



European HIV Quality of Life Review 2004 - 2005

**Full Report
July 2005**

Final Results

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The European Men's Health Forum is an independent, non-governmental, non-profit making organisation established to raise male awareness across Europe. It aims to promote collaboration between interested individuals and organisations on the development and application of health policies, research, education and prevention programmes. EMHF provides a unique platform for non-discriminatory co-operation and information exchange within Europe and with other countries worldwide.

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Contents

Executive Summary	5
HIV epidemiological background	10
Methodology	11
Principal research question	11
Objectives	11
Questionnaire development.....	11
Roll-out and timing	12
Data collection process.....	13
Ethics	13
Results	14
Section 1: Characteristics of respondents	14
Section 2: HIV diagnosis	17
From infection to diagnosis.....	17
CD4 & viral load counts	19
HIV-related opportunistic infections.....	19
Feeling conscious of HIV status	20
Section 3: Medical/health care	21
Reasons for not taking HIV medication	21
From diagnosis to treatment.....	22
First experience of HIV medication.....	22
Current experience of treatment.....	26
Comparison of most recent drug regimen with previous ones	29
Side effects associated with most recent drug regimen	29
Worries about long term effects of medication	31
Drug resistance and adherence to treatment	32
Relationship with clinic doctor.....	34
Satisfaction with treatment centre.....	36
Most important aspects of treatment	37
Section 4: Physical & emotional well-being & satisfaction	39
Current ability to conduct daily living activities	39
Current experience of physical pain, fatigue and disrupted sleeping patterns.....	40
Experience of other diseases	42
Lifestyle changes since diagnosis	42
Emotional well-being.....	45
Outlook on the future	48
Section 5: Social functioning and economic support	53
Others' knowledge of respondent's HIV status.....	53
Other people's reaction and 'perceived likely' reaction	53
Employment/unemployment experience	55
Impact of diagnosis on relations and responsibilities	57
Support from other people and organisations	58
Knowledge of sources of information.....	60
Changes in life since diagnosis	61
Section 6: Overall quality of life satisfaction	66
Overview across dimensions	66
Aspects to be improved	69
Appendix: Questionnaire (En)	71
References	80

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Europe-wide

www.malehealth.co.uk
European Institute for Women's Health
Gender-AIDS e-forum

France

Union National de Lutte contre le Sida (UNALS)
CRIPS
Elus Locaux Contre le Sida (ELCS)
ARCAT

Germany

AIDS-Hilfe e. V.
Hannöversische AIDS-Hilfe e. V.
AIDS-Hilfe Offenburg e.V.
www.lhiving.com
DHIVA (the newsletter on women and AIDS in Germany)

Italy

Sieropositivo
www.gay.it
ARCIGAY
NPS Italia

Spain

Unión para la ayuda y protección de los afectados por el SIDA (UNAPRO)
VIH Positivo
Todo Sida
Komunal

United-Kingdom

UK coalition
National AIDS Manual (NAM) and www.aidsmap.com
Positively Women
National AIDS Trust
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Executive Summary

Introduction

HIV-positive people are now living longer lives as a result of advances in medical technologies. And the incidence of HIV in Europe is on the rise again. The result is an increasing prevalence which trend is set to continue for the foreseeable future. Improving the quality of life of people living with the disease has become a growing concern for patients' advocates and policy makers.

In early 2004, the European Men's Health Forum (EMHF) decided to contribute to the debate by undertaking a study describing the quality of life of men and women living with HIV. By consolidating knowledge from previous surveys and proposing the use of gender as a fresh and useful angle of analysis, the project aimed to provide useful keys to understanding expectations from the HIV community for the future.

Methods

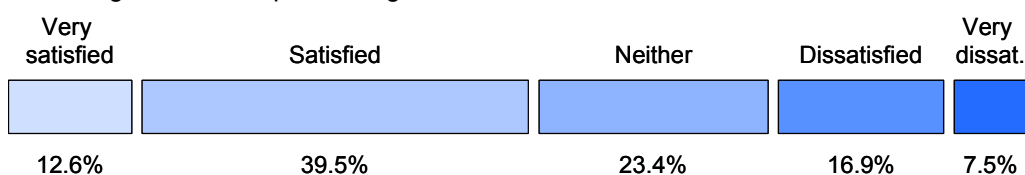
Encompassing several dimensions never brought together before in a single multi-country study – diagnostic and treatment, physical and emotional wellbeing, and social and economic support - the questionnaire was opened to all HIV+ adults residing in Europe. An online and paper questionnaire in English was piloted from July to October 2004, and was promoted to the eligible groups with the support of over 20 HIV patients' organisations. The data collection continued from November 2004 to March 2005, during which period the questionnaire was translated into French, German, Italian, and Spanish, and received the approval of the UK Multi-centre Research and Ethics Committee.

Sample overview

- 534 valid answers: 76% male, 24% female.
- Ethnic background: 85% west European, 9% African.
- 55% gay/lesbian, 30% Heterosexual, 14% bisexual, 1% other
- 46% were in a relationship/married, 44% single, 10% divorced, separated, or widowed.
- Country of permanent residence: 42% UK. 22% Germany, 18% Italy, 8.3% Netherlands, Italy and Spain, 9.3% other non-European countries
- 82% were infected through unprotected sex.
- 32% were infected since 1990, 27% since 2000, and 23% didn't know.
- 48% diagnosed since 2000 (post protease inhibitors).
- Average duration of current regimen is 2 years, with 6 pills a day on average. 70% take their medication twice a day.
- 60% diagnosed within 2 years - 52% start treatment within 1 year but 1/3 waited 2+ years
- Since diagnosis trend is for higher CD4s and particularly reduced viral loads (7% undetectable at diagnosis vs. 62% now) - Over ½ never suffered any opportunistic infections, or it was over one year ago for nearly another 1/3.
- 24% were not on treatment, and of the remaining 76%, 29% had only been on 1 regimen, 46% 2-3, 25% 4-5, and 12% on 5+.

Results

52% don't report much or any satisfaction with their overall quality of life, but results vary according to areas of questioning.



1. Areas of most satisfaction:

Treatment and health services

- Most respondents initially reported severe side effects, uncertainty about the treatment's effectiveness, and issues regarding treatment complexity (number of pills, interaction with food, number of times medication should be taken a day)

Diarrhoea/GI upset (68%), dizziness/insomnia (66%), Lipodystrophy (54%), peripheral neuropathy (42%) and Anaemia (36%) are most often reported.

85% worried about possible liver toxicity. 68% knew about other 'silent' side effects and 64% worried about them.

- 74% of respondents felt most aspects of their newer drug regimens had improved.
60% did not miss any doses in the past month, 28% only 1-2 times, 22% more than twice. Little drug resistance was reported.

Comparison of most recent drug regimen with previous ones

	Worse %	Same %	Better %	Much Better %
Number of pills per day (n = 278)	10.8	25.9	32.4	30.9
Number of times per day (n = 278)	3.2	43.2	24.5	29.1
Interaction with food (n = 257)	8.2	33.9	27.2	30.7
Side effects (n = 267)	13.1	27.3	31.5	28.1
Effectiveness (n = 266)	3.8	36.8	28.9	30.5

- 65% of respondents indicated being highly satisfied with their involvement in clinical decisions, doctors' knowledge of latest medical technologies and concerns for quality of life.

Most also reported being satisfied of their interaction with staff and with treatment facilities.

- Despite this, top-rated desired improvements remain:
 - Ease of medications intake (78%)
 - Visible side effects (73%)
 - Positive relationship with doctor (53%).

Physical wellbeing

Current ability to conduct daily living activities

	Barely able %	Able but difficult %	Easily able %
Daily travelling activities (n = 529)	2.3	16.3	81.5
Care for yourself at home (n = 529)	2.3	13.2	84.5
Maintain waged activities (n = 513)	17.2	24.8	58.1
Practice sports/leisure activities (n = 527)	14.8	27.7	57.5
Social activities (n = 528)	9.5	31.3	59.3

- Only 22% reported moderate to much pain but 45% reported moderate to a lot of fatigue. 42% also reported moderate to much disrupted sleeping patterns. Fatigue is a major source of complaint, and of frequent concern for the maintenance of work prospects.
- Reported changes in lifestyles as a result of diagnosis: 66% improved eating habits; 54% less drinking and 39% less smoking.

2. Areas of least satisfaction:

Emotional wellbeing

- 51% felt conscious of their HIV status some of the time and 44% most or all the time.
Embarrassment about status, anxiety and depressive moods are the most experienced feelings.
Future body shape changes, increased symptom visibility and physical disability were ranked among the top 3 causes of concern for the future.
- 98% of respondents had already told a partner, wife or husband about their status.
Actual reactions from friends and work colleagues often appeared more positive than originally anticipated by respondents, highlighting that fear of disclosure and discrimination still run high.
- The majority of respondents felt that their diagnosis had the most impact on their relationship/marriage.
Their ability to provide for family/care for children, to maintain social networks and employment were also negatively affected by their HIV status.

Work and professional career

55% were university graduates of equivalent. 29% earned under Euro 10k and 36% between Euro 10 and 25k.

- 69% were in employment (¼ worked part-time).
Of these, 30% previously had to quit employment for HIV-related medical reasons for 6+ months and 22% had to change jobs and/or learn new skills. 34% needed to reduce their working hours.

58% felt their diagnosis can affect their career opportunities and a further 24% were unsure. Only 18% did not think so.

- Of the 296 not currently in employment, or had to stop for 6+ months, most difficult aspects returning to work were:
 1. Prospects of heavy workloads
 2. Possible lack of skills and fear of discrimination from employer
 3. Income drop from loss of benefits.

3. Analysis by gender

- 76% males, of which: 71% homosexual, 17% bisexual, 10 heterosexual, 2% other. Ethnic background: 94% West European, 1% African, 5% other
- 24% females, of which: 3% homosexual, 2% bisexual, 92% heterosexual, 3% other. Ethnic background: 56% West European, 35% African, 9% Other.
- The length of time from infection to diagnosis, and from diagnosis to treatment was different for men and for women:
 - 40% of men diagnosed and 58% treated in the year of infection.
 - 55% of women diagnosed 2+ years after infection and 44% start treatment after a further 2 years.
- At least 10% more women than men expressed greater dissatisfaction and less satisfaction across all areas. Women were particularly dissatisfied with social life and professional career aspects. Of note: Male average education and income level is higher than for women.
- Men reported being more able than women to conduct most daily living activities. Men reported less pain (16% M vs. 38% F) and less fatigue (40% F vs. 61% F).#
- Sexual frustration ranked at the same level for men as feelings of depression, loneliness/isolation for women. Women had sexual frustration rank nearly last.

Reported changes in life as a result of HIV diagnosis:

	Improved	Worsened
Most	Overall health awareness	Outlook on life
	Making most of life	Self esteem
	Support networks	Economic status
	Taking less health risks	Number of close friends
Least	Religious/spiritual beliefs	Sense of purpose

- Women reported a greater impact on their economic status than men for whom remaining in relationship and maintaining a positive outlook suffered the most.

Aspects respondents wished to see improved

Rank	Males	Females
1	Treatment side effects	Emotional wellbeing
2	Emotional and physical wellbeing	HIV Discrimination
3	Ease of medication intake	Treatment side effects
4	HIV discrimination	Ease of medication intake

Conclusions

Aspects of treatment were perceived to have dramatically improved in terms of effectiveness at controlling the progression of the disease, ease of medication intake, reduction of side effects. The positive impact of treatment on physical wellbeing was also reported. However, respondents indicated that they wished to see such aspects further improved.

Developments in medical treatment alone will not be enough. Improvements must also be sought in the emotional wellbeing, work and professional career, and social life of people living with HIV. National and local authorities must increase the focus of their policies on reducing fear of disclosure and on continuing the fight against HIV stigma and discrimination.

The emergence of strong gendered patterns of dissatisfaction tends to indicate that considerations for the respective male and female quality of life expectations should be a key determinant in ensuring the effectiveness of new health and social policy measures.

This study demonstrates that gender can be more than just a sex indicator to be controlled for. Gender and health behavioural theories can be particularly useful to inform the elaboration and analysis of such projects. More should be done to develop larger scale research in this way.

HIV epidemiological background

Although the number of newly reported AIDS cases and AIDS-related deaths had been rapidly declining in Western Europe since antiretroviral treatment became available in 1995-1996, annual WHO reports for 1997-2003 show an increase of 47% in newly diagnosed HIV infections.

While new cases of HIV decreased by 9% among injecting drug users, they rose by 116% in people infected through heterosexual contact, largely owing to already HIV-positive immigrants from countries with generalized HIV epidemics outside the European Region.

Unlike in some other parts of the world, the HIV/AIDS epidemic in Europe is widespread among younger, urban males: 75% of all HIV positive people are male. Up to 20% of all HIV-infected people in western and central Europe, and up to 60% in Eastern Europe are under the age of 25. Over 75% of those in Eastern Europe were infected through injecting drug use. Migration from high-prevalence countries outside the Region and East-West migration have a growing significance for the epidemiological situation. Men who have sex with men, injecting drug users, sex workers, prisoners and immigrants remain the most vulnerable to HIV/AIDS.

Discrimination, stigmatisation, social exclusion and marginalisation greatly contribute to the disproportionate risk of HIV for these population groups and limit their ability to access appropriate, effective and affordable prevention, treatment and care services and commodities.

Methodology

Principal research question

How do people living with HIV/AIDS in Europe perceive their quality of life has evolved since diagnosis? The analysis aimed to take account of progress made in the field of medical technologies and their impact in other domains such as physical and emotional well-being, economic and social support.

Objectives

To provide a publicly available update on the valuable knowledge acquired from previous HIV-related quality of life projects, and to propose a new angle of analysis informed by academically-established gender and health behavioural theories of international standing.

Administered separately from any clinical trial, it aims to illustrate the impact of changes in treatment over time, and from various non-medical dimensions will provide keys to understanding expectations from the HIV community for the future. It is expected that the results of this study will be of use to policy makers, academics, and HIV patients' organisations in Europe.

Questionnaire development

This study aims to provide material that can usefully complement often more medically-oriented assessments of side effect profiles severity already well documented. Several studies have already focussed on the topic of HIV-related QoL. A literature review was conducted that encompassed Medline, Pubmed, Internet search for existing QoL models and HIV-specific QoL models, and a search of the Cochrane library. The review revealed several large projects of interest in the field of QoL (see table below).

Models used as a basis for the development of the questionnaire

WHOQoL-HIV	MOS-HIV	Revised FAHI	HAT-QoL	MQoL-HIV	Women Alive study	CIQoL Model
Physical Health	Health Perceptions	Physical Well-being	Overall function	Physical Function	Physical health/functioning	Illness related discrimination
Health Perceptions	Pain	Emotional Well-being	Sexual function	Medical Care	Medical/health care	Barriers to H/C and social services
Physical Function	Physical Functioning	Function and Global well-being	Disclosure worries	Social support	Mental/emotional/spiritual health	Physical well-being
Social Function	Role Functioning	Social well-being	Health Worries	Physical Health	Social functioning/interpersonal issues	Social support
Social Support	Social and Cognitive Funct.	Cognitive functioning	Financial Worries	Cognitive Function	Social support	Coping
Life Satisfaction	Mental Health	HIV specific concerns	HIV Mastery	Intimacy	Financial/ economic	
	Energy/Fatigue		Life satisfaction	Social function	Policy	
	Health Distress		Medical Concerns	Finance	Education/ research	
	Quality of Life		Provider Trust	Sexual function		

No longer tied to restrictions associated with scale designs, the project combined various lines of enquiries underpinning a comprehensive range quality of life dimensions with others most specific to the field of HIV.

Building on knowledge acquired from existing research in the field gender and health behavioural theories (see section on references), the questionnaire was then complemented in order to unveil new gender-related aspects of quality of life and facilitate a fresh angle of analysis.

The questionnaire was designed in collaboration with several HIV patients' organisations in the UK, Germany, France and Italy. Leeds Metropolitan University's Department of Health Education and Promotion, under the leadership of Prof. Jackie Green, also largely contributed to the development and validation of the questionnaire. Finally, the process was reviewed internally with experts in the field of men's and women's health.

The final version of the questionnaire consisted of 46 items arranged in 5 groups:

- Information about respondents' background
- About the respondents' HIV diagnosis
- Medical/health care
- Physical and emotional well-being
- Social functioning and economic support

The survey's target was defined as all HIV positive male and female adults (over 18 years old) residing in one of the European countries. Europe was defined as the enlarged European Union shortly after May 2004 plus Norway and Switzerland.

Roll-out and timing

The study was officially opened to participants from 12 July 2004 when it was launched during the International HIV/AIDS conference in Bangkok.

- A pilot phase ran from July 12 until October 15 2004, where the following information was available in English only.
 - a one-page information leaflet (attached)
 - a 4 page questionnaire - which includes much of the leaflet's in its introduction (attached)
 - International prepaid postage label available from EMHF website or envelope provided with paper version of questionnaire

The questionnaire was accessible online at www.emhf.org, both as an online interactive questionnaire, and as a downloadable PDF file. Some direct mailings were also organised.

The existence of the study was promoted via the websites of EMHF, and of a great number of partners and HIV patients' advocacy organisations listed in the acknowledgement section at the front of this report.

- A second phase ran from December 01 2004 until March 31 2005.

The information provided in English during the pilot phase was translated into French, German, Italian and Spanish. All translated questionnaires and accompanying information were provided in paper form, and as downloadable files (PDF format) or HTML pages for automated online capture on the EMHF website..

Data collection process

Responses collected online were automatically stored on the firewall-protected EMHF server. Completed paper versions of the questionnaire were returned directly to EMHF in Brussels using either international free post envelopes provided with the questionnaire, or by downloading an international prepaid postage label from the EMHF website and affixing it to the respondent's envelope.

All responses were forwarded to Leeds Metropolitan University for compilation and analysis. Given the type of questionnaire used (self administered, mix of closed and open questions) it was decided to analyse responses using descriptive statistics generated using SPSS. The technique provided a statistical analysis of replies to closed questions and allowed the extraction of key themes from open questions.

Ethics

The study aims to recruit HIV-positive adults over 18 years old residing in one of the European countries. No population groups otherwise disadvantaged or underprivileged were targeted. After careful consideration, EMHF believes that participation in this study was highly unlikely to result in any harm physical or psychological to anyone.

