

Levekårsundersøgelse

Denne side er til brug for ambulatorierne

SIDEN SKAL AFRIVES INDEN SKEMAET UDLEVERES TIL PATIENTEN!

ENGELSK VERSION

LIVING CONDITIONS
AND QUALITY OF LIFE
2005

SURVEY OF THE LIVING
CONDITIONS AND QUALITY OF
LIFE OF PERSONS INFECTED
WITH HIV

HIV
DANMARK

Patient information

Questionnaire on the living conditions and quality of life of HIV-infected persons

English version

September 2005

Who is taking part?

We are asking all HIV-positive persons aged 18 or older, and who attend examinations at the Danish HIV-out-patient clinic, to complete this questionnaire.

Purpose

This questionnaire is a part of a larger survey on the living conditions and quality of life of persons who are HIV-positive. The survey is intended to reveal the current problems of HIV-infected persons in Denmark – i.e. what life is like for them right now. Accordingly, many of the questions in the questionnaire relate to the current situation rather than ‘the old days’.

The purpose of the survey is to identify the specific problems and difficulties encountered by HIV-infected persons in their daily lives, so as to be able to propose improvements or alterations in the efforts to help and support people who are HIV-positive.

This survey has been initiated by the HIV-infected persons’ own organisations, so we hope that you will take the time to complete the questionnaire. It is important for the survey that as many people as possible complete the questionnaire.

The survey is being carried out jointly by the HIV-patients’ association HIV-Danmark and the Danish HIV-Cohort, and is expected to be completed by the end of 2006.

Voluntary participation

Participation is voluntary, and if you choose not to take part it will have no influence on your treatment. You can also withdraw your participation at any time, without this having any influence on your treatment.

Confidentiality and registration

Your responses to the questionnaire are confidential. Neither your doctor nor your nurse here at the out-patient clinic will see your responses to the questionnaire. If you wish, you can talk to them about your responses. Your answers will be used only for scientific analysis, and the researchers are bound by a duty of confidentiality. Your questionnaire responses will be registered under a serial number in the database of the Danish HIV-Cohort, but with no name or Danish civil registration number (CPR number).

The survey has been approved

The survey has been submitted to the Danish National Committee on Biomedical Research Ethics, which had

no objections. The Danish Data Protection Agency has approved the survey and has laid down conditions to protect the private lives of those taking part in the survey. The project’s data manager is Consultant Niels Obel MD, Infectious Diseases Research Unit, Odense University Hospital.

What should you do?

It will take you about 30-40 minutes to fill in the questionnaire. It is important that you answer the questions as honestly as possible.

If there are any questions you prefer not to answer, cross them out.

If you complete the questionnaire here at the out-patient clinic, you can return it today using the special questionnaire letter-box. You can also submit it post free in the supplied reply envelope. If you prefer not to fill in the questionnaire, please return it to us anyway and tell us why.

HIV-positive people are not a uniform group, so you may feel that some of the questions are irrelevant to you. Nonetheless, we would like you to answer all the questions as well as you can.

Throughout the questionnaire, you will be presented with multiple-choice questions with several possible answers. You will be asked to place a cross beside the answer that best describes your situation. Only one cross should be placed per question, unless it is specifically stated that you may place several crosses.

If you place a cross in the wrong place, cross out the ‘wrong’ cross completely, and then place a cross in the ‘right’ box.

On the last page, please write the date on which you are filling in the questionnaire. If you fill out the questionnaire over several days, you should write the date on which you finish filling it out.

Help and further information

If you are in any doubt about anything, you are welcome to ask the nurse, or contact Mie Carstensen or Anders Dahl of HIV-Danmark, Skindergade 44, 1159 Copenhagen K, tel. +45 33 32 58 68.

Thank you in advance for your help.

Yours sincerely,

Mie Carstensen Anders Dahl
MSc Social Science Anthropologist, MSc

Address: Infectious Diseases Research Unit, Odense University Hospital, Sdr. Boulevard, 5000 Odense

Quality of life survey

Hiv-Danmark and the Danish HIV-Cohort 2005

Serial number: _____
(Filled in by the HIV-out-patient clinic)

General questions about you

To begin with, here are some general questions about you, your general life situation and how and when you became infected with HIV.

1) Are you:

- ₁ Male
₂ Female

2) In what year were you born?

Year: 19 _____

3) Where were you born?

- ₁ In Denmark
₂ Elsewhere in Scandinavia
₃ In another European country
₄ In the Middle East
₅ In Africa
₆ In North America
₇ In Central or South America
₈ In Asia
₉ In Australia

4) Where were your parents born? (You may place several crosses)

Your mother Your father

- | | | | |
|-----|-----------------------------|---------------------------------------|---------------------------------------|
| 4.1 | In Denmark | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 4.2 | Elsewhere in Scandinavia | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 4.3 | In another European country | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 4.4 | In the Middle East | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 4.5 | In Africa | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 4.6 | In North America | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 4.7 | In Central or South America | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 4.8 | In Asia | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 4.9 | In Australia | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

5) For roughly how long have you lived in Denmark?

- ₁ All your life
₂ Approx. _____ years

6) Which of the following statements of sexual identity best describes you?

- ₁ You are heterosexual
₂ You are homosexual
₃ You are bisexual
₄ You cannot place yourself in any of the above categories

7) Do you have a permanent partner?

- ₁ Yes
₂ No

8) What is your marital status, in a purely legal sense? (Place a cross beside your current marital status)

- ₁ Married
₂ In a registered partnership
₃ Separated
₄ Divorced
₅ Widow or widower
₆ Single

When you were diagnosed HIV-positive

In what year did you receive the diagnosis of HIV-positive?

9) Year: _____

10) What is the most likely way that you became infected? (You may place several crosses)

- ₁ Through heterosexual contact
₂ Through homosexual contact
₃ Via injected drug use
₄ Through the purchase or sale of sexual services
₅ Via blood transfusion/blood products
₆ From mother to child
₇ Other
₈ Not sure

11) Where do you think it is most likely that you became infected with HIV?

- ₁ In Denmark
₂ Elsewhere in Scandinavia
₃ In another European country
₄ In the Middle East
₅ In Africa
₆ In North America
₇ In Central or South America
₈ In Asia
₉ In Australia

12) Do you know in which specific situation you became infected?

- ¹ Yes
- ² No (*Go to question 14*)

13) Did you know that this was a situation that involved a special risk of infection?

- ¹ Yes
- ² No
- ³ Don't know

14) During the first six months following your diagnosis as HIV-positive, was the information and advice that you were given:

- ¹ Very good
- ² Good
- ³ Neither good nor bad
- ⁴ Bad
- ⁵ Very bad

15) Did anyone talk to you about contact tracing (i.e. attempts by you or health care staff to trace the people who may have infected you or whom you may have infected)?

