



Comprehensive Family Medical History Dataset

CODEBOOK

ARCHIVED DATASET 2018

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DOCUMENTATION FOR THE SWAN FAMILY MEDICAL HISTORY DATASET

Who is included in the frozen dataset:

The SWAN Family Medical History Interview was administered up to two times during follow-up. During the interview, SWAN women answered questions about the current status of immediate family members, family history of various health conditions and maternal experiences of and attitudes towards menopause. The initial interview was completed by 2829 women at one of the SWAN visits - Visit 02 (n=2721), Visit 03 (n=86) or Visit 04 (n=22). The follow-up interview was completed by 2509 women at Visit 06 (n=2272), Visit 07 (n=136), Visit 08 (n=73), Visit 09 (n=26) or Visit 10 (n=2). Overall, 2925 women completed at least one questionnaire, with 2411 completing both, 416 completing only the follow-up and 96 completing only the initial. Two women who completed a questionnaire were dropped because they were identified by the study sites as being adopted, so the final dataset has data from 2923 SWAN women.

The final frozen SWAN Family Medical History dataset uses all available data from both interviews to create the most comprehensive picture of SWAN participants' self-reported family medical histories. Where discrepancies were identified between visits, queries were sent back to the sites to confirm the values on the original forms.

Sites were asked to confirm form values in the following instances:

- Indicated at follow up they did not have a previous family medical history but are in initial data set.
- Follow-up form indicated a previous family history was done but are not in the initial data set
- Mother reported on follow-up form as deceased at initial visit, but in initial data set mother is reported alive
- Father reported on follow-up form as deceased at initial visit, but in initial data set father is reported alive (or unknown)
- Mother's age at death reported at follow-up is younger than age she was reported living at initial visit
- Father's age at death reported at follow-up is younger than age he was reported living at initial visit
- Number of brothers on follow-up form does not match number in initial data set but was indicated as correct
- Number of sisters on follow-up form does not match number in initial data set but was indicated as correct
- Said no previous family history was done but ID is in initial data set, and has different number of brothers
- Said no previous family history was done but ID is in initial data set, and has different number of sisters

If sites could not reconcile the discrepancies between forms, flag variables were created.

Created variables:

All variables in the dataset were created using both versions of the family medical history interview when available. In general, data from the follow-up questionnaire were used when available. If the follow-up visit was not available, data from the initial visit were used.

Parental age and death variables:

Mother and father's vital status, age if alive, age at death and cause of death were created as follows:

- If a woman reported her mother/father alive at both visits (or if only one visit was available), the latest visit was used to obtain the age of the parent.
- If a woman reported her mother/father deceased at the initial visit, and this was confirmed in the follow-up data, the age at and cause of death were taken from the initial visit.
- If a woman reported her mother/father alive at the initial visit, but deceased at the follow-up visit, the age at and cause of death were taken from the follow-up visit.

Immediate family history table:

Women were asked if members of their immediate family had ever “been told by a health care provider that s/he had” any of a list of medical conditions. They were asked questions separately for their mother, father, brothers and sisters. If they indicated that a brother or sister was told they had a specific condition, they were then asked how many brothers or sisters had that condition.

To account for women who reported a family member had a condition in the initial interview, but did not report this in the follow-up interview (responded either “No” or “Don’t Know” to that item in the follow-up interview), a third “uncertain” category was created. These variables had values of 1 for “No”, 2 for “Yes” and 3 for “Uncertain.”

Heart disease variables:

In the initial interview, “heart attack” and “other heart disease” were included in the list of conditions in the immediate family history section where women were asked if their immediate family members had even been told by a health care provider that they had specific medical conditions.

In the follow-up interview, more detailed questions were asked about the family history of heart conditions. Participants were asked if their immediate family members (mother, father, brothers, sisters) ever have “angina (chest pain), a heart attack, or a procedure to open a blocked blood vessel in the heart (bypass surgery or angioplasty).” If she responded yes to a question about a family member having one of these conditions, she was asked if it was before they were 55 (if it was her father or brother) or 65 (if it was her mother or sister). No questions were asked about how many brothers or sisters had these conditions.

In order to reconcile these different ways of asking about family history of heart disease, an “any heart disease” indicator variable was created, and used the following rules (this describes how it was done for the mother variables, but the process was identical for all family members):

- If a SWAN participant had family history data from the follow-up interview and initial interview, if she indicated at the initial interview that her mother had been told she had a heart attack or other heart disease, or if she indicated at the follow up interview that her mother had angina/heart attack/a procedure to open a blocked blood vessel, she was considered as having a “any heart disease,” and got a value of “2” for the final variable (HEARTMOM). Otherwise, if she reported “No” for all of the questions at both interviews, she got a “1”. If she reported “Don’t Know” for any of the conditions at any time point (But not “Yes” to any), she received a value of “3” for that variable, indicating uncertainty.
- If a SWAN participant had data from only the initial interview, she could only report if her mother was told by a health care provider if she had a heart attack or “other heart disease.” If she said “Yes” to either of these conditions, she received a value of “2” for HEARTMOM. If she said “No” to both of them, she received a value of “1”, and if she answered “Don’t Know” to either of them (But not “Yes” to any), she received a value of “Don’t Know” for that variable, using the appropriate SWAN missing code (.C).
- If a SWAN participant only had data from the follow-up interview, her response to the question about angina/heart attack/bypass procedure was used for the final variable (HEARTMOM).
- Only SWAN participants who completed the follow-up questionnaire could respond to the questions about the age of the family member at the time of the event. SWAN participants with only data from the initial interview were assigned missing values for those variables (MOHART65, SIHART65 DAHART55 BRHART55).

