
Q-HIV survey

Optimization of quality of care for HIV-infected patients in care in
HIV treatment centres the Netherlands.

With this questionnaire we would like to gain insight into the quality of life of, and quality of care for HIV-positive people. This questionnaire contains questions from two previously developed questionnaires (SF-36 and QUOTE-HIV). **Note: SF-36 not included in this supplementary file**

The information you enter here will be matched to your study ID and not linked to your personal identity.

Please fill in the study ID (“*studienummer*”) and token (“*toegangscode*”) on your information letter.

Study ID:

Token:

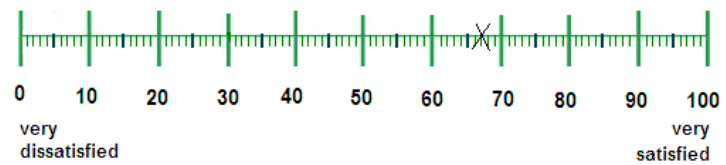
QUESTIONS ABOUT QUALITY OF CARE

The following questions are about quality of care. This section consists of three parts:

- A. The specialist
- B. The HIV nursing consultant
- C. General

The questions in part A and B look similar, but are different! We therefore ask you to answer all of the questions.

Example of filled in satisfaction scale



A. CARE BY THE SPECIALIST

IMPORTANCE: THE SPECIALIST

Not everyone thinks the same way about the quality of care. Some people find it important that their specialist is a good listener. Others prefer to be able to consult him/her at any time of day. Below are a number of statements concerning your HIV SPECIALIST. Please indicate, for each statement, the response that best describes how important it is to you. We would like to know what **you** find important. There are no right or wrong answers.

For each statement, please indicate how **important** it is to you:

		<i>not important</i>	<i>quite important</i>	<i>important</i>	<i>of the greatest importance</i>
	<i>a. Content of care</i>				
1.	The specialist should always explain the advantages and disadvantages of any treatment.				
2.	The specialist should always give me the results of laboratory tests.				
3.	The specialist should have specific expertise in the field of HIV.				
4.	The specialist should always prescribe medicines whose costs are completely covered by my medical insurance.				
	<i>b. Information</i>				
5.	The specialist should always tell me what the possible side-effects of a medicine are.				
6.	The specialist should provide information about how I should take the prescribed HIV medication.				
7.	The specialist should always provide an explanation, <u>in language I can understand</u> , concerning prescribed medicines.				
	<i>c. Relationship with the caregiver</i>				
8.	The specialist should always take me seriously.				
9.	The specialist's attitude should be one of sympathy and involvement.				
10.	The specialist should give 'bad' news carefully.				
11.	The specialist should always take sufficient time to talk to me.				

		<i>not important</i>	<i>quite important</i>	<i>important</i>	<i>of the greatest importance</i>
12.	The specialist should be aware of my current situation at home and at work/school.				
	<i>d. Organisation of the care</i>				
13.	I always want to be treated by my own specialist.				
14.	The specialist should work in close cooperation with other caregivers.				
15.	The specialist should be easily accessible by telephone.				
16.	The specialist should not keep me waiting more than 15 minutes in the waiting room.				
17.	The specialist should have locum services (substitution doctor) well organised.				
18.	The specialist should keep strictly to the appointments and/or agreements that have been made.				
19.	The specialist should ensure that, whenever necessary, I can make an appointment at the clinic at short notice (within 24 hours).				
20.	The specialist should ensure that we are not disturbed during a consultation.				
	<i>e. Patients' rights and privacy</i>				
21.	The specialist should include me in decision-making regarding the treatment that I receive.				
22.	The specialist should tell me that I may ask another doctor for advice ('second opinion').				
23.	The specialist should always allow me to look at my medical file if I wish to.				
24.	The specialist should safeguard my privacy as regards my HIV-status.				
25.	The specialist should have his/her practice laid-out so that I cannot hear what is discussed at reception and in the consulting room.				

PERFORMANCE: THE SPECIALIST

So far, we have asked you about what you find important. This part of the questionnaire is about **your own experiences**. The questions below are about the specialist with whom you have had contact in the past year. You only need to answer these questions if you have received help from your specialist within the **past 12 months**.

I haven't had contact with the specialist in the **past 12 months**: please proceed to page 7.

