



CASCADE – QUESTIONNAIRE

SECTION A: STUDY NUMBER AND DATE

Date of completion: DD/MM/YYYY

Study number:

Will the patient complete the survey unassisted?

- Yes, the patient will complete the survey on their own
- No, assistance will be provided because of literacy, computer competency, or other issues

Please pass the terminal (or paper questionnaire) to patient



CASCADE Questionnaire

Welcome

Thank you for agreeing to take part in the CASCADE questionnaire which aims to better understand the experiences and needs of people who have recently acquired HIV in Europe and Canada. Some of the questions are of a personal nature; however, your replies will be very useful. **You are free to leave out any question you do not want to answer.**

Please do NOT write your name or clinic number on this survey. Your answers will NOT be seen by doctors and nurses in the clinic, and your answers will NEVER be recorded in your clinic notes.

If you have any questions or need any help, please ask the person who gave you this survey.

[if paper format add: Please place your completed survey in the envelope, seal the envelope and give it back to the staff member who gave it to you.]

Thank you for your help!



SECTION B: GENERAL INFORMATION

This first section includes general questions about you and your family.....

1. In which country are you completing this questionnaire?

- Canada
- France
- Greece
- Italy
- Netherlands
- Norway
- Spain
- Sweden
- United Kingdom

2. Age at last birthday (completed years)

3. Which of the following best describes how you think of yourself?

- Man (including trans man)
- Woman (including trans woman)
- Non-binary
- In any other way

4. Is your gender identity the same as you were given at birth?

- Yes
- No

5. How would you describe your sexual orientation?

- Gay or Lesbian/ Homosexual
- Straight/ heterosexual
- Bisexual
- Other

6. Were you born in the country you are completing this questionnaire?

- Yes (**please go to Q7**)
- No

6A. If no, in which country were you born

[ONLINE VERSION: (**Please select a country**) [DISPLAY LIST in drop down menu]

6B. In what year did you first move to the country you now live in? Please DO NOT include holidays and business trips

- YYYY



7. What is the highest level of education that you have completed?

- No formal education
- Primary education (*first stage of basic education*)
- Secondary education (*between ages 11-18*)

7A. At what age did you leave secondary school?

- A university degree or equivalent

8. What is your current work situation? (Mark all possible choices)

- Full time student/education/training
- Employed or self-employed (full or part- time)
- Unemployed/ registered for benefits
- Unemployed/ not registered for benefits
- Long term sick/disabled (for 3 months or more)
- Temporarily sick/disabled (for less than 3 months)
- Not allowed to work (e.g., immigration reasons)
- Voluntary work
- Home/family caring
- Retired
- Other:

9. Are you.....

- Single
- In a relationship, but living apart
- Living with your partner as a couple
- Married or in a legally recognised civil partnership
- Separated/ Divorced/ Widowed

10. Do you have any children (include any children of your own or that you care for)?

- Yes (**please go to Q11**)
- No

10A. Do you want to have children?

- Yes (**please go to Q12**)
- No (**please go to Q12**)

11. Do you plan (or would like) to have more children?

- Yes
- No

12. Which of the following best describes your current accommodation?

- Homeowner
- Renting
- Renting but paid for by housing benefit



- Temporary accommodation (e.g., hostel, shelter, bed & breakfast) (**please go to Q13**)
- Homeless (**please go to Q13**)
- Staying with friends or family

12A. Which best describes your current household composition?

- Living alone
- Living with partner +/- children
- Living with parents or extended family
- Living with house mates or friends
- Other.....

13. How would you rate your quality of life?

- Very good
- Good
- Neither good nor poor
- Poor
- Very poor

14. Do you currently have enough money to cover your basic needs (e.g., food, clothes, heating, accommodation)?

- All of the time
- Most of the time
- Some of the time
- No

15. Thinking back over the past FOUR weeks

| | Never | Rarely or sometimes | Often | Prefer not to say |
|---|-------|---------------------|-------|-------------------|
| <i>Was there ever No Food to eat of any kind in your house because of lack of resources (e.g., money, vouchers etc)?</i> | | | | |
| <i>Did you go to sleep at night hungry because there was not enough food?</i> | | | | |
| <i>Did you go a whole day and night without eating anything at all because there was not enough food?</i> | | | | |

16. What best describes you: (please note this information will not be shared)

- UK Citizen
- EU national
- Permanent resident
- Temporary resident under any kind of visa
- Residence application submitted
- Asylum seeker
- Refugee
- Student Visa or card holder



- Other:
- Prefer not to say

SECTION C: YOUR HEALTH AND HEALTH CARE

17. How satisfied are you with your health?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied

18. Do you have a GP? (General practitioner or family doctor)

- Yes
- No

18A. If YES, have you told your family doctor/GP that you have HIV?

