and the potential impact on patient confidentiality. Medical confidentiality was a particular concern for women living with HIV who had children that were unaware of their status.

- **Voice and redesigning services** People's everyday experiences of healthcare systems meant there were many calls for service improvements. The importance of plwh being involved in designing and developing healthcare services was highlighted. Several regions suggested that medical clinics could link up better with other services (including dental practices, mental health and social services) and provide more holistic services as well as information about where to access HIV support.¹ The idea for a 'one stop shop' approach integrating medical and social care concerns was put forward. This was followed by the request for services to be made more accessible and have more flexible opening hours.
- **Funding for NHS treatment** Fears about the limited amount of NHS funding available and the consequences for HIV care were raised in several regions.² Some felt they may not be being prescribed the most effective drugs because of cost concerns. There were also fears about future National Institute for Clinical Excellence (NICE) decisions and the consequences for the future availability of improved treatment (following the example of certain cancer and Alzheimer's drugs which are not available on the NHS). Some people advocated ring-fenced funding for HIV treatment as they were concerned that money intended for HIV treatment is being spent on other areas.
- **Discrimination in healthcare settings** This was an area raised several times in London and the West Midlands regions. People felt they had received second class treatment because of their status. There was a particular concern about GPs' attitudes to HIV positive patients, with one focus group describing how they had been 'treated as aliens'. Whilst the need for better education for dentists was raised in nearly every region, discrimination in dental services was particularly highlighted in Wales, the East Midlands and East of England. In these regions there was a sense that most dentists don't even have basic HIV awareness and that discrimination was an every day occurrence.
- **Rural services** The lack of services in rural areas and accompanying sense of isolation was raised.³ There was a particular concern about the lack of HIV consultants and local support, and a call for rural services to be better connected. There was an overall sense that people living in urban areas have access to better treatment.

It is worth noting that whilst there were many concerns about NHS services across the UK, there was some positive feedback, particularly from London and the East of England. Specialist nurses, community nurses and specialist pharmacists were particularly singled out for praise.

¹ West Midlands, North West, South Central, South West and East of England.

² London, North West, South Central, Scotland, East of England.

³ West Midlands, South West, Wales, North West and East of England regions

Education

There was consensus in all the regions about the importance of education. A lot of emphasis was placed on the need to have educated health care employees, as discussed above. There were requests for more prevention messages for the general public as well as campaigns to address current myths about the condition and explain the reality of living with HIV. Both TV and radio campaigns were suggested as well as a focus on churches, mosques and schools. It was felt that concerted education campaigns would help to address stigma and discrimination faced by plwh (see below). A young people's group in the North West emphasized the need to ensure that there is education in schools about HIV transmission at an early age. In Scotland there was a call for education around risk for injecting drug users. There were requests for more information to be made available in different languages. People from some BME communities may not have the confidence to seek out sexual health information so education and prevention messages should be made easily available. Welsh groups also mentioned the importance of ensuring education messages reach rural areas where there is currently a lack of understanding. In several regions there was a concern about getting the right balance between ending stigma and ensuring people understand the reality of living with HIV with the need to get out the message that new medication does not mean it is ok to practise unsafe behaviours.

Stigma and discrimination

Concerns about stigma and discrimination were raised in most regions. This issue was closely linked to people's reticence to disclose their HIV status. There was a fear that this reticence makes it more likely that people will hide their status which may mean the virus is more likely to be spread. African respondees feared discrimination from their churches and their local communities. In an attempt to hide their status people travel long distances to access services where they hope they will not be recognised. This sense of secrecy brought with it fear and isolation and forms barriers to forming relationships and entering employment. There was also a concern about how parents can disclose their status to their children and a fear that their children will in turn be discriminated against because of their parents' status. In the North West and East of England, groups highlighted the stigma people felt in rural communities; they felt living with HIV in a big city might be easier. In Scotland people referred to their concern that they suffered multiple discrimination; HIV stigma was felt to be linked to racism and/or homophobia. In response to these fears and concerns there were requests for more public information and education campaigns. There is a need for messages that plwh can lead a productive life, continue to work and have relationships. There were also calls from the West Midlands for prominent spokespeople from the African community, both in the UK and Africa, to talk openly about HIV.

