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Swan

STUDY of WOMEN'S HEALTH ACROSS the NATION

FOLLOW-UP VISIT 14

CODEBOOK

ARCHIVED DATASET 2018

Dataset file nia142018

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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 11, 12, 13, 14, 15, 16 and 17.

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.
- FORMFLG14 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 site 15 saw its first participants. Site 15 saw 256 participants before the other sites started on 09/25/2013.
- ***Site 15 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 site 15 women were set to .B (Not applicable) in the dataset.
  - The site 15 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 site 15 specific bleeding form and not on the interim form. Seven women completed the site 15 specific bleeding form, and none reported a hysterectomy or oophorectomy.
  - Site 15 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) was 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 Data Entered / Initials _____ Date Verified / Initials _____

INTERIM CONTACT FOLLOW UP FORM

INTERIM FOLLOW-UP

Study of Women's Health Across the Nation

SECTION A. GENERAL INFORMATION

AFFIX ID LABEL HERE

A1. RESPONDENT ID: [ ] **ARCHID~**

A2. SWAN STUDY VISIT # 14 **VISIT**

A3. FORM VERSION: 09/01/2013 **#FORM_V**

A4. INTERVIEWER'S INITIALS: ___ ___ ___ **#INITS**

A5. RESPONDENT'S DOB: ___ ___ / ___ ___ / 1 9 ___ ___ **#DOB**
M M D D Y Y Y Y

A6. INTERVIEW COMPLETED IN: **#MAILLOC14**

RESPONDENT'S HOME / VIA MAIL.....1
CLINIC / OFFICE 2
RESPONDENT'S HOME W/ PROXY.....3
CLINIC/OFFICE W/ PROXY 4
TELEPHONE 5
TELEPHONE BY PROXY 6

A7. INTERVIEW LANGUAGE: **LANGUAG14**

ENGLISH 1
SPANISH 2
CANTONESE.....3
JAPANESE 4

A8. INTERVIEWER ADMINISTERED? **#INTADMN14**

NO 1
YES.....2

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

 # Variable Excluded from Public Use Data File

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Please answer the following questions as completely as possible. Please note that the questions included in this survey ask about several different time periods. For example, some questions ask about the time since your last study visit while others ask about the past year or the past 2 weeks. 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!

Your last SWAN study visit was on _____. We would like to ask you a few questions about what's happened to you since then in order to keep our records up to date in preparation for the 2015 SWAN visit if we are successful in obtaining new funding.

Please find the most appropriate response to each question and circle the number for the answer you choose.

B1. Please enter today's date: ___ ___ / ___ ___ / ___ ___ ___ ___ **IRMDAY14†**
M M D D Y Y Y Y

B2. In general, would you say your health is excellent, very good, good, fair or poor? (CIRCLE ONE RESPONSE.) **OVERHLT14**

Excellent.....1
Very good.....2
Good 3
Fair.....4
Poor 5
Don't know ..... -8

The next questions are about your health, medical conditions and procedures that may have occurred since your last study visit.

C1. **Since your last study visit,** has a doctor, nurse practitioner or other health care provider told you that you had diabetes or treated you for it? (CIRCLE ONE RESPONSE.) **DIABETES14**

No.....1 **(GO TO C2, PAGE 3)**
Yes 2
Don't Know .....-8 **(GO TO C2, PAGE 3)**

C1a. **Since your last study visit** have you taken insulin or other medication for treatment of diabetes or high blood sugar? (CIRCLE ONE RESPONSE.) **MEDDIAB14**

No 1
Yes.....2
Don't know ..... -8

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

 # Variable Excluded from Public Use Data File

C2. **Since your last study visit,** have you had a hysterectomy (an operation to remove your uterus or womb)? (CIRCLE ONE RESPONSE.) **HYSTERE14** *(LA asked on bleeding pattern form)*

No ..... 1 **(GO TO C3)**
Yes 2
Don't Know ..... -8 **(GO TO C3)**

C2a. **If YES**, please give date of the hysterectomy: (CHECK BOX IF DATE UNKNOWN.)