- Yes
- No

19. Under each heading, please tick the one box that best describes your health TODAY.

MOBILITY

- I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about

SELF-CARE

- I have no problems washing or dressing myself
- I have slight problems washing or dressing myself
- I have moderate problems washing or dressing myself
- I have severe problems washing or dressing myself
- I am unable to wash or dress myself

USUAL ACTIVITIES (e.g., work, study, housework, family or leisure activities)

- I have no problems doing my usual activities
- I have slight problems doing my usual activities
- I have moderate problems doing my usual activities
- I have severe problems doing my usual activities
- I am unable to do my usual activities

PAIN/ DISCOMFORT

- I have no pain or discomfort
- I have slight pain or discomfort



- I have moderate pain or discomfort
- I have severe pain or discomfort
- I have extreme pain or discomfort

ANXIETY/ DEPRESSION

- I am not anxious or depressed
- I am slightly anxious or depressed
- I am moderately anxious or depressed
- I am severely anxious or depressed
- I am extremely anxious or depressed

20. We would like to know how good or bad your health is TODAY.

This scale is numbered from 0 to 100.

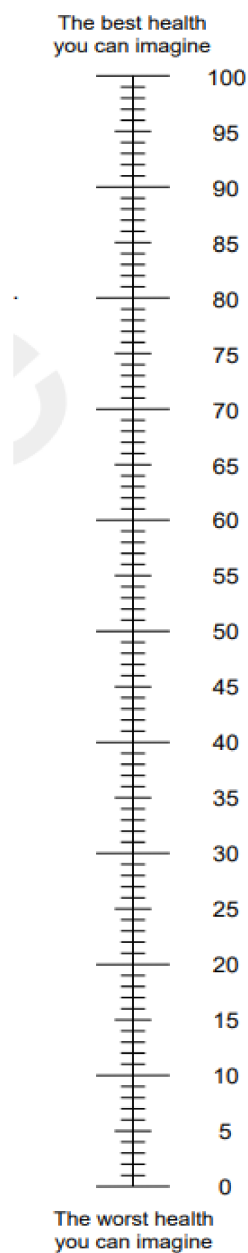
100 means the best health you can imagine.

0 means the worst health you can imagine.

Please mark an X on the scale to indicate how your health is TODAY.

Now, write the number you marked on the scale in the box below.

YOUR HEALTH TODAY =



21. Below are some statements that people sometimes make when they talk about their health. Please indicate how much you agree or disagree with each statement as it applies to you personally. There are no right or wrong answers, just what is true for you. If the statement does not apply to you, mark as N/A.

| | Disagree Strongly | Disagree | Agree | Agree Strongly | N/A |
|--|-------------------|----------|-------|----------------|-----|
| i. I am the person who is responsible for taking care of my health | | | | | |



| | | | | | |
|--|--|--|--|--|--|
| ii. Taking an active role in my own health care is the most important thing that affects my health | | | | | |
| iii. I am confident I can help prevent or reduce problems associated with my health | | | | | |
| iv. I know what each of my prescribed medications is for | | | | | |
| v. I am confident that I can tell a doctor or nurse concerns I have even when he or she does not ask | | | | | |
| vi. I am confident that I can carry out medical treatment I may need to do at home | | | | | |
| vii. I understand my health problems and what causes them | | | | | |
| viii. I know what treatments are available for my health problems | | | | | |
| ix. I have been able to maintain lifestyle changes, like healthy eating or exercising | | | | | |
| x. I know how to prevent problems with my health | | | | | |
| xi. I am confident I can work out solutions when new problems arise with my health | | | | | |
| xii. I am confident that I can maintain lifestyle changes, like healthy eating and exercising, even during times of stress | | | | | |