Employment

Employment was picked out as a central issue in several regions.⁴ There was a mix of experiences from people who had found employers to be supportive to those that had experienced discrimination and lost their jobs. In all regions there were fears about the effect of disclosure on going back to work. People raised the question of how to manage

⁴ London, South East Coast, Scotland, South Central, South West, West Midlands, East of England and North West regions.

employment history gaps. Despite these concerns there was recognition of, and welcome for, the support provided by the Disability Discrimination Act (DDA) 2005. People felt that the protections the DDA offered should be publicised more widely. In Scotland one focus group were concerned that if they successfully sued their employer for discrimination, it might be difficult to then get another job. They also felt that the term 'reasonable adjustments' was too weak. Aside from discrimination, the other main area of concern was that poor health can make it difficult for people to work full time or continue to have demanding jobs. This also had financial implications. People requested additional support to help plwh to fulfil their potential in the workplace. There was a clear message from the West Midlands that plwh want to continue to work and be educated.

Poverty and housing issues

Several regions mentioned the link between HIV, poverty and housing issues.⁵ People noted that living in shared accommodation can make it very difficult to retain confidentiality about one's condition and to adhere to treatment regimes. The financial impact of HIV was linked to an inability to work which then impacts on people's ability to pay rent or mortgage repayments. There were also concerns about people's future ability to secure a mortgage because of their HIV status and also about the expense of securing life or travel insurance. In the South West groups highlighted the need for more support for plwh to plan for their future security highlighting a lack of understanding about pensions. One group felt that insurance companies are failing to recognise the improvements for plwh due to antiretroviral therapy (ART) treatment. Some groups were also concerned that in the future Disability Living Allowances will be scaled down as there is a perception that treatment means plwh can now work. Asylum seekers particularly commented on the effect economic destitution had on their health (see immigration section below).

Disclosure

As mentioned above, disclosure was linked to stigma, discrimination, education and employment in many of the focus groups.⁶ Disclosure and its effect on personal relationships, families and friendships was a particularly heartfelt issue. People were concerned about how and when to disclose their status when beginning a new relationship. There was uncertainty about the legal implications of not disclosing HIV status, and yet fear about the implication of disclosing it. In the South West there was a sense that this fear of disclosure leads to emotional isolation. Some felt that HIV is still seen as 'a sin and a punishment' and this made it even more difficult for people to disclose their HIV status. For representatives from the African community there was a concern that disclosure to people here in the UK may mean that their status is then disclosed to family and friends in Africa where the condition is even more highly stigmatised.

⁵ London, West Midlands, North West, Scotland and East of England, South West and East Midlands

⁶ London, West Midlands, North West, South West, South Central, East of England, East Midlands and West Midlands



Focus Group Guide and Checklist

Introduction

This guide has been produced to assist you in the planning and running of focus groups which are an instrumental part of the **2007 UK & Ireland Conferencing of People Living with HIV and AIDS**.

Our aim is to consult with as many people living with HIV and AIDS (plwha) as possible in the UK & Ireland. One way of achieving this is to run a series of Focus groups between April and June 2007.

This Guide has been compiled by UKC's Community Engagement Volunteers (UKCEVs). It is only meant to be a guide. Some of the specific ideas contained in this guide are our ideas; they may not work for you. We do not want you to feel that the guide is too prescriptive. However, we do want everyone to have as clear an understanding of what we hope to get out of the **2007 Conferencing Experience** focus groups. This baseline guide will assist the UKC in evaluating the results in a uniform manner.

We would suggest that at the outset of the process the aims of the conference and of the conferencing process be made clear to the participants. These could be included in information submitted prior to the focus group, to inform the delegates in advance, otherwise they should be spelt out at the beginning of your focus group.

The aims of the focus groups are as follows:

- Gather and share information to empower plwha as well as feed back and influence policies and services
- Highlight regional differences (if any) to help define themes for debate at the 2007 UK & Ireland Conference of People Living with HIV and AIDS

Annex B

Organisations who contributed included:

ABplus
African Country Association
Africans Getting Involved
AHEAD
Bedfordshire Body Positive
Body Positive Dorset
Body Positive North West
Brigstowe Project
Community Health Action Trust
Derbyshire Positive Support
DHIVERSE
EAST
Eddystone Trust
Feedback South London
Fightback Trust
Freshwinds
George House Trust
Groundswell
HertsAID
HIV Scotland
Haemophilia Society
Ipswich Support Group
Kernow Positive Support
London Ecumenical AIDS Trust
MacFarlane Trust
Midweek
Oasis North London
Peterborough HIV Support Services
Positive Action South West
Positive Habesha
Positive Voice
Positively Women
Ribbons Centre
Selby Centre
Summit House
Str8talk
The Crescent
THT Birmingham
THT Coventry
THT Essex
THT Shropshire
THT Wolverhampton
UK Coalition of People Living with HIV and AIDS (UKC)
UKC Nottingham
Westminster Service User Forum
Women Living Positively



Please return this questionnaire to:
 UKC, Freepost 7768,
 London, SE1 5BR

My life with HIV is...

