

# LIVING CONDITIONS

## SURVEY REWARDED



From the left: Researchers Anders Dahl, MSc Carstensen and chairman Henrik Arildsen (Hiv-Danmark) receiving the reward. Foto: Andy Grysbæk 2008

In May 2008 the Danish AIDS Foundation rewarded the Danish Living Conditions Survey for the outstanding input this project has had to understand the situation of PLHIV in Denmark.

The study was published in October 2007 in a report of 185 pages (in Danish).

The research project was conducted from April 2005 to October 2007 and based on interviews with 36 organisations or institutions that work with PLHIV or with the prevention of HIV. Subsequently a questionnaire with 154 questions was distributed to all PLHIV in contact with outpatient clinics or hospi-

talized. Finally an in-depth interviews with 25 PLHIV followed to clarify some of the findings in the survey.

A total of 1.357 questionnaires were returned, but not all completed. 1.212 questionnaires were either fully or partially completed and included in the analysis.

In the eleven month period the questionnaire was distributed through the HIV treatment centres 3.191 PLHIV was in contact with the centres,

which gives an incredible response rate (around 38 %).

The preliminary interviews with organisations and institutions were conducted to get their input on which areas should be investigated more closely. On the basis of these interviews a questionnaire was developed with the following themes (which can be seen in the box).

- General questions on living conditions (education, occupation, housing, income, etc.)
- Social life (relation with family and friends, social network)
- Reaction of others (stigma and discrimination, informing others about HIV-status)
- Sexuality and sex life
- General health
- Use of alcohol, tobacco and drugs
- Contact with social services
- Contact with medical and mental health care services
- Contact with HIV out-patient clinic (including use of interpreter)
- Contact with HIV-organisations
- How the respondent experiences treatment (ARV)
- Specific issues: (The penal system, foreign travel, pension scheme, children)

# HIGHLIGHTS

## SEXUALITY IS DIFFICULT

Many PLHIV stop having sex.

24 % of heterosexual Danish PLHIV has not had sex since learning about their HIV status and among migrants and IDU the number is close to the same. Among homo- and bisexuals far fewer abstain from having sex, the numbers being respectively 6 and 7 %. In average it is 14 % who has stopped having sex.

At the same time 40 % reported that their sexual needs are met completely or almost completely.

For many respondents, however, having a satisfactory sex life becomes difficult in the wake of receiving an HIV diagnosis. Concerns about HIV transmission through sex are prevalent among most people living with HIV. More than every fifth respondent reports feeling 'extremely worried' about transmitting HIV to a partner through sex.

Reduced desire or lack of desire can be a problem for

many people living with HIV. Every fourth male respondent and every third female respondent reports experiencing reduced desire or lack of desire 'often' or 'all the time' within the last year. This is a considerably higher percentage than that found among the general Danish population, where 15 % of people report experiencing this issue.

### Sexual dysfunction

Among men living with HIV, it was found that their risk of erectile dysfunction is three times greater than among the general Danish population. Among women living with HIV, there is an increased risk of vaginal dryness, but the issue is not as pronounced in

### SEXUAL BEHAVIOUR WITHIN THE LAST 12 MONTHS

	Have not had sex	Have practiced safe sex	Have practiced unsafe sex	No response
All	23 %	40 %	31 %	14 %
Homosexuals	13 %	45 %	23 %	12 %
Heterosexuals DK	39 %	32 %	14 %	15 %
Bisexuals	10 %	54 %	26 %	10 %
Migrants	23 %	36 %	18 %	23 %
Drug users	38 %	18 %	23 %	20 %
The old	25 %	41 %	21 %	12 %
The new	19 %	41 %	26 %	15 %

comparison with the general Danish population as that of male erectile dysfunction.

But not all respondents report experiencing sexual difficulties. Just under a third of all respondents indicated that they have not experienced any sexual difficulties since learning of their HIV positive status.