22. Over the last 2 weeks, how often have you been bothered by any of the following problems?

| | Not at all | Several days | More than half the days | Nearly every day |
|---|------------|--------------|-------------------------|------------------|
| Feeling nervous, anxious or on edge | | | | |
| Not being able to stop or control worrying | | | | |
| Feeling down, depressed or hopeless | | | | |
| Little interest or pleasure in doing things | | | | |

23. Within the last year, have you been humiliated or emotionally abused in other ways by your partner or an ex-partner?

- No
- Yes
- Prefer not to say

24. Within the last year, have you been afraid of your partner or ex-partner?

- No
- Yes
- Prefer not to say

25. Within the last year, have you been kicked, hit, slapped, or otherwise physically hurt by your partner or ex-partner?

- No
- Yes



- Prefer not to say

SECTION D: PRIOR TO HIV DIAGNOSIS

The following questions relate to the time before you were diagnosed HIV positive

26. Prior to your HIV diagnosis, did you feel at risk of acquiring HIV?

- Yes, at high risk
- Yes, at some risk
- Neither at risk nor not at risk
- No, not at risk

27. Before being diagnosed did you ever have a negative HIV test?

- Yes
- No (**please go to Q29**)
- Unsure

28. How long before testing HIV positive did you have your last negative HIV test?

- Less than 3 months
- Between 3 and 12 months
- Between 1 & 5 years
- Over 5 years
- Never had a negative HIV test

29. Had you ever taken PrEP (anti-HIV drugs that can be used to prevent HIV transmission before sex)?

- Yes
- No (**please go to Q30**)

29A. If yes, when did you first ever take PrEP? Please provide date as accurately as possible (MM/YYYY)

29B. Did you take PrEP in the 6 months before you tested positive for HIV?

- Yes
- No

29C. Where did you get the PrEP drugs you used? (Please tick all that apply)

- Public health service e.g., NHS sexual health service
- Internet
- Private prescription
- Other (please specify)

29D. How often did you take PrEP when you last used it?

- Daily
- Event-based (i.e., when you have or think you will have sex)

29E. Did you stop taking PrEP prior to your HIV diagnosis?



- Yes
- No

29F. If yes, why? (Please tick all that apply)

- Side effects of medicine
- I was not having sex
- I forgot to take the pills
- Due to health issues
- Impact on sex life
- I wanted a break from PrEP
- Having sex but didn't feel at risk
- Other:

29G. Whilst taking PrEP, did you use condoms? (Please respond then go to Q31)

- No
- Sometimes
- Most of the time
- Always

30. The next question is for people who did not use PrEP in the 6 months prior to being diagnosed with HIV.

Why did you not take PrEP? (Please tick all that apply):

- I did not know about PrEP
- It was too expensive
- I wasn't having sex
- I was having sex but didn't feel at risk
- I was never offered PrEP
- I was offered PrEP but I refused
- I asked for PrEP but was denied
- I didn't know where to get PrEP
- Due to health issues
- Impact on sex life
- I wanted a break from PrEP
- I was afraid of side effects
- I experienced stigma
- Other _____

31. Had you ever taken antiretroviral drugs after you had sex (i.e., PEP/post-exposure prophylaxis)?

- Yes
- No

The next set of questions is about using (recreational) drugs. This would include drugs such as heroin, cocaine, amphetamines, or steroids, but does not include any drug prescribed by a doctor.



32. In the 12 months before being diagnosed with HIV, have you used any of the following drugs just before or during sex? (Tick all that apply)

- Amphetamine (*speed*)
- Cocaine
- Heroin (*smack*)
- Ketamine (*Vitamin K, K, Special K*)
- GHB/GBL (*Gina, Liquid Ecstasy, Liquid G*)
- Mephedrone (*Drone, MCAT, meow meow*)
- Meth amphetamine (*Crystal meth, ice/glass*)
- Poppers (*Amyl or other nitrate inhalants*)
- Other
- I have not used any of these drugs (**please go to Q34**)

33. Did you inject or slam any of these drugs?

- Yes
- No (**please go to Q34**)

33A. If you have ever injected or slammed, the last time you injected with a needle, where did you get the needles (Tick all that apply)

- Bought from pharmacy or other shop
- Bought on internet
- Needle exchange programme
- Outreach work
- Friends/other people who inject drugs
- Stole them
- Drug dealer

SECTION E: SEXUAL BEHAVIOUR

The questions in this section are about your sex life and sexual behaviour. When answering these questions please include everyone you have ever had sex with, whether it was just once, a few times, a regular partner or wife/husband.