That's what we need to know and here's your opportunity to tell us.

We are beginning to shape next year's **Conference of People Living with HIV and AIDS**. This will be the UK's largest ever conferencing experience for the HIV positive community, with regional conferencing sessions supporting a central conference to be held 18 & 19 September 2007.

We want to hear your views on what it's been like for you living with HIV in every part of the UK since our **Changing Tomorrow** conference in 2004. But most of all we are interested about what your thoughts and concerns are in 2006, for 2007 and beyond.

- Please only complete this survey if you have been diagnosed with HIV.
- All the information you provide will be kept strictly confidential.
- Please complete in **BLOCK CAPITALS**.
- Return by **26 Jan 2007** and you could win **£50** in M&S vouchers
- You can also complete this questionnaire online at www.ukcoalition.org/2007

ABOUT YOU

<p>1. Are you...</p> <p><input type="checkbox"/> Male</p> <p><input type="checkbox"/> Female</p> <p><input type="checkbox"/> Transgender</p> <p><input type="checkbox"/> Transexual</p>	<p>2. Are you...</p> <p><input type="checkbox"/> Lesbian</p> <p><input type="checkbox"/> Gay</p> <p><input type="checkbox"/> Bisexual</p> <p><input type="checkbox"/> Heterosexual</p> <p><input type="checkbox"/> Unknown</p> <p><input type="checkbox"/> Prefer not to say</p>	<p>6. What is your ethnic group?</p> <p>White</p> <p><input type="checkbox"/> British</p> <p><input type="checkbox"/> Irish</p> <p><input type="checkbox"/> Other</p> <p>Mixed</p> <p><input type="checkbox"/> White and black Caribbean</p> <p><input type="checkbox"/> White and black African</p> <p><input type="checkbox"/> White and Asian</p> <p><input type="checkbox"/> Mixed other</p> <p><input type="checkbox"/> Asian or Asian British - Indian</p> <p><input type="checkbox"/> Asian or Asian British - Pakistani</p> <p><input type="checkbox"/> Asian or Asian British - Bangladeshi</p> <p><input type="checkbox"/> Asian or Asian British - other</p> <p><input type="checkbox"/> Black or Black British - Caribbean</p> <p><input type="checkbox"/> Black or Black British - African</p> <p><input type="checkbox"/> Black or Black British - other</p> <p><input type="checkbox"/> Chinese</p> <p><input type="checkbox"/> Other (please state)</p>
<p>3. How old are you?</p> <p><input type="checkbox"/> Under 25 <input type="checkbox"/> 45-54</p> <p><input type="checkbox"/> 25-34 <input type="checkbox"/> 55-64</p> <p><input type="checkbox"/> 35-44 <input type="checkbox"/> 65-74 <input type="checkbox"/> 75 or over</p>	<p>4. In which year were you first diagnosed with HIV?</p> <p>.....</p> <p>Do you associate with being:</p> <p><input type="checkbox"/> Newly Diagnosed (living with HIV for up to five years)</p> <p><input type="checkbox"/> Long-Term Diagnosed (living with HIV for over five years)</p>	<p>5. Do you personally know anyone else who is HIV positive?</p> <p><input type="checkbox"/> No <input type="checkbox"/> Yes <input type="checkbox"/> Don't know</p>

Non-Medical services	Not used/ not needed	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
Social services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Legal advice/solicitor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing office advisor	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Specialist HIV advice services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Phone/advice lines	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peer support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Counsellor/therapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employment & training services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

35. Since being diagnosed with HIV, have you had difficulties with any of the following?

	None	Occasional	Difficulties	Quite a few difficulties	Not applicable
Getting time off work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking medication at work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Organising childcare	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Housing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Experienced real stigma/discrimination	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

36. Do you have other needs relating to your HIV status that have not been met?

.....