- ¹ Yes
- ² Yes, but you preferred to trace them yourself
- ³ No
- ⁴ No, but you have traced them yourself
- ⁵ Not applicable to you

Your housing conditions

16) Do you live in:

- ¹ Copenhagen
- ² A suburb of Copenhagen
- ³ Another large town (an urban area with more than 10,000 inhabitants)
- ⁴ A small town (an urban area with between 2,000 and 10,000 inhabitants)
- ⁵ A village (an urban area with between 200 and 2,000 inhabitants)
- ⁶ A rural district

17) Do you live in:

- ¹ Regional Municipality of Bornholm
- ² Frederiksberg Municipality
- ³ Copenhagen Municipality
- ⁴ Frederiksberg County
- ⁵ Fyn County
- ⁶ Copenhagen County
- ⁷ North Jutland County
- ⁸ Ribe County
- ⁹ Ringkjøbing County
- ¹⁰ Roskilde County
- ¹¹ Storstrøms County
- ¹² Southern Jutland County
- ¹³ Vejle County
- ¹⁴ West Sealand County
- ¹⁵ Viborg County
- ¹⁶ Aarhus County

18) How many people live in your household, counting yourself?

Number: _____

(If you live alone, go to question 20)

19) Do you live with:

	Yes	No	Number
19.1 Your spouse or partner	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	
19.2 Your children	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	_____ 3
19.3 Your parents or parents-in-law	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	_____ 3
19.4 Other family	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	_____ 3
19.5 Other people from your household	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	_____ 3
19.6 Persons you share a house with but who do not belong to your household	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	_____ 3

20) Do you live in:

- ¹ An owner-occupied flat or house (ejerbolig)
- ² A co-operative flat or house (andelsbolig)
- ³ A rented flat or house
- ⁴ With your parents
- ⁵ Other

The financial situation of you and your family

The following questions deal with your financial situation and that of your family. Even if you do not know the exact size of your income or that of your household, or how much you and your family have available to spend on daily items, it is important that you give your best estimate.

21) Roughly how large was the total income of you and your spouse or partner in 2004 (before tax and deductions)?

	Own income	Total income
21.1 No income	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.2 Less than DKK 50,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.3 DKK 50,000 – 99,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.4 DKK 100,000 – 199,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.5 DKK 200,000 – 299,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.6 DKK 300,000 – 399,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.7 DKK 400,000 – 499,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.8 DKK 500,000 – 599,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.9 DKK 600,000 – 699,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.10 DKK 700,000 – 799,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.11 DKK 800,000 – 899,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.12 DKK 900,000 – 999,000	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.13 DKK 1 million or more	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.14 Prefer not to answer	<input type="checkbox"/> 1	<input type="checkbox"/> 2
21.15 Don't know	<input type="checkbox"/> 1	<input type="checkbox"/> 2

22) How much money do you and your partner (if any) have left for daily shopping (food, clothes, footwear, etc.), when all the regular bills and tax have been paid?

- 1 Around DKK 0 – 1,999 per month
- 2 Around DKK 2,000 – 2,999 per month
- 3 Around DKK 3,000 – 3,999 per month
- 4 Around DKK 4,000 – 5,999 per month
- 5 Around DKK 6,000 – 7,999 per month
- 6 Around DKK 8,000 or more per month

23) All in all, how would you assess your financial situation (and that of your partner, if any)? Is it:

- 1 Very good
- 2 Good
- 3 Neither good nor bad
- 4 Bad
- 5 Very bad

Your educational background and employment situation

24) What is your educational and training background?

(Place a cross at the last level you achieved.)

- 1 Primary or elementary school
- 2 Semi-skilled worker training, labour market courses
- 3 Apprenticeship or basic vocational training (EFG)
- 4 Other vocational training (e.g. as laboratory technician, draughtsman, nursing auxiliary, etc.)
- 5 Short course of higher education (e.g. social worker, machine technician, police officer, etc.)
- 6 Medium course of higher education (e.g. B.Sc. in engineering, nurse, elementary school teacher, etc.)
- 7 Long course of higher education (e.g. LLM, MA, medical doctor, etc.)

25) Have you ever failed to apply for admission to a course of education/training, mainly due to HIV?

- 1 Yes
- 2 No

26) What is your main occupation at the moment?

(If you are on holiday, or temporarily absent from work due to illness, or have been given leave of absence, please indicate your main occupation before this – you may place several crosses.)

- 1 Employee (salaried employee, worker, civil servant)
- 2 Self-employed
- 3 Subsidised “flexjob”
- 4 Employed with wage subsidy
- 5 Attending education/training (student, apprentice, school pupil)
- 6 In rehabilitation
- 7 Pensioner (anticipatory pension, retirement pension, etc.)
- 8 Early retirement pensioner (inc. transition pay)
- 9 Unemployed
- 10 Assisting spouse
- 11 Homemaker (wife/husband without paid employment)

27) Do you perform any voluntary work?

(You may place several crosses)

- 1 Yes, voluntary work for an HIV/AIDS-organisation
- 2 Yes, other voluntary work
- 3 No

4 Number of hours of voluntary work per week – on average _____

Quality of life survey

Hiv-Danmark and the Danish Hiv-Cohort 2005

The following questions are for those of you who are not in paid employment.

(If you are in paid employment, go to question 32)

28) If you are without work, or a pensioner, do you receive:

Without work

- ₁ Unemployment benefit
- ₂ Sickness benefit (chronically ill)
- ₃ Cash benefits (unemployed/in work activation)

Pensioner

- ₄ Old age pension
- ₅ Anticipatory pension
- ₆ Anticipatory pension, employed with wage subsidy
- ₇ Other form of pension
- ₈ Early retirement benefit/transition pay

29) Did you stop working because of your HIV-infection?

- ₁ Yes
- ₂ Yes, HIV was one of the reasons
- ₃ No

30) Have you received a pension because of your HIV-infection?

- ₁ Yes
- ₂ Yes, HIV was one of the reasons
- ₃ No
- ₄ Don't know

31) Would you be interested in getting paid full-time or part-time work?

- ₁ Yes, full-time work
- ₂ Yes, part-time work
- ₃ No

The following questions are for those of you who are in paid employment

(If you are not in paid employment, go to question 39)

32) How long have you been employed at your current place of work?

- ₁ Less than 12 months
- ₂ 1-2 years
- ₃ 2-3 years
- ₄ 3-5 years
- ₅ More than 5 years

33) Have you told people at your current place of work that you are HIV-positive?

(You may place several crosses)

- ₁ Yes, everyone knows
- ₂ Yes, most people know
- ₃ Yes, some people know
- ₄ Yes, your immediate superior knows
- ₅ Yes, your immediate colleague knows
- ₆ No (*Go to question 36*)

34) How did your colleagues react when you told them you were HIV-positive?