Also, EMHF ensured that none of the participants or partners in this project financially benefited directly or indirectly from the survey. And none of the information accompanying the questionnaire implied any financial or other material incentives.

Participation in the study was entirely voluntary and could be aborted at any time until the completed form was sent back to EMHF either by post/fax or electronically (online form).

Participation in the study was also anonymous. Anyone wishing to be alerted via email about the final survey results could leave their email address in a designated section of the EMHF website, separately to any data collected for survey purposes.

All details about the aims and objectives of the study including information about the European Men's Health Forum are clearly indicated on the front sheet of the questionnaire or on the introductory page of the online questionnaire. This information was available in English, French, German, Italian and Spanish.

All data was stored with the European Men's Health Forum and shared with Leeds Metropolitan University. Leeds Both organisations had access to individual responses, however none of these records contained any personally identifiable information.

Results

Responses were obtained from 534 individuals. In total, 384 completed the on-line version of the questionnaire and 150 filled out a paper copy. The data were analysed using the statistical software package SPSS. As a rule, percentages were calculated from the total number of individuals who answered a question. However, unless indicated otherwise, where a respondent chose the “not applicable” option, this was grouped with the missing responses and the percentages calculated from the total number of other answers given for a question. For clarity, the total number of responses on which the percentages were calculated is displayed for each question (n). In some cases the percentages may not add up to exactly 100% due to rounding. For some questions a breakdown of the results for males and females is provided. However, these results should be interpreted with caution given the sizeable difference in the number of males and females responding. In some cases, the analysis was based on the responses of a relatively small number of females.

Section 1: Characteristics of respondents

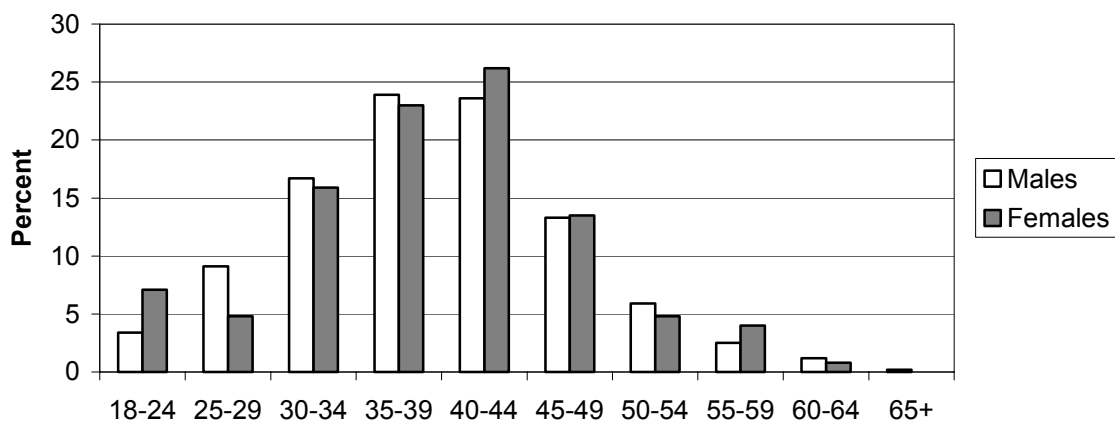
Sex (n = 534)

Approximately three quarters of respondents (76%) were male and 24% female. Two individuals were transgender.

Age (n = 534)

The mean age of respondents was 39.02 years. The youngest respondent was 18 and the oldest 68. Approximately 64% of respondents were between 30-44 years old. The mean age for men was 39.07 years and for women it was 38.8 years. An age breakdown for males and females is shown in figure 1 below.

Figure 1: Age groupings of males & females (n = 534)



Sexuality (n = 531)

Over half of the respondents (55%) were gay/lesbian, 30% were heterosexual/straight and approximately 14% bisexual. The remainder preferred not to say or gave their sexuality as “other”. Analysis of the results by gender showed that 71% of men were gay, 17% bisexual and 10% heterosexual/straight. On the other hand, 92% of women were heterosexual/straight, 3% gay/lesbian and a further 2% bisexual.

Marital status (n = 530)

Overall, 46% of respondents were married or in a relationship and a slightly smaller percentage (44%) were single. Roughly 10% of respondents were divorced/separated or widowed.

Domestic circumstances (n = 532)

Approximately 46% of respondents indicated that they lived alone. One in four (25%) lived with their partner only and one fifth (20%) with immediate family/children. The remaining 10% resided with friends or other people.

Ethnic background (n = 534)

The vast majority of respondents (85%) were West European with a further 9% being African. No other ethnic grouping accounted individually for more than 1% of the total.

A breakdown of the results by gender revealed that 94% of men were West European compared to 56% of women. Conversely, over a third of women (35%) gave their ethnic background as African in contrast to approximately 1% of men. This difference in the composition of the two gender groups should be borne in mind when making any comparison between males and females.

Country of origin (n = 528)

In total, 46 different countries of origin were given. However, 70% of respondents originated from just 3 countries. These were UK/GB (29%) Italy (24%) and Germany (17%). The other most frequently identified countries of origin are listed in the table below.

Table 1: Country of origin

Country of Origin	% of respondents
Spain	3.8%
France	2.7%
Uganda	2.5%
Zimbabwe	2.1%
Ireland	1.5%
Kenya	1.5%
Others (36 countries)	15.9%

Nationality (n = 526)

Approximately 33% of respondents were British/English/Scottish or Welsh. Nearly one quarter were Italian and 18% gave their nationality as German. Only one other nationality made up 4% or more of the total, this being Spanish (4%). Just over 6% of individuals were of various (14) African nationalities, the most common being Zimbabwean (2%). In total 22 other nationalities made up the remaining 15%.

Country of permanent residence (n = 526)

The largest proportion of those responding (42%) were permanent residents of UK/GB. A further 22% were living permanently in Italy and 18% in Germany. Of the remaining 18%, approximately half were permanent residents of 3 other countries:- Spain (3.2%), France

(2.7%) and the Netherlands (2.5%). In total, 21 respondents reported that they were permanent residents of non European countries.

Highest level of education (n = 525)

Over half (55%) of those responding had been educated to university level or equivalent. A further 27% had attended school/college until they were 18-20 years old. The remainder (18%) left education at age 16 or before. A breakdown of education level by gender is shown in the table below.

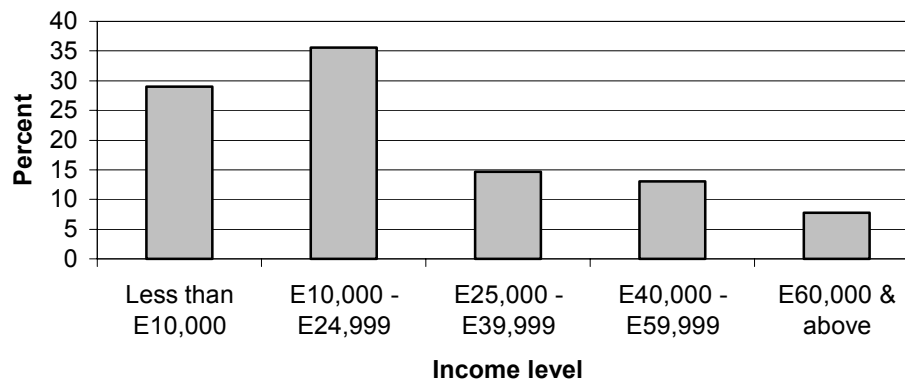
Table 2: Education level of males and females (%)

	Males (n = 401)	Females (n = 122)
College up to 16 years old	17.0	21.3
College until 18-20 years old	26.9	27.0
University or equivalent	56.1	51.6

Income level (n = 525)

Figure 2 shows the gross income of respondents. The largest single percentage of respondents (36%) had a gross income in the last year of between E10,000 & E24,999. A notable proportion (29%) received less than E10,000 and conversely, 21% had an income level of E40,000 or above.

Figure 2: Gross income of respondents (n = 525)



A breakdown of the income of males and females is provided in table 3 below.

Table 3: Income level of males and females (%)

	Males (n = 403)	Females (n = 120)
Less than E10,000	24.3	44.2
E10,000-E24,999	34.5	39.2
E25,000-E39,999	16.1	10.0
E40,000-E59,999	15.6	4.2
E60,000 & above	9.4	2.5

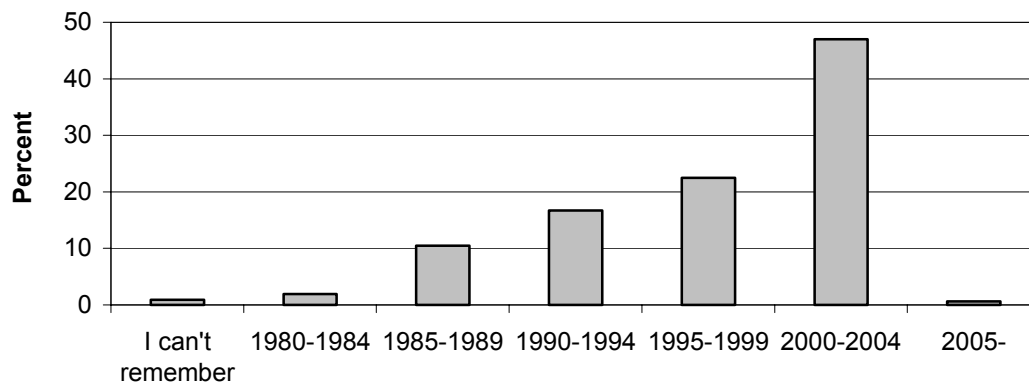
Section 2: HIV diagnosis

From infection to diagnosis

Year of HIV diagnosis (n = 534)

Respondents were asked to indicate the year in which they first tested positive. Figure 3 below shows that nearly half of those responding (48%) were diagnosed within the last 5 years and 70% within the last 10 years. The most frequently cited year for diagnosis was 2004. (71 respondents gave this response, which represents 13% of the total).

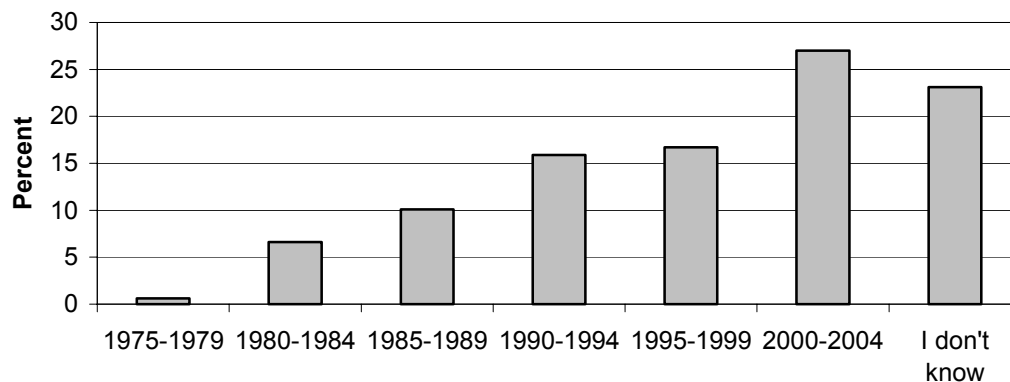
Figure 3: Year of diagnosis (n = 534)



Year of infection (n = 533)

Respondents were also asked to indicate the year in which they thought they had become infected. The results are shown in figure 4 below.

Figure 4: Year of infection (n = 533)



Almost one in four individuals (23%) did not know when they first became infected with the virus. The largest proportion of respondents (27%) thought they had become infected since 2000.

Period of time between infection and diagnosis (n = 409)

The period of time between infection and diagnosis was calculated. (Those respondents who couldn't remember the year of diagnosis and/or didn't know the year of infection were excluded from the analysis). The results showed that 37% of individuals were diagnosed in

the same calendar year as becoming infected and a further 24% within 1 to 2 years. However, the results also suggested that 39% might have been infected for at least two years before being diagnosed. The period of time between infection and diagnosis for males and females is shown in the table below.

Table 4: Period of time between infection and diagnosis for males and females (%)

	Males (n = 326)	Females (n = 82)
Diagnosed in the same calendar year as infection	39.9	24.4
Diagnosed within 1 to 2 years of infection	25.5	20.7
Infected for at least 2 years before diagnosis	34.6	54.9

Mode of infection (n = 532)

Respondents were asked how they thought infection had occurred. Table 5 overleaf shows that 82% of individuals thought they had become infected through unprotected sexual activity. In total, 32% had acquired the virus from their regular sexual partner, but the largest group (51%) had become infected through unprotected sex with someone else. Seven individuals completing the paper version of the questionnaire indicated that they may have contracted the virus either from unprotected sex or from sharing needles. Similarly, one other respondent indicated that the virus was acquired through either unprotected sex or a contaminated blood transfusion. Other modes of infection identified included condom failure, tattooing & piercing, vaccination, “needle incident” and “accident”. Three individuals also believed they had become infected whilst practising safer/protected sex. In addition, two others gave the mode of infection simply as oral sex. No other details were provided, e.g. whether it was with a regular partner or not.

Table 5: Mode of infection

	Frequency	Percentage
Unprotected sex with regular partner	168	31.6
Unprotected sex with other people	270	50.8
Contaminated blood transfusion	8	1.5
Sharing needles	16	3.0
Rape/Sexual assault	15	2.8
I don't know	29	5.5
Other	14	2.6
Prefer not to say	4	0.8
Unprotected sex with regular partner/ sharing needles	2	0.4
Unprotected sex with other people/sharing needles	5	0.9
Unprotected sex with regular partner/ Contaminated blood transfusion	1	0.2

CD4 & viral load counts

In total, 524 individuals responded to the question regarding their first CD4 blood counts and 527 provided a response to the question regarding their present CD4 level. In total, 14% (74) of respondents either couldn't remember or didn't know their first CD4 blood count in contrast to only 5% (24) who did not know their current count. The distribution of the CD4 counts for those who provided this information is presented in table 6 below.

Table 6: CD4 blood counts

	1st CD4 blood count (n = 450)		Present CD4 blood count (n = 503)	
	Frequency	Percentage	Frequency	Percentage
0-50	51	11.3	6	1.2
51-200	77	17.1	42	8.3
201-350	90	20	114	22.7
351-500	80	17.8	136	27
More than 500	152	33.8	205	40.8

Overall there would appear to be a shift towards higher current CD4 counts.

In relation to viral load, 521 individuals responded to the question regarding their first viral load and 529 answered in relation to their present level. Overall, 22% (115) couldn't remember or didn't know their first count. In addition, a further 15% (78) indicated that the test was not available at the time of their diagnosis. Again, respondents were more aware of their current viral load count with only 8% (42) reporting that they did not know or couldn't remember. Three respondents (1%) reported that the test was not available. Table 7 overleaf provides the distribution of viral load counts for those who reported them and shows a shift towards lower current counts.

Table 7: Viral load counts

	1st viral load count (n = 328)		Present viral load count (n = 484)	
	Frequency	Percentage	Frequency	Percentage
Undetectable	24	7.3	301	62.2
Up to 199,000 copies/ml	149	45.4	139	28.7
200,000 to 999,999 copies/ml	116	35.4	38	7.9
1 million to 4.99 million copies/ml	28	8.5	5	1.0
5 million to 25 million copies/ml	9	2.7	0	0.0
More than 25 million copies/ml	2	0.6	1	0.2

HIV-related opportunistic infections

As can be seen from the table below, the majority (53%) of respondents (n=526) had never suffered from a HIV related opportunistic infection. Approximately 30% had suffered an opportunistic infection more than 1 year ago and 17% within the last 12 months.

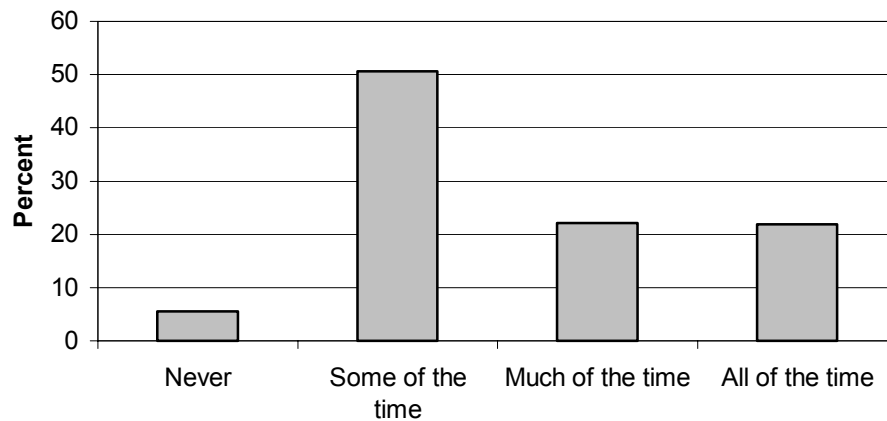
Table 8: HIV related opportunistic infections

	Frequency	Percentage
No, never	277	52.7
Yes, within the last 12 months	90	17.1
More than 1 year ago	159	30.2

Feeling conscious of HIV status

Respondents were asked to comment on the extent to which they felt conscious of their HIV status. The results showed that 51% of respondents felt conscious of their status “some of the time”, with a further 22% feeling that way “much of the time”. Another 22% indicated they felt conscious of their status “all of the time”. Only a small percentage (6%) “never” felt conscious of their positive status.

Figure 5: Conscious of HIV status (n = 530)



A breakdown of responses of males and females is displayed in table 9 below.

Table 9: The extent to which males and females felt conscious of HIV status (%)

	Males (n = 403)	Females (n = 125)
Never	5.0	7.2
Some of the time	49.9	53.6
Much of the time	22.1	22.4
All of the time	23.1	16.8

Section 3: Medical/health care

Reasons for not taking HIV medication

a) Original online version of questionnaire (n = 78)

In the original online version of the questionnaire, respondents who were not currently taking any HIV medication gave the single main reason for this. The results showed that 40 of those responding (51%) cited doctor's advice as the main reason for not taking any HIV medication. A further 18 (23%) indicated that they didn't need treatment as they felt fine. In addition, 2 (3%) were worried about side effects and 13 (17%) had voluntarily interrupted treatment. The reasons given for this included, the side effects of the medication, having a period of rest and loss of motivation to continue taking medication. One individual reported being uncomfortable about disclosure and a further 4 (5%) cited "other" reasons. These included fear, being at the start of the process of medical consultation and awaiting the doctor's decision.

b) Paper and modified online versions of the questionnaire (n = 94)

On the paper and modified online versions of the questionnaire, respondents were able to tick all the main reasons for not currently taking HIV medication that applied to them. Table 10 shows the number and percentage of respondents giving each reason.