Sister table:

The “sister table” was collected at both visits, which contains detailed information about participants’ sisters’ menstrual history. In the initial interview, the “Full/Half” questions were asked for all women in a separate column of the table, but at the follow-up interview these questions were included in the first column of the table and appear to have been skipped for the majority of the sample (for example, 2089 of the 2210 women who had at least 1 sister did not respond to this question for her first sister). Because the most recent information about participants’ family medical history was wanted, the full/half questions were dropped and the latest information available for participants was used. If a woman had a follow-up interview, her data from that interview was used for the sister data in the final dataset. If a woman only had data from the initial interview, that data was used, but the full/half-sister questions were dropped from that data. At the initial interview, women had up to 16 sisters, but at the follow-up visit the maximum number of sisters any participants had was 12.

An attempt to reconcile differences between initial and follow-up interviews was not made due to the passage of time, so it is possible that women reported different sisters on the follow-up interview than the initial interview. There were indicator variables in the follow-up data set for if each sister was previously reported (PRVREP1-PRVREP22), but these variables were only used on the 03/01/2002 version of the form, and have even more missingness than the full/half-sister variables (only 30 had non-missing values for this variable for the first sister).

Breast Cancer questions:

Additional detailed questions about family medical history of breast cancer among female relatives were asked at both the follow-up and initial interviews. Breast cancer diagnosis and age at diagnosis were asked for mother, sisters (up to three), maternal and paternal grandmothers, maternal and paternal aunts and any other blood relatives. Data from the follow-up interview was used when possible, and similar coding was used to the variables for the other conditions to reflect uncertainties (i.e. when a diagnosis was reported at the initial interview but not the follow-up, a value of “3” was assigned, and age at diagnosis was assigned a SWAN missing value of .C). In the initial family history data set, women had up to five other relatives. In the follow-up, the maximum number of relatives with breast cancer was 10.

Mother’s menopause questionnaire

In the initial questionnaire, participants were asked about their biological mother’s menopause and also about the attitudes the woman who raised them had towards menopause. This questionnaire was administered to the women at the follow-up interview **only if they did not have a prior interview**. The data from the initial interview was used for women if the skip pattern was followed correctly (i.e. the site indicated on the form that she had a prior interview and skipped the rest of the questions). If the site incorrectly indicated that a woman did not have a prior interview and administered the questionnaire at the follow-up interview then the data from the initial visit was used.

Created Flags

While reconciling the two interviews, some discrepancies were unable to be resolved by the sites. All efforts were made to track down original versions of both interviews, but in some cases a participant’s responses to the two interviews contradicted themselves (e.g. participant’s mother was reported dead at the initial interview but alive at the follow-up). Several of these had to do with several variables in the follow-up interview that required the sites to know whether or not the participant had an initial visit. For example, the question B1 on the follow-up questionnaire asked the interviewer if the participant’s biological mother was reported deceased during the previous family medical history. If the person at the site filling out the form responded “Yes” to this question, but when analysts checked the initial data, the mother was reported living, the site was queried to confirm the values from both visit forms. If they could not be reconciled via the site, that observation was flagged using the flag variable MOMFLAG1.

The following flag variables were created to indicate when these discrepancies could not be resolved:

Flag variable	Label	Description
MOMFLAG1	FU form incorrectly said mother dead at initial visit. Data indicates alive	Question B1 on follow-up interview was answered as if mother was reported dead at the previous interview, but she was alive in the data set from the initial interview. (All values set to unknown)
DADFLAG1	FU form incorrectly said father dead at initial visit. Data indicates alive	Question B5 on follow-up interview was answered as if father was reported dead at the previous interview, but he was alive in the data set from the initial interview. (All values set to unknown)
MOMFLAG2	FU form reported mother dead at younger than age reported living at initial	Age mother was reported alive in the initial interview (MOMAGE2) was greater than the age she died according to the follow-up interview (B2a)
DADFLAG2	FU form reported father dead at younger than age reported living at initial	Age father was reported alive in the initial interview (DADAGE2) was greater than the age he died according to the follow-up interview (B6a)
MOMFLAG3	FU form indicated mother was dead at initial, but initial not done	Question B1 on follow-up interview was answered as if mother was reported dead at the previous interview, but participant was not in the data set from the initial interview. (All values set to unknown)
DADFLAG3	FU form indicated father was dead at initial, but initial not done	Question B5 on follow-up interview was answered as if father was reported dead at the previous interview, but participant was not in the data set from the initial interview. (All values set to unknown)
BROFLAG1	FU form had different # brothers than initial, but was treated as correct	Question B9 had a number in the line for the previous interview for number of brothers that does not match what is in the dataset at the CC
SISFLAG1	FU form had different # sisters than initial, but was treated as correct	Question B10 had a number in the line for the previous interview for number of sisters that does not match what is in the dataset at the CC
FORMFLAG1	FU form filled as if prior was done, but initial not received	Consistently indicated on follow-up interview form that a prior interview was done (Questions B1, B5, B9, B10, F1), but are not in the data set at the coordinating center
FORMFLAG2	FU form filled as if prior not done, but initial was received	Consistently indicated on follow-up interview form that a prior interview was NOT done (Questions B1, B5, B9, B10, F1), but they ARE in the data set at the coordinating center

Changes made to data based on site responses

When discrepancies were identified between the initial and follow-up data, the Coordinating Center worked with the study sites to confirm the values on both sets of forms or to provide correct values. During the process of confirming values with the sites, two SWAN women were identified as having been adopted and were removed from the data set.