#HYSTERMO __ __ (M M) / **#HYSTERYR** __ __ __ __ (Y Y Y Y) **HYSTDAY14**†

☐ Don't Know (-8)

C3. **Since your last study visit**, did you have one or both ovaries removed (an oophorectomy)? (CIRCLE ONE RESPONSE.) **OOPHORE14** *(LA asked on bleeding pattern form)*

No ..... 1 **(GO TO C4)**
Yes 2
Don't Know ..... -8 **(GO TO C4)**

C3a. Was one ovary removed or were both ovaries removed? **ONEOVAR14**

One Ovary Removed 1
Both Ovaries Removed 2
Don't Know ..... -8

C4. **Since your last study visit,** has a doctor, nurse practitioner or other health care provider told you that you had breast cancer? (CIRCLE ONE RESPONSE.) **LVBRST14**

No ..... 1 **(GO TO C5)**
Yes 2
Don't Know ..... -8 **(GO TO C5)**

C4a. **If YES**, what was the primary site of the breast cancer? (CIRCLE ONE RESPONSE.)

Both breasts 1 **PSBRST14**
Right breast, only 2
Left breast, only 3

C4b. Please record the date of the breast cancer diagnosis: (CHECK BOX IF DATE UNKNOWN.)

#BRSTMO14 / #BRSTYR14 __ __ (M M) __ __ __ __ (Y Y Y Y) ☐ Don't Know (-8) **BRSTDAY14**†

C5. **Since your last study visit,** has a doctor, nurse practitioner or other health care provider told you that you had colon cancer? (CIRCLE ONE RESPONSE.) **LVCOL14**

No ..... 1 **(GO TO C6, PAGE 4)**
Yes 2
Don't Know ..... -8 **(GO TO C6, PAGE 4)**

C5a. Please record the date of the colon cancer diagnosis: (CHECK BOX IF DATE UNKNOWN.)

#COLNMO14 /#COLYR14 __ __ (M M) / __ __ __ __ (Y Y Y Y) ☐ Don't Know (-8) **COLDAY14**†

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

 # Variable Excluded from Public Use Data File

Cardiovascular Events

C6. **Since your last study visit,** have you been diagnosed or treated for heart problems, blocked or narrowed blood vessels, stroke, or other problems with your blood circulation (for example, blood clots in your legs or lungs)? (CIRCLE ONE RESPONSE.) LDXHRT14

No ..... 1 **(GO TO C7, PAGE 5)**
Yes..... 2
Don't Know..... -8 **(GO TO C7, PAGE 5)**

IF YES, PLEASE COMPLETE QUESTION C6a. (BELOW), OTHERWISE GO TO C7, PAGE 5.

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

C6a. **IF YES,** which event(s), if any, occurred since **your last study visit**? (CIRCLE ONE RESPONSE FOR EACH QUESTION.)	NO	YES →	**IF YES, PLEASE PROVIDE THE DATE OF MOST RECENT EVENT (IF MORE THAN ONE EVENT).** (CHECK BOX IF DATE UNKNOWN.)
Have you been or had…			
Diagnosed with or treated for a heart attack (myocardial infarction or MI)? HEARTAT14	1	2 →	#RMIMO14 M M / #RMIYR14 Y Y Y Y RMIDAY14† Don't Know ☐
A heart bypass operation (CABG, coronary artery bypass graft surgery)? BYPASS14	1	2 →	#RCABGMO14 M M / #RCABGYR14 Y Y Y Y RCABGDAY14† Don't Know ☐
A procedure to unblock narrowed vessels to your heart (opening the arteries of the heart with a balloon or other device, some-times called a PTCA, coronary angioplasty, coronary stent, atherectomy or rotoblation)? UNBLKH14	1	2 →	#RPCIMO14 M M / #RPCIYR14 Y Y Y Y RPCIDAY14† Don't Know ☐
Diagnosed with or treated for a stroke? STROKE14	1	2 →	#RCVAMO14 M M / #RCVAYR14 Y Y Y Y RCVADAY14† Don't Know ☐
Diagnosed with or treated for heart failure? HTFAIL14	1	2 →	#RCHFMO14 M M / #RCHFYR14 Y Y Y Y RCHFDAY14† Don't Know ☐
A procedure or operation to unblock narrowed blood vessels in your neck (carotid endartectomy, carotid angioplasty, or carotid stent) UNBLKN14	1	2 →	#RNECKMO14 M M / #RNECKYR14 Y Y Y Y RNECKDAY14† Don't Know ☐
Poor blood circulation or blocked or narrowed blood vessels to your legs or feet (claudication, peripheral arterial disease or PAD, peripheral vascular disease or PVD)? UNBLKL14	1	2 →	#RPADMO14 M M / #RPADYR14 Y Y Y Y RPADDAY14† Don't Know ☐
Blood clots in your legs (deep vein thrombosis or DVT)? DVT14	1	2 →	#RDVTMO14 M M / #RDVTYR14 Y Y Y Y RDVTDAY14† Don't Know ☐
Blood clots in your lungs (pulmonary embolism or PE)? PE14	1	2 →	#RPEMO14 M M / #RPEYR14 Y Y Y Y RPEDAY14† Don't Know ☐