Table 10: Main reasons for not currently taking HIV medication

Reason	No of respondents (94 in total)	Percentage
Doctor's advice	47	50.0
Worried about side effects	15	16.0
Uncomfortable about disclosure	3	3.2
Voluntary treatment interruption	18	19.1
I don't need treatment I feel fine	35	37.2
I don't like taking medications	17	18.1
Other	9	9.6

NB: Respondents could give more than one answer

It can be seen from the table that the most common reason for not taking HIV medication was again doctor's advice. The most common reason given for voluntary treatment interruption was side effects. A couple of other respondents stopped as they were participating in a study. The main "other" reasons given were because treatment was not yet necessary and preference for the use of complementary therapy.

Those respondents currently taking HIV medication or who had done so in the past were asked a range of questions about their treatment.

From diagnosis to treatment

Year of first treatment (n = 409)

Nearly half of the respondents (47%) who answered had their first treatment between 2000 and 2005 and a further 35% between 1995 and 1999. Of the remaining 18%, over two thirds (68%) were first treated between 1990 and 1994.

Period of time between diagnosis and first treatment (n = 398)

The period of time between diagnosis and first treatment was calculated. (Again, those respondents who couldn't remember their year of diagnosis and/or year of first treatment were excluded from the analysis). Overall, over half of the respondents (52%) had their first treatment within the same calendar year as being diagnosed and a further 15% within 1 to 2 years. Approximately 33% had received their first treatment 2 or more years after diagnosis. A breakdown of the period of time between diagnosis and first treatment by gender is shown in table 11 below.

Table 11: Period of time between diagnosis and first treatment for males and females (%)

	Males (n = 296)	Females (n = 101)
First treatment in the same calendar year as diagnosis	57.8	36.6
First treatment within 1 to 2 years of diagnosis	13.2	19.8
First treatment 2 or more years after diagnosis	29.0	43.6

First experience of HIV medication

Respondents were asked to comment on their first experience of taking medication for HIV. The analysis showed that comments tended to focus on the experience of side effects, although there were also some positive experiences. The severity of the side effects emerged as a major issue:

Horrific

Terrible

Dreadful

Very unbearable - 3 very difficult months to get over side effects

Very difficult to tolerate

....very difficult to cope with

It was awful I'd lots of side effects

I was so sick that I thought I'll never live for another day

The wish to die immediately

Felt fine until starting medication, been sick for two years after starting them

The side effects... have been severe and continue to have implications on my wellbeing....

...The treatment was worse than the condition....

For some respondents this had resulted in hospitalisation and coming off or changing treatment. Others had stopped taking medication themselves, even against medical advice. Side effects reported were:

Gastrointestinal

nausea and sickness
diarrhoea
stomach intestine problems
abdominal aches
indigestion

Changes in weight and body shape

change of body shape / amorphous
lipodystrophy
loss of weight
became fat

Sleeping problems

insomnia
difficulty waking up
sleep disturbances
vivid dreams and nightmares

Tiredness / feeling unwell

exhaustion, tiredness, lethargy, fatigue,
listlessness, lack of stamina
general 'washed out' feeling
physical indisposition

Changes in body temperatures

weating / cold sweats
initial reaction with high fever

Neurological/Psychological

headache
dizziness / vertigo
confusion problems concentrating
loss of memory
psychedelic side effects (Sustiva)
feeling stoned
feeling strange and numb
change of personality
mood swings
uncontrollable and irrational behaviour
sense of not being in control or intoxicated
powerlessness over the body
fear / terror
anxiety
depression
loss of libido
neuropathy

Other

erratic bodily functions
anaemia
dry skin / skin disorders
chronic renal failure
liver pains
sense of taste changed
loss of appetite

The general issue of reduced quality of life was also raised. Concern about being able to cope with the side effects was mentioned. In addition to the actual experience of side effects, there were also fears about possible side effects and being able to tolerate them.

The unanticipated severity of the side effects was an issue for some and also uncertainty about what to expect. However for others, albeit a smaller proportion, the side effects were not as bad as anticipated and in some instances there were no side effects.

Went so much better than expected, relief at having taken the plunge.

Thinking I would have lots of side effects and actually had very few.

Good first impressions, easy to take, not too many side effects...

It went completely well.

Very good.

Some people felt that putting up with side effects was a necessary part of treatment.

A necessary malaise.

While severe side effects caused traumatic and unpleasant experiences for many, some respondents gave positive statements of improvements in health and quality of life, including reports of immediate improvement in symptoms:

Before the treatment I was ill all the time. With the Tritherapy I feel like anybody else.

Overall I felt myself just getting and feeling better all round....

Felt much better within days which made me able to look forward to the future.

Almost immediate improvement in energy levels.

Initially felt sick and very tired at all times. After first two weeks up until present; improved appetite, energy levels, libido and a more positive outlook to being HIV+

The incredible amount of energy that seemed to miraculously appear!

Improved viral load and CD4 counts served to reinforce this positive subjective experience. A number of respondents reported trying different combinations of treatment before finding one that suited them.

For some, beginning drug therapy was associated with a sense of loss of control, not achieving goals in relation to deferring treatment and concern about becoming reliant on drugs possibly for the rest of their life.

...not reached my goal of 15 years not on medication.

The enormity of the fact that I would be taking pills to keep me alive for the rest of my life.

I was aware it was the start of something I would have to continue for the rest of my life. It was not a choice and I had to take drugs or die.

After picking up my medication I spent a few days plucking up the courage to take them. I knew I would have to take them for the rest of my life...

...The main feeling was one of resignation.

In contrast, others felt more positive about starting treatment and relief and that they were taking action to improve their health. There were also comments about feeling grateful for treatment and treatment offering hope.

I was optimistic. I felt as though I was actively doing something to improve my health for the first time.

Straightforward. I was very grateful to be able to take medication to restore my health and was very eager to start.

Hope of continuing good health.

I was hoping it would save my life.

I was happy that I was able to get treatment. It changed my way of thinking / planning. Suddenly I was going to live longer.

Thankful they were available, since I had seen so many die.

I was very ill at the time so it was a relief to be given effective treatment that rapidly decreased my viral load.

On the negative side, beginning drug therapy signalled entering the next stage of the disease and the start of a progressive deterioration. A number of respondents mentioned a fear of dying.

I felt it was the beginning of the end.

...the fear of not living a normal life any more.

Scared - this is it for life. Like starting a count down of drugs that will eventually run out....

In relation to the treatment itself, number of pills taken, the complexity of the regimen and the respondent's capacity to remember to take pills and adhere to the regimen emerged as key issues. This included a fear of overdosing.

The amount of tablets to be taken daily was very overwhelming. A chain round my neck.

Too complicated.

...The amount of medication and frequency is a major chore, but tolerable.

The regime of not eating for hours before and after taking the medication and as a consequence losing a lot of weight.

The large size and bad taste of the pills was also mentioned. Taking pills a number of times a day was felt to be very restrictive and a constraint on their way of life, whilst also serving as a constant reminder of the individual's HIV status. A feeling of embarrassment when taking pills in public was also raised.

Forced me to think about HIV three times a day rather than just occasionally. When not on meds you could pretend that life was just going on as normal. Started the process of HIV/AIDS dominating my life for many years to come.

Never being able to forget about being HIV+. The constant pill taking kept my status always on my mind.

I had to alter my lifestyle to accommodate the new drugs. This got easier with time....

...Not easy to fit in with life style.

....Couldn't eat certain types of foods.

However, other respondents reported carrying on life as normal.

I have continued my social life unaffected by my status, and have a busy and demanding career so it rarely enters my mind.

The importance of being positive and learning to live with medication was mentioned. Some people also noted the importance of trust in their doctor and the significance of the doctor's actions.

...efficiency of the doctor.

I had very professional advice and I knew exactly what I was in for both in terms of adherence and potential side effects.

Conversely, there were examples of lack of adequate care, support and information from medical professionals or others.

...being ignored by consultants. I was made to feel that I should be grateful for my treatment (I am) and should put up rather than ask for help.

lack of information leading to an unwillingness to take medication.

...not enough support available.

The issue of 'pressure on family' was also raised as were feelings of loneliness and being scared and vulnerable.

The cost of medication was highlighted by three respondents.

They are extremely expensive. Having to control your income limits your quality of life.

Too expensive., Unbelievably expensive.

Some respondents had started to take medication because they were pregnant. In some instances the motivation derived from the mother's concern to protect her baby, but in others there had been some pressure from medical staff to begin taking medication.

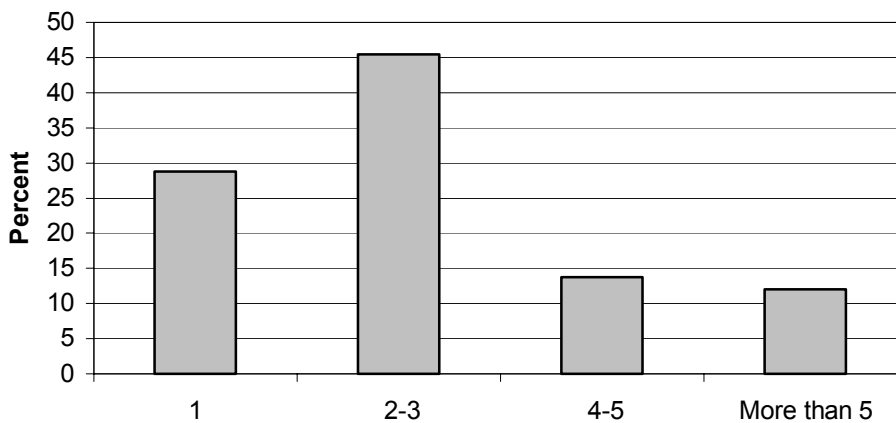
In addition to the experience of drug therapy and side effects, there were also some more general fears and concerns:

- about the future
- not knowing what to expect in terms of side effects
- whether the treatment would work
- future consequences of treatment.

Current experience of treatment

Number of drug regimens (n = 407)

Figure 6: Number of drug regimens (n = 407)



The analysis showed that 46% of those who responded to this question had been on 2-3 drug regimens and 29% had been on one. Over one in ten respondents (12%) had been on more than 5 regimens.

Aspects of treatment contributing to improving quality of life

Respondents were asked what aspects of their treatment experience had contributed the most to improving quality of life.

The comments revealed the importance of finding the right combination of drugs to suit the individual.

Finding the right combination

Clearly, the perception that the drugs are working and a decrease in symptoms are of major importance. More positive aspects such as feeling well, having more energy/feeling less tired and overall quality of life are also important. A substantial proportion of respondents reported improvements in their experience of symptoms and their well-being.

Treatment turned round my health from being very bad to being very good.

It changed me from someone who I felt was dying slowly, to my present condition of exceptional and persistent good health!

The medication, I noticed remarkable improvement in everyday events, i.e. was not tired, felt full of energy.

Taking the pills, seeing them work.

A sense of having their lives return to normal and feeling in control through taking medication were also important factors.

After about a month a great weight had lifted off my shoulders. The drugs had almost completely suppressed the virus and I felt more energised. Because my body was constantly fighting the virus I didn't have the reserves of energy to do the things I would normally do, so I stopped doing them. With the treatment I am now doing the activities I did prior to the virus taking a firm grip of my immune system.

I wanted to have treatment as I had a high VL, declining CD4 and was starting to feel fatigued even though I had not been infected long. Starting treatment put me back in control.

Furthermore, experiencing benefits from therapy reinforced the commitment to adhere to the drug regimen. Improved viral load and CD4 counts provided additional corroboration.

Seeing my blood counts improve immediately.

I feel reassured about the virus being suppressed and stable.

The importance of medication in giving people hope was also mentioned.

The treatment has given me back weight and energy. Above all I was then convinced of the fact that I would not be dying and that I would not die in the next few years. From this conviction a new hope of being able to recover one day was born. This hope made my life more bearable.

The view was expressed that better treatment options are now available. Many people reported fewer or no side effects in relation to their current treatment. There had also been improvements to the regimen itself requiring fewer pills and fitting in better with daily life.

Ease of taking just 3 pills once a day at the same time and with no side effects with my new regime.

The lack of a detrimental impact of my combination on my everyday life.

Changing to a regimen with no dietary restrictions.

The less pills I have to take, the less I think about HIV.

Adhering to the drug regimen and sticking to the timetable was commented on by a number of respondents. In addition to the drug therapy itself, the importance of the relationship with doctors and other medical staff was mentioned, including being treated as a person rather than just a patient. Trust in medical staff was also an issue. The issue of knowledge and being informed about treatment and the options available was also raised - including the positive effects of taking an active role in one's own treatment and education.

Continuity of treatment. Having the same consultant throughout my illness and being able to have open and frank discussions.....

...My active participation in my care plan and drug regime means I am still alive. My consultant is an excellent clinician and a good human being. I am lucky. This relationship has been vital to my survival.

Making a concerted effort to educate and inform myself about anti-retrovirals and other treatment options open to me; becoming actively involved in managing my care...

Understanding this condition and things I could do to make it easier.

In contrast to the comments about the initial experience of treatment, the majority of comments about current treatment were positive. However, there were still a few comments about treatment not being effective or not improving quality of life and consequent discontinuation.

I don't actually feel that anything about the treatment improved the quality of my life. Undoubtedly the medication has kept me alive but the quality of my life is still not good.

A number of respondents were deriving additional benefit from counselling and complementary therapy including relaxation techniques and spiritual healing.

Some respondents mentioned maintaining or improving a healthy lifestyle, for example in relation to diet and exercise.

There was recognition that emotional and mental well-being is important as well as physical well-being. Stable emotional relationships and the support received from family, friends and partner were felt to make a positive contribution in this regard. There was also acknowledgement of emotional support from clinical staff and other organisations.

Non judgemental emotional support from both HIV doctor and Health Adviser Team.

However, one respondent wrote of feeling isolated and of not receiving adequate care and support.

I don't think treatment has contributed to quality of life ...I feel trapped in an isolated world where no one cares...if I ask for help I don't get it ...I'm about to give up the treatment.

There were also comments (albeit very few) about being unable to talk to family or workmates because of the 'shame' and concealing taking drugs from others.

There were a number of comments about having a positive attitude to life and a sense of purpose in relation to children, family or work. The will to live and the belief that one has a future were recognised as important.

The will to go on.

Support of my family and friends, motivation in my work. I never stopped loving life so picked myself up as soon as possible.

My energy back, my perspective back, I make plans again.

Length of time on most recent drug regimen (n = 392)

The mean length of time respondents had been on their most recent drug regimen was 2 years and 7 months. The shortest period of time was less than 1 month and the longest 17 years. The most common response was 2 years.

Number of pills per day taken on most recent drug regimen (n = 402)

The mean number of pills per day taken by those reporting on their most recent regimen was 6. The least number of pills taken was 1 and the most 24.

Number of times per day respondents had to take pills on most recent drug regimen (n = 401)

The mean number of times per day respondents had to take pills on their most recent regimen was 2. The least number of times per day was 1 and the most 6. Overall, the majority of respondents (67%) took their medication twice a day. A further 19% took their pills just once a day and 11% took them three times daily. Only 3% of individuals had to take medication more than 3 times a day.

Comparison of most recent drug regimen with previous ones

Respondents who had been on more than one drug regimen rated from “worse” to “much better” various aspects of their most recent regimen compared to previous ones. The results are shown in table 12 below.

Table 12: Comparison of most recent drug regimen with previous ones

	Worse %	Same %	Better %	Much Better %
Number of pills per day (n = 278)	10.8	25.9	32.4	30.9
Number of times per day (n = 278)	3.2	43.2	24.5	29.1
Interaction with food (n = 257)	8.2	33.9	27.2	30.7
Side effects (n = 267)	13.1	27.3	31.5	28.1
Effectiveness (n = 266)	3.8	36.8	28.9	30.5

The results suggested that respondents’ most recent drug regimen compared favourably to previous ones. Overall:

- 63% of those responding rated the number of pills they had to take per day as “better” or “much better”.
- 54% rated the number of times a day they had to take medication as “better” or “much better.”
- 58% rated their medication’s interaction with food as “better” or “much better.”
- 60% rated the side effects of medication as “better” or “much better.”
- 59% rated the effectiveness of their medication as “better” or “much better.”

For each aspect, most of the remaining respondents thought their most recent drug regimen was the “same” as previous ones. However, 11% indicated the number of pills taken per day on their most recent regimen was “worse”. Similarly, 3% reported that the number of times per day pills had to be taken had worsened. In addition, 13% thought the side effects, 8% the interaction with food and 4% the effectiveness of their most recent drug regimen were also “worse”.

Side effects associated with most recent drug regimen

Respondents who had taken HIV medication also rated how bearable/unbearable were selected side effects associated with their most recent drug treatment. Table 13 below shows the proportion of respondents giving a “not applicable” response for each side effect.

Table 13: % of respondents giving a N/A response

	%
Peripheral neuropathy (n = 383)	58
Anaemia (n = 377)	64
Diarrhoea/GI upset (n = 388)	32
Lipodystrophy (n = 391)	46
Dizziness/Insomnia (n = 388)	34

a) Peripheral neuropathy (n = 383)

Overall 58% of respondents who answered this question gave a “not applicable” response, which suggests that they did not suffer from this particular side effect. Of those 160 respondents who did comment on peripheral neuropathy, just over three quarters (76%) indicated that this side effect was “bearable”. A further 18% indicated that their neuropathy was “almost unbearable”. Less than 6% rated it as “unbearable”.

b) Anaemia (n = 377)

Once again, a high percentage (64%) of respondents answering gave a “not applicable” response. Out of the 135 respondents who did comment on anaemia, 83% indicated it was “bearable”, 12% “almost unbearable” and 5% “unbearable.”

c) Diarrhoea/gastrointestinal upset (n = 388)

More respondents (264) had experienced diarrhoea/gastrointestinal upset than the previous two side effects. Of those who did suffer, over two thirds (68%) considered it to be “bearable”, with 24% rating it as “almost unbearable”. Approximately 8% rated it as “unbearable”.

d) Lipodystrophy (n = 391)

Just under half (46%) of the individuals who answered this question gave a “not applicable” response. Of those 210 who did comment on lipodystrophy, most (55%) found it to be “bearable” and 21% “almost unbearable”. However, almost 1 in 4 (24%) rated the lipodystrophy they suffered as being “unbearable”. This percentage is by far the largest of any of the side effects covered. In fact, the analysis showed that lipodystrophy was described as “unbearable”:-

- By 4 times as many respondents as peripheral neuropathy
- By almost 5 times more respondents than anaemia
- By 3 times as many respondents as diarrhoea/gastrointestinal upset and over 1.5 times as many as dizziness/insomnia.

e) Dizziness/Insomnia (n = 388)

In total, 34% of respondents gave a “non-applicable” response, making dizziness/insomnia the second most frequently rated side effect after diarrhoea/gastrointestinal upset. For those 256 individuals for whom dizziness/insomnia were pertinent, 62% rated them “bearable” and 24% “almost unbearable”. Nearly 15% reported that their dizziness/insomnia was “unbearable.”