### Safer sex support?

The ability to practice safer sex is of prime importance for the majority of PLHIV. This is a concern that should be able to be minimised if the individual has a strong knowledge of modes of transmission

and safer sex practices. In recognition of the fact that many people find it difficult to practice safer sex, the questionnaire asked respondents the following question: 'Would you like help or support to become better at practicing safer sex more consistently?'

The 12 % of respondents answering that they would like help to become better at practicing safer sex must be compared with the 23 % of respondents who indicated that they have had unprotected sex. Thus it can be seen that approximately half of those who have had unprotected sex would like help. Except among the sub-group of homosexual men a relatively good accordance can be seen between the number of people who have had unprotected sex and the desire for help to become better at practising safer sex.

# PSYCHOLOGICAL FRAGILITY

PLHIV experience more difficulties than the general Danish population.

During the interview process, we often encountered a degree of 'psychological fragility' among interviewees who expressed views that it is often the small, unexpected aspects of daily life that cause confusion and, at times, constitute 'the last straw'. The questionnaire contains a number of questions intended to shed light on the daily challenges that PLHIV are faced with.

For the question of 'How often within the last month have you felt able to cope with the irritations of daily life?' 33 % of the general Danish population responded 'very often' while only 17 % of PLHIV chose the same response. Findings were similar for the question of how often the respondent felt in control of his or her daily life within the last month, with 33 % of the general Danish population reporting 'very often', while only 15 % of PLHIV reported the same sense of control. And among the general Danish population, 5 % reported feeling that problems mounted to the extent that they could not deal with them 'often or

### ABOUT FEELINGS AND THOUGHTS – HOW OFTEN HAVE RESPONDENTS FELT THIS WAY WITHIN THE LAST MONTH:

	General population		PLHIV	
	Never / Almost never	Often /Very often	Never / Almost never	Often /Very often
How often have you felt that life was going your way?	11 %	21 %	59 %	38 %
How often have you felt you were unable to control the things that are important in your life?	73 %	46 %	6 %	19 %
How often have you felt that the difficulties were mounting so much that you could no longer cope with them?	76 %	55 %	5 %	16 %

very often' – while among PLHIV, the number was three times higher.

### Noteworthy and alarming

The psychological fragility or increased difficulty coping with everyday life is common among all PLHIV but it is most widespread among migrants and drug users. This is noteworthy and alarming.

Whether these difficulties in dealing with everyday life are

'merely' an aspect of living with a life-threatening illness, or if they are specific to PLHIV, is not known.

In the table above you can see how PLHIV and the general population were answering questions about feelings and thoughts.

### Four times higher

The experience of isolation become clear in the responses to the question concerned with how often the respondent is

alone when he or she really would prefer to be with other people. 14 % of PLHIV responded that they are often alone and wishing that they weren't – a number that is four times higher among this group than that found among the general Danish population. (And PLHIV have just as many friends as those who belong to the general population, and they see them just as often.)

## Income

### INCOME FOR PLHIV, COMPARED WITH GENERAL POPULATION

Not below that of general average.

In Denmark it does not appear that PLHIV are poorer than the general population. Among migrants the revenue is, however, significantly below average. It is though worth remembering that PLHIV with least resources probably are under-represented in surveys of this kind.

Income in DKK	General population	PLHIV	Migrants (PLHIV)
0-199.000	40 %	39 %	64 %
200.000-399.000	42 %	42 %	21 %
400.000-599.000	9 %	11 %	1 %
600.000 and more	4 %	4 %	1 %
Will not answer	1 %	2 %	2 %
Do not know	3 %	2 %	9 %

(1 US \$ = 4.70 DKK)

## Treatment and side effects

### SIDE EFFECTS WITHIN THE LAST MONTH WHILE TAKING ARV?

	Much or some	Slightly	Not at all
Tiredness	38 %	27 %	29 %
Impotence	35 %	44 %	14 %
Reduced fat	35 %	44 %	11 %
Sleep difficulties	28 %	23 %	43 %
Increased fat	24 %	22 %	47 %
Diarrhoea or abdominal pain	21 %	28 %	43 %
Difficulty in concentrating	18 %	25 %	48 %
Headache	17 %	21 %	52 %