- ₁ Very positively
- ₂ Positively
- ₃ Neutrally
- ₄ Negatively
- ₅ Very negatively
- ₆ Both positively and negatively
- ₇ Don't know

35) If you have told people at your workplace that you are HIV-positive – have you subsequently regretted or been glad that you told them?

- ₁ You have been very glad that you told them
- ₂ You have been glad that you told them
- ₃ It has not made any difference to you
- ₄ You have regretted to some degree that you told them
- ₅ You have very much regretted that you told them

36) If you have not told people at your workplace that you are HIV-positive – what is the reason?

- ₁ You are worried about the reactions of others
- ₂ It doesn't concern them
- ₃ You don't want to be talked about behind your back
- ₄ You don't wish to be seen as someone who is HIV-positive
- ₅ It hasn't been a natural thing to do
- ₆ Other reasons
- ₇ Don't know

37) How many hours do you work in a normal week?

- ₁ Less than 10 hours
- ₂ Between 10 and 19 hours
- ₃ Between 20 and 29 hours
- ₄ Between 30 and 36 hours
- ₅ 37 hours or more

38) Have you been forced to reduce your hours of work due to HIV-related problems?

- ₁ Yes
- ₂ No
- ₃ Don't know

Your social life

Support from family and friends plays an important role in many people's daily lives – both in general, and if you are struck by a severe illness. Accordingly, the following questions deal with your social network and your social life.

39) Are your parents alive?

- ¹ Yes, both
- ² Yes, one
- ³ No, they are both dead (*Go to question 43*)
- ⁴ Don't know (*Go to question 43*)

40) If yes, where do your parents live?

- ¹ In Denmark
- ² Abroad
- ³ One parent lives in Denmark and the other abroad
- ⁴ Don't know

41) How often do you normally talk on the phone with your parents/one of your parents?

(If both your parents are alive, your answer should cover the total contact with them both.)

- ¹ Every day
- ² One or more times a week
- ³ One or more times a month
- ⁴ Less than once a month
- ⁵ Never
- ⁶ You live with one or both of your parents

42) When did you last see your parents/one of your parents? *(If both your parents are alive, your answer should cover the total contact with them both)*

- ¹ Today or yesterday
- ² 2-7 days ago
- ³ 8-29 days ago
- ⁴ 1-12 months ago
- ⁵ Not in the last 12 months
- ⁶ You live with one or both of your parents

43) Do you have children? *(Circle the number of children)*

- ¹ Yes 1 2 3 4 more than 4
- ² No (*Go to question 51*)

44) If you have children, how many of these are under 18 years of age? *(Circle the number of children)*

- ¹ None
- 1 2 3 4 More than 4

45) If you have children under 18 years of age, where do they live?

- ¹ In Denmark
- ² Abroad
- ³ You have children under 18 years of age both in Denmark and abroad

46) Are any of your children under 18 years of age infected with HIV?

(You may place several crosses)

- ¹ Yes, and they live in Denmark
- ² Yes, and they live abroad
- ³ No
- ⁴ Don't know

47) Do you live together with any of your children who are under 18 years of age?

(You may place several crosses)

- ¹ Yes
- ² The children live partly with you and partly elsewhere
- ³ No

48) Do you have children under 18 years of age in Denmark that you do not live together with?

(You may place several crosses)

- ¹ Yes, they live with family members or the other parent
- ² Yes, they have been placed in care by the social services department
- ³ No

49) If you have children (irrespective of age) that you do not live together with, and who live in Denmark – how often do you normally talk with them on the telephone?

(If you have more than one child, your answer should cover your total contact with your children)

- ¹ Every day
- ² One or more times a week
- ³ One or more times a month
- ⁴ Less than once a month
- ⁵ Never

50) If you have children (irrespective of age) that you do not live together with, and who live in Denmark – when did you last see them?

(If you have more than one child, your answer should cover your total contact with your children)

- ¹ Today or yesterday
- ² 2-7 days ago
- ³ 8-29 days ago
- ⁴ 1-12 months ago
- ⁵ Not in the last 12 months

51) Do you have friends?

- ¹ Yes
² No (Go to question 53)

52) When did you last see one of your friends?

- ¹ Today or yesterday
² 2-7 days ago
³ 8-29 days ago
⁴ 1-12 months ago
⁵ Not in the last 12 months

53) Who would you turn to, if you had personal problems?

(You may place several crosses)

- ¹ Your spouse/partner
² Your children
³ Parents/parents-in-law
⁴ Grandparents
⁵ Other family members
⁶ Friends
⁷ Your doctor (the GP stated on your medical card)
⁸ The doctor at the HIV-out-patient clinic
⁹ The nurse at the HIV-out-patient clinic
¹⁰ Counsellors from an HIV/AIDS-organisation
¹¹ A priest or other religious minister
¹² Other
¹³ Don't know

54) How many people do you know who are HIV-positive?

- ¹ None
² 1-5 persons
³ 6-10 persons
⁴ More than 10 persons

55) Do you have friends that you knew before you were diagnosed HIV-positive?

- ¹ Yes, close friends
² Yes, but not close friends
³ No

56) Have you made new friends since you were diagnosed HIV-positive?

- ¹ Yes, one
² Yes, several
³ No (Go to question 58)

57) If yes – are they HIV-positive?

- ¹ Yes
² No
³ Both HIV-positive and not HIV-positive
⁴ Don't know

58) Do you ever find yourself alone, even though you would prefer to be together with others?

- ¹ Often
² Once in a while
³ Rarely
⁴ Never
⁵ Don't know

59) To what extent have you experienced the following as a consequence of being HIV-positive:
(Place one cross per line)

	To a large extent	To some extent	To a small extent	Not at all	Not sure
59.1 You have more contact with your family and friends	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
59.2 You receive more care and attention from other people	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
59.3 Other people show more consideration towards you	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
59.4 You have become better at taking decisions about your life	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
59.5 You feel isolated	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
59.6 Other people are afraid of you and keep a physical distance	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
59.7 You feel infectious and keep a physical distance to others	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
59.8 You no longer dare to have sex	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵

Telling people you are HIV-positive

Many people find it difficult to tell their family, friends, employer/colleagues, etc. that they are HIV-positive. Most people need to think carefully about who they will tell – and when. Your experiences can help others to make their choices.

60) How many people have you told that you are HIV-positive? (Health care professionals and HIV/AIDS-counsellors should not be counted)

- ¹ You haven't told anyone (Go to question 64)
² 1-2 persons
³ 3-5 persons
⁴ 6-10 persons
⁵ More than 10 persons

61) How long was it before you told the first person that you were HIV-positive?

