WOMEN'S INTERAGENCY HIV STUDY **F25c: ENGAGEMENT IN CARE**

SECTION A: GENERAL INFORMATION

A1.	PARTICIPANT ID: ENTER NUMBER HERE ONLY IF ID LABEL IS NOT AVAILABLE						
A2.	WIHS STUDY VISIT #:						
A3.	FORM VERSION:	04/01/14					
A4.	DATE OF INTERVIEW:						
A5.	INTERVIEWER'S INITIALS:						
A6.	DATE FORM LAST ADMINISTERED:						
A7.	TIME MODULE BEGAN:	: AM 1 PM 2					
A8.	IS PARTICIPANT HIV-POSITIVE OR HIV-NEGA						
	HIV-POSITIVE HIV-NEGATIVE						
	SECTION B: CONTIN	NUITY OF CARE					
your H regular HIV. 7 include		medical appointments for HIV clinical care. By e to have a check-up on how you're doing with your or hospital admissions for HIV/AIDS; it does not					
B1.	Have you ever received regular HIV care ?						
	YES						
	ll be asking about your regular HIV care over the/	past six months. Six months would have started at					
PROMPT: USE CALENDAR TO SHOW PARTICIPANT THE START DATE. BE SURE TO COUNT BACK SIX MONTHS FROM THE DATE OF THE INTERVIEW (E.G., SIX MONTHS BACK FROM AN INTERVIEW HELD ON 7/15/13 WOULD BE 1/15/13). IF PARTICIPANT HAS AN APPOINTMENT BOOK, USE THAT TO HELP RECALL VISITS.							
B2.	B2. In the last six months, have you gone for any regular HIV care ? YES						

WIHS I	D#	
В3.	In the last six months, how many times did you go for regular HIV care ? # TIME	3
B4.	In the last six months, did you miss any scheduled regular HIV care appointments? By this, I mea did not go for a scheduled appointment and did not re-schedule.	n you
	YES	
	a. How many times did this happen?	S
B5.	In general, how often do your HIV providers want you to see you for your regular HIV care ? Wou you say once a year, twice a year, three times a year, or more frequently?	ld
	ONCE A YEAR	
B6.	IS THIS AN ODD- OR EVEN-NUMBERED VISIT?	
	ODD-NUMBERED VISIT	

SECTION C: TRUST IN HIV CARE PROVIDERS, HEALTH CARE EMPOWERMENT, BARRIERS TO CARE

*Source: Safran Physician Trust Subscale of the PCAS *Source: Johnson et al Health Care Empowerment Inventory *Kalichman Barriers to Care

INTRODUCTION TO PARTICIPANT: Please think now about the HIV care providers who you typically see for your **regular HIV care**. These HIV care providers might be a doctor or doctors, nurse practitioners, physician assistants, or other health care professionals. For each question, please tell me whether you strongly agree, agree, disagree, or strongly disagree. **SHOW PARTICIPANT RESPONSE CARD 12A.**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
C1. You can tell your HIV care providers anything.	1	2	3	4	5
C2. Your HIV care providers sometimes pretend to know things when they are not really sure.	1	2	3	4	5
C3. You completely trust your HIV care provider's judgments about your health care.	1	2	3	4	5
C4. Your HIV care providers care more about holding costs down than about doing what is needed for your health.	1	2	3	4	5
C5. Your HIV care providers would always tell you the truth about your health, even if there was bad news.	1	2	3	4	5

WIHS ID#		

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
C6. Your HIV care providers care as much as you do about your health.	1	2	3	4	5
C7. If a mistake was made in your treatment, your HIV care providers would try to hide it from you.	1	2	3	4	5
C8. All things considered, you trust your HIV care providers.	1	2	3	4	5

INTRODUCTION TO PARTICIPANT: For the next set of questions, I will ask you about caring for yourself, and particularly about your HIV care. For each question, please tell me whether you strongly agree, agree, disagree, or strongly disagree.

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
C9. You prefer to get as much information as possible about treatment options.	1	2	3	4	5
C10. You try to get your health care providers to listen to your preferences for your treatment.	1	2	3	4	5
C11. You are very active in your health care.	1	2	3	4	5
C12. You take your commitment to your treatment seriously.	1	2	3	4	5
C13. You recognize that there will likely be setbacks and uncertainty in your health care treatment.	1	2	3	4	5
C14. You are comfortable with the idea that there may be setbacks in your treatment.	1	2	3	4	5
C15. You have learned to live with the uncertainty of your health condition.	1	2	3	4	5
C16. You accept that the future of your health condition is unknown even if you do everything you can.	1	2	3	4	5

C17. In the last six months, have any of the following happened in terms of your **regular HIV care**?