### More than every third respondent suffers from fatigue

Many PLHIV experiences side effects from their treatment. And the side effects loom large in the lives of many. A number of Living Conditions Survey interviewees expressed lacking information about the side effects of their treatment, and

asked if they experienced side effects, but when asked about specific side effects such as diarrhoea, nausea or tiredness, many reported experiencing these side effects but considering them a natural part of their medical treatment, and that they had found it necessary to learn to live with them.

asked if they experienced side effects, but when asked about specific side effects such as diarrhoea, nausea or tiredness, many reported experiencing these side effects but considering them a natural part of their medical treatment, and that they had found it necessary to learn to live with them.

## DOWNLOAD REPORT FOR FREE

WWW.LEVEKAAR.DK

A 30 page English summary of the report, as well as the questionnaire and more tables, can be downloaded from [www.levenaar.dk](http://www.levenaar.dk)

## Being diagnosed

Still a profound shock to almost everyone.

There is no indication that being diagnosed with HIV today is any less traumatic than it was 15 or 20 years ago, despite current treatment possibilities. Nor is there anything to indicate that the optimism that ARV treatment has evoked in many other areas has had any influence on the reaction of the individual who receives the diagnosis that he or she is infected with HIV.

In many of the interviews, the most difficult aspect for interviewees was discussing what it was like to receive the diagnosis. Many people became very emotional and had tears in their eyes, or wept. Learning that one is HIV positive is an overwhelming and existential event for the vast majority of people.

"You can't see anything in front of you, when you get such a message", says 26 year old male, diagnosed with HIV in 2004

## INFORMING OTHERS

### Fewer people now disclose their HIV status than they did in the past.

Everyone infected with HIV is faced with the prospect of telling – or not telling – others of their HIV status. The issue is not only whether to tell others, but also who should be told, how they should be told, and for many people, the order in which they should be told. Only a minority of PLHIV are fully disclosed about their HIV status. The vast majority are very careful about who they select for disclosure about their HIV status.

Very few people have not told anyone else about their HIV status, but quite a few people – more than every third – have told only a small number of friends or family members about their HIV status. There is every indication that a significant number of PLHIV keep their HIV status to themselves to a large extent. The difference in the figures

### HOW MANY PEOPLE HAVE YOU TOLD THAT YOU ARE HIV POSITIVE? (NURSES, DOCTORS AND COUNSELLORS SHOULD NOT BE COUNTED)

	Haven't told anyone	Have told maximum five people*)
All	5 %	35 %
Homosexuals	2 %	26 %
Heterosexuals DK	6 %	34 %
Bisexuals	10 %	55 %
Migrants	10 %	68 %
Drug users	0 %	22 %
The old	3 %	23 %
The new	6 %	47 %

\*) Includes those who haven't told anyone else

between 'the old' and 'the new' strongly indicate that fewer people now disclose their HIV status than they did in the past.

### Disclosure: no end goal

It is important to emphasise that disclosure of HIV status is not a goal in itself, and that the

aim is not to have as many people as possible being open about their HIV status – after all, illness is a personal matter. However, there is a great deal of indication that this is not the only reason that many people decide to keep their HIV status to themselves. Fear of negative reactions plays a large role in this decision.

The survey also showed that for many PLHIV, the ability to control knowledge of one's HIV status is very important. Thus it is every third respondent who answered affirmatively that they are nervous that rumours about their HIV status may go around among people they know. Many of those interviewed described the various ways in which control was important to them, and how the sense of lack of control can throw them off balance and cause anxiety.

### ARE YOU NERVOUS THAT RUMOURS MAY GO AROUND THAT YOU ARE HIV-POSITIVE?

	Yes	No	Don't know
All	36 %	50 %	14 %
Homosexuals	30 %	59 %	11 %
Heterosexuals DK	42 %	44 %	14 %
Bisexuals	42 %	39 %	19 %
Migrants	54 %	25 %	21 %
Drug users	36 %	46 %	18 %
The old	28 %	60 %	12 %
The new	46 %	38 %	16 %

## THE NEED FOR MORE INFORMATION

The lack of knowledge is surprisingly high.

