

Participant ID #: _____ Staff Initials: _____ Date __ / __ / _____

FLORIDA COHORT WAVE 3

STIGMA QUESTIONNAIRE

(Version 1.0 – 3/17/2022)

Thank you for taking the time to fill out this survey!

This questionnaire is about HIV-related stigma, including experiences you may have had when first diagnosed, more recent experiences, and how you feel now. There are no correct or incorrect answers on this survey. Please respond to each statement as honestly and accurately as you can. Your answers will be kept strictly confidential. Your honest and thoughtful responses are important to us.

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THE FLORIDA COHORT TEAM



ATTITUDES AND BELIEFS

This section is about negative attitudes and beliefs about people living with HIV, which is called HIV-related stigma. We are going to show you statements that some people living with HIV have said they feel or experienced. We are asking about these statements to better understand how these experiences may impact people living with HIV. These statements are not things that we or anyone on this project thinks. Some questions in this section may seem similar to each other or to the questions you have already answered.

There are 40 statements below. Please choose one response option for each statement. Each statement has four response options: 1-Strongly Disagree, 2-Somewhat Disagree, 3-Somewhat Agree, 4-Strongly Agree.

1. In many areas of my life, no one knows I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

2. I feel guilty because I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

3. People or society's attitudes about HIV make me feel worse about myself

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

4. I feel unsafe telling someone that I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

5. People with HIV who work could fear negative reactions from coworkers if their HIV status was known

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

6. I work hard to keep my HIV a secret

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

7. I feel inferior to others because I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

8. I never feel ashamed of having HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

9. People with HIV are treated like outcasts

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

10. Most people believe a person who has HIV is dirty

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

11. I tend to avoid new relationships because I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

12. Having HIV makes me feel unclean

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

13. I feel set apart and isolated from the rest of the world because I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

14. Most people think a person with HIV is disgusting

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

15. Having HIV makes me feel like I'm not good enough

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

16. Most people with HIV are rejected when others find out

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

17. I am very careful who I tell that I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

18. I have become distant from others who know my HIV status

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

19. I worry about people discriminating against me because of my HIV status

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

20. Most people are uncomfortable being around someone with HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

21. At times, I feel the need to hide the fact I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

22. I worry that people may judge me when they learn I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

23. I feel disgusted when I think about having HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

24. I have been hurt by how people reacted to learning I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

25. I worry people who know I have HIV will tell others

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

26. I regret having told some people that I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

27. Telling others that I have HIV has been a mistake

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

28. People have avoided touching me once they know I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

29. People I care about have become distant from me after learning I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

30. People blame me for getting HIV because of my lifestyle

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

31. Some people close to me are afraid that others will reject them if those other people find out that I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

32. People don't want me around their family or friends once they know I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

33. People have physically backed away from me when they learn I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

34. Some people act as though it is my fault that I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

35. I have stopped socializing with some people because of their reactions to my having HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

36. I have lost relationships by telling them that I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

37. I have told people close to me to keep the fact that I have HIV a secret

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

38. People who know I have HIV tend to ignore good things about me

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

39. People seem afraid of me once they learn I have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

40. People focus on mistakes in you when they find out you have HIV

- 1- Strongly Disagree
- 2- Somewhat Disagree
- 3- Somewhat Agree
- 4- Strongly Agree

DISCRIMINATION

The next few questions ask about times when people may have treated you differently or discriminated against you.

41. For each statement below, please tell us if you have experienced the following:

	No	Yes, but NOT in the <u>last 12</u> months	Yes, in the <u>last 12</u> months
I have been hurt by how people reacted to learning I have HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone has avoided touching me once they knew I have HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone I care about has become distant from me after learning I have HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Someone has physically backed away from me after learning that I have HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have stopped socializing with some people because of their reactions to my having HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have lost a relationship by telling them I have HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have heard friends or co-workers say negative things about people with HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have seen posts on social media (Facebook, Instagram, or others) that are negative about people living with HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have been rejected or sent mean messages on dating apps (Tinder, Grindr, or others) after telling people that I have HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

42. For each statement below, please tell us if you have experienced the following in a healthcare setting, such as an emergency room, clinic, or doctor's office