On the basis of the percentage of respondents who provided an actual rating for each side effect (i.e. did not provide a “not applicable” response), the results suggested that diarrhoea/GI upset and dizziness/insomnia were the most commonly experienced of the selected side effects. However, as described above, lipodystrophy was most likely to be described as “unbearable” by those who experienced it.

The above results are summarised in the table below.

Table 14: Experience of side effects

	Bearable %	Almost unbearable %	Unbearable %
Peripheral neuropathy (n = 160)	76.3	18.1	5.6
Anaemia (n = 135)	83	11.9	5.2
Diarrhoea/GI upset (n = 264)	67.8	23.9	8.3
Lipodystrophy (n = 210)	55.2	20.5	24.3
Dizziness/insomnia (n = 256)	61.7	23.8	14.5

Worries about long term effects of medication

A large majority (85%) of those who answered (n = 402) were worried about the long term effects of their HIV medication.

Silent side effects

a) Knowledge (n = 403)

Respondents were asked about their knowledge of silent side effects of HIV medication- (changes in cardiovascular risk factors such as levels of cholesterol and triglycerides). Over two thirds of respondents (68%) knew about these side effects.

b) Impact (n = 400)

In total, 35% of respondents felt that such silent side effects did impact on them, compared to 37% who felt that they did not. Approximately 28% of those responding did not know.

c) Concern about silent side effects (n = 400)

Just over 64% of individuals reported being worried about these silent side effects.

Effects of HIV medication on the liver (n = 408)

Respondents were asked to indicate the extent to which they were worried about the effects on the liver of HIV medication.

Table 15: Level of concern about the effects of HIV medication on the liver

	Frequency	Percentage
Not at all	43	10.5
Somewhat	196	48.0
Very much	152	37.3
I don't know	17	4.2

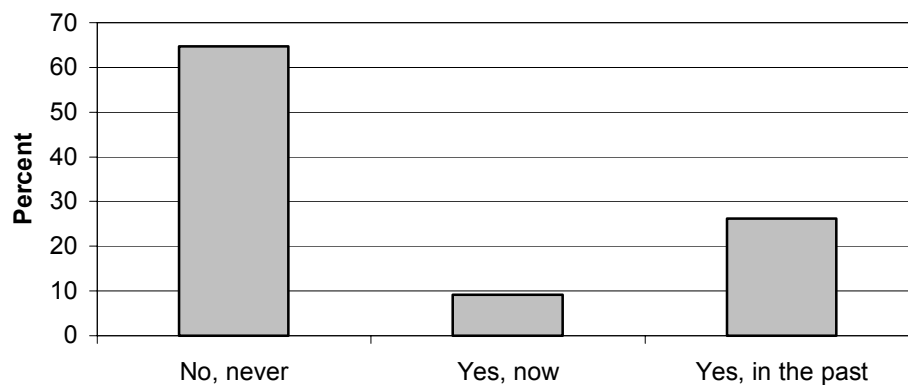
It is clear from the results that most respondents were concerned to some degree about the effects of the medication on the liver. As can be seen from the table above, 85% of respondents worried “somewhat” or “very much” about these effects.

Drug resistance and adherence to treatment

Experience of drug resistance (n = 405)

Figure 7 below shows the percentage of respondents who had experienced drug resistance. Whilst most respondents (65%) had never experienced this problem, quite a substantial proportion of individuals (just over 35%) was either currently experiencing drug resistance or had done so in the past.

Figure 7: Drug resistance (n = 405)



Concern about drug resistance (n = 392)

Perhaps not surprisingly, just under three quarters (72%) of respondents who answered indicated they were worried about drug resistance.

Missed medication (n = 365)

Respondents were further asked to give the number of times they had missed taking their medication in the last month. Table 16 below shows that 60% had not missed taking their drugs at all within the last month and a further 28% had missed a dose once or twice. Just under 4% had missed taking their drugs more than 10 times.

Table 16: Number of times respondents had missed taking their medication in last month

	Frequency	Percentage
0	220	60.3
1-2	101	27.7
3-4	25	6.8
5-10	6	1.6
More than 10	13	3.6

Reasons for missing medication

Frequently respondents indicated they had simply forgotten to take their medication. Others said that they had sometimes missed a dose due to disruption of their normal routine, for example going out socialising, leaving home earlier than normal, or going away from home and not taking their medication with them. Other reasons that were cited included:

- tiredness;
- not having eaten;
- change in regimen (e.g. timing or frequency of medication);
- too busy, stress/pressure of work;
- not wanting to take them;
- side effects.

Table 17: Table 16 split by gender (%)

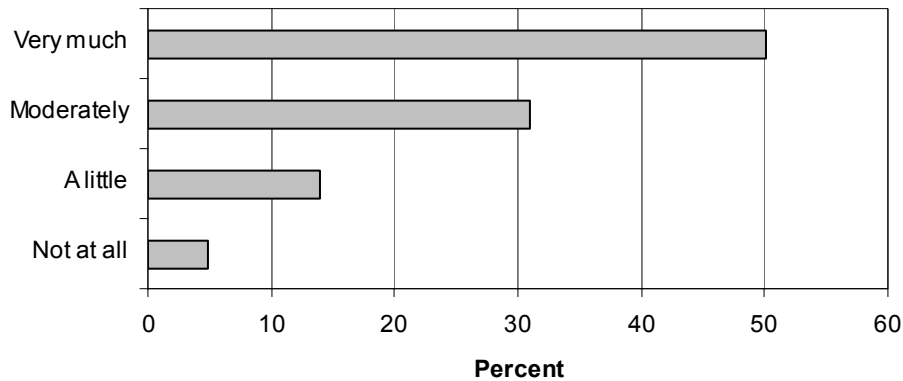
	Males (n = 265)	Females (n = 99)
0	61.5	56.6
1-2	28.3	26.3
3-4	4.9	12.1
5-10	1.9	1.0
More than 10	3.4	4.0

Relationship with clinic doctor

a) Involvement in clinical decisions (n = 407)

Respondents were asked to rate from “not at all” to “very much” the extent to which they felt involved in clinical decisions.

Figure 8: Involvement in clinical decisions (n = 407)

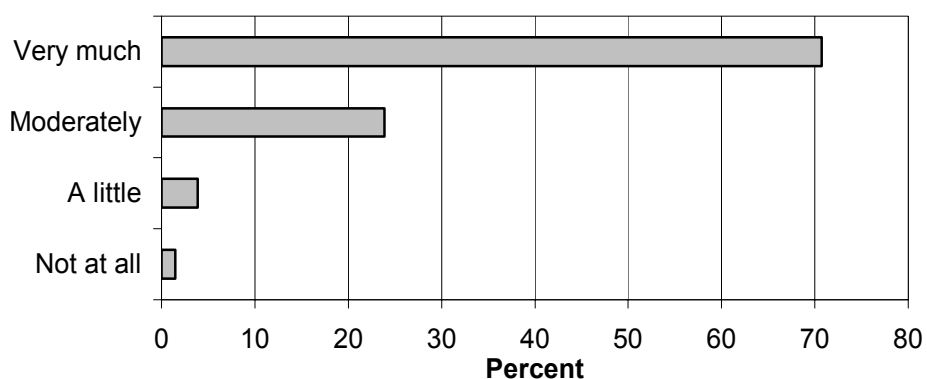


The results showed that half of the respondents (50%) felt “very much” involved in clinical decisions with a further 31% “moderately” so. In addition, 14% felt only “a little” involved, whilst 5% did not feel they had any involvement at all.

b) Doctor’s perceived awareness of the latest medical innovations about HIV (n = 406)

For this question, respondents were asked to rate from “not at all” to “very much” the extent to which they felt their doctor was aware of the latest medical innovations about HIV.

Figure 9: Doctor’s perceived awareness of the latest medical innovations about HIV (n = 406)

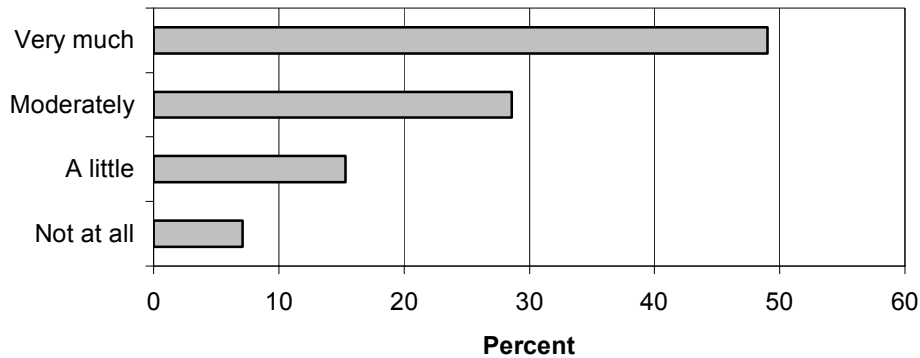


A high percentage of respondents (71%) felt that their doctor was “very much” aware of the latest advances in HIV treatment. Of the remaining 29% of respondents, most (83%) felt that their doctor was “moderately” aware of the latest advances in HIV treatment.

c) *Doctor's perceived concern about the impact of treatment on respondent's quality of life (qol) (n = 406)*

Respondents were asked to rate from "not at all" to "very much" the extent to which they felt their doctor was concerned about the impact of treatment on quality of life.

Figure 10: Doctor's perceived concern about the impact of treatment on quality of life (n = 406)

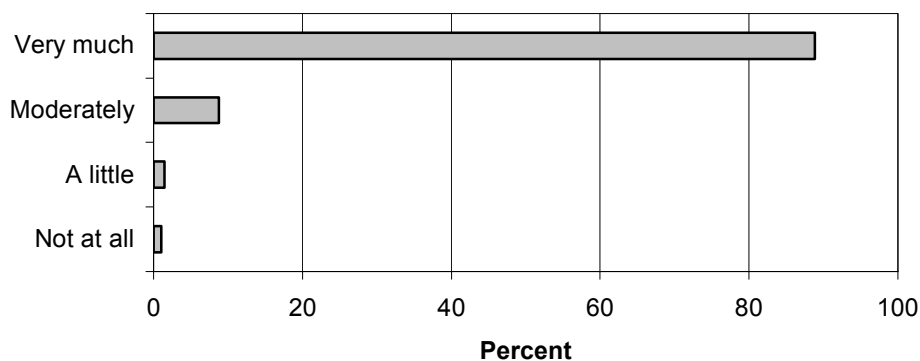


The responses to this question were similar to those concerning involvement in clinical decisions. Almost half (49%) felt that their doctor was very concerned with the impact of treatment on quality of life. A further 29% felt their doctor was "moderately" concerned and 15% concerned "a little". Only a small percentage (7%) felt their doctor wasn't concerned at all with this issue.

d) *Importance of a comfortable relationship with doctor (n = 410)*

Finally, respondents were asked to rate from "not at all" to "very much" the extent to which they felt a comfortable relationship with their doctor was important.

Figure 11: Importance of a comfortable relationship with Doctor (n = 410)



Perhaps not surprisingly, a large majority (89%) felt that it was very important to have a comfortable relationship with their doctor. Less than 3% felt it wasn't important at all, or important just "a little". The responses of males and females are broken down in the table below.

Table 18: Feelings of males and females about clinic doctor (%)

		Not at all	A little	Moderately	Very much
Feel involved in clinical decisions	Males (n = 303)	4.6	13.9	31.7	49.8
	Females (n = 103)	5.8	14.6	29.1	50.5
Doctor's perceived awareness of the latest medical innovations	Males (n = 304)	1.3	3.9	25.3	69.4
	Females (n = 101)	2.0	4.0	19.8	74.3
Doctor's perceived concern about the impact of treatment on qol	Males (n = 304)	6.9	15.5	30.3	47.4
	Females (n = 101)	7.9	14.9	22.8	54.5
Importance of a comfortable relationship with doctor	Males (n = 304)	0.7	1.6	8.2	89.5
	Females (n = 105)	1.9	1.0	10.5	86.7

Satisfaction with treatment centre

Respondents rated their level of satisfaction with various aspects of their treatment centre. The results are shown in the table below.

Table 19: Satisfaction with treatment centre (%)

	Not at all	A little	Moderately	Very much
Distance from home (n = 409)	12.7	14.2	33.5	39.6
Interaction with staff (n = 408)	4.9	8.3	27.9	58.8
Range of treatment facilities available (n = 406)	5.2	11.8	31.5	51.5

The analysis found that most respondents were very satisfied with their interaction with staff (59%) and the range of treatment facilities available (52%). In addition, almost 40% of respondents were also very satisfied with the distance of the treatment centre from home. Nevertheless, it was with this aspect that the greatest proportion of respondents were least satisfied. In total, a significant minority (27%) indicated they were "not at all" satisfied or satisfied only "a little" with the distance of the treatment centre from home. This compares with 13% for interaction with staff and 17% for range of treatment facilities. Whilst the overall percentage is relatively small (13%), over twice as many respondents were "not at all" satisfied with the distance from home, as were for either of the other 2 aspects.

Table 20: Satisfaction of males and females with treatment centre (%)

		Not at all	A little	Moderately	Very much
Distance from home	Males (n = 304)	11.8	15.1	36.2	36.8
	Females (n = 104)	15.4	11.5	26.0	47.1
Interaction with staff	Males (n = 303)	2.6	10.2	27.7	59.4
	Females (n = 104)	11.5	2.9	28.8	56.7
Range of treatment facilities available	Males (n = 303)	4.6	11.9	33.3	50.2
	Females (n = 102)	6.9	11.8	26.5	54.9

Most important aspects of treatment

Respondents were asked to rank, in their experience, the 3 most important aspects of treatment. Table 21 shows that 37% of those responding ranked ease of medication intake as being the most important aspect of treatment. Furthermore, in total 78% of respondents ranked ease of medication intake as being one of the 3 most important aspects. Similarly, nearly three quarters of respondents (74%) ranked visible side effects in the top 3, with 26% ranking this aspect as the most important. Almost two thirds of individuals (65%) thought silent side effects and 53% relationship with clinic doctor were 1 of the 3 most important aspects. A smaller percentage (30%) ranked satisfaction with treatment centre in their top 3 aspects.

Table 21: Most important aspects of treatment

	% of respondents ranking aspect most important (n = 380)	% of respondents ranking aspect 2 nd most important (n = 379)	% of respondents ranking aspect 3 rd most important (n = 379)
Ease of medication intake	36.8	16.9	24.0
Visible side effects	26.3	30.1	17.7
Silent side effects	14.7	25.1	25.1
Relationship with clinic doctor	15.8	19.3	18.2
Satisfaction with treatment centre	6.3	8.7	15.0

Table 22: Most important aspects of treatment identified by males and females

	% of respondents ranking aspect most important		% of respondents ranking aspect 2 nd most important		% of respondents ranking aspect 3 rd most important	
	Males (n = 291)	Females (n = 88)	Males (n = 291)	Females (n = 87)	Males (n = 291)	Females (n = 87)
Ease of medication intake	36.1	38.6	16.8	17.2	24.1	24.1
Visible side effects	28.5	19.3	31.3	25.3	16.2	23.0
Silent side effects	17.5	5.7	26.5	20.7	24.7	25.3
Relationship with clinic doctor	11.3	30.7	19.9	17.2	17.9	19.5
Satisfaction with treatment centre	6.5	5.7	5.5	19.5	17.2	8.0

Section 4: Physical & emotional well-being & satisfaction

Current ability to conduct daily living activities

Table 23: Current ability to conduct daily living activities

	Barely able %	Able but difficult %	Easily able %
Daily travelling activities (n = 529)	2.3	16.3	81.5
Care for yourself at home (n = 529)	2.3	13.2	84.5
Maintain waged activities (n = 513)	17.2	24.8	58.1
Practice sports/leisure activities (n = 527)	14.8	27.7	57.5
Social activities (n = 528)	9.5	31.3	59.3

a) Daily travelling activities (n = 529)

A large percentage of respondents (82%) felt “easily able” to conduct daily travelling activities. A further 16% were able to conduct daily travelling activities, but found it difficult and 2% indicated they were “barely able”.

A breakdown of the results for males and females is shown in table 24. It can be seen that there were considerable differences in the responses of men and women to this question. Overall, a large majority of men (87%) felt “easily able” to conduct daily travelling activities, in comparison to 65% of women. Almost one third of women (30%) indicated they found it difficult compared to just 12% of men.

b) Care for yourself at home (n = 529)

A large proportion of respondents (85%) also felt “easily able” to care for themselves at home. Approximately 13% found it difficult, and only a small percentage (2%) were “barely able”.

The results suggested that men generally were more able to care for themselves at home than women. In total, 88% of men indicated they were “easily able” to look after themselves in contrast to 75% of women. Over one in five women (22%) found it difficult compared to 10% of men.

c) Maintain waged activities (n = 513)

A somewhat smaller proportion of those responding (58%) could easily maintain waged activities, but this still represents a majority. One quarter of individuals (25%) were able to work but found it difficult. A further 17% felt “barely able” to continue with work, which was the highest proportion for any of the activities.

As shown in table 24, nearly two thirds of males (64%) felt “easily able” to maintain waged activities, 21% found it difficult and 15% were “barely able”. However, for females, there was a more even split between the responses. Nearly 39% felt “easily able” to work, 36% found it difficult and 25% indicated that they were “barely able”.

d) Practice sports/leisure activities (n = 527)

Most individuals (58%) were “easily able” to practice sports/leisure activities, but almost 28% found it difficult. The remaining 15% were “barely able” to play sports, or pursue other leisure pastimes.