Initial SWAN Family Medical History Interview Form

Study of Women's Health Across the Nation FAMILY MEDICAL HISTORY INTERVIEW

SECTION A. GENERAL INFORMATION

AFFIX ID LABEL HERE

A1. RESPONDENT ID:

ARCHID~

A2. SWAN STUDY VISIT #

INITVISIT

A3. FORM VERSION:

02/01/1998

#FORM_V

A4. DATE FORM COMPLETED:

____ / ____ / ____
M M D D Y Y Y Y

INITDAY[†]

A5. INTERVIEWER'S INITIALS:

#INITS

A6. RESPONDENT'S DOB:

____ / ____ / ____
M M D D Y Y

#DOB

VERIFY WITH RESPONDENT

A7. INTERVIEW COMPLETED IN:

#LOCATION

- | | |
|---------------------------------|---|
| RESPONDENT'S HOME | 1 |
| CLINIC/OFFICE | 2 |
| RESPONDENT'S HOME BY PROXY..... | 3 |
| CLINIC/OFFICE BY PROXY..... | 4 |

A8. INTERVIEW LANGUAGE:

INITLANG

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

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

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

During this section of the interview, I am going to ask you about your family medical history. One's family history may play an important role in that person's own health. Thus, it is important for us in assessing the health of women in our study to have an understanding of health and illness in their families. Please include information about the health of all your relatives even if some are deceased. We realize that some of these questions may be difficult or sensitive. Please be assured that we appreciate any information you wish to provide, and we will treat it confidentially, as we do with all of your information. However, as always, you are free to refuse to answer any question you do not wish to.

B1. Is your biological mother (the one who gave birth to you) still living? **MOMALIVE**

NO	1
YES	2 (B1b)
DON'T KNOW	-8 (B2)

B1a. How old was your mother when she died? _____ YEARS **MOMDIED**
DON'T KNOW-8

B1a1. What was the cause of death? _____ (B2) #**MOMCOD**

DON'T KNOW	8
REFUSED.....	7

B1b. How old is your mother now? _____ YEARS **MOMAGE**
DON'T KNOW-8

B2. Is your biological father still living? **DADALIVE**

NO	1
YES	2 (B2b)
DON'T KNOW	-8 (B3)

B2a. How old was your father when he died? _____ YEARS **DADDIED**
DON'T KNOW-8

B2a1. What was the cause of death? _____ (B3) #**DADCOD**

DON'T KNOW	8
REFUSED.....	7

B2b. How old is your father now? _____ YEARS **DADAGE**
DON'T KNOW-8

B3. How many brothers do you have, including brothers who may have died? Include only blood relatives -- full or half. Do not include step- or adopted brothers.

_____ BROTHERS **NUMBROS**

Next, we are interested in learning more about your sisters and some of their menstrual history. Each woman's menstrual history may be affected by a number of factors, and we are interested in learning whether the menstrual history of women in your family may be related to your own menstrual experiences. We realize that you may not know some of the answers.

B4. How many sisters do you have, including sisters who may have died? Include only blood relatives -- full or half. Do not include step- or adopted sisters. **NUMSIS**

_____ SISTERS (IF NONE, GO TO QUESTION C1)

I would like to obtain some more information about each of your sisters.

What is the <u>first</u> name of each of your sisters?	a. Is this sister still living?		b. Is / was she a full or half sister?		c. How old is she? (OR: How old was she when she died?)		d. Has she had a period in the last year?		e. At what age did she stop having periods?		f. Did her periods stop naturally, because of current pregnancy or breast feeding, due to surgery, or due to medication or radiation?					
	NO	YES	FULL	HALF	AGE IN YEARS	DON'T KNOW	NO	YES	DON'T KNOW	AGE IN YEARS	DON'T KNOW	NATURAL	PREGNANT OR BREAST-FEEDING	SURGERY	MEDICATION OR RADIATION	DK
B5. #SISTER1	1	2	1	2	-8		1	2 (B6)	-8 (B6)	-8		1	2	3	4	-8
	<u>SISLVNG1</u>		<u>#FULHAL1</u>		<u>SISAGE1</u>		<u>SISPERI1</u>		<u>AGESTOP1</u>		<u>SISSTOP1</u>					
B6. #SISTER2	1	2	1	2	-8		1	2 (B7)	-8 (B7)	-8		1	2	3	4	-8
	<u>SISLVNG2</u>		<u>#FULHAL2</u>		<u>SISAGE2</u>		<u>SISPERI2</u>		<u>AGESTOP2</u>		<u>SISSTOP2</u>					
B7. #SISTER3	1	2	1	2	-8		1	2 (B8)	-8 (B8)	-8		1	2	3	4	-8
	<u>SISLVNG3</u>		<u>#FULHAL3</u>		<u>SISAGE3</u>		<u>SISPERI3</u>		<u>AGESTOP3</u>		<u>SISSTOP3</u>					
B8. #SISTER4	1	2	1	2	-8		1	2 (B9)	-8 (B9)	-8		1	2	3	4	-8
	<u>SISLVNG4</u>		<u>#FULHAL4</u>		<u>SISAGE4</u>		<u>SISPERI4</u>		<u>AGESTOP4</u>		<u>SISSTOP4</u>					
B9. #SISTER5	1	2	1	2	-8		1	2 (B10)	-8 (B10)	-8		1	2	3	4	-8
	<u>SISLVNG5</u>		<u>#FULHAL5</u>		<u>SISAGE5</u>		<u>SISPERI5</u>		<u>AGESTOP5</u>		<u>SISSTOP5</u>					
B10. #SISTER6	1	2	1	2	-8		1	2 (B11)	-8 (B11)	-8		1	2	3	4	-8
	<u>SISLVNG6</u>		<u>#FULHAL6</u>		<u>SISAGE6</u>		<u>SISPERI6</u>		<u>AGESTOP6</u>		<u>SISSTOP6</u>					

