

Measuring the Prevalence of Autistic Traits in a Cohort of Adults Living with Human Immunodeficiency Virus or Taking HIV Pre-exposure Prophylaxis and Mapping Safer-sex Barriers and Facilitators: a Study Protocol

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ELECTRONIC ANNEXES

Annex 1 – Sociodemographic questioned in phase 1

1. Clinic where I am followed for prevention or treatment of HIV:

- Institute of Tropical Medicine, ANTWERP
- U.Z. Brussels, JETTE
- Cliniques Universitaires Saint-Luc, WOLUWE-SAINT-LAMBERT
- C.H.U. Saint-Pierre, BRUXELLES
- Hôpital Erasme, BRUXELLES (ANDERLECHT)
- C.H.U. de CHARLEROI
- C.H.U. de LIEGE
- Jessa Hospital, HASSELT
- C.H.U. Mont-Godine, YVOIR
- U.Z. GENT
- U.Z. LEUVEN
- A.Z. Sint-Jan BRUGES

2. I belong to the following age group:

- 18 to 25 years
- 26 to 35 years
- 36 to 45 years
- Over 46 years old

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3. Reason I'm in follow-up at the HIV-clinic:

- I'm a person with HIV
- I am a person who takes or wants to take PrEP

4. I am (biologically) born as a:

- Man
- Woman
- Intersex (unclear or mixed sex characteristics)

5. I feel sexually attracted to:

- Only men
- Especially men, but also women
- Men and women, both equally
- Especially women, but also men
- Only women
- None of the above (fill in)

6. My sex partners of the past twelve months were:

- Men only
- Both men and women, but more men than women
- Both men and women, with approximately equal numbers of men and women
- Both men and women, but more women than men
- Women only
- Other (fill in)

7. I already have an official diagnosis of autism

- YES
- A. I was diagnosed by a psychiatrist
- B. I was diagnosed by a neurologist
- C. I was diagnosed by a psychologist
- D. I got my diagnosis from a multi-disciplinary team
- E. Other (fill in)

NO

8. I have a child with:

- A form of autism (e.g. autism spectrum disorder or the former Asperger syndrome or PDD-NOS)
- Another developmental disorder (e.g. ADHD or learning difficulties) but no diagnosis of autism
- None of the above, but I do have one or more children
- Not applicable, because I have no children

Annex 2 : Questionnaire about barriers and facilitators

Important:

- Every time you read the term "sex" or "sexual contact", in this questionnaire it means contact between one person's penis, vagina and/or anus and another person's penis, vagina and/or anus or mouth. For example: someone puts their penis in your mouth, vagina, or anus. Or you put your penis in someone's mouth, vagina, or anus yourself.

- Whenever you read the term "safe sex" in this questionnaire, it means:

- o Sex where the risk of contracting sexually transmitted diseases is very low (for example because a condom is used during penetration or because you are in a permanent monogamous relationship with one person who was tested for sexually transmitted diseases at the start of the relationship and/or

- o Sex where the risk of serious psychological damage is very low (psychological damage can be, for example, that you develop depression as a result of sexual abuse).

1. I belong to the following age category:

- 18 to 25 years old
- 26 to 35 years old
- 36 to 45 years
- Older than 46 years

2. I was born (biologically) as :

- Man
- Woman
- Intersex (unclear or mixed sex characteristics)

3. Reason for which I am being followed up in the HIV clinic:

- I am a person with HIV
- I am a person who takes or wants to take PrEP

4. The number of different partners I had sex with in the past twelve months was:

- 0
- 1
- More than 1 and less than 5
- 5 or more, but less than 10
- More than 10

5. I am sexually attracted to:

- Men only
- Mainly men, but also women
- Men and women, both equally
- Especially women, but also men
- Only women
- None of the above (fill in)

6. In the past twelve months, I have had sexual contacts with:

- Men only
- Both men and women, but more men than women
- Both men and women, with about the same number of men and women
- Both men and women, but more women than men
- Only women
- Other (fill in)

7. With casual sex partners of the past twelve months, a condom was used if there was penetration of the penis into the vagina or the anus.

- Never
- Sometimes, but with less than half of my casual sex partners
- Sometimes, with about half of my casual sex partners
- Sometimes, with more than half of my casual sex partners
- Always
- Not applicable, because I have not had a casual sex partner in the past twelve months

8. During sex with casual sex partners in the past twelve months, where there was penetration of the penis into the vagina or anus, I have tried to persuade the other not to use a condom:

- Never
- Sometimes, but with less than half of my casual sex partners
- Sometimes, with about half of my casual sex partners
- Sometimes, with more than half of my loose sex partners
- Always

9. I think it is important not to get (new) sexually transmitted diseases in the future:

Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

10. *To be completed only by persons born physically as male*

I have had sex with men in the past twelve months, because sex with men is easier to obtain for me than sex with women:

Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

11. *Only if you answered 'somewhat agree' or 'agree' to the previous question:*

I would be less likely to have sex with men if I could have affordable sex with a reliable female sex worker who has been trained in safe sex and in the sexual needs of people with characteristics of autism (e.g. through a recognized association that supports that type of sexual activity).

Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

The following questions often involve sexual boundaries.

If someone goes beyond your sexual boundaries, it means that they are engaging in sexual activities that you don't like to experience because they make you feel bad. That bad feeling could be:

- because there is too much risk of sexually transmitted diseases, or
- because you have physical pain against your will during these sexual activities, or
- because the sex partner does something that makes you feel psychologically bad (for example, you feel disrespected for certain sexual actions, or it makes you sad, or you feel inferior, or you are not ready for it yet).

12. I know exactly what my sexual boundaries are (examples: I don't want anal sex without a condom, or I don't want sex under the influence of drugs, or I don't want sex with multiple people, or I don't want sex on a first date) :

Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

13. I have, once or more, allowed sexual activities that in retrospect were beyond my boundaries, because I didn't know well enough what my sexual boundaries were at that moment:

Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

14. I could use support from a specialized health worker to make a detailed list of my sexual boundaries:

Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

15. Having a detailed list of my personal sexual boundaries would help me have safer sex:

Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

The following questions are about communicating during sex:

16. I can clearly say (orally) to new sex partners what I do and don't want in terms of safe sex (e.g. I only want penetration with a condom, e.g. I only want oral sex without a condom, e.g. I don't want drugs) :

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

17. I can clearly write to new sex partners (e.g. via chat) what I do and do not want in terms of safe sex (e.g. I want penetration only with a condom, e.g. I only want oral sex without a condom, e.g. I don't want drugs):

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

18. I would prefer to communicate about safe sex with new sex partners via:

- spoken language (oral)
- written language (e.g. chat)
- no preference

19. I can negotiate well enough if a sex partner and I don't want the same in terms of safe sex (for example I want a condom for penetration but the other doesn't, or the other wants drugs with sex but I don't):

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

20. Very concrete tips on how to negotiate safe sex would help me have safer sex:

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

21. People can suffer when many stimuli come at them at the same time. It can then be difficult to calmly think about what is happening, and to make decisions. That can also happen during sex.

If I could take breaks from sex in an appropriate way, to think about whether what the sex partner is doing is still within my boundaries, it would help me have safer sex:

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

The following questions are about reasons why people choose to seek sexual contact:

22. I sometimes use sex as a way to have social contact:

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

23. ONLY TO BE FILLED IN IF YOU ANSWERED 'SOMEWHAT AGREE' OR 'AGREE' TO THE PREVIOUS QUESTION

When I use sex as a means of social contact, I don't want to scare off potential sex partners by talking about sexually transmitted diseases and safe sex for fear of losing my social contact of that moment:

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

24. ONLY TO BE FILLED IN IF YOU ANSWERED 'SOMEWHAT AGREE' OR 'AGREE' TO QUESTION 22

I would be less likely to use sex as a means of social contact if I were able to participate in non-sexual social activities:

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

25. I sometimes use sex as an outlet for stress:

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

26. ONLY TO BE FILLED IN IF YOU ANSWERED 'AGREE' OR 'SOMEWHAT AGREE' TO PREVIOUS QUESTION

At times when I use sex as an outlet for stress, I don't pay enough attention to the safety of sex:

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

27. ONLY TO BE FILLED IN IF YOU ANSWERED 'AGREE' OR 'SOMEWHAT AGREE' TO QUESTION 25

I would have unprotected sex less often if a health worker would help me to find non-sexual ways to reduce my stress:

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

28. I sometimes use sex because being able to get a sex partner boosts my self-confidence.

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

29. ONLY TO BE FILLED IN IF YOU ANSWERED 'AGREE' OR 'SOMEWHAT AGREE' TO THE PREVIOUS QUESTION

On days when I have low self-confidence, I don't want to scare off potential sex partners by talking about sexually transmitted diseases and safe sex, for fear that the sex partner will reject me, making me even less confident.

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

30. I can judge well whether a sexual partner is trustworthy. Note: by the word "trustworthy" we mean here that the partner will not put you at risk of HIV or other sexually transmitted diseases, and that the partner will treat you with respect.

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

31. Warning: Below you will find some questions about sexual abuse. You can skip these questions if you want. Then go straight to question 33. You can always talk to your care provider about the consequences of possible abuse. You can also contact the researcher so that she can refer you specifically.

For your information, sexual abuse means:

- sexual activities for which you do not give clear consent, or
- sex that is forced, or
- sex where the other is not equal to you. For example, the other person is much stronger, or has more power, or there are several people together, so you don't dare to say 'no', even if you don't actually want sex with that person at that moment.

