

FOLLOW-UP VISIT 14

CODEBOOK

ARCHIVED DATASET 2018

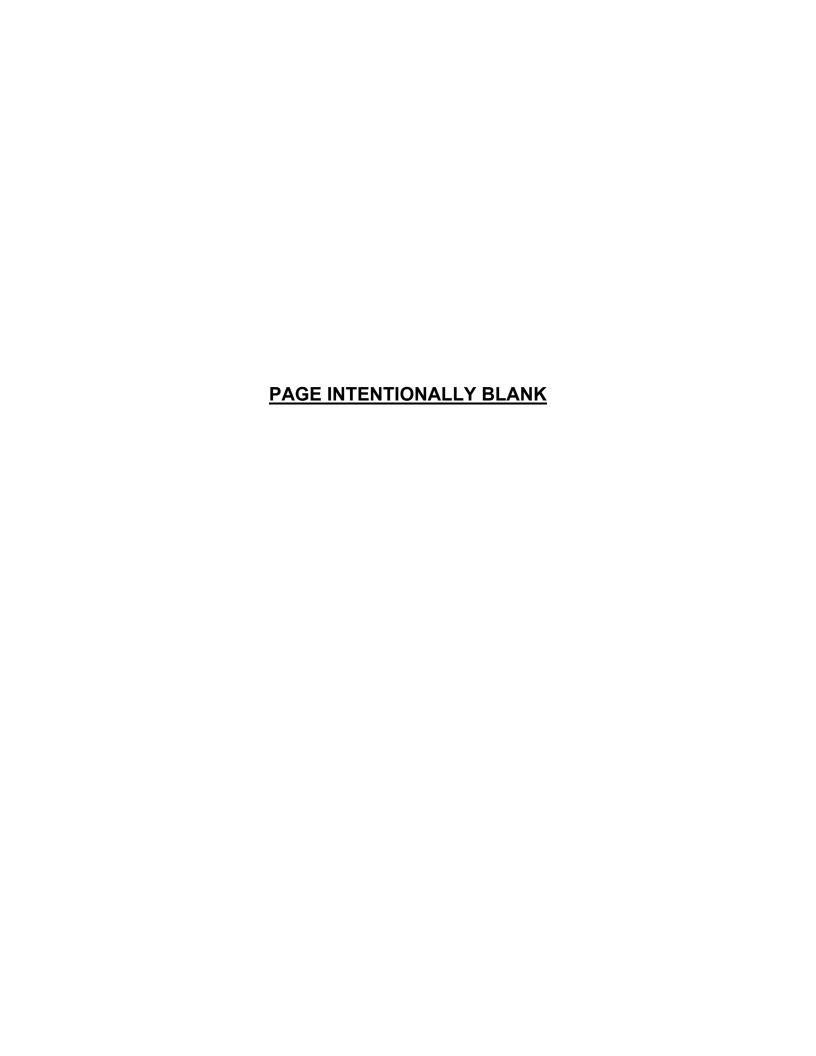


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1. Who is included in the public use dataset:

The dataset contains follow-up visit 14 information for the subset of the original cohort still participating in the SWAN longitudinal study from the seven clinical sites. The sites include Boston, MA, Pittsburgh, PA, Oakland and Los Angeles, CA, Detroit, MI, Chicago, IL, and Newark, NJ.

2. How this codebook is constructed:

Following this documentation section are copies of each of the questionnaires that were used at visit 14. A list of additional variables is also provided. The questionnaires include the variables available for public use next to the question in bold red uppercase underlined letters. Those variables not available for public use have a # before the variable and are in blue. Any special notes are indicated with footnotes at the bottom of the page.

The assigned participant ID has been replaced with a randomly generated ARCHID in order to protect participant privacy. The *baseline* interview date is denoted as day 0 and is used as the basis for all other dates. All other questionnaires or data collected that have a date attached have been converted to the number of days from the baseline interview.

All variables for visit 14 have a 14 at the end of the variable name.

3. Missing data coding:

Original missing codes (-1: not applicable, -7: refused, -8: don't know, -9: missing) have been recoded to SAS missing codes (.B: not applicable, .D: refused, .C: don't know, and .A: missing).

