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MEASURING HIV
STIGMA AND
DISCRIMINATION
AMONG HEALTH
FACILITY STAFF

STANDARDIZED BRIEF QUESTIONNAIRE

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#### INTRODUCTION

# New Globally Tested Tool for Measuring HIV-related Stigma and Discrimination in Health Facilities

For people living with and affected by HIV, stigma and discrimination within health facilities are serious barriers to healthcare access and engagement. Researchers have documented numerous instances worldwide of people living with HIV receiving substandard care or being deterred from seeking care. Although progress has been made in training and other interventions to reduce HIV-related stigma in healthcare facilities, these programs have not been institutionalized as routine practice or implemented on a large scale. Moreover, the tools for measuring stigma tend to be overly long and time-consuming to administer, thus infeasible for use in facilities.

In an effort to address these issues, an international team of researchers developed a brief, globally standardized questionnaire for measuring stigma and discrimination in health facilities. This tool can help facilitate routine monitoring of HIV-related stigma, as well as the expansion and improvement of programming and policies at the health-facility level.

The questionnaire was developed and tested through a collaborative, deliberative process that involved experts from multiple countries. The experts agreed to focus on four areas that are especially relevant to stigma and discrimination in healthcare settings: 1) fear of HIV infection among health facility staff; 2) stereotypes and prejudice related to people living with or thought to be living with HIV; 3) observed and secondary stigma and discrimination; and 4) policy and work environment.

A questionnaire was created and researchers field tested it in China (n=300), Dominica (n=335), Egypt (n=300), Kenya (n=350), Puerto Rico (n=301), and St. Kitts and Nevis (n=307). The testing involved administration to clinical and nonclinical staff members, with a mix of self- and interviewer-administered modes. After the field testing, the research team gathered to consider the survey items' performance across the six sites, examining psychometric properties and contextual issues.

The resulting questionnaire measures programmatically actionable drivers of HIV-related stigma and discrimination among healthcare facility staff. It also captures observations of HIV-related stigma and discrimination within the facility and the extent to which providers experience stigma and discrimination as a result of providing care to people living with or believed to be living with HIV.

Two questionnaires are publicly available: a comprehensive brief version for program planning, evaluation, and research purposes, and a monitoring questionnaire that includes only the eight questions needed to collect six globally approved indicators for measuring stigma and discrimination in health facilities. These indicators can be found in the UN indicator registry—a repository of indicators used to track the AIDS epidemic and the national, regional, and global response—located at <a href="http://www.indicatorregistry.org">http://www.indicatorregistry.org</a>. Each questionnaire can be used for high-prevalence or low-prevalence settings.

More information on implementation of the questionnaire is available in the user manual found at <a href="http://www.healthpolicyproject.com/index.cfm?id=StigmaPackage">http://www.healthpolicyproject.com/index.cfm?id=StigmaPackage</a>.

For further information, please contact Laura Nyblade at <a href="mailto:lnyblade@rti.org">lnyblade@rti.org</a>.

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### **SECTION 1: BACKGROUND INFORMATION**

d. Key population stigma and discrimination

First we will ask about your background. 1. How old were you at your last birthday? **2.** What is your sex? ☐ Female ☐ Male **3.** What is your current job? (Adjust as appropriate for country context by adding or deleting categories according to sample.) ☐ Accountant ☐ Cashier ☐ Cleaning Staff ☐ Clinical Officer ☐ Dentist ☐ Dental Technician/Hygienist □ Doctor ☐ Educator ☐ Laboratory Technician ☐ Lay Health Worker/Peer Educator ☐ Medical Records Personnel ☐ Medical Technician □ Nurse ☐ Pharmacist ☐ Receptionist ☐ Security Guard ☐ Ward Attendant ☐ Phlebotomist ☐ Other: **4.** How many years have you worked in healthcare? years **5.** Have you ever worked in a clinic/hospital/department that specialized in HIV care and treatment? □ Yes  $\square$  No **6.** If low prevalence, use question 6a. If high prevalence, use question 6b. a. In the past 12 months, approximately how many HIV-positive patients did you provide with care or services? b. In a typical week, approximately how many HIV-positive patients do you provide with care or services? **7.** Did you ever receive training in the following subjects? (Check all that apply.) a. HIV stigma and discrimination b. Infection control and universal precautions (including post-exposure prophylaxis) c. Patients' informed consent, privacy, and confidentiality 

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## **SECTION 2: INFECTION CONTROL**

Now we will ask you about infection concerns in your health facility.