Once again there were notable differences in the responses of men and women. A majority of men (62%) indicated they were “easily able” to play sports etc compared to under half of women (42%). Furthermore, nearly one quarter of women (24%) were “barely able” to perform these kinds of activities but only 12% of men felt this way. Approximately one third of women (34%) and 26% of men were able but found it difficult to practice sports/leisure activities.

e) Social activities (n = 528)

Just over 59% of individuals also felt “easily able” to conduct social activities. A further 31% indicated they could conduct social activities, but found it difficult. Less than 10% were “barely able”.

The analysis further suggested that men were also generally more able to conduct social activities than women. In total 64% of men rated themselves as “easily able” to conduct social activities, but for women the figure was only 45%. A further 39% of women and 29% of men indicated that they were able to socialise, but found it difficult. In addition, over twice as many women than men felt “barely able” to socialise (16% compared 7%).

Table 24: Current ability of males and females to conduct daily living activities

		Barely able %	Able but difficult %	Easily able %
Daily travelling activities	Males (n = 403)	1.5	11.9	86.6
	Females (n = 124)	4.8	29.8	65.3
Care for yourself at home	Males (n = 404)	2.0	10.1	87.9
	Females (n = 123)	3.3	22.0	74.8
Maintain waged activities	Males (n = 397)	14.6	21.4	64.0
	Females (n = 114)	25.4	36.0	38.6
Practice sports/leisure activities	Males (n = 404)	11.9	26.0	62.1
	Females (n = 121)	24.0	33.9	42.1
Social activities	Males (n = 404)	7.2	29.0	63.9
	Females (n = 122)	16.4	38.5	45.1

Current experience of physical pain, fatigue and disrupted sleeping patterns

a) Current experience of physical pain (n = 529)

Respondents were asked the extent to which they were currently experiencing physical pain.

Figure 12: Current experience of physical pain (n = 529)

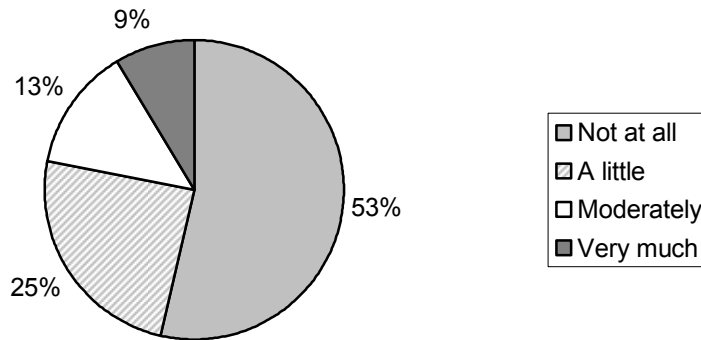


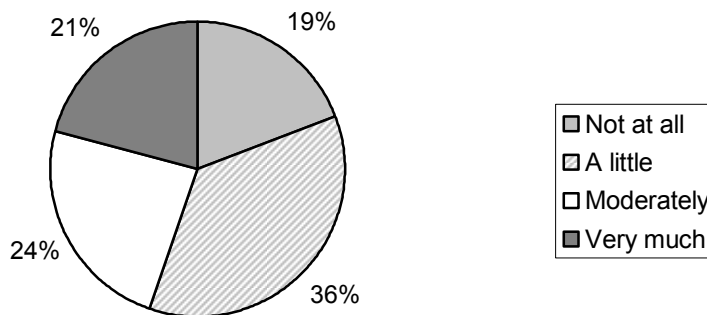
Figure 12 above shows that most respondents (53%) were not currently experiencing physical pain. Over one third (38%) indicated they were suffering “a little” or moderate amounts and 9% were experiencing a lot of pain.

Of the 122 females who responded, 62% were currently suffering some physical pain. Approximately 24% were experiencing moderate levels, 21% “a little” and a further 17% a lot of pain. In contrast, out of the 405 males who responded only 42% were currently experiencing physical pain with 26% suffering “a little”, 10% “moderately” and 6% “very much”.

b) Current experience of fatigue (n = 529)

Respondents were asked the extent to which they were currently experiencing fatigue. The results are shown in figure 13 below.

Figure 13: Current experience of fatigue (n = 529)



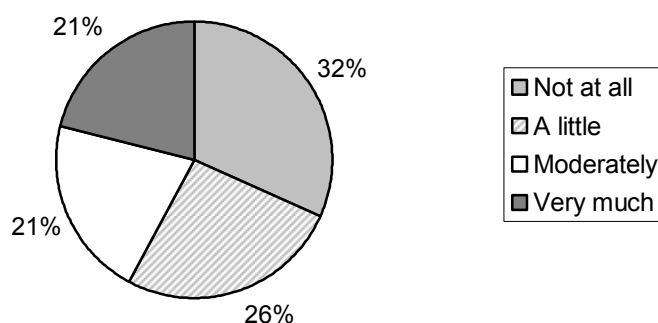
Clearly, the majority of respondents (81%) were suffering from fatigue to some degree. The greatest proportion (36%) was experiencing “a little” fatigue. However, nearly one quarter (24%) felt “moderately” fatigued and around 1 in 5 individuals (21%) “very much” so.

In total, 405 males and 122 females responded to this question. The analysis showed that 80% of men and 85% of women were currently experiencing fatigue. Approximately 61% of women reported moderate (29%) to high levels (32%) of fatigue compared to 40% of men (23% reported moderate levels and 17% high levels). In contrast, 40% of men were suffering from “a little” fatigue compared to 24% of women.

c) *Current experience of disrupted sleeping patterns (n = 530)*

Finally, respondents were asked the extent to which they were currently experiencing disrupted sleeping patterns. Once again, most individuals (68%) were experiencing this problem to a certain extent. In addition, as shown in the figure overleaf equal proportions of respondents were suffering “moderately” and “very much” from disturbed sleep.

Figure 14: Current experience of disrupted sleeping patterns (n = 530)



Out of the 123 females who responded to this question, 75% were experiencing a degree of disrupted sleep patterns. Nearly one third (32%) were suffering “very much”, 24% “moderately” and 19% “a little”. Out of the 405 males who responded, 66% were suffering this problem to some extent. Just under 29% were experiencing disrupted sleeping patterns “a little”, 20% “moderately” and 17% “very much”.

Experience of other diseases

Overall 3% of respondents (n = 531) had recently suffered from Tuberculosis, 8% Hepatitis C, 11% Syphilis and 4% other sexually transmitted diseases. In total, 404 of those responding were male. In total, 3% of men had recently suffered from Tuberculosis, 6% Hepatitis C, 13% Syphilis and 2% other sexually transmitted diseases. Of the 125 females who responded, 4% had recently suffered from Tuberculosis, 16% Hepatitis C, 2% Syphilis and 13% other sexually transmitted diseases.

Lifestyle changes since diagnosis

Respondents were next asked to rate from “much less” to “much more” the extent to which various aspects of their lifestyle had altered since being diagnosed HIV positive.

a) *Eating healthily (n = 508)*

Table 25: Eating healthily since diagnosis

	Frequency	Percentage
Much less	13	2.6
A bit less	16	3.1
No change	145	28.5
A bit more	178	35.0
Much more	156	30.7

Two thirds of respondents (66%) had started eating healthily “a bit more” or “much more” since becoming aware of their status. Only 6% were not eating healthily as much and for 29% of the respondents there hadn’t been any change. A comparison of the extent to which males and females had been eating healthily since diagnosis is provided in table 26.

Table 26: Extent to which males and females had been eating healthily since diagnosis

	Much less	A bit less	No change	A bit more	Much more
Males (n = 386)	1.6	2.8	30.3	34.2	31.1
Females (n = 120)	5.8	4.2	22.5	38.3	29.2

Overall, it can be seen that the responses of males and females were quite similar. Approximately 7% more women had changed their behaviour since diagnosis, with 10% eating less healthily compared to just over 4% of men.

b) Smoking (n = 524)

Overall, 47% of respondents who answered gave a “not applicable” response, which suggests that these individuals did not smoke either before or after diagnosis. Table 27 below shows the responses of the 278 who did.

Table 27: Smoking behaviour since diagnosis

	Frequency	Percentage
Much less	62	22.3
A bit less	45	16.2
No change	121	43.5
A bit more	25	9.0
Much more	25	9.0

It can be seen from the results that approximately 39% of respondents for whom this question was applicable had cut down on their tobacco use since diagnosis, with 22% smoking “much less”. However, 18% indicated they had actually started smoking more.

Of the 45 females and 231 males for whom this question was applicable:-

- 11 females (24%) and 51 males (22%) were smoking “much less”
- 8 females (18%) and 37 males (16%) were smoking “a bit less”
- 20 females (44%) and 100 males (43%) had not changed their smoking behaviour
- 3 females (7%) and 22 males (10%) were smoking “a bit more”
- 3 females (7%) and 21 males (9%) were smoking “much more”.

c) Drinking (n = 527)

Again, a notable percentage of respondents (25%), perceived this question not to be applicable. Table 28 shows the responses of the 396 individuals for those who did.

Table 28: Drinking behaviour since diagnosis

	Frequency	Percentage
Much less	132	33.3
A bit less	82	20.7
No change	128	32.3
A bit more	31	7.8
Much more	23	5.8

Over half (54%) of these respondents had cut down to some extent on their drinking. Indeed, one third (33%) indicated they had been drinking “much less” since finding out about their positive status. Just over 32% had not changed their drinking behaviour.

This question was applicable to 76 women and 318 men.

- 25 women (33%) and 107 men (34%) had been drinking “much less”
- 20 women (26%) and 62 men (20%) and had been drinking “a bit less”
- For 19 women (25%) and 109 men (34%) there had been “no change” in the amount they were drinking
- 10 women (13%) and 21 men (7%) had been drinking “a bit more”
- 2 women (3%) and 19 men (6%) had been drinking “much more”.

d) Using recreational drugs (n = 518)

This question was not relevant for 59% of individuals who gave a “not applicable” response. Table 29 shows the responses of the 213 respondents for whom this question was perceived relevant.

Table 29: Recreational drug use since diagnosis

	Frequency	Percentage
Much less	68	31.9
A bit less	21	9.9
No change	83	39.0
A bit more	21	9.9
Much more	20	9.4

Approximately 19% of these respondents, had started to use more recreational drugs, but a greater proportion (42%) were using less. For 39% of users there had been “no change”.

Out of the 32 women and 179 men for whom this question was applicable:-

- 11 women (34%) and 57 men (32%) were using recreational drugs “much less”
- 3 women (9%) and 18 men (10%) were using recreational drugs “a bit less”
- 9 women (28%) and 74 men (41%) had not changed the amount they were using recreational drugs
- 7 women (22%) and 14 men (8%) were using recreational drugs “a bit more”
- 2 women (6%) and 16 men (9%) were using recreational drugs “much more”.

e) Injecting drugs (n = 519)

In total, 82 individuals provided a response other than “not applicable”. For 36 respondents (44%) there had been “no change” in their level of injecting. Twenty eight respondents (34%) reported injecting “much less” and 3 (4%) a bit less. Conversely 15 (18%) were currently injecting “a bit more” or “much more”.

This question was applicable to 13 women and 67 men. Of these:-

- 9 women (69%) and 19 men (28%) had been injecting “much less”
- 1 woman (8%) and 2 men (3%) had been injecting “a bit less”
- 3 women (23%) and 33 men (49%) indicated there had been no change in their amount of injecting
- No women and 5 men (8%) had been injecting “a bit more”
- No women and 8 men (12%) indicated they had been injecting “much more”
- One of the respondents who was transgender had also started injecting “much more”

f) Practising safe sex (n = 326)

Respondents provided an indication of the extent to which they had been practising safe sex. Of the 268 for whom this question was relevant, 64% had been practising safe sex “much more” and a further 8% “a bit more” since diagnosis. Roughly 21% had not changed their sexual behaviour, but 8% had been practising safe sex “a bit less” or “much less”.

This question was applicable to 85 women and 182 men.

- 67 women (79%) and 104 men (57%) had been practicing safe sex “much more”
- 5 women (6%) and 16 men (9%) had practicing safe sex “a bit more”
- For 10 women (12%) and 45 men (25%) there had been “no change” in their sexual behaviour
- No women and 8 men (4%) had been practicing safe sex “a bit less”
- 3 women (4%) and 9 men (5%) had been practicing safe sex “much less”.

Emotional well-being

Table 30 below shows the extent to which respondents were currently experiencing a range of conditions.

Table 30: Experience of selected psychosocial factors (%)

	Not at all	A little	Moderately	Very much
Loneliness/isolation (n = 530)	34.7	28.3	18.5	18.5
Embarrassment about status (n = 531)	26.4	27.1	23.9	22.6
Embarrassment about appearance (n = 532)	51.7	24.4	12.6	11.3
Anxiety (n = 528)	20.1	33.9	25.8	20.3
Depression (n = 532)	24.6	32.5	23.5	19.4
Low libido (n = 528)	35.6	21.8	19.7	22.9
Sexual frustration (n = 527)	34.0	21.4	23.1	21.4

a) Loneliness/isolation (n = 530)

It can be seen from table 30 that almost 35% of individuals did not currently feel at all lonely or isolated. Approximately 28% felt "a little" lonely/isolated. A total of 37% felt "moderately" or very lonely/isolated.

b) Embarrassment about status (n = 531)

Respondents next indicated the extent to which they were currently experiencing embarrassment about their status. Table 30 shows there was a fairly even balance between the responses. However, just under half of respondents (47%) felt either "moderately" or very embarrassed about their status.

c) Embarrassment about appearance (n = 532)

The results showed that just over half of respondents (52%) were "not at all" currently embarrassed about their appearance. Almost a quarter (24%) were "a little" embarrassed and a further 24% felt "moderately" or very embarrassed.

d) Anxiety (n = 528)

It can be seen from table 30 that while a fifth of respondents (20%) felt "not at all" anxious and just over a third of respondents (34%) felt only "a little" anxiety, almost a half of respondents (46%) were feeling "moderately" or very anxious, including a fifth (20%) feeling high levels of anxiety.

e) Depression (n = 532)

Three quarters of respondents (75%) were experiencing depression to some extent including almost a fifth (19%) who felt "very much" depressed. However, a quarter of respondents (25%) reported feeling "not at all" depressed.

f) Low libido (n = 528)

Over a third of respondents (36%) reported that they were not experiencing low libido and over a fifth (22%) said that they were only experiencing "a little". However, low libido was more of a serious issue for 43% of respondents, with 20% experiencing low libido "moderately" and 23% "very much".

g) Sexual frustration (n = 527)

As shown in table 30, 34% of respondents were not experiencing any sexual frustration and 21% just "a little". The remaining 44% were feeling "moderately" (23%) or very (21%) sexually frustrated.

To facilitate comparison, a mean score for each of the conditions was calculated. This was done by assigning a value to each of the response options in the following way: Not at all = 0 ; A little = 1 ; Moderately = 2 ; Very much = 3

The possibilities were then ranked in order according to their mean score (from highest to lowest).

Table 31: Ranked mean score for each condition

	Mean score
Anxiety (n = 528)	1.46
Embarrassment about status (n = 531)	1.43
Depression (n = 532)	1.38
Sexual frustration (n = 527)	1.32
Low libido (n = 528)	1.30
Loneliness/isolation (n = 530)	1.21
Embarrassment about appearance (n = 532)	0.83

As can be seen from the table above, anxiety was the condition currently being experienced the most by respondents, followed quite closely by embarrassment about status.

A breakdown of the responses for males and females is provided in table 32 below.

Table 32: The extent to which males and females were currently experiencing a range of psychosocial factors (%)

		Not at all	A little	Moderately	Very much
Loneliness/isolation	Males (n = 404)	37.1	29.0	19.0	14.9
	Females (n = 124)	27.4	25.8	16.9	29.8
Embarrassment about status	Males (n = 405)	27.7	28.1	24.4	19.8
	Females (n = 124)	22.6	24.2	22.6	30.6
Embarrassment about appearance	Males (n = 405)	55.8	24.7	10.9	8.6
	Females (n = 125)	39.2	24.0	18.4	18.4
Anxiety	Males (n = 405)	20.7	36.3	26.2	16.8
	Females (n = 121)	18.2	26.4	24.8	30.6
Depression	Males (n = 405)	25.7	35.3	22.7	16.3
	Females (n = 125)	21.6	24.0	26.4	28.0
Low libido	Males (n = 405)	37.0	21.5	21.0	20.5
	Females (n = 121)	31.4	23.1	15.7	29.8
Sexual frustration	Males (n = 405)	33.8	21.2	24.2	20.7
	Females (n = 120)	35.0	22.5	20.0	22.5

As shown by table 32, between a quarter and a third of women reported they were currently experiencing 5 of the 7 conditions “very much”. These were:

- Loneliness/isolation
- Embarrassment about status
- Anxiety
- Depression
- Low libido

The results further showed that 23% of women were currently feeling very sexually frustrated. A similar proportion of men (21%) were also feeling a high degree of sexual frustration. Furthermore, approximately 21% of men reported experiencing low libido “very much” and a fifth also felt very embarrassed about their status. However, with the exception of sexual frustration, notably lower percentages of men than women reported experiencing “very much” the conditions covered by this question. It can also be seen that 37% of men were not currently experiencing loneliness/isolation at all compared to 27% of women. Similarly 56% of men reported that they did not feel at all embarrassed about their appearance in contrast to 39% of women.

The ranked mean scores for males and females are shown in the tables below. Anxiety and embarrassment about status were the main psychosocial issues for both males and females.