I have been sexually abused at least once.

- Yes
- No

32. Only to be completed with "yes" to previous question.

The sex in the context of sexual abuse happened at least once without a condom:

- Yes
 No

33. A partner may mislead you about the reason for having a sexual relationship with you. For example, the partner says that he/she has sex with you because he/she loves you. But actually he/she wants to use you for reasons such as money or shelter.

I have had one or more sexual relations with someone that I later discovered had been using me for money, gifts, residency papers, shelter, or other material benefits:

- Yes
 No

34. ONLY TO BE COMPLETED IF "yes" TO THE PREVIOUS QUESTION

With the person that I later found out had used me for money, gifts, residence permits, shelter, or other material benefits, sex was always done with a condom:

- Yes
 No

35. ONLY TO BE COMPLETED IF "no" TO THE PREVIOUS QUESTION.

I became infected with HIV or another sexually transmitted disease (such as herpes, chlamydia, gonorrhea, syphilis, genital warts) by the person that I later found out was using me for money, gifts, residency papers, shelter, or other material benefits. , Genital Warts...):

- Yes
 No

36. I once or more have had sex with someone because I received money, gifts, residence permits, shelter or other material benefits from that person in return:

- Yes
 No

37. To be completed only if "yes" to previous question.

I once or more have had sex without a condom with someone because I received money, gifts, residence permits, shelter, or other material benefits from that person in return:

- Yes
 No

38. Only complete if you answered "yes" to question 36.

I once or more had sex in exchange for money or gifts because it was difficult for me to find or keep another paid job, so I had little money:

0 0 0 0 0
 Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

39. Only complete if you answered "yes" to question 36.

If I had a paid job that was adapted to the needs of people with characteristics of autism, I would not have had sex for money:

0 0 0 0 0
 Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

Sometimes people use alcohol or drugs before or during sex. That can affect the decisions you make. The following questions are about whether you use substances before or during sex with partners.

40. I have had more than five glasses of alcohol before sex on at least one occasion:

- Yes
- No

41. To be completed only if "yes" to previous question.

The most frequent reason for my alcohol use before sex was:

- I needed alcohol to have enough self-confidence
- I needed alcohol to feel less stressed when interacting with other people
- I needed alcohol to feel less anxious during sex
- I needed alcohol to be less bothered by disturbing stimuli such as body odor, sounds, some touches
- I drank alcohol for pleasure and happened to have sex afterwards
- Other (fill in)

42. To be completed only if "yes" to question 40.

Due to the use of alcohol, at least one sexual risk occurred, such as sex without a condom with a casual partner, or sex while I was not fully conscious.

- Yes
- No

43. Note: The next question is about drugs. For this study, we do not count the use of poppers, nitrous oxide and cannabis as drugs. So if you only use poppers, nitrous oxide or cannabis for sex, you can answer "no" to this question.

I have at least once used drugs (e.g. XTC, coke, GBL, 3MMC...) before sex.

- Yes
- No

44. Only to be completed if "yes" to previous question

The most frequent reason for my drug use during sex was:

- I needed drugs to have enough self-confidence
- I needed drugs to feel less stressed when interacting with other people
- I needed drugs to feel less anxious during sex
- I needed drugs to be less bothered by disturbing stimuli such as body odor, sounds, some touches
- I like drugs because it enhances the sexual experience (e.g. sex lasts longer, or is more intense, or you are more focused during sex, or your orgasm is better)
- I drank alcohol for pleasure and happened to have sex afterwards
- Other (fill in)

45. To be completed only if "yes" to question 43.

Due to the use of alcohol, at least one sexual risk occurred, such as sex without a condom with a casual partner, or sex while I was not fully conscious.

- Yes
- No

46. I would like to have conversation about sexually safe behavior with a health worker with knowledge about sexuality.

0 0 0 0 0
 Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

Only complete if 'somewhat agree' or 'agree' to previous question

47. I find it helpful if the health worker I talk to about sexually safe behavior is also knowledgeable about frequent challenges in safe sex in people with features of autism

0 0 0 0 0
 Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

48. Only to be completed if you consider yourself lesbian, gay, bisexual, transgender, queer or intersex (LGBTQI).

Conversations about safe sex with other LGBTQI individuals could help me have safer sex.

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

49. Only complete if 'somewhat agreed' or 'agree' to previous question

I find it helpful if the LGBTQI individuals I talk to about safe sex have characteristics of autism:

0 0 0 0 0
Disagree Somewhat disagree Neither agree or disagree Somewhat agree Agree

OPEN QUESTIONS

50. Are there any topics that were not covered in the questionnaire but that you feel have a negative impact on how safe you are having sexual contact? If so, please fill in and explain these topics here.

51. Are there any topics that were not covered in the questionnaire but that you think have a positive influence on how safe you are in sexual contact? If so, please fill in and explain these topics here.