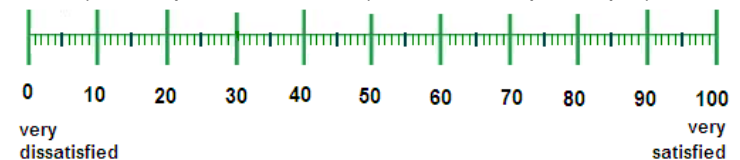
For each statement, please indicate the response that best reflects **your experience**:

		<i>never</i>	<i>sometimes</i>	<i>usually</i>	<i>always</i>
<i>a. Content of care</i>					
1.	My specialist explains the advantages and disadvantages of any treatment.				
2.	My specialist gives me the results of laboratory tests.				
3.	My specialist has specific expertise in the field of HIV.				
4.	My specialist prescribes medicines whose costs are completely covered by my medical insurance.				
<i>b. Information</i>					
5.	My specialist tells me what the possible side-effects of a medicine are.				
6.	My specialist provides information about how I should take the prescribed HIV medication.				
7.	My specialist provides an explanation, <u>in language I can understand</u> , concerning prescribed medicines.				
<i>c. Relationship with the caregiver</i>					
8.	My specialist takes me seriously.				
9.	My specialist's attitude is one of sympathy and involvement.				
10.	My specialist gives 'bad' news carefully.				
11.	My specialist takes sufficient time to talk to me.				
12.	My specialist is aware of my current situation at home and at work/school.				

		<i>never</i>	<i>sometimes</i>	<i>usually</i>	<i>always</i>
<i>d. Organisation of the care</i>					
13.	I am treated by my own specialist.				
14.	My specialist works in close cooperation with other caregivers.				
15.	My specialist is easily accessible by telephone.				
16.	My specialist keeps me waiting more than 15 minutes in the waiting room.				
17.	My specialist has locum services (substitution doctor) well organised.				
18.	My specialist keeps strictly to the appointments and/or agreements that have been made.				
19.	My specialist ensures that, whenever necessary, I can make an appointment at the clinic at short notice (within 24 hours).				
20.	During a consultation I am able to talk to my specialist undisturbed.				
<i>e. Patients' rights and privacy</i>					
21.	My specialist includes me in decision-making regarding the treatment that I receive.				
22.	My specialist has told me that I may ask another doctor for advice ('second opinion').		<i>yes</i>	<i>no</i>	
23.	My specialist allows me to look at my medical file if I wish to.				
24.	My specialist safeguards my privacy as regards my HIV-status.				
25.	My specialist has his/her practice laid-out so that I cannot hear what is discussed at reception and in the consulting room.				

Below are some **general** questions about the care you receive from your HIV-specialist.

- a. Is the care you receive from your specialist:
 - adequate too little too much
- b. Please use the 0-100 scale to indicate how satisfied in general you are about the care you received from your specialist (related to your HIV infection) in the past 12 months (see the example on p.4).



B. CARE BY THE HIV NURSING CONSULTANT

IMPORTANCE: HIV NURSING CONSULTANT

Some people find it important that their HIV nursing consultant is a good listener. Others prefer to be able to consult him/her at any time of day. Below are a number of statements concerning your HIV NURSING CONSULTANT. Please indicate, for each statement, the response that best describes how important it is to you. We would like to know what **you** find important. There are no right or wrong answers.

For each statement, please indicate how **important** it is to you:

		<i>not important</i>	<i>quite important</i>	<i>important</i>	<i>of the greatest importance</i>
	<i>a. Content of care</i>				
1.	The HIV nursing consultant should always explain the advantages and disadvantages of any treatment.				
2.	The HIV nursing consultant should have specific expertise in the field of HIV.				
	<i>b. Information</i>				
3.	The HIV nursing consultant should always tell me what the possible side-effects of a medicine are.				
4.	The HIV nursing consultant should provide information about how I should take the prescribed HIV medication.				
5.	The HIV nursing consultant should always provide an explanation, in language I can understand, concerning prescribed medicines.				
	<i>c. Relationship with the caregiver</i>				
6.	The HIV nursing consultant should always take me seriously.				
7.	The HIV nursing consultant's attitude should be one of sympathy and involvement.				
8.	The HIV nursing consultant should give 'bad' news carefully.				
9.	The HIV nursing consultant should always take sufficient time to talk to me.				