4. Ways this data can be used and additional notes

Interim Contact Follow-up Form

- The variables in this 'visit 14 Interim Contact' (IRM) data are mostly found in 'Interviewer-Administered'
 data (abbreviated as *INT*) for the previous visits. On the other hands, smoking-related variables and
 vasomotor symptoms' variables (such as hotflas14) are found in Self-Administered Questionnaire Part A
 (SAA) for the previous visits.
- In general, most 'Other, specify' text fields are not included in the dataset.
- Age (AGE14) was calculated from date of birth to when the interview form was completed, and is rounded to the next lowest integer.
- <u>FORMFLG14</u> was created indicating whether the data come from Interim Contact Follow-up (IRM),
 Interim Contact form AND Bleeding Pattern form (IRMBLD), or Bleeding Pattern form only (BLD).
- OUTOF14 (Out of Visit Collection Window Flag) is a flag variable for the 29 cases where the questionnaire was completed after the study-wide Visit 14 cut-off date of 01/31/2014 (OUTOF14 = 1). Visit 14 officially began on 05/17/2013 when Los Angeles saw its first participants. The Los Angeles site saw 256 participants before the other sites started on 09/25/2013.
- Los Angeles participants completed a different site-specific version of the Visit 14 Interim Form. Questions NOT asked by this site are indicated in GREEN on the data collection form.
 - Questions that were not asked of the Los Angeles women were set to .B (Not applicable) in the dataset.
 - The Los Angeles site-specific interim form collected hormone use with five questions using a timeframe of "since your last study visit". The SWAN interim form collected information about hormone use using a single question with a timeframe of "during the past 2 weeks".
 - Hysterectomy and oophorectomy data were collected on the Los Angeles site-specific bleeding form and not on the interim form. Seven women completed the Los Angeles site-specific bleeding form, and none reported a hysterectomy or oophorectomy.

 Los Angeles started four months before the other sites. 256 women were contacted in the timeframe between their startup and that of the other sites.

Bleeding form

The few participants that were not yet postmenopausal at their last study visit were administered questions concerning menstruation via the Bleeding Pattern form.

Additional Measures

A variable describing the race/ethnicity of participants (RACE) and study site (SITE) were added from the Screener dataset. See the Additional Measures section at the end of the codebook for descriptions.

Date of completion variables (IRMDAY14, PHYDAY14, HYSTDAY14, etc.) are given in days from interview date at baseline. Note that for 5 participants, interview completion dates at baseline were not available and alternative dates were substituted either from the Self-Administered Questionnaire-A or Physical Measures completion dates at baseline.

Longitudinal Measures

Please note that additional study measures are provided in separate longitudinal datasets. These datasets include: Menopausal Status, Bone Mineral Density, Medication Drug Groups, and Vitamin D.

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Date I	Data Entered / Initials	Date Verified / Init	tials
	INTER	RIM CONTACT FOLLOW UP F	ORM
		INTERIM FOLLOW-UP	
	Stud	y of Women's Health Across the Nat	ion
	5	SECTION A. GENERAL INFORMATION	
A1.	RESPONDENT ID:	AFFIX ID LABEL HERE	<u>ARCHID</u> -
A2.	SWAN STUDY VISIT#	14	<u>VISIT</u>
A3. FO	RM VERSION:	09/01/2013	#FORM_V
A4.	INTERVIEWER'S INITIALS	:	#INITS
A5.	RESPONDENT'S DOB:	$\overline{M} = \overline{M} = $	#DOB
A6.	INTERVIEW COMPLE	TED IN:	#MAILLOC14
	CLINIC / OFFICE RESPONDENT'S CLINIC/OFFICE \ TELEPHONE	HOME / VIA MAIL HOME W/ PROXY W/ PROXY PROXY	
A7.	INTERVIEW LANGUA	GE:	LANGUAG14
	SPANISH CANTONESE		2 3
A8.	INTERVIEWER ADMINISTE	ERED?	#INTADMN14
	NO		1

YES......2

~ A randomly generated ID will be provided that is different from the original ID.

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Please answer the following questions as completely as possible. Please note that the questions included in this survey ask about <u>several different time periods</u>. For example, some questions ask about the time <u>since your last study visit</u> while others ask about <u>the past year</u> or the past <u>2 weeks</u>. Please take as much time as you need with each question. It is very important to us that you complete the entire questionnaire. Please remember, this information will remain confidential. Thank you for your dedication and commitment to the SWAN study!

