

AK11. HIV SELF-STIGMA SCALE

USE WHEN YOU WANT TO EVALUATE:

Outcomes :

- ✓ Awareness and knowledge

Intervention types:

- ✓ Targeted education activities for priority population
- ✓ Targeted awareness activities for priority population
- ✓ Skill building sessions to increase capacity to engage in risk reduction behaviors
- ✓ Outreach to priority populations for awareness and education

Worked well with these populations:

- ✓ People living with or affected by HIV

Interventions for:

- ✓ HIV

DESCRIPTION

Description:

This 40-question measure has been used in many studies of self-stigma or negative attitudes toward self among people living with HIV. It can be divided into four shorter versions, each measuring a more specific aspect of self-stigma: personalized stigma subscale; disclosure subscale; negative self-image subscale; and public attitudes subscale.

WHY THIS TOOL MIGHT BE USEFUL FOR COMMUNITY-BASED INTERVENTIONS

- ✓ Use of this measure in a prevention intervention designed to reduce high risk sexual behavior in older adults living with HIV/AIDS found that it decreased their stigma about having HIV as well as their risk behavior
- ✓ Suitable for pre-post/longitudinal analysis
- ✓ Easily completed and analysed
- ✓ Could easily be programmed to be given electronically

Developed in:

- ✓ English

ADMINISTRATION, DESIGN, SCORING and ANALYSIS CONSIDERATIONS

ADMINISTRATION

- These questions will take about 20 minutes to fill out each time.
- Tell participants why you are using the questionnaire, being clear that it is to evaluate the intervention, to help make it better and not them,.
- Participation should be voluntary, so tell participants that it is ok if they do not complete it, and assure participants that there are no negative consequences if they don't want to complete, it. Give them a way to do something else at the same time that looks similar to completing the scale so that the confidentiality of this decision is protected. (For further information on ethical considerations in carrying out evaluations, see [Ethics Resources](#))
- If used in a group setting, ensure that people feel safe and that the space is confidential; no one can see their answers (can see their screen or papers), and put completed questionnaires into a sealed envelope.

Measuring before and after change (this is the best option because it measures real change)

1. **WHEN TO USE:** Have the questionnaires filled out before the intervention or at the very beginning of it,



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and again after, as close to the end as possible (often the very last session is not suitable because it may be a celebration, or have low attendance).

2. **LINKING RESULTS:** Include a way to match the same person’s pre and post questionnaires while protecting confidentiality, for example using a password or unique identifier that respondents generate and remember (see [Tips for passwords](#)).

3. **SCORING:** Create each person’s total pre-program and post-program HIV Self-Stigma Scores by calculating the [average](#) of the 40 questions. Before calculating the average, reverse the scoring on questions 17 and 31 as shown. Average scores can range from 1 to 4.

If you use one or more subscales instead of all 40 questions, follow the same procedures using only those questions.

Questions to use in the measures of specific aspects of self-stigma

	Number of questions	Which questions
Personalized stigma	18	1 through 16, 33, 37
Disclosure subscale	10	17 through 24, 32, 40
Negative self-image	13	6, 8, 10, 15, 20, 25 through 32
Public attitudes	20	3,6,7,9,10,11, 14,15,16, 23,24, 32 though 40

4. **ANALYSIS:** Compare the pre and post scores for each individual, noting how many people improve, how many stay the same, and how many get worse.

Measuring change only after the end of an intervention: (this is the second best option, because people often think the intervention has had more effect than it really did)

1. Adapt all the questions so that they ask people what their answer is now and what it was before the intervention

For example, for question 11, ask: *“Now I feel set apart, isolated from the rest of the world”* AND *“Before the workshop, I felt set apart, isolated from the rest of the world”* (See an [example](#) of a questionnaire with before and after versions)

2. **SCORING:** Create each person’s total pre-program and post-program HIV Self-Stigma Scores by calculating the [average](#) of the 40 questions. Before calculating the average, reverse the scoring on questions 17 and 31 as shown. Average scores can range from 1.0 to 4.0.

If you use one or more subscales instead of all 40 questions, follow the same procedures using only those questions. **Questions to use in the measures of specific aspects of self-stigma: see above.**

3. **ANALYSIS:** Compare the pre and post scores for each individual, noting how many people say they improve, how many stay the same, and how many get worse.

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	Strongly disagree	Disagree	Agree	Strongly agree
1. I have lost friends by telling them I have HIV	1	2	3	4
2. I have been hurt by how people reacted to learning I have HIV	1	2	3	4
3. People avoid touching me if they know I have HIV	1	2	3	4
4. I stopped socializing with some people due to their reactions	1	2	3	4
5. People I care about stopped calling after learning I have HIV	1	2	3	4
6. People seem afraid of me because I have HIV	1	2	3	4
7. People have physically backed away from me	1	2	3	4
8. Some people who know that I have HIV have grown more distant	1	2	3	4
9. People who know that I have HIV tend to ignore my good points	1	2	3	4
10. People don't want me around their children once they know that I have HIV	1	2	3	4
11. I feel set apart, isolated from the rest of the world	1	2	3	4
12. I regret having told some people that I have HIV	1	2	3	4
13. Some fear they'll be rejected because of my HIV	1	2	3	4
14. Some people act as though it's my fault I have HIV	1	2	3	4
15. As a rule, telling others that I have HIV has been a mistake	1	2	3	4
16. Some people told me HIV is what I deserve for how I lived	1	2	3	4
17. *I never feel I need to hide the fact I have HIV	4	3	2	1
18. I worry people who know I have HIV will tell others	1	2	3	4
19. I am very careful whom I tell that I have HIV	1	2	3	4
20. I work hard to keep my HIV a secret	1	2	3	4
21. I told people close to me to keep my HIV a secret	1	2	3	4
22. In many areas of my life, no one knows I have HIV	1	2	3	4
23. Telling someone I have HIV is risky	1	2	3	4
24. I worry that people may judge me when they learn I have HIV	1	2	3	4
25. Having HIV makes me feel I'm a bad person	1	2	3	4
26. I feel I'm not as good as others because I have HIV	1	2	3	4
27. Having HIV makes me feel unclean	1	2	3	4
28. Having HIV in my body is disgusting to me	1	2	3	4

29. People's attitudes make me feel worse about myself	1	2	3	4
30. I feel guilty because I have HIV	1	2	3	4
31. *I never feel ashamed of having HIV	4	3	2	1
32. It's easier to avoid friendships than worry about telling people	1	2	3	4
33. Most people think a person with HIV is disgusting	1	2	3	4
34. Most with HIV are rejected when others learn	1	2	3	4
35. People with HIV lose jobs when employers learn about it	1	2	3	4
36. Most people believe a person who has HIV is dirty	1	2	3	4
37. Most people are uncomfortable around someone with HIV	1	2	3	4
38. Knowing you have HIV, people look for flaws in your character	1	2	3	4
39. People with HIV are treated like outcasts	1	2	3	4
40. I worry about people discriminating against me	1	2	3	4

Sources:

Berger, B., Ferrans, C., Lashley, F. **Measuring Stigma in People With HIV: Psychometric Assessment of the HIV Stigma Scale**; *Research in Nursing & Health*, 2001, 24, 518±529

Echenique, M., Illa, L., SaintJean, G., Avellaneda, V. B., Sanchez Martinez, M., & Eisdorfer, C. (Apr 2013). **Impact of a secondary prevention intervention among HIV-positive older women**. *AIDS Care*, 25(4), 443-446