	YES	NO	NA
a. Not having transportation to get to or from a regular HIV care visit.	1	2	
b. Not being able to pay for a regular HIV care visit.	1	2	
c. Not knowing where to go for HIV regular care.	1	2	

WIHS ID#		

	YES	NO	NA
d. Not having someone to watch your children or other people in your care while you go to a regular HIV care visit.	1	2	3
e. Not feeling that you need to go for regular HIV care because your HIV is under control.	1	2	
f. Not having time or not being able to take off work during the hours that regular HIV care is available.	1	2	
g. Not wanting to go to the HIV clinic because people you know might see you there.	1	2	
h. Not wanting to go for regular HIV care because you felt too sick.	1	2	

SECTION D: SOCIAL SUPPORT, SOCIAL ISOLATION, ANXIETY

*Source: Loneliness scale (Hughes; shortened version of the R-UCLA)
*Tangible and Emotional Support subscales of MOS SSS, with additional questions added
*GAD-7 assessment of anxiety

INTRODUCTION TO PARTICIPANT: The next questions ask about your feelings these days. Please tell me how often you feel the way described in each of the following statements.

D1.	How often do y	ou feel that y	ou lack com	nanionshin?	Is it hardly	ever	some of the time.	or often?
D1.	TIOW OILCII GO	you reer mat y	ou lack com	pamonsmp:	18 It Harury	CVCI,	some of the time,	, or orten:

HARDLY EVER	1
SOME OF THE TIME	2
OFTEN	3

D2. How often do you feel left out? Is it hardly ever, some of the time, or often?

HARDLY EVER	I	
SOME OF THE TIME	2	,
OFTEN	3	í

D3. How often do you feel isolated from others? Is it hardly ever, some of the time, or often?

HARDLY EVER	. 1
SOME OF THE TIME	.2
OFTEN	. 3

INTRODUCTION TO PARTICIPANT: People sometimes look to others for company, for help, or for other kinds of support. How often are each of the following kinds of support available to you when you need it? **SHOW PARTICIPANT RESPONSE CARD 12B.**

	None of the time	A little of the time		Most of the time	All of the time	NA
D4. Someone you can count on to listen to you when you need to talk.	1	2	3	4	5	
D5. Someone to give you information to help you understand a situation.	1	2	3	4	5	

WIHS ID#		

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	NA
D6. Someone to give you good advice about a crisis.	1	2	3	4	5	
D7. Someone to confide in or talk to about yourself or your problems.	1	2	3	4	5	
D8. Someone whose advice you really want.	1	2	3	4	5	
D9. Someone to share your most private worries and fears with.	1	2	3	4	5	
D10. Someone to turn to for suggestions about how to deal with a personal problem.	1	2	3	4	5	
D11. Someone who understands your problems.	1	2	3	4	5	
D12. Someone to help you if you were confined to bed.	1	2	3	4	5	
D13. Someone to take you to the doctor or somewhere you had to go if you needed it.	1	2	3	4	5	
D14. Someone to prepare your meals if you were unable to do it yourself.	1	2	3	4	5	
D15. Someone to help with daily chores like grocery shopping if you were sick.	1	2	3	4	5	
D16. Someone to care for children/ grandchildren/others in your care, even for a short time if you were unable.	1	2	3	4	5	6
D17. Someone to give you a place to live if you needed it even if for a short time.	1	2	3	4	5	
D18. Someone to give you money for things you really needed like food and clothing.	1	2	3	4	5	

INTRODUCTION TO PARTICIPANT: These next questions ask about your feelings over the last two weeks. Over the last two weeks, how often have you been bothered by the following problems? Please tell me whether you have not felt this way at all, you have felt it for several days, for over half of the days, or nearly every day over the last two weeks. **SHOW PARTICIPANT RESPONSE CARD 12C.**

	Not at all	Several days	Over half the days	Nearly every day
D19. Feeling nervous, anxious, or on edge.	0	1	2	3
D20. Not being able to stop or control worrying.	0	1	2	3
D21. Worrying too much about different things.	0	1	2	3

	Not at all	Several days	Over half the days	Nearly every day
D22. Trouble relaxing.	0	1	2	3
D23. Being so restless that it's hard to sit still.	0	1	2	3
D24. Becoming easily annoyed or irritable.	0	1	2	3
D25. Feeling afraid as if something awful might happen.	0	1	2	3

D26. IS THIS AN ODD- OR EVEN-NUMBERED VISIT?