		<i>not important</i>	<i>quite important</i>	<i>important</i>	<i>of the greatest importance</i>
10.	The HIV nursing consultant should be aware of my current situation at home and at work/school.				
	<i>d. Organisation of the care</i>				
11.	I always want to be treated by my own HIV nursing consultant.				
12.	The HIV nursing consultant should work in close cooperation with other caregivers.				
13.	The HIV nursing consultant should be easily accessible by telephone.				
14.	The HIV nursing consultant should not keep me waiting more than 15 minutes in the waiting room.				
15.	The HIV nursing consultant should keep strictly to the appointments and/or agreements that have been made.				
16.	The HIV nursing consultant should ensure that, whenever necessary, I can make an appointment at the clinic at short notice (within 24 hours).				
17.	The HIV nursing consultant should ensure that we are not disturbed during a consultation.				
	<i>e. Patients' rights and privacy</i>				
18.	The HIV nursing consultant should tell me that I may ask another doctor for advice ('second opinion').				
19.	The HIV nursing consultant should always allow me to look at my medical file if I wish to.				
20.	The HIV nursing consultant should safeguard my privacy as regards my HIV-status.				
21.	The HIV nursing consultant should have his/her practice laid-out so that I cannot hear what is discussed at reception and in the consulting room.				

PERFORMANCE: HIV NURSING CONSULTANT

So far, we have asked you about what you find important. This part of the questionnaire is about **your own experiences**. The questions below are about the HIV nursing consultant with whom you have had contact in the past year. You only need to answer these questions if you have received help from your HIV nursing consultant within the **past 12 months**.

I haven't had contact with the HIV nursing consultant in the past 12 months: please proceed to page 9.

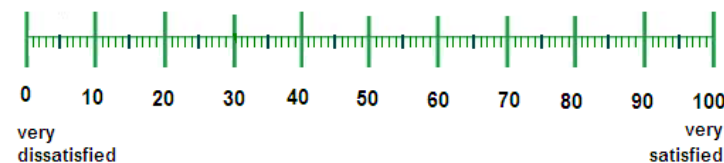
For each statement, please indicate the response that best reflects **your experience**:

	<i>a. Content of care</i>	<i>never</i>	<i>sometimes</i>	<i>usually</i>	<i>always</i>
1.	My HIV nursing consultant explains the advantages and disadvantages of any treatment.				
2.	My HIV nursing consultant has specific expertise in the field of HIV.				
	<i>b. Information</i>				
3.	My HIV nursing consultant tells me what the possible side-effects of a medicine are.				
4.	My HIV nursing consultant provides information about how I should take the prescribed HIV medication.				
5.	My HIV nursing consultant provides an explanation, in language I can understand, concerning prescribed medicines.				
	<i>c. Relationship with the caregiver</i>				
6.	My HIV nursing consultant takes me seriously.				
7.	My HIV nursing consultant's attitude is one of sympathy and involvement.				
8.	My HIV nursing consultant gives 'bad' news carefully.				
9.	My HIV nursing consultant takes sufficient time to talk to me.				
10.	My HIV nursing consultant is aware of my current situation at home and at work/school.				

	<i>d. Organisation of the care</i>	<i>never</i>	<i>sometimes</i>	<i>usually</i>	<i>always</i>
11.	I am treated by my own HIV nursing consultant.				
12.	My HIV nursing consultant works in close cooperation with other caregivers.				
13.	My HIV nursing consultant is easily accessible by telephone.				
14.	My HIV nursing consultant keeps me waiting more than 15 minutes in the waiting room.				
15.	My HIV nursing consultant keeps strictly to the appointments and/or agreements that have been made.				
16.	My HIV nursing consultant ensures that, whenever necessary, I can make an appointment at the clinic at short notice (within 24 hours).				
17.	During a consultation I am able to talk to my HIV nursing consultant undisturbed.				
	<i>e. Patients' rights and privacy</i>				
18.	My HIV nursing consultant has told me that I may ask another doctor for advice ('second opinion').		<i>yes</i>	<i>no</i>	
19.	My HIV nursing consultant allows me to look at my medical file if I wish to.				
20.	My HIV nursing consultant safeguards my privacy as regards my HIV-status.				
21.	My HIV nursing consultant has his/her practice laid-out so that I cannot hear what is discussed at reception and in the consulting room.				