| 8. |          | ow worried would you be about getting HIV if you did the following?  nny of the following is not one of your job responsibilities, please select "Not applicable."  |
|----|----------|---|
|    | a.       | Touched the clothing of a patient living with HIV $\Box$ Not worried $\Box$ A little worried $\Box$ Worried $\Box$ Very worried $\Box$ Not applicable   |
|    | b.       | Dressed the wounds of a patient living with HIV  ☐ Not worried ☐ A little worried ☐ Worried ☐ Very worried ☐ Not applicable   |
|    | c.       | Drew blood from a patient living with HIV  ☐ Not worried ☐ A little worried ☐ Worried ☐ Very worried ☐ Not applicable   |
|    | d.       | Took the temperature of a patient living with HIV  ☐ Not worried ☐ A little worried ☐ Worried ☐ Very worried ☐ Not applicable   |
| 9. | Do<br>HI | you typically use any of the following measures when providing care or services for a patient living with V?  |
|    | a.       | Avoid physical contact  ☐ Yes ☐ No ☐ Not applicable   |
|    | b.       | Wear double gloves  ☐ Yes ☐ No ☐ Not applicable   |
|    | c.       | Wear gloves during all aspects of the patient's care  ☐ Yes ☐ No ☐ Not applicable   |
|    | d.       | Use any special infection-control measures with patients living with HIV that you do not use with other patients $\Box$ Yes $\Box$ No $\Box$ Not applicable   |
| SE | EC       | TION 3: HEALTH FACILITY ENVIRONMENT   |
|    |          | ve will ask about practices in your health facility and your experiences working in a y that provides care to people living with HIV.   |
| 10 | . In 1   | the past 12 months have you seen a person living with HIV in your health facility?  |
|    |          | Yes — > go to question 11  No — > skip to question 12  Don't know — > skip to question 12   |
| 11 |          | the past 12 months, how often have you observed the following in your health facility?  Healthcare workers unwilling to care for a patient living with or thought to be living with HIV  □ Never □ Once or twice □ Several times □ Most of the time |

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| <ul> <li>b. Healthcare workers providing poorer quality of care to a patient living with or thought to be living with HIV, relative to other patients</li> <li>□ Never □ Once or twice □ Several times □ Most of the time</li> </ul> |
|--|
| □ Never □ Once or twice □ Several times □ Most of the time   |
| c. Healthcare workers talking badly about people living with or thought to be living with HIV  ☐ Never ☐ Once or twice ☐ Several times ☐ Most of the time  |
| <b>12.</b> If low prevalence, use question 12a. If high prevalence, use question 12b.  |
| a. How worried are you about   |
| <ul> <li>i. People talking badly about you because you care for patients living with HIV?</li> <li>□ Not worried □ A little worried □ Worried □ Very worried</li> </ul>  |
| <ul> <li>ii. Friends and family avoiding you because you care for patients living with HIV?</li> <li>□ Not worried □ A little worried □ Worried □ Very worried</li> </ul>  |
| <ul><li>iii. Colleagues avoiding you because of your work caring for patients living with HIV?</li><li>□ Not worried □ A little worried □ Worried □ Very worried</li></ul>   |
| b. In the past 12 months, how often have you   |
| <ul> <li>i. Experienced people talking badly about you because you care for patients living with HIV?</li> <li>□ Never □ Once or twice □ Several times □ Most of the time</li> </ul>   |
| <ul> <li>ii. Been avoided by friends and family because you care for patients living with HIV?</li> <li>□ Never □ Once or twice □ Several times □ Most of the time</li> </ul>  |
| iii. Been avoided by colleagues because of your work caring for patients living with HIV?  ☐ Never ☐ Once or twice ☐ Several times ☐ Most of the time  |
| <b>13.</b> How hesitant are healthcare workers in this facility to work alongside a coworker living with HIV, regardless of their duties?  |
| $\square$ Not hesitant $\square$ A little hesitant $\square$ Somewhat hesitant $\square$ Very hesitant   |
| SECTION 4: HEALTH FACILITY POLICIES  |
| Now we are going to ask about the institutional policy and work environment in your facility.  |
| <b>14.</b> In my facility it is not acceptable to test a patient for HIV without their knowledge.  ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree   |
| <b>15.</b> I will get in trouble at work if I discriminate against patients living with HIV.  ☐ Yes ☐ No ☐ Don't Know  |

Standardized Brief Questionnaire **16.** Do you strongly agree, agree, disagree, or strongly disagree with the following statements? a. There are adequate supplies in my health facility that reduce my risk of becoming infected with HIV. ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree b. There are standardized procedures/protocols in my health facility that reduce my risk of becoming infected with HIV. ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree 17. My health facility has written guidelines to protect patients living with HIV from discrimination. ☐ Yes  $\square$  No ☐ Don't Know

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## **SECTION 5: OPINIONS ABOUT PEOPLE LIVING WITH HIV**

Now we are going to ask about opinions related to people living with HIV.