(Health care professionals and HIV/AIDS-counsellors should not be counted)

- ¹ Immediately
- ² 0-1 years
- ³ 1-2 years
- ⁴ 2-3 years
- ⁵ 3-5 years
- ⁶ More than 5 years

62) Who was the first person you told that you were HIV-positive? (Health care professionals and HIV/AIDS-counsellors should not be counted)

- ¹ Spouse/partner
- ² Boyfriend/girlfriend
- ³ Parents
- ⁴ Brother or sister
- ⁵ Own children
- ⁶ Friends
- ⁷ Others *(please specify, if possible):* _____

63) Have you told any of the following persons that you are HIV-positive? (Place one cross on each line)

	Yes	No	You don't have one
63.1 Your spouse/partner	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
63.2 Boyfriend/girlfriend	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
63.3 Parents	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
63.4 Brother or sister	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
63.5 Own children	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
63.6 Friends	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³
63.7 Others	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³

64) If you answered No to having told one or more of the above persons – what is the reason why you have not told this person you are HIV-positive? (You may place several crosses)

- ¹ You don't feel it concerns them
- ² You are afraid that they will blame you for being ill
- ³ It is a life-threatening illness, and you don't want them to be sad
- ⁴ You are afraid that they will reject you
- ⁵ You don't wish to be seen as someone who is HIV-positive
- ⁶ You are afraid of being talked about behind your back
- ⁷ You will tell him/her/them at a later time
- ⁸ Other

Other people's reactions

People who are HIV-positive can encounter both negative and positive reactions when they tell others that they are HIV-positive. The following questions can help to illuminate the possible reactions.

65) What kinds of reaction have you encountered within the last five years from the people around you when you told them you were HIV-positive?

- ¹ You have mainly encountered positive reactions
- ² You have mainly encountered negative reactions
- ³ The reactions have been mixed
- ⁴ Don't know *(Go to question 69)*

66) If you have experienced positive reactions within the last 5 years, what kind of experiences have they been? (You may place several crosses)

- ¹ You have experienced that people are more considerate of you
- ² You have experienced more care and support
- ³ You have experienced that other people treat you as they always have done
- ⁴ You have experienced that other people were glad that you shared your worries with them
- ⁵ Other *(please specify, if you wish):* _____

67) If you have experienced negative reactions within the last 5 years, what kind of experiences have they been? (You may place several crosses)

- ¹ You have experienced that people rejected you or avoided you
- ² You have experienced that other people talked about your HIV-status behind your back
- ³ You have heard derogatory remarks about people who are HIV-positive (or about you, because you are HIV-positive)
- ⁴ You have experienced being badly treated because you are HIV-positive
- ⁵ You have experienced being physically harassed because you are HIV-positive
- ⁶ You have experienced that public employees failed to keep your HIV-status confidential
- ⁷ Other *(please specify, if you wish):* _____

Some HIV-positive people have experienced discrimination because of their HIV-status, such as being fired from their jobs, refused admission to a sports club or an educational institution, or failing to gain a job – solely because of their HIV-status.

68) Have you within the last 5 years experienced discrimination because of your HIV-status?
(You may place several crosses)

- ¹ At your workplace
- ² At an educational institution
- ³ In connection with leisure activities
- ⁴ In another context
- ⁵ No (Go to question 70)
- ⁶ Don't know (Go to question 70)

For many people, their workplace plays a central role in their efforts to go on living a "normal" life. Accordingly, the following questions deal specifically with discrimination at work.

(If you have never experienced discrimination at work – go to question 70).

69) If you replied Yes to experiencing discrimination at your place of work – how have you experienced this? (You may place several crosses)

- ¹ Failure to get a job
- ² Firing
- ³ Failure to be promoted
- ⁴ Demotion
- ⁵ Bullying
- ⁶ Unpleasant hints
- ⁷ Being left out
- ⁸ Don't know
- ⁹ Other (please specify, if you wish): _____

Even if you have never experienced negative reactions from other people or been discriminated against because of your HIV-status, you may well be worried and insecure about how other people will react if you tell them you are HIV-positive.

70) Are you nervous that rumours may go around among those who know you that you are HIV-positive?

- ¹ Yes
- ² No
- ³ Don't know

71) Have you experienced changes within the last five years in relation to how people around you view those who are HIV-positive?

- ¹ You experience more concern and support from the people around you
- ² You experience less concern and support from the people around you
- ³ You have not experienced any change
- ⁴ Don't know/can't judge

Your sex life and sexual issues

In the following, there will be a number of questions about sexuality and sexual behaviour. You may find some of these questions very private. However, as HIV can be passed on through sexual contact, many people who are HIV-positive experience problems with their sex lives. The following questions are asked in order to gain greater insight into any problems or difficulties. The aim is to improve the help and support given to HIV-positive people who have sexual problems.

72) Which of the following best describes your sexual partners?

- ¹ Only people of the opposite sex
- ² Mainly people of the opposite sex, but also one or more people of your own sex
- ³ More or less equally men and women
- ⁴ Mainly persons of your own sex, but also one or more persons of the opposite sex
- ⁵ Only persons of your own sex
- ⁶ You have never had a sexual partner

73) To what extent have you been able to satisfy your sexual needs over the past year?

- ¹ Completely
- ² Almost completely
- ³ Partly
- ⁴ Slightly
- ⁵ Not at all
- ⁶ You have not had sexual needs over the past year
- ⁷ Don't know

74) How often have you had sex with another person, on average, over the past year?

- ¹ Every day
- ² 3-6 times a week
- ³ 1-2 times a week
- ⁴ 1-3 times a month
- ⁵ Less than once a month
- ⁶ Not at all in the past year
- ⁷ Don't know

75) The first time you have sex with a new partner, do you tell them that you are HIV-positive?
(You may place several crosses)

- 1 You always tell them, no matter whether you have safe or unsafe sex
- 2 You tell them if you have unsafe sex
- 3 You sometimes tell them, no matter whether you have safe or unsafe sex
- 4 You never tell 'one-night stands' or casual sexual partners
- 5 You never tell them
- 6 You have not had sex with a new sexual partner since you were diagnosed HIV-positive

76) When you have sex with a person who is not HIV-positive – how worried are you that you might infect this person with HIV?
(Answer on a scale from 1 to 10 by placing a cross in one of the boxes)

- 1 You have not had sex after being diagnosed HIV-positive
- 2 1 Not worried at all
- 3 2
- 4 3
- 5 4
- 6 5
- 7 6
- 8 7
- 9 8
- 10 9
- 11 10 Extremely worried

Many people find it hard to practise safe sex every time, and we have only limited knowledge of the extent of these difficulties and their nature. Consequently, we do not know to what extent it may be necessary to support people who would like to become better at practising safe sex.