 # Variable Excluded from Public Use Data File

Broken Bones

C7. Have you broken any bones other than fingers or toes **since your last study visit**? (CIRCLE ONE RESPONSE.) BONEBRK14

No ..... 1 **(GO TO D1, PAGE 6)**
Yes 2
Don't know ..... -8 **(GO TO D1, PAGE 6)**

C7a. **IF YES,** which bones were broken since **your last study visit**? (CIRCLE ONE RESPONSE FOR EACH BONE.)	NO	YES→	**IF YES, PLEASE PROVIDE MOST RECENT DATE BONE WAS BROKEN.** (CHECK BOX IF DATE UNKNOWN.)
Wrist BRWRIST14	1	2 →	#RWRTMO14 M M / #RWRTYR14 Y Y Y Y — RWRTYR14† Don't Know ☐
Hip BRHIP14	1	2 →	#RHIPMO14 M M / #RHIPYR14 Y Y Y Y — RHIPDT14† Don't Know ☐
Spine BRSPINE14	1	2 →	#RBACKMO14 M M / #RBACKYR14 Y Y Y Y — RBACKDT14† Don't Know ☐
Pelvis BRPELVS14	1	2 →	#RPELMO14 M M / #RPELYR14 Y Y Y Y — RPELDT14† Don't Know ☐
Ribs BRRIBS14	1	2 →	#RRIBMO14 M M / #RRIBYR14 Y Y Y Y — RRIBDT14† Don't Know ☐
Remainder of arm (other than wrist) BRARM14	1	2 →	#RARMMO14 M M / #RARMYR14 Y Y Y Y — RARMDT14† Don't Know ☐
Remainder of leg (other than hip) BRLEG14	1	2 →	#RLEGMO14 M M / #RLEGYR14 Y Y Y Y — RLEGDT14† Don't Know ☐
Other, please specify which bone: BROTH14 _____ #BROTHS14 _____	1	2 →	#ROTHMO14 M M / #ROTHYR14 Y Y Y Y — ROTHDT14† Don't Know ☐

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

 # Variable Excluded from Public Use Data File

Falls

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

D1. **In the past year**, have you fallen and landed on the floor or ground (or fallen and hit an object like a table or stair)? (CIRCLE ONE RESPONSE.) FALLEN14

No ..... 1 **(GO TO D2)**
Yes 2

D1a. **IF YES**, how many times have you fallen ***in the past year***? (CIRCLE ONE RESPONSE.) NUMFALL14

Once 1
2 times 2
3 times 3
4 times 4
More than 4 times 5

D1b. ***During the past year,*** were you injured in any of these falls? (CIRCLE ONE RESPONSE.)

NO ..... 1 **(GO TO D2)** INJURED14
YES 2

D1b1. **IF YES** and you were injured in any of the falls you had **during the past year**, which of the following injuries did you experience?

(CIRCLE ONE RESPONSE FOR EACH QUESTION.)

			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 describe below)? OINJ14		1	2	-8

#OINJS14_____

_____

D2. Are you afraid of falling? (CIRCLE ONE RESPONSE.) FEARFAL14

No 1
A little fearful 2
Moderately fearful 3
Very fearful 4

D3. How much do you weigh? ___ ___ ___ (lbs) WGHTLBS14

 # Variable Excluded from Public Use Data File

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

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** (1) **(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.) BOTHOTF14

Not at all.....1
Very little 2
Moderately 3
A lot.....4

E2. **Over the past two weeks,** how often have you had cold sweats? COLDSWE14
(CHECK ONE BOX AND ANSWER THE NEXT QUESTIONS AS INSTRUCTED.)