| 18 | . Do  | you strongly agree, agree, disagree, or strongly disagree with the following statements?   |
|----|-------|--|
|    | a.    | Most people living with HIV do not care if they infect other people.  □ Strongly Agree □ Agree □ Disagree □ Strongly Disagree  |
|    | b.    | People living with HIV should feel ashamed of themselves.  ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree   |
|    | c.    | Most people living with HIV have had many sexual partners.  □ Strongly Agree □ Disagree □ Strongly Disagree  |
|    | d.    | People get infected with HIV because they engage in irresponsible behaviors.  □ Strongly Agree □ Agree □ Disagree □ Strongly Disagree  |
|    | e.    | HIV is punishment for bad behavior.  □ Strongly Agree □ Agree □ Disagree □ Strongly Disagree   |
| 19 | . Wo  | omen living with HIV should be allowed to have babies if they wish.  ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree   |
| 20 | . Ple | ase tell us if you strongly agree, agree, disagree, or strongly disagree with the following statement:   |
|    | a.    | If I had a choice, I would prefer not to provide services to people who inject illegal drugs.  ☐ Strongly Agree → go to question 20b ☐ Agree → skip to question 21 ☐ Strongly Disagree → skip to question 21   |
|    | i     | I prefer not to provide services to people who inject illegal drugs because (check all reasons that apply i. They put me at higher risk for disease.   Agree Disagree ii. This group engages in immoral behavior.   Agree Disagree ii. I have not received training to work with this group. |
| 21 | . Ple | ease tell us if you strongly agree, agree, disagree, or strongly disagree with the following statement:  |
|    | a.    | If I had a choice, I would prefer not to provide services to men who have sex with men.  ☐ Strongly Agree → go to question 21b  ☐ Agree → go to question 21b  ☐ Disagree → skip to question 22  ☐ Strongly Disagree → skip to question 22  |

b. I prefer not to provide services to men who have sex with men because (check all reasons that apply) i. They put me at higher risk for disease. ☐ Agree ☐ Disagree ii. This group engages in immoral behavior. ☐ Agree ☐ Disagree iii. I have not received training to work with this group. ☐ Agree ☐ Disagree **22.** Please tell us if you strongly agree, agree, disagree, or strongly disagree with the following statement: a. If I had a choice, I would prefer not to provide services to sex workers (specify: male or female or both, depending on context). ☐ Strongly Agree ——  $\rightarrow$  go to question 22b ☐ Agree → go to question 22b
☐ Disagree → skip to question 23 ☐ Strongly Disagree → skip to question 23 b. I prefer not to provide services to sex workers because (check all reasons that apply) i. They put me at higher risk for disease. ☐ Agree ☐ Disagree ii. This group engages in immoral behavior. ☐ Agree ☐ Disagree iii. I have not received training to work with this group. ☐ Agree ☐ Disagree

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# MODULE 1: ANTENATAL CARE, PREVENTION OF MOTHER-TO-CHILD TRANSMISSION, AND LABOR AND DELIVERY WARDS

The following section is to be completed by service providers who work with pregnant women in antenatal care, prevention of mother-to-child transmission of HIV, and in labor and delivery rooms. If you do not work in one of these areas, you have completed the questionnaire.

| 23. | . Ho   | w worried are you about assisting in labor and delivery if the woman is living with HIV?   |
|-----|--------|--|
|     |        | $\square$ Not worried $\square$ A little worried $\square$ Worried $\square$ Very worried $\square$ Not applicable   |
| 24. | . In t | the past 12 months, how often have you observed other healthcare providers   |
|     | a.     | Performing an HIV test on a pregnant woman without her informed consent?  ☐ Never ☐ Once or twice ☐ Several times ☐ Most of the time   |
|     | b.     | Neglecting a woman living with HIV during labor and delivery because of her HIV status?  ☐ Never ☐ Once or twice ☐ Several times ☐ Most of the time  |
|     | c.     | Using additional infection-control procedures (e.g., double gloves) with a pregnant woman living with HIV during labor and delivery because of her HIV status?  ☐ Never ☐ Once or twice ☐ Several times ☐ Most of the time |
|     | d.     | Disclosing the status of a pregnant woman living with HIV to others without her consent?  □ Never □ Once or twice □ Several times □ Most of the time   |
|     | e.     | Making HIV treatment for a woman living with HIV conditional on her use of family planning methods?  □ Never □ Once or twice □ Several times □ Most of the time  |
| 25. | . Do   | you strongly agree, agree, disagree, or strongly disagree with the following statements?   |
|     | a.     | If a pregnant woman is HIV positive, her family has a right to know.  ☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree  |
|     | b.     | Pregnant women who refuse HIV testing are irresponsible.  □ Strongly Agree □ Agree □ Disagree □ Strongly Disagree  |
|     | c.     | Women living with HIV should not get pregnant if they already have children.  □ Strongly Agree □ Disagree □ Strongly Disagree  |
|     | d.     | It can be appropriate to sterilize a woman living with HIV, even if this is not her choice.  □ Strongly Agree □ Disagree □ Strongly Disagree   |

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