What is the first name of each of your sisters?	a. Is this sister still living?		b. Is / was she a full or half sister?		c. How old is she? (OR: How old was she when she died?)		d. Has she had a period in the last year?		e. At what age did she stop having periods?		f. Did her periods stop naturally, because of current pregnancy or breast feeding, due to surgery, or due to medication or radiation?				
	NO	YES	FULL	HALF	AGE IN YEARS	DON'T KNOW	NO	YES	DON'T KNOW	AGE IN YEARS	DON'T KNOW	NATURAL	PREGNANT OR BREAST-FEEDING	SURGERY	MEDICATION OR RADIATION
B11. #SISTER7	1 SISLVNG7	2 #FULHAL7	1 SISAGE7	2 SISPERI7	-8 AGESTOP7	1 SISSTOP7	3	4	-8						
B12. #SISTER8	1 SISLVNG8	2 #FULHAL8	1 SISAGE8	2 SISPERI8	-8 AGESTOP8	1 SISSTOP8	3	4	-8						
B13. #SISTER9	1 SISLVNG9	2 #FULHAL9	1 SISAGE9	2 SISPERI9	-8 AGESTOP9	1 SISSTOP9	3	4	-8						
B14. #SISTER10	1 SISLVNG10	2 #FULHAL10	1 SISAGE10	2 SIPERI10	-8 AGESTOP10	1 SISSTOP10	3	4	-8						
B15. #SISTER11	1 SISLVNG11	2 #FULHAL11	1 SISAGE11	2 SIPERI11	-8 AGESTOP11	1 SISSTOP11	3	4	-8						
B16. #SISTER12	1 SISLVNG12	2 #FULHAL12	1 SISAGE12	2 SIPERI12	-8 AGESTOP12	1 SISSTOP12	3	4	-8						

C1. Do you know at about what age your biological mother stopped menstruating?

AGESTOP

<30	1
30-34	2
35-39	3
40-44	4
45-49	5
50-54	6
55+	7
STILL MENSTRUATING WHEN SHE DIED	8 (C4)
UNCERTAIN IF STILL MENSTRUATING WHEN SHE DIED	9 (C4)
STILL MENSTRUATING DUE TO TAKING HORMONES	10 (C4)
DON'T KNOW	-8

C2. Did she stop menstruating naturally or did she stop due to surgery, medication or radiation treatments? **STOPMEN**
(CIRCLE ONLY ONE)

NATURAL.....	1
SURGERY.....	2
MEDICATION OR RADIATION.....	3
DON'T KNOW	-8

C3. Did your biological mother have any symptoms such as hot flashes, irregular or heavy periods, sleep problems or mood changes or problems associated with stopping her menstruation? **SYMPTOM**

NO	1 (C4)
YES	2
DON'T KNOW	-8 (C4)

C3a. Which of the following did she have?

	NO	YES	DON'T KNOW	
1. Hot flashes?	1	2	-8	HOTFLAS
2. Irregular or heavy periods?	1	2	-8	HEVYPER
3. Sleep problems?	1	2	-8	SLEEPRO
4. Mood changes or problems?	1	2	-8	PSYPROB
5. Other?	1	2	-8	OTHRPRO
SPECIFY				#OTHRPRS

Now, we would like to ask you a few questions about the woman who raised you. This might be, for example, your biological mother, a step-mother, an aunt, or a grandmother.

- C4. How much did the woman who raised you discuss her menopause with you? [HERMENO](#)
- | | |
|----------------------|---------|
| Not at all | 1 |
| In some detail | 2 |
| In great detail..... | 3 |
| NOT APPLICABLE | -1 (D1) |
- C5. How often did she discuss menopause in general with you? [GENMENO](#)
- | | |
|-----------------------------|---|
| Never..... | 1 |
| Occasionally or rarely..... | 2 |
| Sometimes | 3 |
| Often..... | 4 |
- C6. Which of the following best describes her overall attitudes or perceptions about menopause? [ATTIMEN](#)
- | | |
|------------------|----|
| Neutral..... | 1 |
| Positive..... | 2 |
| Negative | 3 |
| DON'T KNOW | -8 |

Now, I'm going to read you a list of medical conditions. Please tell me if anyone in your immediate family has ever been told by a health care provider that she/he had any of the following conditions? Please include only blood relatives.