Table 33: Ranked mean score for each condition by gender

	Males	Females	
Anxiety (n = 405)	1.39	1.68	Anxiety (n = 121)
Embarrassment about status (n = 405)	1.36	1.61	Embarrassment about status (n = 124)
Sexual frustration (n = 405)	1.32	1.61	Depression (n = 125)
Depression (n = 405)	1.30	1.49	Loneliness/isolation (n = 124)
Low libido (n = 405)	1.25	1.44	Low libido (n = 121)
Loneliness/isolation (n = 404)	1.12	1.30	Sexual frustration (n = 120)
Embarrassment about appearance (n = 405)	0.72	1.16	Embarrassment about appearance (n = 125)

Outlook on the future

Table 34: Extent to which respondents were currently worried about a range of possibilities (%)

	Not at all	A little	Moderately	Very much
Death/dying (n = 532)	21.6	36.8	23.5	18
Getting other diseases (n = 532)	9.4	32.9	32.3	25.4
Worsening of side effects (n = 527)	12.1	26	28.5	33.4
Future body shape changes (n = 528)	8	24.1	26.3	41.7
Increased symptom visibility (n = 531)	11.9	23.5	24.9	39.7
Physical disability (n = 530)	13	21.9	26.4	38.7
Physical pain (n = 533)	14.4	26.8	27.2	31.5
Deteriorating mental health (n = 532)	13.9	21.2	25.6	39.3

a) *Death/dying* (n = 532)

Over a fifth of individuals (22%) were not currently worried at all by the possibility of death. Around 37% were worried “a little”, with another 24% “moderately” worried. The remaining 18% were very concerned about dying.

b) *Getting other diseases* (n = 532)

Approximately 91% of all respondents currently worried to some extent about the possibility of getting other diseases, with 25% being very worried and 32% “moderately” so.

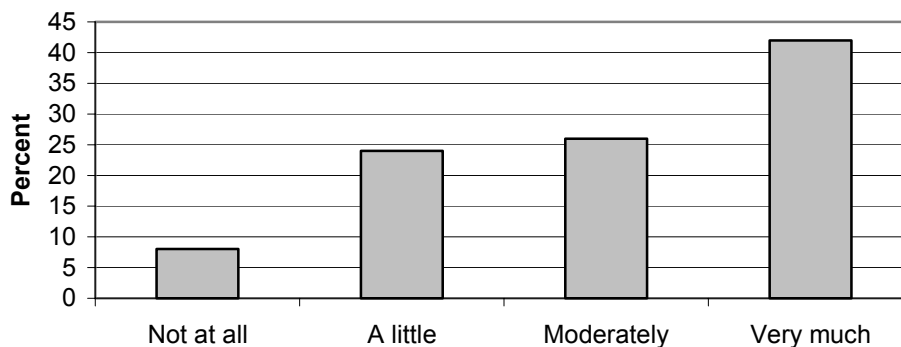
c) *Worsening of side effects* (n = 527)

A third of individuals (33%) were currently worried “very much” about the possible worsening of side effects. A further 55% were worried either “a little” or “moderately”. Only 12% weren’t worried at all.

d) *Future body shape changes* (n = 528)

The possibility of future body shape changes was clearly an issue that concerned respondents. The vast majority of respondents (92%) expressed a degree of concern, with 42% being very worried.

Figure 15: Currently worried about the possibility of future body shape changes (n = 528)



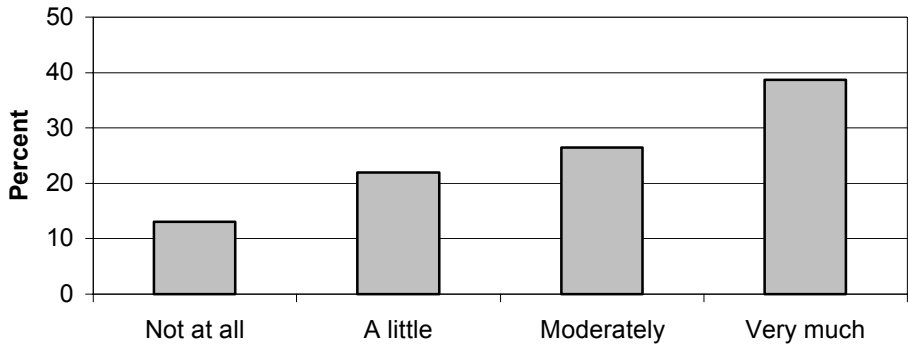
e) *Increased symptom visibility* (n = 531)

Again, the majority of respondents (88%) were currently worried about their symptoms becoming more visible. Almost 40% were worried “very much” and a further quarter (25%) were “moderately” so.

f) *Physical Disability* (n = 530)

The results for physical disability were similar to those for future body shape changes and increased symptom visibility. Approximately 39% were very worried about developing a physical disability with a further 48% currently worrying “a little” or “moderately”.

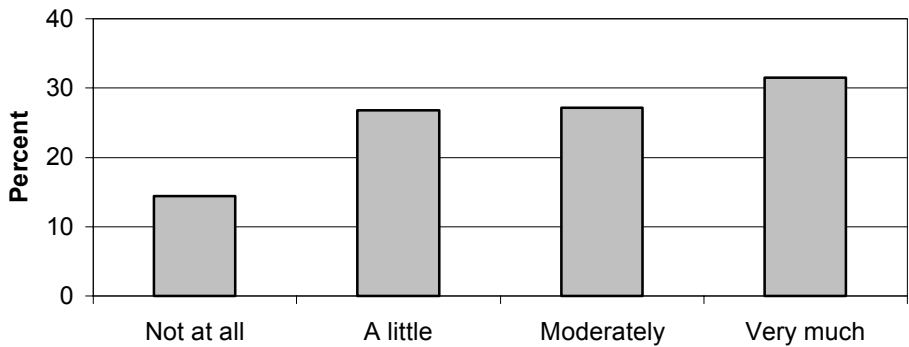
Figure 16: Currently worried about the possibility of physical disability (n = 530)



g) Physical pain (n = 533)

Figure 17 below shows that almost a third of respondents (32%) were “very much” worried about the possibility of developing physical pain. A further 54% reported feeling “a little” or “moderately” worried about this possibility. Less than 15% of respondents were “not at all” worried.

Figure 17: Currently worried about the possibility of physical pain (n = 533)



h) Deteriorating mental health (n = 532)

Most respondents (86%) worried to some extent about their mental health deteriorating, with about one in four (26%) worrying “moderately” and 39% worrying “very much”.

A mean score for each of the possibilities above was calculated, with the response options being assigned the following values:

Not at all = 0 ; A little = 1 ; Moderately = 2 ; Very much = 3

The possibilities were then ranked in order according to their mean score (from highest to lowest).

Table 35: Ranked mean score for each possibility

	Mean score
Future body shape changes (n = 528)	2.02
Increased symptom visibility (n = 531)	1.92
Physical disability (n = 530)	1.91
Deteriorating mental health (n = 532)	1.90
Worsening of side effects (n = 527)	1.83
Physical pain (n = 533)	1.76
Getting other diseases (n = 532)	1.74
Death/dying (n = 532)	1.38

The results suggested that the possibility currently worrying the respondents most was future body shape changes, which had a mean “worry” rating of above 2. The possibility of death/dying had the lowest mean score and was ranked last.

A breakdown of the results for males and females is shown in table 36 below.

Table 36: The extent to which males and females were currently worried about a range of possibilities (%)

		Not at all	A little	Modera tely	Very much
Death/dying	Males (n = 406)	22.4	38.7	23.2	15.8
	Females (n = 124)	19.4	31.5	25	24.2
Getting other diseases	Males (n = 406)	8.4	33.3	35.2	23.2
	Females (n = 124)	12.9	32.3	23.4	31.5
Worsening of side effects	Males (n = 405)	11.6	26.4	30.1	31.9
	Females (n = 120)	14.2	25.0	23.3	37.5
Future body shape changes	Males (n = 405)	6.7	24.0	28.1	41.2
	Females (n = 121)	12.4	24.8	20.7	42.1
Increased symptom visibility	Males (n = 405)	11.9	22.0	27.2	39.0
	Females (n = 124)	12.1	29.0	16.9	41.9
Physical disability	Males (n = 405)	12.6	22.5	27.7	37.3
	Females (n = 123)	14.6	20.3	22.0	43.1
Physical pain	Males (n = 406)	14.5	28.3	28.1	29.1
	Females (n = 125)	14.4	22.4	24.0	39.2
Deteriorating mental health	Males (n = 405)	14.3	20.2	26.4	39.0
	Females (n = 125)	12.8	24.8	23.2	39.2

Overall women appeared to worry more about death/dying than men. In total, 49% of women were currently worried “moderately” or “very much” about death/dying compared to 39% of men. In contrast, a reasonably higher proportion of men than women reported being “moderately” or “very much” concerned about future body shape changes (69% compared to 63%) and increased symptom visibility (66% compared to 59%). It can also be seen from the table that more women than men reported being “not at all” worried about future body shape changes. Just over 12% of women were “not at all” worried about future body shape changes in contrast to around 7% of men.

Tables 37 (below) shows the ranked mean score for each possibility by gender. It can be seen that men were most concerned about future body shape changes and least concerned about death/dying. Women were also least concerned about death/dying while physical disability and future body shape changes were ranked equally as the possibilities that worried them the most.

Table 37: Ranked mean score for each possibility (Males)

	Males	Females	
Future body shape changes (n = 405)	2.04	1.93	Future body shape changes (n = 121)
Increased symptom visibility (n = 405)	1.93	1.93	Physical disability (n = 123)
Physical disability (n = 405)	1.90	1.89	Increased symptom visibility (n = 124)
Deteriorating mental health (n = 405)	1.90	1.89	Deteriorating mental health (n = 125)
Worsening of side effects (n = 405)	1.82	1.88	Physical pain (n = 125)
Getting other diseases (n = 406)	1.73	1.84	Worsening of side-effects (n = 120)
Physical pain (n = 406)	1.72	1.73	Getting other diseases (n = 124)
Death/dying (n = 406)	1.32	1.54	Death/dying (n = 124)

Section 5: Social functioning and economic support

Others' knowledge of respondent's HIV status

a) Partner/husband/wife (n = 239)

Of those respondents currently married or in a relationship, almost all (98%) had told their partner, husband or wife about their HIV status.

b) Family (n = 530)

The extent to which respondents had told family members about their HIV status varied considerably. Quite a high percentage of respondents (31%) had not told any member of their family. A further 39% had told some of their family and 31% all members.

c) Friends (n = 527)

Interestingly, only 19% of respondents had not told any friends, which is considerably less than hadn't told any of their family. Approximately 57% of respondents indicated they had told at least some of their friends. Nearly one in four (24%) had told all their friends.

d) Employer (n = 513)

In total, 153 of those answering (30%) indicated that this question was not relevant for them. Of the 360 for whom it was, 61% had not told their employer about being HIV positive.

e) Work colleagues (n = 352)

Of those respondents currently employed, 46% had not told any of their work colleagues. A further 40% had told some of their work colleagues, while 15% had told all of them.

Other people's reaction and 'perceived likely' reaction

Respondents were asked to indicate how a range of people reacted or were thought likely to react to being told about their status. Table 38 shows the reaction/perceived likely reaction of each group of individuals.

Table 38-: Reaction/perceived likely reaction to being told about respondent's positive status

	I don't know %	Very negative %	Negative %	Positive %	Neither %	Mixed %
Partner/husband/wife (n = 360)	3.9	8.6	8.1	60.0	7.8	11.7
Parents (n = 376)	6.1	15.7	14.1	35.1	10.9	18.1
Children (n = 105)	18.1	11.4	12.4	36.2	4.8	17.1
Friends (n = 491)	4.5	3.9	5.3	52.5	9.4	24.4
Employer (n = 280)	14.3	15.4	14.3	38.6	9.6	7.9
Work colleagues (n = 306)	11.4	12.7	14.4	36.3	8.8	16.3

It can be seen from the table that partners and friends were the two groups who reacted most positively, or were thought most likely to react positively.

Further analyses were carried out on the data to separate the actual reaction from the perceived likely reaction for several of the groups.

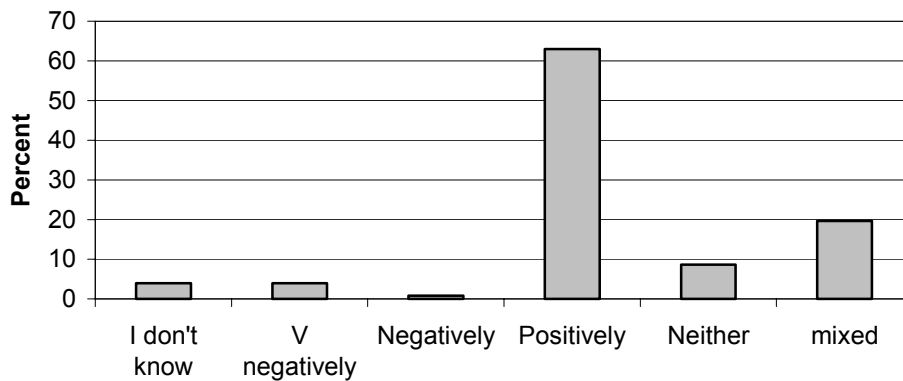
a) Reaction of current partner/husband/wife (n = 218)

Over 72% indicated that their current partner/husband/wife reacted “positively” to finding out. Approximately 6% reacted “negatively” or “very negatively” and 12% “mixed”. Just under 9% of partners reacted neither positively nor negatively.

b) Reaction of friends (n = 127)

In total, 127 respondents had told all their friends about their status. The reaction they received is shown in figure 18.

Figure 18: The reaction of friends (n = 127)

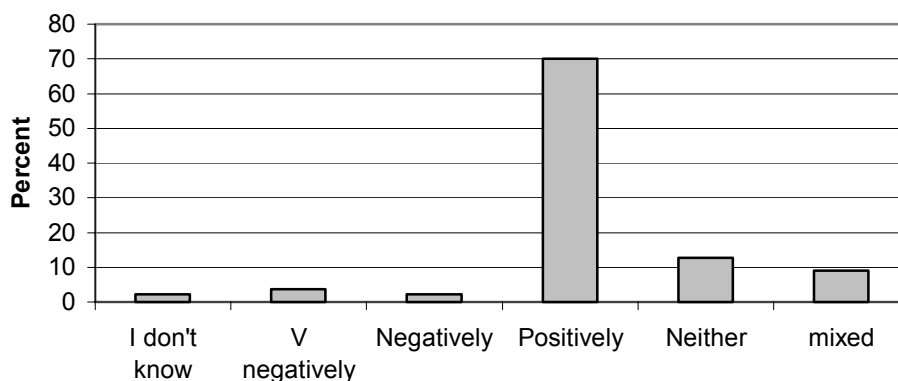


The analysis suggested that a majority of friends (80) (63%) reacted “positively” to being told. Only 6 respondents (5%) had been given a negative or very negative reaction. However, 25 (20%) had received a “mixed” reaction from friends.

c) The reaction of employers (n = 134)

The way in which employers reacted to being told about respondents’ HIV status is shown in figure 19 below.

Figure 19: The reaction of employers (n = 134)



It can be seen from figure 19 that 70% of employers reacted “positively”. Only a small proportion (7%) reacted “negatively” or “very negatively”.

d) Perceived likely reaction of friends (n = 65)

Out of those respondents who had not told any of their friends, 26 (40%) felt they would receive a positive reaction if they were to tell them. However, 16 (25%) would expect a “mixed” reaction and a further 11 (17%) believed their friends would react “negatively” or “very negatively”.

e) Perceived likely reaction of employers (n = 104)

Out of those respondents who had not told their employer, over half (53%) would expect to receive a negative or very negative reaction if they were to do so. A further 29% did not know how their employer would react. Only 7% thought their employer would react “positively” to finding out.

Employment/unemployment experience

a) Individuals currently in employment (n = 369)

Respondents were asked whether they were working full-time or part-time. Of those who answered, 74% worked full time and 26% part time.

Respondents were then asked whether, for HIV related medical reasons, if they have ever had to:

Quit waged employment (n = 437)

Just under 30% indicated they had at some point quit waged employment for HIV related medical reasons, the majority had not (70%). In total, 25% of the 360 males who responded had quit waged employment due to HIV related medical reasons compared to 50% of the 76 females who provided an answer.

Change jobs (n = 407)

Over one in five respondents (22%) had changed jobs for HIV related medical reasons. Overall, 342 males and 64 females responded to this question. The analysis revealed that 18% of males and 39% of females had changed jobs for these reasons.

Learn new skills (n = 414)

Overall, 22% had needed to learn new skills as a result of their status. Out of 341 males, 17% had needed to learn new skills compared to 43% of the 72 female respondents.

Reduce working hours (n = 417)

A higher percentage (34%) of those responding had needed to reduce their working hours due to HIV related medical reasons. Overall, 345 males and 71 females responded to this question. The results showed that 30% of males and 52% of females had needed to reduce their working hours for these reasons.

Effect of status on career opportunities (n = 471)

Respondents were asked whether they felt their diagnosis can affect career opportunities. Overall, most (58%) did believe this to be the case, 18% did not think so and 24% were not sure.

b) Respondents not in employment (n = 296)

Respondents not in employment, or those who had previously needed to stop working for 6 months or more, were asked whether this was a result of HIV related disability. Of those who responded, 53% indicated that it was because of HIV related disability.

Most difficult aspects of returning to work: Online version of the questionnaire (n = 187)

Respondents completing the online version of the questionnaire indicated the single most difficult aspect of returning to work. The largest proportion of respondents (39%) considered “potentially heavy workloads” to be the most difficult aspect of returning to work and a further 24% cited perceived discrimination from employer/colleagues. In addition, 17% of respondents suggested that a possible lack of skills was/would be most difficult and 14% cited income drop from getting off state benefits. A small proportion (7%) stated there were “other” factors which made returning to work difficult. Unfortunately, respondents quite often did not state the nature of these factors. Of those that did, the most common response was fatigue/tiredness.

Most difficult aspects of returning to work: Paper copy of the questionnaire (n = 89)

On the paper version of the questionnaire respondents were able to identify all the aspects that applied to them. Table 39 shows the number and percentage of respondents citing each aspect.

Table 39: Most difficult aspects of returning to work

	No of respondents (89 in total)	Percentage
Potentially heavy workloads	46	51.7
Possible lack of skills	25	28.1
Perceived discrimination from employer/colleagues	35	39.3
Income drop from getting off state benefit	32	36.0
Other	21	23.6

NB: Respondents could give more than one answer

As can be seen from the table, “potentially heavy workloads” was the response given most frequently followed by perceived discrimination from employers/colleagues and income drop from getting off state benefit. “Other” aspects commonly cited included tiredness, the side effects of medication, anxiety/depression, low confidence and levels of pain.

Impact of diagnosis on relations and responsibilities

Respondents were asked to rate from “not at all” to “very much” the extent to which their diagnosis impacted on various aspects of life. The results are showed in table 40 below.