Below are some **general** questions about the care you receive from your HIV nursing consultant.

- a. Is the care you receive from your HIV nursing consultant:
 - adequate too little too much
- b. Please use the 0-100 scale to indicate how satisfied in general you are about the care you received from your HIV nursing consultant (related to your HIV infection) in the past 12 months.



C. GENERAL

IMPORTANCE: **GENERAL**

In this section you will find some general points that are not directly related to the specialist or nursing consultant, but that could be of importance to you as an HIV-positive person.

For each statement, please indicate how **important** it is to you:

		<i>not important</i>	<i>quite important</i>	<i>important</i>	<i>of the greatest importance</i>
	Alternative therapy for my hiv-treatment should be completely covered by my medical insurance.				
	I should be able to make an appointment at a time that suits me.				
	The opening hours of the blood test department should be extensive (also beyond office hours).				
	My health care providers at HIV the treatment centre should be able to refer me to other professionals.				

PERFORMANCE: **GENERAL**

For each statement, please indicate the response that best reflects **your experience**:

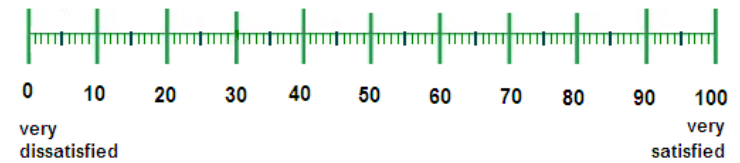
		<i>never</i>	<i>sometimes</i>	<i>usually</i>	<i>always</i>
	I make use of alternative therapy				
	I am able to make an appointment at a time that suits me.				

Alternative therapy for my hiv-treatment is completely covered by my medical insurance.

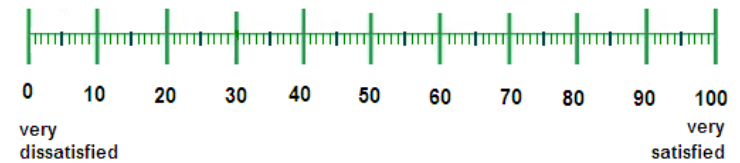
Yes No I don't know

(You may indicate what type of alternative therapy you make use of and for which complaints):

Please use the 0-100 scale to indicate how satisfied in general you are about the opening hours of the blood test department.

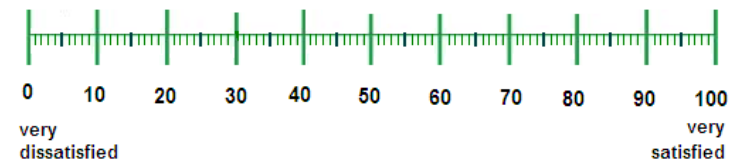


Please use the 0-100 scale to indicate how satisfied in general you are about the waiting times at the blood test department.



Please use the 0-100 scale to indicate how satisfied in general you are about the referral by your providers at the HIV-treatment centre to other professionals (if applicable).

not applicable



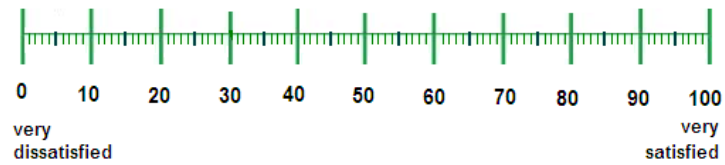
The costs of medication are being critically assessed worldwide. The costs of 3 separate pills are generally much lower than the cost of a combination drug with the same active ingredients. Would you be willing to take 3 pills at the same time instead of 1 pill?

Yes No Maybe

Please fill in your comment here:

.....

Please use the 0-100 scale to indicate how satisfied in general you are about the hiv-related care you received in the treatment centre (from the entire treatment team) in the past 12 months.



If you have any comments regarding the HIV-care that you have received, please note them below.

If you have any comments regarding this questionnaire, please note them below.

Have you filled in your study ID and token on the cover page of the survey?

THANK YOU FOR COMPLETING THE SURVEY!