	a. Mother?			b. Father?			c. Any sisters?			d. How many of your sisters had this?	e. Any brothers?			f. How many of your brothers had this?
	NO	YES	DK	NO	YES	DK	NO	YES	DK		NO	YES	DK	
D1. Arthritis?	1 <u>ARTHRMOM</u>	2 	-8 	1 <u>ARTHRDAD</u>	2 	-8 	1 (D1e) <u>ARTHRSIS</u>	2 	-8 (D1e) 	<u>ARTHSNUM</u>	1 (D2) <u>ARTHRBRO</u>	2 	-8 (D2) 	<u>ARTHBNUM</u>
D2. High blood pressure?	1 <u>HIBPMOM</u>	2 	-8 	1 <u>HIBPDAD</u>	2 	-8 	1 (D2e) <u>HIBPSIS</u>	2 	-8 (D2e) 	<u>HIBPSNUM</u>	1 (D3) <u>HIBPBRO</u>	2 	-8 (D3) 	<u>HIBPBNUM</u>
D3. Diabetes?	1 <u>DIABMOM</u>	2 	-8 	1 <u>DIABDAD</u>	2 	-8 	1 (D3e) <u>DIABSIS</u>	2 	-8 (D3e) 	<u>DIABSNUM</u>	1 (D4) <u>DIABBRO</u>	2 	-8 (D4) 	<u>DIABBNUM</u>
D4. Stroke?	1 <u>STRKMOM</u>	2 	-8 	1 <u>STRKDAD</u>	2 	-8 	1 (D4e) <u>STRKSIS</u>	2 	-8 (D4e) 	<u>STRKSNUM</u>	1 (D5) <u>STRKBRO</u>	2 	-8 (D5) 	<u>STRKBNUM</u>
D5. Heart attack?	1 <u>HEARTMOM</u>	2 	-8 	1 <u>HEARTDAD</u>	2 	-8 	1 (D5e) <u>HEARTSIS</u>	2 	-8 (D5e) 	<u>#HRTNUMS</u>	1 (D6) <u>HEARTBRO</u>	2 	-8 (D6) 	<u>#HRTNUM</u>
D6. Other heart disease?	1 <u>#OHDMOM</u>	2 	-8 	1 <u>#OHDDAD</u>	2 	-8 	1 (D6e) <u>#OHDSIS</u>	2 	-8 (D6e) 	<u>#OHDNUMS</u>	1 (D7) <u>#OHDBRO</u>	2 	-8 (D7) 	<u>#OHDNUM</u>
D7. Hip fracture?	1 <u>HIPMOM</u>	2 	-8 	1 <u>HIPDAD</u>	2 	-8 	1 (D7e) <u>HIPSIS</u>	2 	-8 (D7e) 	<u>HIPSNUM</u>	1 (D8) <u>HIPBRO</u>	2 	-8 (D8) 	<u>HIPBNUM</u>
D8. Osteoporosis (brittle bones)?	1 <u>OSTEOMOM</u>	2 	-8 	1 <u>OSTEODAD</u>	2 	-8 	1 (D8e) <u>OSTEOSIS</u>	2 	-8 (D8e) 	<u>OSTEOSNUM</u>	1 (D9) <u>OSTEOBRO</u>	2 	-8 (D9) 	<u>OSTEOBNUM</u>
D9. Spine fractures?	1 <u>SPINEMOM</u>	2 	-8 	1 <u>SPINEDAD</u>	2 	-8 	1 (D9e) <u>SPINESIS</u>	2 	-8 (D9e) 	<u>SPINESNUM</u>	1 (D10) <u>SPINEBRO</u>	2 	-8 (D10) 	<u>SPINEBNUM</u>
D10. Dowager's (spine) hump?	1 <u>HUMPMOM</u>	2 	-8 	1 <u>HUMPDAD</u>	2 	-8 	1 (D10e) <u>HUMPSIS</u>	2 	-8 (D10e) 	<u>HUMPSNUM</u>	1 (D11) <u>HUMPBRO</u>	2 	-8 (D11) 	<u>HUMPBNUM</u>
D11. Colon cancer?	1 <u>COLONMOM</u>	2 	-8 	1 <u>COLONDAD</u>	2 	-8 	1 (D11e) <u>COLONSIS</u>	2 	-8 (D11e) 	<u>COLOSNUM</u>	1 (D12) <u>COLONBRO</u>	2 	-8 (D12) 	<u>COLONBNUM</u>
D12. Depression lasting longer than 4 weeks?	1 <u>DEPRMOM</u>	2 	-8 	1 <u>DEPRDAD</u>	2 	-8 	1 (D12e) <u>DEPRSIS</u>	2 	-8 (D12e) 	<u>DEPRSNUM</u>	1 (E1) <u>DEPRBRO</u>	2 	-8 (E1) 	<u>DEPRBNUM</u>

Have any of the following blood relatives had breast cancer?