	No	Yes, but NOT in the <u>last 12 months</u>	Yes, in the <u>last 12 months</u>
Someone on the staff (someone at the front desk, a nurse, or a doctor) exhibited hostility or a lack of respect towards me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clinic or office staff has given me less attention than other patients	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I was refused service in an emergency room, clinic, or doctor's office	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staff talked about my HIV status among themselves	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have heard healthcare workers say negative things about people with HIV	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

IF YOU SELECTED "NO" FOR ALL OF QUESTIONS IN 42, SKIP TO PAGE 11, QUESTION 46

43. Please check all the reasons you think you were treated differently in a healthcare setting (*check all that apply*)

- My HIV status
- My alcohol or drug use
- My race or ethnicity
- My sexual preferences
- My gender

44. Which kind of healthcare worker was involved? (Check all that apply)

- Physician
- Nurse
- Medical assistant
- Pharmacist
- Non-medical staff (for example, people at the front desk or at check out)
- Other (**Please specify**) _____

45. What kind of healthcare setting was involved? (Check all that apply)

- Emergency room
- Hospital
- HIV clinic
- Medical clinic (not HIV)
- Pharmacy
- Health Department
- Dentist
- Other (**Please specify**) _____

46. How interested would you be in talking to the following people about your experiences of discrimination or about being treated differently because you have HIV?

	Very interested	Somewhat interested	Not interested
My HIV care provider	○	○	○
My primary care provider	○	○	○
My case manager	○	○	○
A counselor or therapist	○	○	○
A peer (someone else living with HIV)	○	○	○
A religious leader	○	○	○
Other (Please specify) _____	○	○	○

EXPERIENCES WITH DIS

When you were first diagnosed with HIV you might have talked with a Disease Intervention Specialist or DIS. A DIS is someone from the Department of Health who may have been informed you about your HIV diagnosis and given you information about HIV treatment. They also may have asked for the names of sexual or drug-sharing partners. This person may have sent you letters, texted or called you, or come to your home.

47. Do you remember talking with a DIS around the time you were diagnosed with HIV?

- Yes
- No
- Unsure

SKIP TO PAGE 14, ANSWER QUESTION 57

48. If yes, how well do you remember this conversation?

- Very well
- Somewhat well
- Not very well

SKIP TO PAGE 14, QUESTION 57

49. What was the gender of the DIS that you spoke with?

- Male
- Female
- Unsure

50. What was the race or ethnicity of the DIS that you spoke with?

- Hispanic or Latino/Latina
- Asian
- White
- Other (***Please specify***) _____
- Black
- Unsure

51. Where did this conversation occur?

- At my home
- In a clinic
- At another private location
- Other (***Please specify***) _____
- Unsure

**52. Please tell us whether you agree or disagree with the following statements:
“The DIS made me feel...”**

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Judged	<input type="radio"/>				
Comfortable	<input type="radio"/>				
Guilty	<input type="radio"/>				
Supported	<input type="radio"/>				
Afraid	<input type="radio"/>				

53. Thinking about your experience with the DIS, please tell us whether you agree or disagree with the following statements:

	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
The DIS was nice to me	<input type="radio"/>				
Talking with the DIS made me want to avoid care	<input type="radio"/>				
My talk with the DIS felt private	<input type="radio"/>				
My talk with the DIS helped me learn about my HIV care options	<input type="radio"/>				
I was surprised when the DIS came to talk to me	<input type="radio"/>				
The DIS was able to answer all my questions about HIV and treatment options	<input type="radio"/>				

54. How helpful was the information the DIS gave you?

- Very helpful
- Somewhat helpful
- Not at all helpful
- The DIS did not give me any information
- Unsure

55. Overall, would you say your conversation with the DIS was...?

- Very good
- Good
- Neither good nor bad
- Bad
- Very bad
- Unsure

56. If there is anything else that you remember about your talk with the DIS and would like to share, please tell us below:

57. Are there other questions about HIV-related stigma that you think are important for researchers to ask, but did not appear to be a part of this survey? Please enter your answer below.

THANK YOU FOR COMPLETING THE
SURVEY!

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