HIV is an infectious disease and PLHIV should have a very thorough knowledge of modes of transmission – everything else will counteract that the individual will be able to take responsibility for his or her sex life. In the questionnaire it was asked whether the respondent is in need of more information about risk of infection in connection with normal social interaction and about risk of infection in connection with having sex.

Every tenth PLHIV expresses a need for more knowledge of risk of infection in connection with ordinary social interaction, and looking at the sub-groups of bisexuals, migrants and drug users, then the need for information is greater. It is also remarkable

that among 'the new' there is almost twice as great a need for more information as there is for 'the old'.

The numbers are surprisingly high. HIV is not transmitted by ordinary social interaction with others, but yet the numbers more than indicate that a very large group of PLHIV are unsure of this fact – and this is a signal that is important to listen to.

The insecurity is even greater when it comes to the need for more information regarding risk of infection in connection with sex. Here it is almost every fifth person that expresses a need for more information. Again it is a much higher number among bisexuals, migrants and drug users. And, as before, the need for more information is much higher among 'the new' than among 'the old'.

### NEED MORE INFORMATION ON THE RISK OF HIV TRANSMISSION THROUGH ...

	... ordinary social interaction with other people	... sex
All	9 %	18 %
Homosexuals	4 %	14 %
Heterosexuals DK	12 %	18 %
Bisexuals	18 %	32 %
Migrants	23 %	37 %
Drug users	33 %	33 %
The old	7 %	14 %
The new	12 %	22 %

These numbers are also surprisingly high. In Denmark HIV is primarily transmitted by sex, and if as an HIV-infected person one does not have a precise and accurate knowledge of modes of transmission, it can in principle

cause two effects: Either that the person puts limits on his or her sexual activity, because they are afraid of infecting others, or – if they do not limit their sexual activity – that they risk infecting others.

Terms used	
All	Is equivalent to the number of accepted questionnaires either fully or partially completed
Homosexuals	Include those who indicated on the question concerning sexual identity that this category best fits them – irrespective of country of origin
Heterosexuals	Include only Danish-born men and women who indicated that they consider themselves to be heterosexual
Bisexuals	Include men and women who indicated that they consider themselves to be bisexual them – irrespective of country of origin
Migrants	Include men and women born outside of Europe – irrespective of sexual identity
Drug users	Include all of those who indicate that they were most likely infected with HIV through intravenous drug use
The Old	Include those who indicated that they were diagnosed with HIV in 1996 or earlier
The New	Include those who indicated that they were diagnosed with HIV in 1997 or later
HIV Treatment Centres	Designation for the eight Danish hospitals with specialised treatment centres for people living with HIV (out-patient or in-patient facilities)
PLHIV	People living with HIV

Note that some of the categories are not mutual excluding each other

### Danish figures

Denmark has a population of 5.4 million people. It is estimated that about 5.000 people are infected with HIV (2007). About 1.000 of these do not know that they are infected. 250 – 300 people are tested HIV-positive every year and this number has been stable for many years. Every year between 40 and 50 PLHIV dies of AIDS.



This poster will be displayed August 2008 at the XVII International AIDS Conference in Mexico City by the Living Conditions Survey at Hiv-Danmark.

Hiv-Danmark is a national organisation for all people living with HIV and those affected by HIV, living in Denmark, irrespective of nationality, gender, sexuality or method of infection.

Hiv-Danmark advocates for people living with HIV, relatives and bereaved. Hiv-Danmark is an umbrella organisation for individuals, self-help groups and other societies for people living with HIV as well as groups attached to HIV wards at hospitals.

Hiv-Danmark, Skindergade 44, 2nd floor DK-1159 Copenhagen K, Denmark [www.hiv-danmark.dk](http://www.hiv-danmark.dk)

Author: Anders Dahl, anthropologist  
Layout: Morten Eierstedt, Hiv-Danmark