ODD-NUMBERED VISIT 1 (**SECTION F**) EVEN-NUMBERED VISIT 2

SECTION E: SPIRITUALITY

*Source: Detroit Area Study, 1995 every day discrimination *FACIT-SP for spirituality

INTRODUCTION TO PARTICIPANT: These questions ask about how you have been feeling over the past seven days. **SHOW PARTICIPANT RESPONSE CARD 12D.**

	Not at all	A little bit	Some- what	Quite a bit	Very much	NA
E1. I feel peaceful.	0	1	2	3	4	
E2. I have a reason for living.	0	1	2	3	4	
E3. My life has been productive.	0	1	2	3	4	
E4. I have trouble feeling peace of mind.	0	1	2	3	4	
E5. I feel a sense of purpose in my life.	0	1	2	3	4	
E6. I am able to reach down deep into myself for comfort.	0	1	2	3	4	
E7. I feel a sense of harmony within myself.	0	1	2	3	4	
E8. My life lacks meaning and purpose.	0	1	2	3	4	
E9. I find comfort in my faith or spiritual beliefs.	0	1	2	3	4	
E10. I know that whatever happens with my illness, things will be OK.	0	1	2	3	4	5
E11. My illness has strengthened my faith or spiritual beliefs.	0	1	2	3	4	5
E12. I find strength in my faith or spiritual beliefs.	0	1	2	3	4	

WIHS ID#						
SECTION F: 1 *Source: Williams et al 2008 / Ma				mental quest	ions	
F0. CHECK VCS: WERE QUESTIONS A PREVIOUS VISIT? YESNO		1 (F9)		ON ADMINI	STERED AT A	A
INTRODUCTION TO PARTICIPANT : In the treated you or your <i>beliefs</i> about how other peopfollowing has ever happened to you. SHOW PEACH QUESTION.	ple have trea	ated you. For	each question	on, please tel	l me if any of the	
F1. At any time in your life, have you ever bee been unfairly denied a promotion in a job?	•	ired from a jo	ob or	YES 1	NO 2 (F2)	
a. How many times has this happened in your	lifetime? _		·			
b. When was the last time this happened? Was it in the past week, past month, past year, or more than a year ago?	1 Past week	2 Past month	3 Past year	4 More than a year ago		
c. How much do you think your gender had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	
d. How much do you think your race/ethnicity had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	
e. How much do you think your HIV had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	6 NA
F2. For unfair reasons, have you ever <u>not</u> been	hired for a	job?		YES 1	NO 2 (F3)	
a. How many times has this happened in your	lifetime? _					
b. When was the last time this happened? Was it in the past week, past month, past year, or more than a year ago?	1 Past week	2 Past month	3 Past year	4 More than a year ago		
c. How much do you think your gender had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	
d. How much do you think your race/ethnicity had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	

1

Nothing

2

A little

3

Some

4

A lot

5

Everything

6

NA

e. How much do you think your HIV had to do with this?

WIHS ID#			
	•	•	
1			

F3. Have you ever been unfairly stopped, sear threatened or abused by the police?	ally	YES 1	NO 2 (F4)				
a. How many times has this happened in your lifetime?							
b. When was the last time this happened? Was it in the past week, past month, past year, or more than a year ago?	1 Past week	2 Past month	3 Past year	4 More than a year ago			
c. How much do you think your gender had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything		
d. How much do you think your race/ethnicity had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything		
e. How much do you think your HIV had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	6 NA	

F4. Have you ever been unfairly discouraged be continuing your education?	om	YES 1	NO 2 (F5)			
a. How many times has this happened in your	lifetime? _					
b. When was the last time this happened? Was it in the past week, past month, past year, or more than a year ago?	1 Past week	2 Past month	3 Past year	4 More than a year ago		
c. How much do you think your gender had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	
d. How much do you think your race/ethnicity had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	
e. How much do you think your HIV had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	6 NA

F5. Have you ever been unfairly prevented from moving into a neighborhood because the landlord or realtor didn't want to sell or rent you a house or apartment?				YES 1	NO 2 (F6)	
a. How many times has this happened in your	lifetime? _					
b. When was the last time this happened? Was it in the past week, past month, past year, or more than a year ago?	1 Past week	2 Past month	3 Past year	4 More than a year ago		
c. How much do you think your gender had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	
d. How much do you think your race/ethnicity had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	
e. How much do you think your HIV had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	6 NA
F6. Have you ever been unfairly denied a bank loan?				YES 1	NO 2 (F7)	
a. How many times has this happened in your lifetime?						
b. When was the last time this happened? Was it in the past week, past month, past year, or more than a year ago?	1 Past week	2 Past month	3 Past year	4 More than a year ago		
c. How much do you think your gender had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	
d. How much do you think your race/ethnicity had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	
e. How much do you think your HIV had to do with this?	1 Nothing	2 A little	3 Some	4 A lot	5 Everything	6 NA
F7. Overall, how much has discrimination inter	fered with y	ou having a f	full and prod	uctive life?		
A lot Some A little Not at all		2 3 4				
F8. Overall, how much harder has your life bee			on?			
A lot		2				
F9. TIME MODULE ENDED:		1 1 1.1	1 1	AM1		

WIHS ID#