******	Tomam comidential. Thank you	a for your dodloation and	oonmanone to the evil at olday.
			. We would like to ask you len in order to keep our records up to accessful in obtaining new funding.
	ase find the most appropriate wer you choose.	e response to each que	estion and <u>circle the number for the</u>
B1.	Please enter today's date:	$\frac{1}{M} \frac{1}{M} \frac{1}{D} \frac{1}{D}$	$\frac{1}{Y} = \frac{1}{Y} = \frac{1}{Y} = \frac{1}{Y}$
B2. (CIR	In general, would you say you CLE ONE RESPONSE.)	ır health is excellent, very go	ood, good, fair or poor? OVERHLT14
	Excellent		1
	Very good		2
	Good		3
	Fair		4
	Poor		5
	Don't know		8
	next questions are about your e your last study visit.	health, medical condition	s and procedures that may have occurred
C1.	Since your last study visit, hat you had diabetes or treate		ner or other health care provider told you ERESPONSE.) <u>DIABETES14</u>
	No — Yes		1 (GO TO C2, PAGE 3)
	Don't Know		8 (GO TO C2, PAGE 3)
	C1a. Since your last studiabetes or high ble	udy visit have you taken ins ood sugar? (CIRCLE ONE I	sulin or other medication for treatment of RESPONSE.) <u>MEDDIAB14</u>
	No		1
	Yes		2
	Don't know		8

[†] Dates are given in days since the initial baseline interview, which is day zero.

C2.	Since your last study visit, have you had a hysterector (CIRCLE ONE RESPONSE.)	my (an operation to re <u>HYSTERE14</u> (LA a			
	No		1 (GC) TO C3)	
	Yes		2		
	Don't Know		8 (G () TO C3)	
	C2a. If YES, please give date of the hysterectomy: (CHECK BOX IF DATE UNKNOWN.)	#HYSTERMO M M	/	STERYR Y Y	HYSTDAY14 Don't Know (-8) [
	Since your last study visit, did you have one or both ovari RESPONSE.)	ies removed (an oop OOPHORE14(LA a			
	No		1 (GC) TO C4)	
	Yes		2		
	Don't Know		8 (G () TO C4)	
C	3a▶Was one ovary removed or were both ovaries ren	noved?	NEOVAR14	<u>.</u>	
	One Ovary Removed		1		
	Both Ovaries Removed				
	Don't Know		8		
C4.	Since your last study visit, has a doctor, nurse protoid you that you had breast cancer? (CIRCLE ONITIVE No	E RESPONSE.) <u>LV</u>	<u>/BRST14</u> 1 (G0		
	Don't Know		8 (G () TO C5)	
	C4a. If YES , what was the primary site of the <u>brooms</u>	east cancer? (CIR0	CLE ONE	RESPONS	E.)
	Both breasts Right breast, only Left breast, only	2	<u>PSBR</u>	<u>ST14</u>	
	C4b. Please record the date of the breast cand	<u>cer</u> diagnosis: (CHI	ECK BOX	IF DATE U	INKNOWN.)
	#BRSTM014 / #BRSTYR14 $\overline{M}\overline{M}$	Y Y		't Know (-8) <u>[DAY14</u> †)
C5.	Since your last study visit, has a doctor, nurse protold you that you had <u>colon cancer</u> ? (CIRCLE ONE		nealth care <u>LVCC</u>	•	
	No Yes		•) TO C6, F	PAGE 4)
	Don't Know		8 (G () TO C6, F	PAGE 4)
	C5a. Please record the date of the colon canc	<u>er</u> diagnosis: (CHE	CK BOX I	F DATE UI	NKNOWN.)
	#COLNMO14 /#COLYR14	Y Y	Don't	t Know (-8) <u>AY14</u> †	

 $^{^{\}dagger}$ Dates are given in days since the initial baseline interview, which is day zero.