		NO	YES	NOT APPLICABLE	DON'T KNOW	a. How old was she when her breast cancer was first diagnosed? (If you don't know the exact age, please guess as closely as you can.)
E1. Mother?	<u>BCMOM</u>	1 (E2)	2		-8 (E2)	<u>BCDIAMO</u> ____ years
E2. Sister(s)?	<u>BCSIS</u>	1 (E3)	2		-8 (E3)	b. Is/was she a full or half sister? FULL HALF
E2.1. How many sisters had breast cancer?	<u>BCNUMSIS</u> ____ (E2a)					<u>BCDIAS1</u> years <u>BCSISFH1</u> 1 2 <u>BCDIAS2</u> years <u>BCSISFH2</u> 1 2 <u>BCDIAS3</u> years <u>BCSISFH3</u> 1 2
E3. Maternal Grandmother (your mother's mother)?	<u>BCMGR</u>	1 (E4)	2		-8 (E4)	<u>BCDIAMG</u> ____ years
E4. Paternal Grandmother (your father's mother)?	<u>BCPGR</u>	1 (E5)	2		-8 (E5)	<u>BCDIAPG</u> ____ years
E5. Maternal Aunt (s) (your mother's sisters)?	<u>BCMAU</u>	1 (E6)	2	-1 (E6)	-8 (E6)	<u>BCDIAM1</u> ____ years <u>BCDIAM2</u> ____ years <u>BCDIAM3</u> ____ years
E5.1. How many maternal aunts had breast cancer?	<u>BCNUMMAU</u> (E5a)					
E6. Paternal Aunt (s) (your father's sisters)?	<u>BCPAU</u>	1 (E7)	2	-1 (E7)	-8 (E7)	<u>BCDIAP1</u> ____ years <u>BCDIAP2</u> ____ years <u>BCDIAP3</u> ____ years
E6.1. How many paternal aunts had breast cancer?	<u>BCNUMPAU</u> ____ (E6a)					

	NO	YES	NOT APPLICABLE	DON'T KNOW	a. How old was she when her breast cancer was first diagnosed? (If you don't know the exact age, please guess as closely as you can.)
E7. Other blood relatives? <u>BCOTH</u>	1	2		-8	
E7.1 Please specify relationship <u>BCOTH1</u> _____					<u>BCDIAOT1 – BCDIAOT10</u> _____ years _____ years _____ years

Follow-up SWAN Family Medical History Interview Form

**Study of Women's Health Across the Nation
FAMILY MEDICAL HISTORY INTERVIEW**

SECTION A. GENERAL INFORMATION

AFFIX ID LABEL HERE

A1. RESPONDENT ID: **ARCHID~**

A2. SWAN STUDY VISIT # **FUPVISIT**

A3. FORM VERSION: 03/01/2002 **#FORM_V**

A4. DATE FORM COMPLETED: M M / D D / Y Y Y Y **FUPDAY[†]**

A5. INTERVIEWER'S INITIALS: **#INITS**

A6. RESPONDENT'S DOB: M M / D D / 1 Y Y Y Y **VERIFY WITH RESPONDENT
#DOB**

A7. INTERVIEW COMPLETED IN: **#LOCATION**

- | | |
|----------------------------------|---|
| RESPONDENT'S HOME..... | 1 |
| CLINIC/OFFICE | 2 |
| RESPONDENT'S HOME BY PROXY | 3 |
| CLINIC/OFFICE BY PROXY | 4 |
| TELEPHONE..... | 5 |
| TELEPHONE BY PROXY | 6 |

A8. INTERVIEW LANGUAGE: **FUPLANG**

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

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

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

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SWAN Family Medical History Dataset Codebook

During this section of the interview, I am going to ask you about your family medical history. One's family history may play an important role in that person's own health. Thus, it is important for us in assessing the health of women in our study to have an understanding of health and illness in their families. Please include information about the health of all your relatives even if some are deceased. We realize that some of these questions may be difficult or sensitive. SWAN is thinking about adding some family health information in the future. To learn if this is possible, we will ask where each of your family members lives. Please be assured that we appreciate any information you wish to provide, and we will treat it confidentially, as we do with all of your information. However, as always, you are free to refuse to answer any question you do not wish to. IF RESPONDENT COMPLETED A PREVIOUS FAMILY MEDICAL HISTORY INTERVIEW, ALSO SAY, We know that most of these questions were asked several years ago, but it will be very helpful to go through them again today.

B1. WAS THE PARTICIPANT'S BIOLOGICAL MOTHER REPORTED DECEASED DURING THE PREVIOUS FAMILY MEDICAL HISTORY INTERVIEW? **#MOMRPTDE**

NO, BECAUSE NO PREVIOUS FAMILY HISTORY INTERVIEW WAS DONE0

NO.....1

YES.....2 (GO TO B5)

B2. Is your biological mother (the one who gave birth to you) still living? **MOMALIVE**

NO.....1

YES.....2 (GO TO B3)

DON'T KNOW.....-8 (GO TO B5)

B2a. How old was your mother when she died? ____ YEARS **MOMDIED**

DON'T KNOW-8

B2a1. What was the cause of death? _____ (GO TO B5) **#MOMCOD**

DON'T KNOW-8

REFUSED-7

B3. How old is your mother now? ____ YEARS

DON'T KNOW.....-8

MOMAGE

B4. Where does your mother currently live?