34. In the 3 months before being diagnosed with HIV, how many people have you had vaginal and/or anal sex with?

- (**Please specify**)
- None (**please go to Q35**)

34A. In the 3 months BEFORE being diagnosed with HIV have you had vaginal and/or anal sex without a condom with:

- Men only (*including trans men*)
- Women only (*including trans women*)
- Men and women
- Non – binary
- Not had sex (**please go to Q35**)
- Prefer not to say



- Other (*please specify*)

34B. In the 3 months before being diagnosed with HIV, with how many casual partners did you have vaginal or anal sex without a condom? (Casual partners are defined as people who have had sex together just once, or a few times)

- Please state the number:
- None

34C. In the 3 months before being diagnosed with HIV, with how many regular partners did you have vaginal or anal sex without a condom? (Regular partners are defined as people who have had sex together regularly, more than a few times)

- Please state the number:
- None

34D. In the 3 months before being diagnosed with HIV, did you have group sex (sex with 3 or more people)?

- Yes
- No
- Prefer not to say

34E. Did you or your sexual partner use a condom the last time you had sex?

- Yes
- No
- Prefer not to say

35. Have you had sex since your HIV diagnosis? (sex includes oral, vaginal or anal)

- Yes
- No
- Prefer not to say

36. How satisfied are you with your sex life currently (within past two weeks)?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied

37. In the last 12 months, have you had a sexually transmitted infection (STI)?

- Yes
- No

38. In the last 12 months, have you been diagnosed with any of the following? (Tick all that apply)

- Gonorrhoea
- Syphilis
- Chlamydia (including LGV)
- Shigella



- Monkeypox

39. In the last 12 months, have you had sex with someone so that they would give you money, shelter, food or drugs?

- Yes
- No
- Prefer not to say

40. In the last 12 months, have you paid (with money, food, drugs or shelter) someone for sex?

- Yes
- No
- Prefer not to say

41. Within the last 12 months, have you been raped or forced to have any kind of sexual activity?

- Yes
- No (**please go to Q42**)
- Prefer not to say (**please go to Q42**)

41A. If yes, was this by your partner or ex-partner?

- Yes
- No
- Prefer not to say

SECTION F: LIFE WITH HIV

This section is about living with HIV. So please focus on the time since your HIV diagnosis

42. Please answer whether your ability to meet your needs has been positively affected, not affected, or negatively affected by your HIV status (please select one response for each item below)

| | Has been <u>POSITIVELY</u> affected by my HIV status | Has <u>NOT</u> been affected by my HIV status | Has been <u>NEGATIVELY</u> affected by my HIV status | Not sure |
|---|---|--|---|-----------------|
| My self-confidence | | | | |
| My self-respect | | | | |
| My ability to respect others | | | | |
| My ability to cope with stress | | | | |
| My ability to have close and secure relationships with others | | | | |
| My ability to find sexual partners | | | | |
| My ability to find love | | | | |
| My desire to have children | | | | |
| My achievement of my personal or professional goals | | | | |
| My ability to contribute to the community | | | | |



| | | | | |
|--|--|--|--|--|
| My ability to practice a religion/faith as I want to | | | | |
|--|--|--|--|--|

43. Which, if any, of the following services have you received support from since being diagnosed with HIV? (Please tick all that apply)

- HIV community organisations/charities
- Non-HIV community organisations/charities
- Peer support (support from someone who is also living with HIV)
- Psychologist/counsellor
- Other:
- I have not received any support

44. We would like to know what personal support you should have, should you need it. Please tick the column that best describes your situation:

| | None of the time | A little of the time | Some of the time | Most of the time | All of the time |
|--|------------------|----------------------|------------------|------------------|-----------------|
| Someone to confide in or talk to about yourself or your problems | | | | | |
| Someone to share your most private worries and fears with | | | | | |
| Someone to help you if you were confined to bed | | | | | |
| Someone to prepare your meals if you were unable to do it yourself | | | | | |
| Someone to get together with for relaxation | | | | | |