.....

.....

INVOLVEMENT - HAVING YOUR SAY

In this section we would like to ask you about your involvement in the issues relating to HIV. By involvement we mean being able to have your say in your medical and non-medical needs.

37. Do you know how to get involved in decisions about:

	Yes	No
Your treatment/medication	<input type="checkbox"/>	<input type="checkbox"/>
Quality of/access to medical services	<input type="checkbox"/>	<input type="checkbox"/>
Your welfare needs	<input type="checkbox"/>	<input type="checkbox"/>
Quality of/access to non-medical/welfare services	<input type="checkbox"/>	<input type="checkbox"/>

38. How would you rate your current level of involvement in the following?

	None	Low	About right	High
Your medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quality of/access to medical services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your welfare needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quality of/access to non-medical/welfare services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

39. In the past, if you have been involved, how satisfied have you been with the outcome in decisions made about:

	Not involved	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
Your treatment/medication	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quality of/access to medical services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your welfare needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quality of/access to non-medical/welfare services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

40. What, if anything, prevents you increasing your personal involvement in decisions affecting how you and others live with HIV?

.....

.....

.....

.....

.....

41. What do you feel you could offer if you became more involved in decisions affecting how you and others live with HIV?

.....

.....

.....

.....

.....

2007 UK CONFERENCING OF PEOPLE LIVING WITH HIV & AIDS

42. Are there particular UK-wide topics you would like to see covered at the central conference in London in September 2007? These will be informed by the regions, but for example:

- Prosecution for transmission of HIV
- Medication/treatment
- HIV and work
- Building local networks of people living with HIV and AIDS
- Immigration issues
- Other

43. Are there locally specific topics you would like to see covered at your regional conferencing sessions?

.....

.....

.....

.....

44. I came across this questionnaire

In Positive Nation magazine

At the following HIV organisation

.....

Other – please specify

.....

45. Did you attend 2004 Changing Tomorrow conference of people living with HIV and AIDS

Yes No

Thank you for taking part in this questionnaire. If you would like to be kept informed of details of the conference, please write your name and address below. This information will be kept separately.

Name:.....

Address:.....

.....

.....

Email:.....

Telephone:.....

Would you prefer to be contacted by (tick all that apply)

Post Email Telephone

All your personal details will remain confidential and are protected under the Data Protection Act 1998.

If you would like us to contact you to discuss your ideas about the conference further, please tick this box:

If you would like to be involved in a conferencing session in your region to develop the ideas covered in this survey, please tick this box:

7. What is your country of origin?

.....

8. What is your immigration status?

- I am a UK citizen
 - ILR - (Indefinite Leave to Remain) I have the right to stay for an indefinite amount of time
 - ELR - (Exceptional Leave to Remain) I am a refugee with the right to stay for a fixed amount of time
 - I am a refugee formally seeking asylum
 - I am in the UK on a student visa
 - I have a work permit
 - I am a citizen of another EU country
- Which country
-

- Over-stayer
 - Rather not say
 - Other please specify
-

Arrived in UK (year)

.....

9. Do you live in:

- UK: please specify
 - England
 - Northern Ireland
 - Scotland
 - Wales
 - Town/city?
 - Borough?
 - County?
 - Outside the UK: please specify which country
-

10. Are you...

- Employed
- Full-time
- Part-time
- Unemployed
- Accessing benefits
- Medically retired
- Do not have right to work
- Undertaking voluntary work
- Other - please state
- In full or part time education

11. If unemployed are you...

- Seeking work
- In education

- In a back-to-work programme
- Full-time carer
- Too ill to consider employment

12. If unemployed how long have you been out of work?

- Less than 6 months
 - 6-11 months
 - 12-23 months
 - 24-25 months
 - 3 years +
- If over 3 years exactly how long?