Carc	liov	ascu	lar	Eve	nts
------	------	------	-----	-----	-----

C6. Since your last study visit, he narrowed blood vessels, stroke clots in your legs or lungs)? (Contact of the study visit, he narrowed blood vessels, stroke clots in your legs or lungs)?	e, or other proble	ms with you	ur blood circulati		
No			1	(GO TO C7, PAGI	E 5)
Yes Don't Know			8	(GO TO C7, PAGI	E 5)
IF YES, PLEASE COMPLETE QU) TO C7, PAGE 5.	
Dates are given in days since the initiate C6a. IF YES, which event(s), if are occurred since your last structured (CIRCLE ONE RESPONSE EACH QUESTION.)	ny, udy visit? NO	YES -	IF YES, PL OF MOST THAN ONE	EASE PROVIDE T RECENT EVENT (E EVENT). OX IF DATE UNKN	IF MORE
Have you been or had			`		,
Diagnosed with or treated for a <u>hea</u> (myocardial infarction or MI)? <u>HEA</u>		1 2 →	#RMIMO14 M M	#RMIYR14 / Y Y Y Y	RMIDAY14 [†] Don't Know
A <u>heart bypass operation</u> (CABG, c bypass graft surgery)? <u>BYF</u>	oronary artery PASS14	1 2 >	#RCABGMO14 M M	#RCABGYR14 /	RCABGDAY14 [†] Don't Know
A procedure to unblock narrowed wheart (opening the arteries of the healloon or other device, some-time PTCA, coronary angioplasty, coronatherectomy or rotoblation)?	eart with a s called a ary stent,	1 2 >	#RPCIMO14 M M	#RPCIYR14 /	RPCIDAY14 [†] Don't Know
Diagnosed with or treated for a <u>stro</u>	oke? ROKE14	1 2 >	$\frac{\text{\#RCVAMO14}}{M}$	#RCVAYR14 /	RCVADAY14 [†] Don't Know
Diagnosed with or treated for <u>heart</u> <u>HTF</u>	failure? AIL14	1 2 🗲	#RCHFMO14 M M	#RCHFYR14 /	RCHFDAY14 [†] Don't Know
A procedure or operation to unblock blood vessels in your <u>neck</u> (carotid carotid angioplasty, or carotid stent <u>UNE</u>	endartectomy,	1 2 >	#RNECKMO14 M M	#RNECKYR14 /	RNECKDAY14 [†] Don't Know
,	claudication, peripheral BLKL14	1 2 >	#RPADMO14 M M	#RPADYR14 / <u>Y Y Y Y</u>	RPADDAY14 [†] Don't Know
Blood clots in your legs (deep vein DVT)?		1 2 >	$\frac{\text{\#RDVTMO14}}{M}$	$/ \frac{\text{\#RDVTYR14}}{Y} / \frac{Y}{Y} / \frac{Y}{Y} / \frac{Y}{Y}$	RDVTDAY14 [†] Don't
Blood clots in your lungs (pulmonal PE)? PE14		1 2 →	#RPEMO14 M M	#RPEYR14 / Y Y Y Y	RPEDAY14 [†] Don't ☐ Know

Broken Bones

C7.	Have you broken any bones (RESPONSE.)	other than fingers or toes <u>since your last study visit</u> ? BONEBRK14	CIRCLE ONE
	RESPONSE.)	BONEBRK 14	
		1 (GO TO D1, PA	GE 6)
	Yes	2	
	Don't know	8 (GO TO D1, PA	GE 6)

C7a. IF YES, which bones were be since <u>your last study visit?</u> (CIRCLE ONE RESPONSE FOR <u>EACH</u> I	?	YES→	IF YES, PLEASE PROVIDE MOST RECENT DATE BONE WAS BROKEN. (CHECK BOX IF DATE UNKNOWN.)
Wrist <u>BRWRIST14</u>	1	2 →	#RWRTM014 #RWRTYR14 RWRTYR14 † Don't Know \square
Hip <u>BRHIP14</u>	1	2 →	#RHIPMO14 #RHIPYR14 ${M} \frac{1}{M} \frac$
Spine BRSPINE14	1	2 →	#RBACKM014 #RBACKYR14 RBACKDT14 [†] TY TY TY TY TY Don't Know
Pelvis <u>BRPELVS14</u>	1	2 →	#RPELMO14 #RPELYR14 RPELDT14 † Don't Know
Ribs <u>BRRIBS14</u>	1	2 →	#RRIBMO14 #RRIBYR14 ${M} {M} {M} {M} {M} {Y} \frac$
Remainder of arm (other that wrist) <u>BRARM14</u>	an 1	2 →	#RARMM014 #RARMYR14 ${M} {M} {M} = \frac{\frac{RARMDT14}{}{Y}}{{Y} {Y} {Y} {Y} {Y} = \frac{RARMDT14}{}{Y}$
Remainder of leg (other than BRLEG14	n hip) 1	2 →	#RLEGM014 #RLEGYR14 ${M}$ ${M}$ ${M}$ ${Y}$ ${Y}$ ${Y}$ ${Y}$ ${Y}$ Don't Know \square
Other, please specify which BROTH14 #BROTHS14	bone: 1	2 →	#ROTHMO14 #ROTHYR14 ${M} = \frac{M}{M} = \frac{M}{$

[†] Dates are given in days since the initial baseline interview, which is day zero.