45. People react to HIV in different ways. Please indicate whether you agree or disagree with the following statements:

| | Strongly Disagree | Disagree | Neutral | Agree | Strongly agree |
|---|-------------------|----------|---------|-------|----------------|
| I have been hurt by how people reacted to learning I have HIV | | | | | |
| I have stopped socializing with some people because of their reactions of my having HIV | | | | | |
| I have lost friends by telling them I have HIV | | | | | |
| I am very careful who I tell that I have HIV | | | | | |
| I worry that people who know I have HIV will tell others | | | | | |
| I feel that I am not as good a person as others because I have HIV | | | | | |
| Having HIV makes me feel unclean | | | | | |
| Having HIV makes me feel that I'm a bad person | | | | | |
| Most people think that a person with HIV is disgusting | | | | | |



| | | | | | |
|--|--|--|--|--|--|
| Most people with HIV are rejected when others find out | | | | | |
|--|--|--|--|--|--|

46. Have you experienced stigma and/or discrimination for reasons other than your HIV status?

- Yes
- No (**please go to Q47**)

46A. Please indicate why you felt stigmatized and/or discriminated against (tick all that apply)

Because of:

- My gender
- My ethnicity
- My disability
- My age
- My religion
- My sexual orientation
- My drug use
- Being perceived as a foreigner
- Sex work
- Other (specify):.....

SECTION G: HIV MEDICATION

47. Has your doctor advised you to take HIV medicine?

- Yes
- No (**please go to Q50**)

48. Are you currently taking HIV (antiretroviral) medication?

- Yes
- No (**please got to Q50**)

49. If your doctor has advised you to take HIV medicine, how important were the following factors when making a decision?

| | Very important | Somewhat important | Not at all important |
|--|----------------|--------------------|----------------------|
| Side effects of medication | | | |
| Feeling depressed or overwhelmed | | | |
| Don't want to think about being HIV positive | | | |
| Using alcohol or recreational drugs | | | |
| Don't want anyone to see the medication | | | |
| Homelessness | | | |
| Taking alternative or complementary medicines | | | |
| Medication is too complicated to take | | | |
| Medication is harmful | | | |
| Information from friends or support groups | | | |
| Information from media (e.g., TV, newspapers, search engine) | | | |
| Information from social media | | | |



49A. During the past 2 weeks, on how many days have you missed taking any of your pills?

- None (not missed any doses)
- 1 day
- 2 or 3 days
- 4 or 5 days
- More than 5 days
- Not taken any medication
- My HIV medication is given by injection

50. Thinking about taking HIV medicine, please indicate your degree of agreement with the following:

| | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree |
|---|-------------------|----------|-----------|-------|----------------|
| My health, at present, depends on these medicines | | | | | |
| My health in the future will depend on these medicines | | | | | |
| These medicines are my best hope for the future | | | | | |
| These medicines keep me alive | | | | | |
| Having to take these medicines worries me | | | | | |
| I sometimes worry about becoming too dependent on these medicines | | | | | |
| These medicines give me unpleasant side effects | | | | | |
| The taste of this medicine makes me feel unwell | | | | | |

51. Please indicate your agreement with the following sentences:

| | Strongly disagree | Disagree | Uncertain | Agree | Strongly agree |
|--|-------------------|----------|-----------|-------|----------------|
| The demands of everyday life often get me down | | | | | |
| I am quite good at managing the many responsibilities of my daily life | | | | | |
| In general, I feel I am in charge of the situation in which I live | | | | | |

52. Please indicate your agreement with the following statements

| | TRUE | FALSE | I DON'T KNOW |
|---|------|-------|--------------|
| Everyone who has HIV has AIDS (i.e. HIV=AIDS) | | | |
| You cannot pass on HIV sexually if you are on treatment and have an undetectable viral load | | | |
| Laboratory tests are not necessary to tell whether my drugs are working or not | | | |



| | | | |
|---|--|--|--|
| People living with HIV can live a long and healthy life | | | |
|---|--|--|--|

Do you have any comments or suggestions about this survey?

Free text answer:

[IF ONLINE]: Thank you very much for completing this survey

Please click submit.

[if paper] **Please seal the survey in the envelope provided and give it back to the staff member who gave it to you.**

Thank you!