Table 40: Impact of diagnosis on various aspects of life

	Not at all %	A little %	Moderately %	Very much %
Provide for the family (n = 321)	21.5	26.2	28.3	24.0
Care for your children (n = 166)	32.5	21.1	15.1	31.3
Remain in a relationship/marriage (n = 442)	23.2	19.2	24.0	33.5
Maintain a circle of friends (n = 513)	34.3	25.7	20.3	19.7
Work with colleagues (n = 439)	38.5	19.8	21.6	20.0

The results showed that most of those who answered felt that their HIV status affected all these aspects of life to at least some degree. Notably, it can be seen from the table that a considerable minority of respondents believed that being HIV positive impacted “moderately” or “very much” on their ability to maintain a circle of friends (40%), work with colleagues (42%) and care for children (46%). Similarly, over half of the respondents felt that their positive status impacted “moderately” or “very much” on their ability to remain in a relationship (58%) and provide for the family (52%). Significantly, the data also show that approximately a third of respondents believed that their diagnosis had impacted “very much” on their ability to care for their children and remain in a relationship/marriage.

A mean score for each of the above aspects of life was calculated. This was done by assigning a value to each of the response options in the following way:

Not at all = 0 ; little = 1 ; Moderately = 2 ; Very much = 3

The aspects were then ranked in order according to their mean score (from highest to lowest).

Table 41: Ranked mean score for each aspect

	Mean score
Remain in a relationship/marriage (n = 442)	1.68
Provide for the family (n = 321)	1.55
Care for your children (n = 166)	1.45
Maintain a circle of friends (n = 513)	1.25
Work with colleagues (n = 439)	1.23

The results showed that remaining in a relationship/marriage was the aspect felt to be most affected by diagnosis, followed by providing for the family. The perceived effect of diagnosis on ability to work with colleagues had the lowest mean score and was ranked last.

Table 42: Ranked mean score for each aspect (Males)

	Mean score
Remain in a relationship/marriage (n = 340)	1.64
Provide for the family (n = 230)	1.44
Care for your children (n = 83)	1.20
Maintain a circle of friends (n = 396)	1.18
Work with colleagues (n = 346)	1.18

Table 43: Ranked mean score for each aspect (Females)

	Mean score
Provide for the family (n = 90)	1.81
Remain in a relationship/marriage (n = 100)	1.80
Care for your children (n = 82)	1.68
Maintain a circle of friends (n = 115)	1.49
Work with colleagues (n = 91)	1.41

The tables above show that the broad pattern was similar for males and females. However, remaining in a relationship/marriage was felt by men to be the aspect most affected by diagnosis, whereas for women it was providing for the family.

Support from other people and organisations

Respondents were also asked to indicate how supported they felt by a range of different people and organisations.

Table 44: Levels of support

	Not at all %	Not so well %	Well %	Very well %
Family (n = 399)	16.3	14.0	28.1	41.6
Friends (n = 460)	7.0	10.7	39.8	42.6
People at work (n = 217)	26.3	13.8	33.2	26.7
Volunteer HIV support groups (n = 350)	21.1	15.4	32.9	30.6
HIV advocacy organisations (n = 324)	23.8	17.6	30.6	28.1
Social services (n = 313)	40.9	25.2	23.0	10.9
Government health policy (n = 439)	33.0	35.1	24.8	7.1

It is clear from the results that a large proportion of respondents did not feel supported by either social services or government health policy in particular. Overall, 66% of those who answered felt “not at all” or “not so well” supported by social services and for government health policy this figure was 68%. In fact, 41% of respondents did not feel at all supported by

social services. Approximately 1 in 4 respondents did not feel at all supported by people at work (26%) or HIV advocacy organisations (24%), while over a fifth of respondents (21%) did not feel at all supported by volunteer HIV support groups. However, most respondents did feel “well” or “very well” supported by all 3 of these groups. While a majority of respondents (70%) felt “well” or “very well” supported by family, conversely quite a sizeable percentage (30%) did not feel at all or “not so well” supported by their family. Interestingly, a higher proportion of individuals felt “well” or “very well” supported by friends than by family.

A mean score for the level of support from each group of individuals etc was again calculated. In this case, the values for each response option were assigned as follows:-

Not at all = 0 ; Not so well = 1 ; Well = 2 ; Very well = 3

The ranked mean scores are shown in table 45 below.

Table 45: Ranked mean score for levels of support

	Mean Score
Friends (n = 460)	2.18
Family (n = 399)	1.95
Volunteer HIV support groups (n = 350)	1.73
HIV advocacy organisations (n = 324)	1.63
People at work (n = 217)	1.60
Government health policy (n = 439)	1.06
Social services (n = 313)	1.04

As can be seen from the table, only friends had a mean “support” score of more than 2, although the score for family was approaching this level. As highlighted previously, a majority of respondents indicated that they felt “not at all” or “not so well” supported by social services and government health policy. This is also reflected in the rankings above, with social services having the lowest mean score (1.04) and government health policy the second lowest (1.06).

Tables 46 and 47 below show the ranked mean score for level of support by gender.

Table 46: Ranked mean score for levels of support (Males)

	Mean Score
Friends (n = 353)	2.18
Family (n = 290)	1.92
Volunteer HIV support groups (n = 247)	1.57
People at work (n = 181)	1.54
HIV Advocacy organisations (n = 233)	1.52
Government health policy (n = 341)	1.05
Social services (n = 227)	0.98

Table 47: Ranked mean score for levels of support (Females)

	Mean Score
Friends (n = 106)	2.17
Volunteer HIV support groups (n = 102)	2.09
Family (n = 107)	2.07
People at work (n = 35)	1.91
HIV Advocacy organisations (n = 90)	1.90
Social services (n = 85)	1.18
Government health policy (n = 97)	1.11

The scores for men and women were similar for support from friends. However, women tended to report higher levels of support from the other groups, particularly so for volunteer HIV support groups.

Membership of a HIV patient organisation (n = 529)

Over a quarter of respondents (29%) were a member of a HIV patient organisation.

Membership of a group of HIV positive people (n = 530)

Nearly 37% of individuals belonged to a group of people who are HIV positive.

Knowledge of sources of information

Respondents were asked whether they knew where to obtain information about a range of topics:-

a) State health benefits (n = 531)

A majority (62%) knew where to obtain information about state health benefits. A fifth of respondents (20%) weren't sure and 18% had 'no idea'.

b) Community health & social services (n = 528)

Once again, most respondents (61%) knew where to get information about community health & social services. Almost a quarter (24%) weren't sure and 14% didn't know.

c) HIV medications (n = 529)

Almost all respondents (94%) knew where to get information regarding HIV medications. Fewer than 5% weren't sure and just under 2% did not know.

d) Treatment centres (n = 529)

Similarly, a large proportion (88%) of respondents knew where they could obtain information about treatment centres. Approximately 10% weren't sure and 2% had 'no idea'.

e) *Living with HIV* (n = 530)

Approximately 83% of respondents were aware of where they could obtain information about living with HIV. Only 5% did not know and the remainder (12%) weren't sure.

Changes in life since diagnosis

Respondents were asked to rate from “much worse” to “much better” the extent to which various aspects of life had changed since becoming aware of their HIV status. The results are shown in table 48 below.

Table 48: Changes in life since diagnosis

	Much worse %	A bit worse %	No change %	A bit better %	Much better %
Economic status (n = 509)	23.0	17.1	39.3	10.2	10.4
No of close friends (n = 514)	12.6	20.8	51.6	9.9	5.1
Quality of relationship with partner (n = 361)	21.9	14.7	31.9	16.3	15.2
Quality of relationships with family (n = 454)	8.8	12.8	50.2	17.4	10.8
Quality of relationships with friends (n = 490)	6.5	16.9	52.4	13.9	10.2
Support networks (n = 300)	10.0	8.0	35.0	29.0	18.0
Self esteem/self worth (n = 524)	21.9	31.9	20.6	12.4	13.2
Sense of purpose (n = 524)	21.4	25.6	18.9	15.5	18.7
Sense of identity (n = 521)	16.5	25.1	24.6	16.1	17.7
Outlook on life (n = 524)	24.0	34.7	14.9	13.0	13.4
Overall health awareness (n = 525)	7.6	16.4	14.5	28.6	33.0
General lifestyle (n = 525)	9.0	22.5	22.7	27.2	18.7
Taking risks (n = 490)	9.2	15.7	35.9	15.1	24.1
Religious/spiritual beliefs (n = 411)	8.0	5.1	54.7	16.3	15.8
Making the most of life (n = 512)	10.4	14.1	20.5	20.7	34.4

Overall, for about half of these aspects, 75% or more of those responding indicated that they had experienced “no change” or a degree of improvement. These were:

- quality of relationships with family;
- quality of relationships with friends;
- support networks;
- overall health awareness;
- taking risks;
- religious/spiritual beliefs;
- making the most of life.

For a further 5 aspects, between 58% and 69% of respondents also believed there had been “no change” or some improvement. These were:-

- economic status;
- number of close friends;
- quality of relationship with partner;
- sense of identity;
- general lifestyle.

Nevertheless, it is clear that for each of these aspects a sizeable minority felt things had got worse to some extent. For example,

- 42% felt that their sense of identity had got a “bit worse” or “much worse”.
- 40% reported that their economic status had got a “bit worse” or “much worse”.
- 37% reported the quality of the relationship with their partner was now a “bit worse” or “much worse”.

In addition, just over half of the respondents (53%) felt there had been no change or a degree of improvement in their sense of purpose. Nearly 59% felt their outlook on life had got a “bit worse” or “much worse”, with 54% feeling the same about their self esteem/self worth. In addition, it can also be seen that for between 21% and 24% of individuals, the following aspects had all got “very much” worse.

- economic status;
- relationship with partner;
- self esteem/self worth;
- sense of purpose;
- outlook on life.

A mean score was calculated for each aspect, with the response options being assigned the following values:

Much worse = 1 ; A bit worse = 2 ; No change = 3 ; A bit better = 4 ; Much better = 5

The ranked mean score for each aspect is shown in table 49 overleaf. A score of 3 would indicate no change, more than 3 an improvement and less than 3 a deterioration.

Table 49: Ranked mean score for changes in life since diagnosis

	Mean Score
Overall health awareness (n = 525)	3.63
Making most of life (n = 512)	3.55
Support networks (n = 300)	3.37
Taking risks (n = 490)	3.29
Religious/spiritual beliefs (n = 411)	3.27
General lifestyle (n = 525)	3.24
Quality of relationship with family (n = 454)	3.09
Quality of relationship with friends (n = 490)	3.04
Sense of identity (n = 521)	2.93
Quality of relationship with partner (n = 361)	2.88
Sense of purpose (n = 524)	2.85
No of close friends (n = 514)	2.74
Economic status (n = 509)	2.68
Self esteem/self worth (n = 524)	2.63
Outlook on life (n = 524)	2.57

Overall, 8 out of the 15 aspects had a mean score of above 3. In terms of respondents' personal relationships with others, the results again suggested that the relationships with partners had suffered the most. As can be seen from the table, the quality of the relationship with family had a mean score of 3.09 and for friends it was 3.04. However, the quality of the relationship with partner had a lower mean score of 2.88.

A detailed comparison of the responses of men and women is provided in table 50 overleaf. It can be seen that overall, 59% of women reported a deterioration in their economic status compared to just 34% of men. A notably larger percentage of women than men also believed their economic status had become "much worse" (35% compared to 19%). In addition, 12% more women than men believed the quality of the relationship with their partner had worsened to some degree. Similarly, 11% more women also felt there had been a deterioration in the number of close friends. The results further showed that considerably higher percentages of women than men reported that their sense of identity and sense of purpose had become "much worse" since diagnosis. Interestingly, over half of the women (54%) felt that their religious/spiritual beliefs had now improved compared to just one quarter (25%) of men.

Table 50: Changes in life since diagnosis for males and females

		Much worse %	A bit worse %	No change %	A bit better %	Much better %
Economic status	Males (n = 394)	19.3	15	43.4	10.4	11.9
	Females (n = 113)	34.5	24.8	25.7	9.7	5.3
No of close friends	Males (n = 396)	11.4	19.4	55.1	8.8	5.3
	Females (n = 116)	16.4	25	40.5	13.8	4.3
Quality of relationship with partner	Males (n = 283)	19.8	13.8	32.9	17.7	15.9
	Females (n = 76)	27.6	18.4	28.9	11.8	13.2
Quality of relationships with family	Males (n = 339)	8	11.2	53.1	18.3	9.4
	Females (n = 113)	10.6	17.7	41.6	15	15
Quality of relationships with friends	Males (n = 378)	5.3	15.9	55.3	14	9.5
	Females (n = 111)	10.8	20.7	43.2	12.6	12.6
Support networks	Males (n = 204)	8.8	8.3	38.2	31.9	12.7
	Females (n = 95)	11.6	7.4	28.4	23.2	29.5
Self esteem/self worth	Males (n = 401)	20	33.4	21.7	12.2	12.7
	Females (n = 121)	27.3	27.3	17.4	13.2	14.9
Sense of purpose	Males (n = 400)	18.8	26.8	20.5	15.5	18.5
	Females (n = 122)	28.7	22.1	13.9	15.6	19.7
Sense of identity	Males (n = 398)	13.3	26.9	26.4	16.1	17.3
	Females (n = 121)	25.6	19.8	19	16.5	19
Outlook on life	Males (n = 401)	22.9	37.2	16.2	12.2	11.5
	Females (n = 121)	26.4	27.3	10.7	15.7	19.8
Overall health awareness	Males (n = 402)	7.5	18.4	14.4	28.9	30.8
	Females (n = 121)	7.4	9.9	14.9	27.3	40.5
General lifestyle	Males (n = 401)	7	24.2	22.7	28.9	17.2
	Females (n = 122)	14.8	17.2	23	21.3	23.8
Taking risks	Males (n = 384)	8.6	17.7	35.7	15.9	22.1
	Females (n = 104)	9.6	8.7	37.5	12.5	31.7
Religious/spiritual beliefs	Males (n = 308)	9.1	5.5	60.4	13.3	11.7
	Females (n = 101)	4	4	38.6	24.8	28.7
Making the most of life	Males (n = 390)	9.2	15.4	23.3	20.5	31.5
	Females (n = 120)	13.3	9.2	11.7	21.7	44.2

A breakdown of the ranked mean score for changes in life since diagnosis by gender is provided in the tables overleaf.

Table 51: Ranked mean score for changes in life since diagnosis (Males)

	Mean Score
Overall health awareness (n = 402)	3.57
Making the most of life (n = 390)	3.50
Support networks (n = 204)	3.31
Taking risks (n = 384)	3.25
General lifestyle (n = 401)	3.25
Religious/spiritual beliefs (n = 308)	3.13
Quality of relationships with family (n = 339)	3.10
Quality of relationships with friends (n = 378)	3.07
Sense of identity (n = 398)	2.97
Quality of relationship with partner (n = 283)	2.96
Sense of purpose (n = 400)	2.88
Economic status (n = 394)	2.81
No of close friends (n = 396)	2.77
Self esteem/self worth (n = 401)	2.64
Outlook on life (n = 401)	2.52

Table 52: Ranked mean score for changes in life since diagnosis (Females)

	Mean Score
Overall health awareness (n = 121)	3.83
Making the most of life (n = 120)	3.74
Religious/spiritual beliefs (n = 101)	3.70
Support networks (n = 95)	3.52
Taking risks (n = 104)	3.48
General lifestyle (n = 122)	3.22
Quality of relationships with family (n = 113)	3.06
Quality of relationships with friends (n = 111)	2.95
Sense of identity (n = 121)	2.83
Sense of purpose (n = 122)	2.75
Outlook on life (n = 121)	2.75
No of close friends (n = 116)	2.65
Quality of relationship with partner (n = 76)	2.64
Self esteem/self worth (n = 121)	2.61
Economic status (n = 113)	2.27

For both males and females, similar aspects of life had a mean score of above 3, indicating an improvement in the way respondents compared themselves now to before they became aware of their HIV status.

Section 6: Overall quality of life satisfaction

Overview across dimensions

An overview of levels of satisfaction with a range of different issues is provided in table 53 below.

Table 53: Levels of satisfaction (%)

	Very dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
Experience of health services (n = 522)	5.2	10.9	18.8	43.1	22.0
Treatment (n = 475)	5.1	8.2	13.1	45.3	28.4
Physical well being (n = 531)	5.1	15.3	22.2	41.6	15.8
Emotional well being (n = 529)	12.9	22.9	21.9	31.6	10.8
Work & professional career (n = 485)	16.3	18.4	20.6	30.7	14.0
Social life (n = 532)	11.5	21.4	18.4	35.0	13.7
Overall quality of life (n = 531)	7.5	16.9	23.4	39.5	12.6

a) Satisfaction with experience of health services (n = 522)

Table 53 shows that nearly two thirds (65%) of respondents were either “satisfied” or “very satisfied” with their experience of health services. Only a relatively small percentage (16%) expressed any dissatisfaction.

A breakdown of the results for males and females is provided in table 54. It can be seen that 66% of women were “satisfied” or “very satisfied” with their experience of health services compared to 65% of men. One in five women (20%) expressed a degree of dissatisfaction. The proportion of men that did so was around 15%. Furthermore, one in five men (20%) was “neither satisfied nor dissatisfied” compared to 14% of women.

b) Satisfaction with treatment (n = 475)

Respondents on the whole expressed satisfaction with their treatment. Overall 74% rated themselves as “satisfied” or “very satisfied”. Only around 13% of those responding were “dissatisfied” or “very dissatisfied” with their treatment.

The results showed (see table 54) that roughly equal proportions of men and women were dissatisfied to some extent with their treatment (13% & 14% respectively). However, the analysis further suggested that 79% of women were either “satisfied” or “very satisfied” with their treatment compared to 72% of men. In addition, over twice as many men than women felt “neither satisfied nor dissatisfied” (15% compared with 7%).

c) Satisfaction with physical well-being (n = 531)

Overall, 42% of respondents were “satisfied” and 16% “very satisfied” with their physical well being. Approximately 20% expressed a degree of dissatisfaction, with a further 22% being “neither satisfied nor dissatisfied”.