☐ **Not at all** (1) **(GO TO E3)**

☐ **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? NUMCLDS14

NUMBER OF TIMES PER DAY: ___ ___ **(GO TO E2b)**

E2b. How much are you usually bothered by cold sweats? (CIRCLE ONE RESPONSE.) BOTCLDS14

Not at all 1
Very little..... 2
Moderately..... 3
A lot 4

E3. **Over the past two weeks,** how often have you had night sweats? NITESWE14
(CHECK ONE BOX AND ANSWER THE NEXT QUESTIONS AS INSTRUCTED.)

☐ **Not at all** (1) **(GO TO E4, 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.) BOTNITS14

Not at all.....1
Very little 2
Moderately 3
A lot.....4

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

E4. Stiffness or soreness in joints, neck or shoulders? **STIFF14**
(CHECK ONE BOX AND ANSWER THE NEXT QUESTION AS INSTRUCTED.)

☐ **Not at all** (1) **(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 1
Very little.....2
Moderately.....3
A lot 4

E5. Vaginal dryness? **VAGINDR14**
(CHECK ONE BOX AND ANSWER THE NEXT QUESTION AS INSTRUCTED.)

☐ **Not at all** (1) **(GO TO F1)**

☐ **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 1
Very little.....2
Moderately.....3
A lot 4

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

F1. **During the past 2 weeks**, have you used prescription hormone therapy (such as, estrogen, estrogen/progesterone pill or patch)? (CIRCLE ONE RESPONSE.) **RXHRT2W14**

No ..... 1 **(END)**
Yes..... 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 VISIT

A3. FORM VERSION: 09/13/2013 #FORM_V_BL

A4. INTERVIEWER'S INITIALS: ___ ___ ___ #INITS

A5. RESPONDENT'S DOB: ___ ___ / ___ ___ / 1 9 ___ ___ #DOB
M M D D Y Y Y Y

A6. INTERVIEW COMPLETED IN: #MAILLOCBL

RESPONDENT'S HOME / VIA MAIL.....1
CLINIC / OFFICE.....2
RESPONDENT'S HOME W/ PROXY.....3
CLINIC/OFFICE W/ PROXY.....4
TELEPHONE.....5
TELEPHONE BY PROXY.....6

A7. INTERVIEW LANGUAGE:

ENGLISH.....1
SPANISH.....2
CANTONESE.....3
JAPANESE.....4

A8. INTERVIEWER ADMINISTERED? #INTADM_BL

NO.....1
YES.....2

 # Variable Excluded from Public Use Data File

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At your last SWAN visit (_____), according to our study records, you were not yet 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.

B1. Please enter today's date: __ __ / __ __ / __ __ __ __ (M M / D D / Y Y Y Y) **BLEFRMDAY14**†

B2. Did you have any menstrual bleeding **since your last study visit**? (CIRCLE ONE RESPONSE.) **BLEEDNG14**

No .....1 **(END FORM)**
Yes 2

B3. Did you have any menstrual bleeding **in the last 3 months**? (CIRCLE ONE RESPONSE.) **BLD3MON14**

No 1
Yes 2

B4. What was the date that you started your most recent menstrual bleeding?

__ __ / __ __ / __ __ __ __ (M M / D D / Y Y Y Y)

#BLEEMO14 **#BLEEDAY14** **#BLEEYR14**

[IF YOU DO NOT KNOW THE EXACT DAY, ENTER THE MONTH AND YEAR.]

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.

B5. Which of the following best describes your menstrual periods **since your last study visit**? Have they: (CIRCLE ONE RESPONSE.) **DESCPER14**

Become farther apart? 1
Become closer together? 2
Occurred at more variable intervals? 3
Stayed the same? 4
Become more regular? 5
Don't Know .....-8
Not Applicable .....-1 **(END)**

B6. A menstrual cycle is the period of time from the beginning of bleeding from one menstrual period to 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.) **LENGCYC14**

Less than 24 days 1
24-35 Days 2
More than 35 days 3
Too variable or irregular to say 4
Don't know .....-8

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