77) How often, within the past year, have you had unsafe vaginal or anal sex (i.e. without a condom) with another person who was either not infected with HIV, or whose HIV-status you did not know?

- 1 You have not had unsafe sex within the past year
- 2 Once
- 3 2-4 times
- 4 5-10 times
- 5 More than 10 times
- 6 Don't know
- 7 Prefer not to answer

78) If you have had unsafe sex one or more times within the past year – can you say why this happened? (You may place several crosses)

- 1 Because it is more intimate and close
- 2 Because it feels better
- 3 Because you were under the influence of alcohol or drugs
- 4 Because you didn't have any condoms
- 5 Because the other person did not wish to use a condom
- 6 Because you need to "let go" once in a while
- 7 Because you don't feel you are very infectious
- 8 Because you were depressed or sad
- 9 Because you forgot
- 10 Because a condom signals mistrust
- 11 Because a condom signals HIV/AIDS
- 12 Because you knew the other person was HIV-positive
- 13 Because you assumed that the other person was HIV-positive
- 14 Because condoms take the pleasure out of sex
- 15 Other (please specify, if you wish): _____

79) Would you like help or support to become better at practising safe sex more consistently?

- 1 Yes
- 2 No (Go to question 81)
- 3 Don't know (Go to question 81)
- 4 Not applicable to you (Go on to question 81)

80) If yes – who would you prefer to receive this help or support from? (You may place several crosses)

- 1 The doctor at the HIV-out-patient clinic
- 2 The nurse at the HIV-out-patient clinic
- 3 Another counsellor
- 4 A psychologist
- 5 Your doctor (GP)
- 6 Friends
- 7 Other HIV-positive people/network group
- 8 Others
- 9 Don't know

81) Would you like the staff (doctor or nurse) at the HIV-out-patient clinic to talk to you regularly (e.g. once a year) about any sexual problems you may have (such as lack of desire, fear of infecting others, difficulties in practising safe sex, etc.)

- 1 Yes
- 2 No
- 3 Don't know

82) How important it is for you to have a good sex life?

- 1 Extremely important
- 2 Very important
- 3 Important
- 4 Not very important
- 5 Not important at all

83) Have you, within the past year, experienced a lack of desire or reduced desire for sex?

- 1 Yes, all the time
- 2 Yes, often
- 3 Yes, once in a while
- 4 Yes, but rarely
- 5 No, never (*Go on to question 85*)

84) Has this lack of desire or reduced desire been a problem for you?

- 1 Yes
- 2 No

85) Do any of the following statements apply to your sex life since you were diagnosed HIV-positive?

Your sex life has changed

- A1 Very much
- A2 To some degree
- A3 Not at all
- A4 Don't know

You have fewer sexual partners

- B1 Very much
- B2 To some degree
- B3 Not at all
- B4 Don't know

You have more difficulty finding a partner or boyfriend/girlfriend

- C1 Very much
- C2 To some degree
- C3 Not at all
- C4 Don't know

You have become afraid to have sex

- D1 Very much
- D2 To some degree
- D3 Not at all
- D4 Don't know

You choose HIV-positive sexual partners

- E1 Very much
- E2 To some degree
- E3 Not at all
- E4 Don't know

The following questions relate to men's sexual problems. Women should go to question 88.

86) How often within the past year have you experienced the following in sexual situations?
(Place one cross per line)

- | | Every time | Often | Once in a while | Rarely | Not at all |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 86.1 Your erection has not been strong enough for penetration | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 86.2 You have not been able to keep your erection long enough to hold the condom on | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 86.3 You have not been able to have an orgasm, or have done so only with great difficulty | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| <input type="checkbox"/> 86.4 You have not had sex with someone else within the past year (<i>Go to question 94</i>) | | | | | |

87) If you have experienced one or more of the above in sexual situations, has it been a problem for you?

- 1 Yes
- 2 Partly
- 3 No

The following questions relate to women's sexual problems.

Men should go to question 90

88) How often within the past year have you experienced the following in sexual situations?
(Place one cross per line)

- | | Every time | Often | Once in a while | Rarely | Not at all |
|--|----------------------------|----------------------------|----------------------------|----------------------------|----------------------------|
| 88.1 You have not been sufficiently moist in your vagina | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 88.2 You have not been able to have an orgasm, or have done so only with great difficulty | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| 88.3 You have experienced pain in your vagina during sexual intercourse | <input type="checkbox"/> 1 | <input type="checkbox"/> 2 | <input type="checkbox"/> 3 | <input type="checkbox"/> 4 | <input type="checkbox"/> 5 |
| <input type="checkbox"/> 88.4 You have not had sex with someone else within the past year (<i>Go to question 94</i>) | | | | | |

89) If you have experienced one or more of the above in sexual situations, has it been a problem for you?

- ₁ Yes
₂ Partly
₃ No

The remaining questions are for both men and women

90) If you have sexual problems – have they become worse since you were diagnosed HIV-positive?

- ₁ Yes
₂ Yes, to some degree
₃ No
₄ Don't know

91) If you have sexual problems, have they become worse since you began treatment?

- ₁ You are not in treatment
₂ Yes
₃ Yes, to some degree
₄ No
₅ Don't know

92) Have you sought help for your sexual problems since being diagnosed HIV-positive?
(You may place several crosses)

- ₁ You have had sexual problems, but have not needed help
₂ You have needed help, but have not asked for it
₃ You have talked to the doctor or the nurse at the HIV-out-patient clinic
₄ You have talked to your doctor (GP)
₅ You have talked to another counsellor
₆ You have talked to a sex therapist
₇ You are taking or have taken medication (e.g. Viagra) to treat your sexual problems
₈ You have not had sexual problems *(Go to question 94)*

93) How would you describe the help you have received in connection with your sexual problems?

- ₁ Very good
₂ Good
₃ Neither good nor bad
₄ Bad
₅ Very bad

Your health

The following questions deal with your health and your smoking and drinking habits, in order to learn more about your general health and lifestyle.

94) All in all, how would you assess your health?

- ₁ Very good
₂ Good
₃ OK
₄ Bad
₅ Very bad

95) The next questions concern your feelings and thoughts within the last month – for each question, please state how often you have felt this way within the last month.

(Place one cross per line)

- | | Never | Almost never | Once in a while | Often | Very often |
|--|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| 95.1 How often have you felt that life was going your way? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| 95.2 How often have you felt able to cope with the irritations of daily life? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| 95.3 How often have you felt you were in control of things? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| 95.4 How often have you felt you were unable to control the things that are important in your life? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| 95.5 How often have you felt unsure of whether you could cope with your personal problems? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |
| 95.6 How often have you felt that the difficulties were mounting up so much that you could no longer cope with them? | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ | <input type="checkbox"/> ₃ | <input type="checkbox"/> ₄ | <input type="checkbox"/> ₅ |

96) Have you taken any of the following types of medicines for a longer period while you have been HIV-positive?