<u>Falls</u>

The next questions ask about falls you may have had in the past year.

D1.			have you fallen and landed or)? (CIRCLE ONE RESPON		nd (or fa FALLE		d hit an o	object
	No			,	1 (GC	 D TO D2	2)	
					•		-,	
	\downarrow							
	D1a. IF YES	, how	many times have you fallen	in the past year?	(CIRCL		RESPO	ONSE.)
	Once)			1			
	2 time	es			2			
	3 time	es			3			
	4 time	es			4			
	More	than	4 times		5			
			oast year, were you injured in	-	,			,
						10 02	114301	CED14
	∀ D1b1.	<u>dur</u>	'ES <u>and</u> you were injured in a <u>ing the past year</u> , which of to you experience?	,				
		(CIF	RCLE ONE RESPONSE FOR	R EACH QUESTIO	N.)	NO	YES	DON'T KNOW
		1.	Broken or fractured bone?	INJFXBN14		1	2	-8
		2.	Hit or injured head?	INJHEAD14		1	2	-8
		3.	Sprain or strain?	INJSPRN14		1	2	-8
		4.	Bruises?	INJBRUI14		1	2	-8
		5.	Bleeding?	INJBLEE14		1	2	-8
		6.	Other kind of injury (please OINJ14			1	2	-8
			#OINJS14					
					_			
D2.	•		alling? (CIRCLE ONE RESF	•	<u>FEARI</u>	FAL14		
	ΑI	ittle fe	earful	2				
	Mo	odera	tely fearful	3				
	Ve	ry fea	arful	4				
D3.	How much d	o you	ı weigh? (lbs)		<u>WGHT</u>	LBS14		
# Vari	able Excluded	from	Public Use Data File					

The following questions are about specific symptoms you may have had over the <u>past two weeks</u>.

E1.	Over the past two weeks, how often have you had hot flashes or flushes? HOTFLAS14 (CHECK ONE BOX AND ANSWER THE NEXT QUESTIONS AS INSTRUCTED.)						
	☐ Not at all (I) (GO TO E2)						
	☐ 1-5 days (2) ☐ 6-8 days (3) ☐ 9-13 days (4) ☐ Every day (5)	E1a. On the days that you have hot flashes or flushes, how many times each day do you usually have them? NUMHOTF14 NUMBER OF TIMES PER DAY: (GO TO E1b) E1b. How much are you usually bothered by hot flashes or flushes? (CIRCLE ONE RESPONSE.) Not at all					
E2.	<u> </u>	w often have you had cold sweats? WER THE NEXT QUESTIONS AS INSTRUCTED.)					
	☐ 1-5 days (2) ☐ 6-8 days (3) ☐ 9-13 days (4) ☐ Every day (5)	E2a. On the days that you have cold sweats, how many times each day do you usually have them? NUMBER OF TIMES PER DAY: (GO TO E2b) E2b. How much are you usually bothered by cold sweats? (CIRCLE ONE RESPONSE.) Not at all					
E3.	•	v often have you had night sweats? NITESWE14 WER THE NEXT QUESTIONS AS INSTRUCTED.) PAGE 8)					
	☐ 1-5 days (2) ☐ 6-8 days (3) ☐ 9-13 days (4) ☐ Every day (5)	E3a. On the days that you have night sweats, how many times each night do you usually have them? NUMNITS14 NUMBER OF TIMES PER NIGHT: (GO TO E3b) E3b. How much are you usually bothered by night sweats? (CIRCLE ONE RESPONSE.) Not at all 1 Very little 2 Moderately 3					
	riable Excluded from Public Use w-up 14 Interim Contact Form	A lot					

Thinking back over the past two weeks, how often have you had...

E4.	. Stiffness or soreness in joints, neck or shoulders? (CHECK ONE BOX AND ANSWER THE NEXT QUESTION AS INSTRUCTED.)				
	☐ Not at all (I) (GO TO E5)				
	 ☐ 1-5 days (2) ☐ 6-8 days (3) ☐ 9-13 days (4) ☐ Every day (5) 	E4a. How much are you usually bothered by stiffness or soreness in joints, neck or shoulders? (CIRCLE ONE RESPONSE.) BOTSTIF14 Not at all			
E5.	□ Not at all (I) (GO TO F1)	VAGINDR14 VER THE NEXT QUESTION AS INSTRUCTED.)			
	 □ 1-5 days (2) □ 6-8 days (3) □ 9-13 days (4) □ Every day (5) 	E5a. How much are you usually bothered by vaginal dryness? (CIRCLE ONE RESPONSE.) BOTVAGD14 Not at all			

The following question about hormone therapy refers to the past two weeks.