13. If employed - Income source

(please tick all that apply)

- Private income
- Salary from employer
- No income
- Income support
- Incapacity benefit
- DLA
- Job Seekers Allowance
- NASS support
- Other

14. What do you consider to be YOUR biggest barriers to gaining meaningful employment?

(please tick all that apply)

- My HIV status
 - My general health
 - Physical health
 - Age
 - Benefits trap
 - My educational qualifications
 - My vocational qualifications/skills
 - My attitude
 - My confidence
 - Care commitments
 - Asylum status
 - Attitudes of others
 - Gaps in employment
 - Race/culture
 - Support network
 - My children
 - Criminal conviction
 - Filling out job applications/CVs
 - I choose not to work
 - Other - please state
-

15. Have you ever disclosed your HIV status at work?

- Yes
- No

16. Have you ever been asked to disclose your HIV status at work?

- Yes
- No

17. Have you experienced any discrimination at work relating to your HIV status?

- Yes
- No

18. Would you ever disclose your HIV status to an employer?

- Never
- Sometimes
- Only if I knew they would be supportive
- Always

19. What do you consider to be YOUR biggest barriers managing your career?

- My HIV status
 - My general health
 - Undisclosed HIV status
 - Managing health check-ups
 - My attitude
 - Attitude of others
 - My confidence
 - Care commitments
 - Maintaining work/life balance
 - Other - please state
-

20. What help/support do you feel you need to manage your career?

- Confidence that my employer has knowledge of managing HIV in the workplace
- Support structure for people living with HIV around managing work
- Advice on managing treatment/my health care at work
- Support from well trained union/staff representatives
- Legislation to support people living with HIV at work
- More education for co-workers on HIV

21. What was your approximate (gross) income in the last year, including benefits and other unwaged income?

- Less than £5,000
- Between £5,000 and £9,999
- Between £10,000 and £14,999
- Between £15,000 and £19,999
- Between £20,000 and £24,999
- Between £25,000 and £29,999
- Between £30,000 and £44,999
- Over £45,000

22. Which of the following educational qualifications do you have?

(Please tick all that apply)

- I have no educational qualifications
- O-Levels/CSE/GCSE
- A-Levels or equivalent
- Degree or equivalent, or above
- Other qualification

Please specify

.....

23. Are you...

- Single
- In a relationship and living with your partner
- In a relationship and not living with your partner
- Married/in a registered civil partnership and living with your partner
- Married/in a registered civil partnership but not living with your partner
- Divorced/Separated
- Widowed

24. Do you and your regular partner have the same HIV status?

- Yes, we have the same HIV status
- No, one of us is positive and the other negative
- Don't know whether we have the same status or not
- I don't have a regular partner

25. Do you have children (or stepchildren or adopted children) under 18?

- Yes
- No

26. Do your children live with you?

- Yes
- No

27. Do you have any other dependants?

- Yes
- No

If so, who?

.....

AWARENESS, NEEDS AND ACCESS TO SERVICES AND SUPPORT

28. Where do you prefer to go to get tested for STIs (Sexually Transmitted Infections)?

- GUM clinic
- HIV clinic
- Your own GP
- Family planning clinic
- Other local care facility

29. How easy is it for you to get information relating to HIV?

- Very difficult
- Difficult
- Not sure
- Easy
- Very easy

30. Where do you get information relating to HIV?

Which one(s)

.....

- Clinics

Which one(s)

.....

- HIV support organisations

Which one(s)

.....

- Magazines

Which one(s)

.....

- Newsletters

Which one(s)

.....

- Other (please specify)
-

31. Do you have access to the internet?

- Yes
- No

If so, where?

.....

34. From your personal experience in the last 12 months, how satisfied are you with the following?

Medical Services

- GP surgery/local doctor
- NHS direct (telephone)
- Hospital accident and emergency unit (A&E)
- HIV clinic/nursing
- HIV consultant
- GUM/STD clinic
- Dentist
- Optician
- Pharmacy
- Complementary/alternative clinic
- Psychologist/psychiatrist
- NHS specialist services (eg Cardiologists, Gynaecologists etc)
- Other please specify.....

	Not used/ not needed	Very satisfied	Satisfied	Dissatisfied	Very dissatisfied
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

32. How easy is it for you to get support relating to HIV?

- Very easy
- Easy
- Sometimes hard, sometimes easy
- Hard
- Very hard
- Unsure

33. How do you feel about the following statements?

I would always disclose my HIV status to a sexual partner

- Strongly agree
- Agree
- Not sure
- Disagree
- Strongly disagree

Employers will always discriminate against HIV positive employees

- Strongly agree
- Agree
- Not sure
- Disagree
- Strongly disagree

The media always represent people living with HIV in a fair way

- Strongly agree
- Agree
- Not sure
- Disagree
- Strongly disagree