B4a) City _____ **#MOMCITY** _____

B4b) State _____ **#MOMSTATE**

B4c) USA _____ **#MOMCOUNT**

DON'T KNOW-8

REFUSED-7

DON'T KNOW-8

REFUSED-7

Other Country _____ **#MOTHCOUN** _____

DON'T KNOW -8

REFUSED -7

B5. WAS THE PARTICIPANT'S BIOLOGICAL FATHER REPORTED DECEASED DURING THE PREVIOUS FAMILY HISTORY INTERVIEW? **#DADRPTDE**

NO, BECAUSE NO PREVIOUS FAMILY HISTORY INTERVIEW WAS DONE0
NO.....1
YES.....2 **(GO TO B9)**

B6. Is your biological father still living? **DADALIVE**

NO.....1
YES.....2 **(GO TO B7)**
DON'T KNOW.....-8 **(GO TO B9)**

B6a. How old was your father when he died? _____ YEARS **DADDIED**
DON'T KNOW-8

B6a1. What was the cause of death? _____ **(GO TO B9) #DADCOD**
DON'T KNOW-8
REFUSED-7

B7. How old is your father now? _____ YEARS **DADAGE**
DON'T KNOW.....-8

B8. Where does your father currently live?

B8a) City _____ #DADCITY	B8b) State _____ #DADSTATE	B8c) USA #DADCOUNT
DON'T KNOW-8	DON'T KNOW-8	Other Country _____ #DAOHTCOU _____
REFUSED-7	REFUSED-7	DON'T KNOW -8
		REFUSED -7

B9. IF NO PREVIOUS FAMILY HISTORY, ASK "How many brothers do you have? This includes only blood relatives -- full or half brothers and does *not* include step- or adopted brothers." (CIRCLE "0" & RECORD # IN 9a), OTHERWISE ASK, "According to the information you gave us a few years ago, you have NUMBROS brothers. This includes only blood relatives -- full or half brothers and does *not* include step- or adopted brothers. Is this correct?" **#CRRCTNBR**

NO, B/C NO PREVIOUS FAM HX INTERVIEW DONE0 **#NEWNUMBR**
NO.....1 **IF NO:** B9a. How many brothers do you have? _____
YES.....2
.....BROTHERS

B9b. COMMENTS: **#BROCOMMT**

B10. IF NO PREVIOUS FAMILY HISTORY, ASK "How many sisters do you have? This includes only blood relatives -- full or half sisters and does *not* include step- or adopted sisters." (CIRCLE "0" & RECORD # IN B10a), OTHERWISE ASK, "According to the information you provided us with a few years ago, you have **NUMSIS** sisters. This includes only blood relatives -- full or half sisters and does *not* include step- or adopted sisters. Is this correct?" **#CRRCTNSI**

NO, B/C NO PREVIOUS FAM HX. INTERVIEW DONE 0

#NEWNUMSI

NO 1

IF NO: B10a. How many sisters do you have? _____

YES..... 2

SISTERS

B10b. COMMENTS: **#SISCOMMT**

(IF NO SISTERS/LIVING SISTERS, GO TO C1)

Next, we are interested in learning more about your sisters and some of their menstrual history. We realize that you may not know some of the answers.

The first sister we will be talking about is.... IF NO PREVIOUS FAMILY HISTORY, Is she a full- or half-sister? F=FULL H=HALF	a. Is this sister still living?		b. How old is she? (OR: How old was she when she died?) <i>IF DECEASED, SKIP QUESTIONS c-f and GO TO NEXT SISTER</i>	c. Where does she live?	d. Has she had a period in the last year?			e. At what age did she stop having periods?	f. Did her periods stop naturally, because of current pregnancy or breast feeding, due to surgery, or due to medication or radiation?						
NO	YES	AGE IN YEARS	DON'T KNOW	CITY STATE COUNTRY	NO	YES	DON'T KNOW	AGE IN YEARS	DON'T KNOW	NATURAL	PREGNANT OR BREAST-FEEDING	SURGERY	MEDICATION OR RADIATION	DON'T KNOW	
#FULHAL1 B11. F H	1	2	-8		1	2 (B12)	-8 (B12)		-8	1	2	3	4	-8	
#SISTER1	SISLVNG1	SISAGE1		SISLIV1		SISPERI1					SISSTOP1				
#FULHAL2 B12. F H	1	2	-8		1	2 (B13)	-8 (B13)		-8	1	2	3	4	-8	
#SISTER2	SISLVNG2	SISAGE2		SISLIV2		SISPERI2					SISSTOP2				
#FULHAL3 B13. F H	1	2	-8		1	2 (B14)	-8 (B14)		-8	1	2	3	4	-8	
#SISTER3	SISLVNG3	SISAGE3		SISLIV3		SISPERI3					SISSTOP3				
#FULHAL4 B14. F H	1	2	-8		1	2 (B15)	-8 (B15)		-8	1	2	3	4	-8	
#SISTER4	SISLVNG4	SISAGE4		SISLIV4		SISPERI4					SISSTOP4				