F1.	During the past 2 weeks, h	nave you used prescription hormone the	apy (such as, estrogen,
	estrogen/progesterone pill o	r patch)? (CIRCLE ONE RESPONSE.)	RXHRT2W14
	No	1	(END)
	Vec	2	

All of the SWAN Investigators and Staff thank you most sincerely for your many valuable contributions over the last 15 years. We hope to see you at another SWAN visit soon!

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Date Data Entered / Initials	Date Verified / Initials

INTERIM SUPPLEMENTAL BLEEDING PATTERN FORM

INTERIM FOLLOW-UP

Study of Women's Health Across the Nation

SECTION A. GENERAL INFORMATION

A1	RESPONDENT ID:	AFFIX ID LABEL HERE		ARCHID
A2	SWAN STUDY VISIT #	14		<u>VISIT</u>
А3	FORM VERSION:	09/13/2013		#FORM_V_BL
A4	INTERVIEWER'S INITIALS:			#INITS
A5	RESPONDENT'S DOB:	M M / D D / 1 9 Y	<u>Y</u> <u>Y</u>	#DOB
A6.	INTERVIEW COMPLETED IN:		#MAILI	LOCBL
	CLINIC / OFFICERESPONDENT'S HOME V CLINIC/OFFICE W/ PROX TELEPHONE	VIA MAILV/ PROXYY		2 3 1 5
A7.	INTERVIEW LANGUAGE:			
	SPANISH CANTONESE		2 3	<u>2</u> 3
A8.	INTERVIEWER ADMINISTERED?		#INTAE	DM_BL

PLEASE do not write anything on this page. This page is for OFFICE USE ONLY. -), according to our study records, you were not yet At your last SWAN visit (_ postmenopausal (by that, we mean that you had not yet gone 12 months without bleeding). We would like to update your menopause stage by asking you a familiar series of questions about your bleeding patterns. The next questions are about your menstrual periods since your last study visit. Please enter today's date: B1. $\frac{1}{M} \frac{1}{M} \frac{1}{D} \frac{1}{D} \frac{1}{D} \frac{1}{Y} \frac{1}{Y} \frac{1}{Y} \frac{1}{Y} \frac{1}{Y}$ B2. Did you have any menstrual bleeding since your last study visit? (CIRCLE ONE RESPONSE.) B3. Did you have any menstrual bleeding in the last 3 months? (CIRCLE ONE RESPONSE.) No....... 1 What was the date that you started your most recent menstrual bleeding? B4. [IF YOU DO NOT KNOW THE EXACT DAY, ENTER THE MONTH AND YEAR.1 #BLEEMO14 #BLEEDAY14 **LMPDAY**† For the next two questions, we would like to ask you to think about your periods since your last study visit, during times when you were not using birth control pills or other hormone medications. Which of the following best describes your menstrual periods since your last study visit? Have B5. they: (CIRCLE ONE RESPONSE.) **DESCPER14** Become farther apart? 1 Become closer together? 2 Don't Know.....-8 Not Applicable-1 (END) A menstrual cycle is the period of time from the beginning of bleeding from one menstrual period to B6. the beginning of bleeding of the next menstrual period. Since your last study visit, what was the usual length of your menstrual cycles? (CIRCLE ONE RESPONSE.) Less than 24 days 1

Thank you very much for your time.

† This date is given in days since the baseline interview and is found in the Longitudinal Menopausal Status dataset.

[#] Variable Excluded from Public Use Data File

ADDITIONAL MEASURES COLLECTED

RACE/ETHNICITY

RACE Participant race/ethnicity is provided from the Screener dataset, coded as:

- 1= Black
- 2= Chinese/Chinese American
- 3= Japanese/Japanese American
- 4= White Non-Hispanic
- 5= Hispanic

SITE

<u>SITE</u> Participant study site is provided from the Screener dataset, coded as:

- 11= Detroit, MI
- 12= Boston, MA
- 13= Chicago, IL
- 14= Oakland, CA
- 15= Los Angeles, CA
- 16= Newark, NJ
- 17= Pittsburgh, PA