(You may place several crosses)

- ₁ Sleeping pills
₂ Tranquillisers or other sedatives due to psychological problems
₃ Tranquillisers or other sedatives due to physical problems
₄ Prozac/SSRIs
₅ Other antidepressive medicine

97) Have you taken any of the following types of medicine within the last month?

(You may place several crosses)

- ₁ Sleeping pills
- ₂ Tranquillisers or other sedatives due to psychological problems
- ₃ Tranquillisers or other sedatives due to physical problems
- ₄ Prozac/SSRIs
- ₅ Other antidepressive medicine

Alcohol, cigarettes and drugs

98) How often do you drink alcoholic drinks?

- ₁ Never *(Go to question 101)*
- ₂ Not more than once a month
- ₃ 2-4 times a month
- ₄ 2-3 times a week
- ₅ 4 times a week or more often
- ₆ More or less every day

99) How often do you drink five or more units of alcohol on the same occasion?

- ₁ Every day, or nearly every day
- ₂ Once a week
- ₃ Once a month
- ₄ Less often
- ₅ Never

100) In what situations do you usually drink alcohol?

(You may place several crosses)

- ₁ At home – on your own
- ₂ At home – together with family or friends
- ₃ On visits to your family or friends
- ₄ At parties
- ₅ At work
- ₆ In cafés, bars, restaurants or discotheques, or at concerts
- ₇ In connection with leisure activities
- ₈ On the street, in a park, on the beach, or in other outdoor places

101) Do you smoke tobacco?

- ₁ Yes, every day
- ₂ Yes, occasionally
- ₃ No, you used to smoke but stopped in: _____ *(please write the year, in four digits)* *(Go to question 103)*
- ₄ No, you have never smoked *(Go to question 104)*

102) How many cigarettes do you smoke a day, on average?

- ₁ You don't smoke every day
- ₂ 1-4 cigarettes
- ₃ 5-9 cigarettes
- ₄ 10-14 cigarettes
- ₅ 15-19 cigarettes
- ₆ 20-24 cigarettes
- ₇ 25-29 cigarettes
- ₈ 30 cigarettes or more
- ₉ Tobacco, other than cigarettes: _____ *(please specify)*
- ₁₀ Ved ikke

103) For how many years have you smoked every day?

- ₁ All in all, you have smoked every day for about: _____ years
- ₂ You have never smoked every day

104) Do you smoke hash?

- ₁ Every day
- ₂ Once a week
- ₃ Once a month
- ₄ Less often
- ₅ Never

105) Do you take other drugs besides alcohol and/or hash (such as cocaine, ecstasy, heroin, benzodiazepines, "street methadone")?

- ₁ Every day
- ₂ Once a week
- ₃ Once a month
- ₄ Less often
- ₅ No *(Go to question 112)*

106) If yes – have you ever fixed (used a needle) with any of the above substances?

- ₁ Yes
- ₂ No *(Go to question 112)*

107) Have you fixed within the last month?

- ₁ Yes
- ₂ No
- ₃ Don't know

108) Have you ever shared works with others? (syringes, needles, mixing dish, cotton wool, etc.)

- ₁ You have shared works/needles at least once
- ₂ You have shared works/needles more than once
- ₃ You have fixed, but have not shared works *(Go to question 112)*
- ₄ You always use sterile works from sealed packets *(Go to question 112)*
- ₅ Don't know *(Go to question 112)*

109) Have you shared works with others within the last month?

- ₁ Once
- ₂ Several times
- ₃ No (Go to question 112)
- ₄ Don't know (Go to question 112)

110) What was the reason that you shared works?
(You may place several crosses)

- ₁ Because you did not have access to clean works
- ₂ Because you were in prison and did not have access to clean works
- ₃ Because you don't feel you are very infectious
- ₄ Because you didn't think about the risk of infection
- ₅ Because it signals mistrust not to want to share works
- ₆ Because it signals HIV/AIDS not to want to share works
- ₇ Because it signals solidarity to share works
- ₈ Because you were under the influence of alcohol or drugs
- ₉ Other
- ₁₀ Don't know

111) Are you receiving treatment with subutex/methadone?

- ₁ Yes
- ₂ No

**Journeys abroad/Insurance policies/
Pension schemes**

112) Have you refrained from going abroad because of your HIV-infection?

(You may place several crosses)

- ₁ Yes – you no longer have the energy to travel
- ₂ Yes – you are afraid of being forced to reveal that you are HIV-positive
- ₃ Yes – you are afraid of getting ill
- ₄ You don't want to travel abroad
- ₅ No – you travel as you did before you were diagnosed HIV-positive

113) Has your HIV-infection prevented you from obtaining the best life insurance, pension scheme or private health insurance?

(You may place several crosses)

- ₁ Yes, life insurance
- ₂ Yes, pension scheme
- ₃ Yes, private health insurance
- ₄ No
- ₅ Not applicable to you

Penal Code

The Penal Code contains a provision (§ 252) that relates amongst other things to people infected with HIV. The following questions are asked in order to find out how much is known about this part of the Penal Code and its importance.

114) Do you think you can receive a prison sentence if you, as someone who is HIV-positive, have unsafe sex with a person who is not HIV-positive? (You may place several crosses)

- ₁ Yes, but only if you don't tell the other person that you are HIV-positive
- ₂ Yes, no matter whether or not you tell the other person that you are HIV-positive
- ₃ Yes, but only if you have had unsafe sex several times
- ₄ No, you can't be sentenced to prison for having unsafe sex
- ₅ Don't know

115) Have the Penal Code's provisions had any influence on your sexual behaviour?

- ₁ No, the Penal Code has not had any influence on your sexual behaviour
- ₂ Yes, you have had less unsafe sex
- ₃ Yes, you have had fewer partners
- ₄ Yes, you have stopped having sex
- ₅ Yes, you always or sometimes tell your sexual partners that you are HIV-positive
- ₆ Yes, you have had more unsafe sex or more sexual partners
- ₇ Don't know

116) Do the Penal Code's provisions worry you?

- ₁ No, you never think about it
- ₂ Yes, it worries you once in a while
- ₃ Yes, it often worries you
- ₄ Don't know

117) Have you ever been reported to the police?

- ₁ Yes
- ₂ No

118) Have you ever been threatened with being reported to the police?

- ₁ Yes
- ₂ No

Having children

In Denmark it is possible to help couples in which one partner is HIV-positive to have children without risking infecting the other partner and possibly the coming child. The offer of help applies to couples in which only one partner is infected.