Table 54 shows that 59% of men rated themselves as “satisfied” or “very satisfied” with their physical health. The proportion of women who also rated themselves that way was just over 54%.

d) Satisfaction with emotional well-being (n = 529)

The results showed that respondents were generally less satisfied with their emotional well being. Overall, 42% of respondents were either “satisfied” or “very satisfied” with their emotional health. However, in comparison just over 57% were “satisfied” or “very satisfied” with their physical well-being. Furthermore, over one third of respondents (36%) were dissatisfied to some extent with their emotional well being.

It can be seen from table 54 that approximately 41% of the 121 women who responded to this question expressed some dissatisfaction with 19% being “very dissatisfied”. Conversely 34% of the 406 men who answered reported a degree of dissatisfaction with 11% being “very dissatisfied”.

e) Satisfaction with work & professional career (n = 485)

In total, 31% of respondents were “satisfied” and 14% “very satisfied” with their work and professional career. Conversely, 35% expressed some dissatisfaction and nearly 21% were “neither satisfied nor dissatisfied”.

The analysis revealed that almost half (49%) of the women were “dissatisfied” or “very dissatisfied” with their work and professional career compared to 31% of men. Furthermore, 48% of men expressed a degree of satisfaction with their work and professional career, but only 35% of women did so.

f) Satisfaction with social life (n = 532)

Nearly half of the respondents expressed a degree of satisfaction with their social life - 35% being “satisfied” and 14% “very satisfied”. However, one third reported dissatisfaction, with 21% being “dissatisfied” and 12% “very dissatisfied”.

Table 54 overleaf shows that 53% of men felt “satisfied” or “very satisfied” with their social life compared to just 37% of women. Conversely, 42% of women were “dissatisfied” or “very dissatisfied” with their social life, but for men this figure was closer to 30%.

g) Satisfaction with overall quality of life (n = 531)

A considerable proportion of respondents (52%) were “satisfied” or “very satisfied” with their overall quality of life. Less than one in five (17%) were “dissatisfied” and 8% reported feeling “very dissatisfied”. Slightly more than 23% were “neither satisfied nor dissatisfied”.

Table 54 overleaf shows that overall 45% of women and around 55% of men indicated they were “satisfied” or “very satisfied” with their quality of life. On the other hand, almost one third (32%) of women expressed some dissatisfaction compared to 22% of men.

In summary, it is clear from the results that for most of the aspects covered in this question, a greater proportion of women than men expressed a degree of dissatisfaction and conversely more men than women were “satisfied or “very satisfied”. Indeed, for 3 of the 7 aspects (work & professional career, social life and overall quality of life) there were quite sizeable differences in the satisfaction levels of males and females. In each of these 3 aspects:-

- At least 10% more women than men expressed some dissatisfaction
- At least 10% more men than women expressed a degree of satisfaction.

Table 54: Satisfaction levels of males and females (%)

		Very dissatisfied	Dissatisfied	Neither	Satisfied	Very satisfied
Experience of health services	Males (n = 399)	4.5	10.0	20.3	42.9	22.3
	Females (n = 121)	6.6	13.2	14.0	44.6	21.5
Treatment	Males (n = 360)	5.3	7.5	15.0	43.9	28.3
	Females (n = 113)	3.5	10.6	7.1	49.6	29.2
Physical well-being	Males (n = 404)	4.2	15.1	22.0	43.1	15.6
	Females (n = 125)	7.2	16.0	22.4	37.6	16.8
Emotional well-being	Males (n = 406)	10.8	23.2	21.7	32.8	11.6
	Females (n = 121)	19.0	21.5	23.1	28.1	8.3
Work & professional career	Males (n = 380)	15.0	15.5	21.8	33.2	14.5
	Females (n = 103)	19.4	29.1	16.5	22.3	12.6
Social life	Males (n = 405)	10.1	19.8	17.5	37.8	14.8
	Females (n = 125)	15.2	26.4	21.6	26.4	10.4
Overall quality of life	Males (n = 405)	6.4	15.6	23.5	41.2	13.3
	Females (n = 124)	10.5	21.0	23.4	34.7	10.5

Aspects to be improved

Respondents were asked to rank in order of importance the 3 aspects they would most like to see improved. The results are shown in the table below.

Table 55: Aspects respondents would most like to see improved

	% of respondents ranking aspect most important to be improved (n = 492)	% of respondents ranking aspect 2 nd most important to be improved (n = 490)	% of respondents ranking aspect 3 rd most important to be improved (n = 491)
Ease of medication intake	14.4	10.0	13.0
Treatment side effects	23.8	19.8	12.4
Relationship with doctor	3.0	4.5	6.1
Satisfaction with treatment centre	2.0	2.7	3.5
Ability to maintain a professional career	6.9	7.3	11.2
Ability to maintain a social network	1.8	5.9	7.1
HIV-related discrimination	13.6	9.0	11.4
Physical well being	16.1	15.7	13.8
Emotional well being	15.2	19.6	15.5
Community support	3.0	5.5	5.9

The analysis showed that the single largest percentage of respondents (24%) thought it was most important to improve treatment side effects. Moreover, in total 56% considered this to be 1 of the 3 aspects they would like to see improved the most. Furthermore, half of the respondents (50%) ranked emotional well being and 46% ranked physical well-being in the top 3. However, physical well being was ranked first by a slightly greater proportion of individuals than emotional wellbeing. Of the remaining aspects, only ease of medication intake, HIV-related discrimination and ability to maintain a professional career were ranked in the top 3 by more than 25% of respondents.

Table 56: Aspects men and women would most like to see improved

	% of respondents ranking aspect most important to be improved		% of respondents ranking aspect 2 nd most important to be improved		% of respondents ranking aspect 3 rd most important to be improved	
	Males (n = 392)	Females (n = 98)	Males (n = 392)	Females (n = 96)	Males (n = 392)	Females (n = 97)
Ease of medication intake	15.6	10.2	9.9	10.4	13.8	10.3
Treatment side effects	25.8	16.3	20.7	16.7	13.8	6.2
Relationship with doctor	3.1	3.1	4.8	3.1	5.4	9.3
Satisfaction with treatment centre	2.0	2.0	2.3	4.2	3.3	4.1
Ability to maintain a professional career	6.9	6.1	7.1	8.3	10.5	14.4
Ability to maintain a social network	2.0	1.0	5.9	6.3	6.4	10.3
HIV-related discrimination	11.2	23.5	8.9	8.3	10.2	16.5
Physical well being	16.1	16.3	17.1	9.4	15.1	9.3
Emotional well being	14.5	17.3	18.6	24	15.6	14.4
Community support	2.8	4.1	4.6	9.4	6.1	5.2

As shown in table 56, the greatest proportion of men (26%) believed it was most important to improve treatment side effects with 60% ranking this aspect in the top 3. In addition, 16% ranked physical well being, a further 16% ease of medication intake and 15% emotional well being as the most important aspect to be improved. In total, a roughly equal proportion of men considered emotional well being (49%) and physical well being (48%) to be 1 of the top 3 aspects. The responses provided by women differed somewhat to those of the men. Only 16% of women thought it was most important to improve treatment side effects, although 39% still ranked this aspect in the top 3. HIV related discrimination was the aspect ranked by the largest proportion of women (24%), as the most important to be improved, with 48% ranking it in the top 3. In comparison, only 11% of men rated HIV related discrimination as the most important aspect and 30% ranked it in the top 3. Approximately 17% of women felt it was most important to improve emotional well being. However, overall nearly 56% of women ranked emotional well being in the top 3, which is the highest percentage of any of the aspects. In total, 35% of women considered physical well being to be 1 of the 3 aspects that they would most like to see improved.

Appendix: Questionnaire (En)

The questionnaire presented in the following pages was available for download from www.emhf.org and, in paper form, was used in direct mailings.

This version was printed 2 panels per page, and presented on one double-sided sheet of A3 paper folded down the middle.

Additional versions were produced in French, German, Italian and Spanish.



European HIV-related Quality of Life Review

Introduction

The European Men's Health Forum (EMHF) is undertaking a study describing the quality of life of men and women living with HIV following the recent One Vision initiative aimed at reducing HIV related stigma in Europe.

This project will provide an update on the valuable knowledge acquired from previous HIV-related quality of life projects. Administered separately from any clinical trial, it will illustrate the impact of changes in treatment over time, and from various non-medical dimensions will provide keys to understanding expectations from the HIV community for the future.

Information about the European Men's health forum, is available from www.emhf.org or please contact us at office@emhf.org. To find out about the One Vision initiative please visit www.onevision.org.

This survey was made possible through an unrestricted educational grant from Bristol-Myers Squibb.

Why should you fill it in?

By taking approximately 10 minutes of your time, you can help improve the quality of life of people living with HIV in Europe. From the results of this study, EMHF will produce a report by the end of this year which will be presented to representatives of the EU Institutions and WHO Europe, and to national authorities for input into their policy agenda.

Who should fill it in?

Any HIV positive adult (over 18 years old) residing in one of the European countries can take part.

Instructions:

Please fill in using CAPITALS. Download freepost label from www.emhf.org or write to: EMHF, 50/28 rue Wiertz, B-1050 Brussels, Belgium. Post back to us or fax: +32 2 401 6868 before **March 31 2005**.

Your input will remain totally anonymous and results will be made publicly available on the EMHF website. Because we know you are interested to hear about the result of your contribution, you can leave you email address on our website and we will drop you a line when the survey results are ready for consultation.

1. About you ...

1.1. Are you ... Male female transgender

1.2. How old are you? _____ (age in years)

1.3. Are you ...

Bisexual Gay/lesbian Heterosexual/straight
Other Prefer not to say

1.4. Are you ...

Married/in a relationship Single
Divorced/separated Widowed

1.5. Do you live ...

Alone With partner only With other people
With friends With immediate family

1.6. Your ethnic background is ...

- White: West European , East European , Other _____
- Black : African , Caribbean , Other _____
- Asian: India, Pakistani, Bangladeshi , Other _____
Chinese , Japanese , Other _____
- Latin American: Hispanic , Other _____
- Arabic: Middle Eastern , north African , Other _____
- Mixed: (Asian and/or Black and/or White) , Other _____
- Other: _____ Prefer not to say

1.7. What is your country of origin? _____ and nationality? _____

1.8. What country are you a permanent resident of? _____

1.9. What is your highest level of education?

- College up to 16 y.o. College until 18-20 y.o. University or equivalent

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

- Not employed €10,000 – €24,999 €40,000– €59,999
Less than €10,000 €24,999 – €39,999 €60,000 and above

1.11. How satisfied are you currently with your ...

	Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied	Not Applicable
Experience of health services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical well-being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Emotional well being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Work and professional career	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Overall quality of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

2. Your HIV Diagnosis ...

2.1. What year did you first test positive? _____ (e.g. 1996) I can't remember

2.2. What year do you think you were first infected? _____ I don't know

2.3. How do you think you became infected?

- Unprotected sex with regular partner Sharing needles
Unprotected sex with other people Rape/sexual assault
Contaminated blood transfusion Don't know
Other _____ Prefer not to say

2.4. As far as you can remember, what were your first blood counts?

CD4 count _____ Viral load _____ I can't remember

2.5. What are your counts now?

CD4 count _____ Viral load _____ I don't know

2.6. Have you ever suffered from HIV-related opportunistic infections?

Yes, last month No, never
2-12 months ago
more than 1 year ago

2.7. If you are NOT taking any HIV medication, tell us the main reason(s) ...

Doctor's advice No easy access to treatment
Worried about side effects I don't need treatment , I feel fine
Uncomfortable about disclosure I don't like taking medications
Voluntary treatment interruption , why? _____

Other _____

2.8. To what extent do you feel conscious of your HIV status when you go about your normal life?

Never Some of the time Much of the time All the time

3. Medical/health care

Go to section 4, if you have **NEVER** taken any HIV medication.

3.1. What year was your first treatment? _____ (e.g. 1996) I can't remember

3.2. What are the main impressions you keep from your first experience of taking HIV medications?

3.3. How many drug regimens have you ever been on?

1 2-3 4-5 5+

3.4. According to your treatment experience, what would you say most contributed to improving your quality of life?

3.5. About your most recent drug regimen ...

How long have you been on it? ____ Year(s) ____ month(s)

How many pills do you take a day? _____ How many times a day? _____

3.6. How would the following aspects of your most recent regimen compare with previous ones?

	Worse	Same	Better	Much better	N/A
Number of pills a day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Number of times a day	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Interaction with food	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Side effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Effectiveness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

3.7. What is your experience of side effects associated with your most recent regimen?

	Bearable	Almost unbearable	Unbearable	N/A
Peripheral neuropathy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anaemia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diarrhoea/Gastro-intestinal upset	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lipodystrophy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dizziness, insomnia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.8. Do you worry about the long term effects of your medication? Yes No

3.9. Potential 'silent' side effects: long term cardiovascular risk factors ⁽¹⁾

Do you know about them? Yes No

Do they impact you? Yes No I don't know

Do you worry about them? Yes No I don't know

⁽¹⁾ Effects of less visibility and immediacy such as changes in levels of cholesterol and triglycerides.

3.10. How worried are you about the effects of your medication on your liver?

Not at all Somewhat Very much I don't know

3.11. How many times have you missed taking your drugs in the past month?

0 1-2 3-5 5-10 More than 10 N/A

Why? _____

3.12. About virus resistance to your medication ...

Have you ever experienced the problem? Yes, in the past Yes, now No, never

Do you worry about it? Yes No

3.13. About your clinic doctor, how much do you feel ...

	Not at all	A little	Moderately	Very much
Involved in clinical decisions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your doctor is aware of the latest medical innovations about HIV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Your doctor is concerned with the impact of treatment on your quality of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A comfortable relationship with your doctor is important?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.14. How satisfied are you with your treatment centre?

	Not at all	A little	Moderately	Very much
Distance from your home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Interaction with staff	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Range of treatment facilities available	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3.15. Which of the following are the three most important aspects of treatment in relation to your own experience? How would you rank them in order of importance?

	Rank
Ease of medication intake	<input type="checkbox"/>
Visible side effects	<input type="checkbox"/>
Silent side effects	<input type="checkbox"/>
Relationship with clinic doctor	<input type="checkbox"/>
Satisfaction with treatment centre	<input type="checkbox"/>

4. Physical and emotional well-being

4.1. How well are you currently able to conduct daily living activities?

	Barely able	Able but difficult	Easily able
Daily travelling activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care for yourself at home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Maintain waged activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practice Sports/ leisure activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.2. To what extent are you currently experiencing ...

	Not at all	A little	Moderately	Very much
Physical pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fatigue	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Disrupted sleeping patterns	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.3. Have you recently had any of these diseases?

Tuberculosis Hepatitis C Syphilis Other sexually transmitted diseases

4.4. As a result of knowing your status, have you been ...

	Much less	A bit less	No change	A bit more	Much more	N/A
Eating healthily	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Smoking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Drinking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Using recreational drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Injecting drugs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practising safe sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.5. To what extent are you currently experiencing ...

	Not at all	A little	Moderately	Very much
Loneliness, isolation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Embarrassment about status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Embarrassment about appearance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Anxiety	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Depression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Low libido	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sexual frustration	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4.6. How much do you currently worry about the possibility of ...

	Never	A little	Moderately	Very much
Death/dying	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Getting other diseases	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worsening of side-effects	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Future body shape changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Increased symptom visibility	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physical pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Deteriorating mental health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Social functioning and economic support

5.1. Who have you told about your HIV status?

Partner/Husband/wife	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>		
Family	All	<input type="checkbox"/>	Some members	<input type="checkbox"/>	None	<input type="checkbox"/>
Friends	All	<input type="checkbox"/>	Some members	<input type="checkbox"/>	None	<input type="checkbox"/>
Employer	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>	n/a	<input type="checkbox"/>
Work colleagues	All	<input type="checkbox"/>	Some members	<input type="checkbox"/>	None	<input type="checkbox"/>

5.2. How did people react – or you think they would react – about your status?

	Very Negatively	Negatively	Positively	Neither	Mixed	I don't know	N/A
Partner/Husband/wife	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Employer	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work colleagues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.3. If you ARE in employment

Are you working ... full time
 part-time

Have you, for HIV-related medical reasons, ever had to ...

- Quit waged employment Yes No
- Change job Yes No
- Learn new skills Yes No
- Reduce your working hours Yes No

Do you feel your diagnosis can affect your career opportunities?

Yes No Not sure

5.4. If you are NOT in employment (or if you previously had to stop working for 6 months or more)

Did this situation arise as a result of HIV-related disability? Yes No

What do you feel was/would be most difficult returning to work?

- Potentially heavy workloads
- Possible lack of skills
- Perceived discrimination from employer/colleagues
- Income drop from getting off state benefits
- Other _____

5.5. How much do you feel your diagnosis can affect your ability to:

	Not at all	A little	Moderately	Very much	Not applicable
Provide for the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Care for your children	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Remain in a relationship/marriage	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Maintain a circle of friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Work with colleagues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.6. How well do you feel supported by

	Not at all	Not so well	Well	Very well	Not applicable
Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People at work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Volunteer HIV support groups	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV Advocacy organisations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Government health policy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.7. Are you a member of an HIV patient organisation?

Yes No

5.8. Do you belong to a group of people who are HIV positive?

Yes No

5.9. Do you know where to obtain information about ...

	No idea	I am not sure	Yes, I do
State health benefits	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community health and social services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
HIV medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Treatment centres	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Living with HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5.10. Comparing yourself now to before you became aware of your HIV status, how have the following changed?

	Much worse	A bit worse	No Change	A bit better	Much better	N/A
Your economic status	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Number of close friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Quality of relationships:						
Partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support networks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Self esteem/self worth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sense of purpose	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sense of identity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Outlook on life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Overall health awareness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General lifestyle	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Taking risks	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Religious/spiritual beliefs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Making the most of life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- How would you rank in order of importance, **three** of the following aspects you would most like to see improved?

	Rank
Ease of medication intake	<input type="checkbox"/>
Treatment side effects	<input type="checkbox"/>
Relationship with doctor	<input type="checkbox"/>
Satisfaction with treatment centre	<input type="checkbox"/>
Ability to maintain a professional career	<input type="checkbox"/>
Ability to maintain a social network	<input type="checkbox"/>
HIV-related discrimination	<input type="checkbox"/>
Physical well being	<input type="checkbox"/>
Emotional well being	<input type="checkbox"/>
Community support	<input type="checkbox"/>

THANK YOU FOR FILLING IN THIS FORM

You can leave your email address on our website www.emhf.org and we will let you know via email as soon as these are available.

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