119) Which of the following best describes your situation? (You may place several crosses)

- 1 You feel you have been sufficiently informed about the possibilities for help to have children
- 2 You lack information
- 3 You did not realise that help was available
- 4 It is relevant for you to be able to get this help
- 5 It could become relevant for you to get this help
- 6 Don't know
- 7 Not applicable to you (Go to question 121)

120) How important is it to you that this help is available?

- 1 Very important
- 2 Important
- 3 Not important
- 4 Not applicable to you
- 5 Don't know

Contact with the social services

For many different reasons, people who are HIV-positive may come in contact with the social services. The following questions deal with the nature of this contact.

121) Have you in the course of the last 12 months been in contact with the local social services department (in your municipality)?

- 1 Yes
- 2 No (Go to question 129)

122) What was the reason for your contact?

- 1 Benefits (application/following up, etc.)
- 2 Anticipatory pension (application/information, etc.)
- 3 Sickness benefit (application/following up, etc.)
- 4 Financial support in the form of single payments, grants for medicine, dental treatment, etc.
- 5 Financial support to pay for psychological help
- 6 Financial support to move house
- 7 Application for disability aids
- 8 Grant to look after sick or handicapped relative
- 9 Help for your HIV-positive children
- 10 Work activation
- 11 Rehabilitation (application/following up, etc.)
- 12 Subsidised flexjob (application/following up, etc.)
- 13 Other

123) How would you describe the help you receive from the social services?

- 1 Very good
- 2 Good
- 3 Neither good nor bad
- 4 Bad
- 5 Very bad

124) Have you received any of the following kinds of help/support from the social services? (You may place several crosses)

- 1 Support due to psychological problems
- 2 Support/practical help in own home
- 3 District nurse visits
- 4 Help in connection with substance abuse
- 5 Other (please specify, if you wish): _____
- 6 You have not received this type of help

125) If yes – how would you describe the help, you receive/received?

- 1 Very good
- 2 Good
- 3 Neither good nor bad
- 4 Bad
- 5 Very bad

126) Have you told the social services that you are HIV-positive?

- 1 Yes
- 2 No (Go to question 129)

127) If you have told some of the staff of the social services that you are HIV-positive, are you worried that they might not keep this information confidential?

- ¹ Yes
² No
³ Don't know

128) Do you feel you have received different treatment from the social services since you told them that you are HIV-positive?

- ¹ You feel that you have been treated better
² You have experienced reluctance and prejudice
³ You feel you are treated more or less the same as before
⁴ Other
⁵ Don't know

Contact with the health service and psychiatric service

HIV-positive persons are in contact with the health service, some more than others. Some are mainly in contact with the HIV-out-patient clinic, while others are in contact with various different parts of the health service. The following questions deal with the nature of this contact.

129) Does your doctor (the GP on your medical card) know that you are HIV-positive?

- ¹ Yes (Go to question 131)
² No
³ Don't know (Go to question 131)

130) If no – why does your doctor not know that you are HIV-positive?

- ¹ You don't see your doctor
² It is a coincidence
³ You haven't told him/her yet, but you intend to do so
⁴ You don't feel it's necessary for your doctor to be told
⁵ You would like to be able to talk to your doctor without being seen as "the person who is HIV-positive"
⁶ You are worried that your doctor might give your poor treatment
⁷ You are worried that your doctor might tell someone else
⁸ Other (please specify): _____

131) How many times have you been in contact with the following parts of the health service in the course of the last 12 months? (Place one cross per line)

	0 times	1-2 times	3-5 times	6 times or more
131.1 Psychologist	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
131.2 Psychiatrist	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
131.3 District psychiatric services	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
131.4 Psychiatric hospital (without being admitted)	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
131.5 Admitted to psychiatric hospital	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴

132) If you have been in contact with any of the above parts of the health service in the course of the last 12 months – how would you describe the help you receive/received? (You may place several crosses)

	Very good	Good	Neither good nor bad	Bad	Very bad
132.1 Psychologist	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
132.2 Psychiatrist	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
132.3 District psychiatric services	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
132.4 Psychiatric hospital (without being admitted)	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵
132.5 Admitted to psychiatric hospital	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴	<input type="checkbox"/> ⁵

133) Have you at any time needed to speak to a psychologist, psychiatrist or therapist in connection with your HIV-status, but have not done so because (You may place several crosses):

- ¹ You could not get an appointment
² You could not afford to pay for it yourself
³ The waiting time was too long
⁴ You didn't know how to contact one
⁵ Other reasons
⁶ No, you have not needed to talk to any of them

Contact with the HIV-out-patient clinic

134) Do you feel that the doctor at the HIV-out-patient clinic has enough time to talk to you?

- ₁ Always or almost always
- ₂ Often
- ₃ Sometimes
- ₄ Rarely
- ₅ Never
- ₆ Not applicable for you
- ₇ Don't know

135) Do you feel that the nurse at the HIV-out-patient clinic has enough time to talk to you?

- ₁ Always or almost always
- ₂ Often
- ₃ Sometimes
- ₄ Rarely
- ₅ Never
- ₆ Not applicable for you
- ₇ Don't know

136) How would you rate your contact with the doctor and nurse at the out-patient clinic?

- | | Doctor | Nurse |
|----------------------------|---------------------------------------|---------------------------------------|
| 136.1 Very good | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 136.2 Good | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 136.3 Neither good nor bad | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 136.4 Bad | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 136.5 Very bad | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |

137) Before you go for examinations at the hospital...

(You may place several crosses)

- ₁ You always prepare for what you need to talk about with the doctor
- ₂ You always prepare for what you need to talk about with the nurse
- ₃ You sometimes prepare
- ₄ You don't need to prepare
- ₅ You never prepare because you don't feel able to do so
- ₆ Don't know

138) Do you need more information on some of the following subjects?

(You may place several crosses)

- | | Need more information | Do not need more information |
|---|---------------------------------------|---------------------------------------|
| 138.1 Risk of infection in connection with sex | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 138.2 Risk of infection through ordinary social contact with other people | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 138.3 A good sex life | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 138.4 Sexual problems | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 138.5 Medicine use and side-effects | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 138.6 A healthy diet | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 138.7 Lifestyle changes (e.g. stopping smoking, losing weight, exercise) | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 138.8 Alternative medicine | <input type="checkbox"/> ₁ | <input type="checkbox"/> ₂ |
| 138.9 Other (please specify): | <input type="checkbox"/> ₁ | |
| | ----- | |

(If your mother tongue is Danish, go to question 142)

Interpreters

Language can sometimes be a barrier to good communication and mutual confidence, which is why interpreters can often be important to create a good contact between the patient and the hospital staff.

139) Over the last two years, approximately, has there been an interpreter present when you were examined at the HIV-out-patient clinic?

- ₁ Interpreters are not relevant for you (Go to question 142)
- ₂ Always
- ₃ Sometimes
- ₄ Rarely
- ₅ No, never

140) Have you ever refused to use an interpreter, even though the staff offered this?

- ₁ Yes
- ₂ No
- ₃ Don't know

141) How do you feel about having to use an interpreter (You may place several crosses)?

- ¹ You prefer to use an interpreter, so that you can be sure you have understood everything
- ² You feel insecure about using an interpreter
- ³ You prefer to manage without an interpreter
- ⁴ You don't care whether an interpreter is used or not
- ⁵ Don't know

Treatment

Many people have difficulty taking their HIV-medication according to the instructions. In order to be able to help, it is important that we know more about the difficulties that people who are HIV-positive have with taking their medication. Accordingly, the following questions deal with your use of medications.

142) Are you taking, or have you ever taken, HIV-medication (combination therapy)?

- ¹ Yes
- ² No (Go to question 152)

143) Are you afraid that other people may discover you are taking medication?

- ¹ Yes, always or usually
- ² Yes, once in a while
- ³ Yes, but rarely
- ⁴ No

144) Do you understand what the doctor and the nurse at the HIV-out-patient clinic tell you about your HIV-treatment?

- ¹ Always or almost always
- ² Sometimes
- ³ Rarely
- ⁴ Never

145) How often do you ask questions of the doctor or the nurse at the HIV-out-patient clinic, if there is something you don't understand about your HIV-treatment?

- ¹ Always or almost always
- ² Sometimes
- ³ Rarely
- ⁴ Never

146) Some people experience various side-effects or discomfort in connection with their HIV-medication. To what extent have you experienced the following side-effects or discomfort, within the last month while you have been taking the medication? (You may place several crosses)

		Much	Some	Slightly	Not at all
146.1	Nausea	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.2	Vomiting	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.3	Diarrhoea or abdominal pain	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.4	Pain in the kidneys or when urinating	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.5	Tiredness	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.6	Headache	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.7	Difficulty in concentrating	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.8	Sleep problems	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.9	Buzzing or pain in the hands or feet due to inflamed nerves	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.10	Impotence or reduced sexual desire	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.11	Reduced fat on the face, arms, legs or buttocks	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.12	Increased fat on the stomach, chest or neck	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.13	Discomfort in swallowing large tablets	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.14	Discomfort due to unpleasant taste of medication	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.15	Skin problems (rashes/ itching)	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.16	Problems with mucous membranes (dryness)	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴
146.17	Other major side-effects	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴

Please specify, if possible: _____

147) When have you last taken some of your HIV-medication?

- ¹ Today or yesterday
- ² 2-6 days ago
- ³ 1-2 weeks ago
- ⁴ 2-4 weeks ago
- ⁵ 1-3 months ago
- ⁶ More than 3 months ago
- ⁷ You have never taken any of your HIV-medication

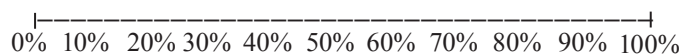
148) Over the last four days – on how many of these days have you failed to take all of your HIV-medication?

- ₁ No days
- ₂ One day
- ₃ Two days
- ₄ Three days
- ₅ Four days

149) Over the last 12 months, have you ever taken an uninterrupted break from your medication for seven or more days in a row, without this being agreed with your doctor?

- ₁ Yes
- ₂ No

150) Over the last 30 days – approximately how much of your medication do you think you have taken? (*Place a cross on the line*)



151) There can be various reasons why people fail to take their medication. Here is a list of possible reasons. Have you ever skipped taking your medication because you ...

(You may place several crosses)

		Often	Some- times	Rarely	Never
151.1	Were away from home?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.2	Were busy with other things?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.3	Forgot?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.4	Had too many tablets to take?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.5	Wanted to avoid side-effects?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.6	Did not wish people to find out you were taking medication?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.7	Had a change in your daily routine?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.8	Felt that the medication was poisonous/harmful?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.9	Fell asleep/were sleeping at the time the dose should be taken?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.10	Felt sick or bad?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.11	Felt depressed/"could not cope with more"?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.12	Had problems with taking the medication at particular times (with food, on an empty stomach, etc.)?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.13	Did not have any more pills?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.14	Felt well?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.15	Had a bad relationship with the doctor?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.16	Had misunderstood the information on the medication or the dose?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.17	Felt that the treatment worked just as well anyway?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.18	Wanted to take a break from thinking about HIV?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.19	Had drunk alcohol?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.20	Had taken drugs (e.g. cocaine, ecstasy, heroin, benzodiazepines, "street methadone")?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.21	Had problems taking the tablets because of their taste or size?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
151.22	Lacked support from your partner, family or friends?	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

Your contact with HIV/AIDS-organisations and other HIV-positive people

The following questions deal with the support and guidance offered by HIV/AIDS-organisations. It is important that these services match the actual needs of people who are HIV-positive.

Date: _____

Thank you very much for your help!

152) Have you ever received guidance or support from any of the following organisations, and how would you assess the help you received? (You may place several crosses)

Have you made use of?		Were you satisfied?	
		Yes	No
152.1	<input type="checkbox"/> AIDS-Linien	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.2	<input type="checkbox"/> Center for Sex og Sundhed (formerly Aids-Info/Fyn)	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.3	<input type="checkbox"/> The HIV- and AIDS-priest in Copenhagen	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.4	<input type="checkbox"/> Hiv-Danmark	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.5	<input type="checkbox"/> Hiv-Pensionatet	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.6	<input type="checkbox"/> Hivinfo.dk	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.7	<input type="checkbox"/> Positivgruppen	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.8	<input type="checkbox"/> STOP AIDS – the gay men’s HIV-organisation	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.9	<input type="checkbox"/> TICC	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.10	<input type="checkbox"/> Others (please specify, if possible): _____	<input type="checkbox"/> ¹	<input type="checkbox"/> ²
152.11	<input type="checkbox"/> No, you have not made use of any of them		

153) If you have not made use of any of the offers of the HIV/AIDS-organisations for guidance/ support – what is the reason? (You may place several crosses)

- ₁ The service you need doesn’t exist
- ₂ You have considered it, but didn’t get around to it
- ₃ You don’t have confidence in the
- ₄ The offers are not good enough
- ₅ You prefer to use your own network
- ₆ You didn’t know about the offers
- ₇ Don’t know

154) Do you regularly meet with other HIV-positive people, either in organised groups such as the Positive Group, or friends who are also HIV-positive? (You may place several crosses)

- ₁ Yes, in an organised group
- ₂ Yes, with HIV-positive friends
- ₃ No, because you don’t need/want to
- ₄ No, because there aren’t any in the area where you live
- ₅ No, because there are no groups you would like to participate in