The next sister we will be talking about is.... IF NO PREVIOUS FAMILY HISTORY, Is she a full- or half-sister?	a. Is this sister still living? b. How old is she? (OR: How old was she when she died?) <i>IF DECEASED, SKIP QUESTIONS c-f and GO TO NEXT SISTER</i>												c. Where does she live? d. Has she had a period in the last year? e. At what age did she stop having periods? f. Did her periods stop naturally, because of current pregnancy or breast feeding, due to surgery, or due to medication or radiation?												
	F=FULL H=HALF		NO	YES	AGE IN YEARS	DON'T KNOW	CITY STATE COUNTRY	NO	YES	DON'T KNOW	AGE IN YEARS	DON'T KNOW	NATURAL	PREGNANT OR BREAST-FEEDING	SURGERY	MEDICATION OR RADIATION	DON'T KNOW								
#FULHAL5 B15. F H #SISTER5	1	2	-8				1	2 (B16)	-8 (B16)		-8		1	2	3	4	-8								
<u>SISLVNG5</u>				<u>SISAGE5</u>		<u>SISLIV5</u>																			
#FULHAL6 B16. F H #SISTER7	1	2	-8				1	2 (B17)	-8 (B17)		-8		1	2	3	4	-8								
<u>SISLVNG6</u>				<u>SISAGE6</u>		<u>SISLIV6</u>																			
#FULHAL7 B17. F H #SISTER7	1	2	-8				1	2 (B18)	-8 (B18)		-8		1	2	3	4	-8								
<u>SISLVNG7</u>				<u>SISAGE7</u>		<u>SISLIV7</u>																			
#FULHAL8 B18. F H #SISTER8	1	2	-8				1	2 (B19)	-8 (B19)		-8		1	2	3	4	-8								
<u>SISLVNG8</u>				<u>SISAGE8</u>		<u>SISLIV8</u>																			
#FULHAL9 B19. F H #SISTER9	1	2	-8				1	2 (B20)	-8 (B20)		-8		1	2	3	4	-8								
<u>SISLVNG9</u>				<u>SISAGE9</u>		<u>SISLIV9</u>																			
#FULHAL10 B20. F H #SISTER10	1	2	-8				1	2 (B20)	-8 (B20)		-8		1	2	3	4	-8								
<u>SISLVG10</u>				<u>SISAGE10</u>		<u>SISLIV10</u>																			
#FULHAL11 B21. F H #SISTER11	1	2	-8				1	2 (B21)	-8 (B21)		-8		1	2	3	4	-8								
<u>SISLVG11</u>				<u>SISAGE11</u>		<u>SISLIV11</u>																			
#FULHAL12 B22. F H #SISTER12	1	2	-8				1	2 (B23)	-8 (B23)		-8		1	2	3	4	-8								
<u>SISLVG12</u>				<u>SISAGE12</u>		<u>SISLIV12</u>																			

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SWAN Family Medical History Dataset Codebook

SECTION C. FAMILY HEART DISEASE HISTORY

We would like to get some information about history of heart disease in your blood relatives. This includes your mother and father and brothers and sisters. For these next few questions we want you to think about these relatives even if they have died.

- C1. Did your mother ever have angina (chest pain), a heart attack, or a procedure to open a blocked blood vessel in the heart (bypass surgery or angioplasty)?

HEARTMOM

NO.....	1	(GO TO C2)
YES.....	2	
DON'T KNOW.....	-8	(GO TO C2)

- C1a. IF YES, was this before she was 65 years old?

MOHART65

NO.....	1
YES.....	2
DON'T KNOW.....	-8

- C2. Did a sister ever have angina (chest pain), a heart attack, or a procedure to open a blocked blood vessel in the heart (bypass surgery or angioplasty)?

HEARTSIS

NO.....	1	(GO TO C3)
YES.....	2	
NOT APPLICABLE (No Sisters).....	-1	(GO TO C3)
DON'T KNOW.....	-8	(GO TO C3)

- C2a. IF YES, was this before she was 65 years old?

SIHART65

NO.....	1
YES.....	2
DON'T KNOW.....	-8

- C3. Did your father ever have angina (chest pain), a heart attack, or a procedure to open a blocked blood vessel in the heart (bypass surgery or angioplasty)? **HEARTDAD**

NO.....	1	(GO TO C4)
YES.....	2	
DON'T KNOW.....	-8	(GO TO C4)

- C3a. IF YES, was this before he was 55 years old? **DAHART55**

NO.....	1	
YES.....	2	
DON'T KNOW.....	-8	

- C4. Did a brother ever have angina (chest pain), a heart attack, or a procedure to open a blocked blood vessel in the heart (bypass surgery or angioplasty)? **HEARTBRO**

NO.....	1	(GO TO D1)
YES.....	2	
NOT APPLICABLE (No Brothers).....	-1	(GO TO D1)
DON'T KNOW.....	-8	(GO TO D1)

- C4a. IF YES, was this before he was 55 years old? **BRHART55**

NO.....	1	
YES.....	2	
DON'T KNOW.....	-8	

SECTION D. FAMILY MEDICAL HISTORY

Now, I'm going to read you a list of medical conditions. Please tell me if anyone in your immediate family has ever been told by a health care provider that she/he had any of the following conditions? Please include only blood relatives.

	a. Mother?			b. Father?			c. Any sisters?			d. How many of your sisters had this?	e. Any brothers?			f. How many of your brothers had this?
	NO	YES	DK	NO	YES	DK	NO	YES	DK		NO	YES	DK	
D1. Arthritis?	1 <u>ARTHRMOM</u>	2 -8		1 <u>ARTHRDAD</u>	2 -8		1 (D1e) <u>ARTHRSIS</u>	2 -8 (D1e)		<u>ARTHSNUM</u>	1 (D2) <u>ARTHRBRO</u>	2 -8 (D2)		<u>ARTHBNUM</u>
D2. High blood pressure?	1 <u>HIBPMOM</u>	2 -8		1 <u>HIBPDAD</u>	2 -8		1 (D2e) <u>HIBPSIS</u>	2 -8 (D2e)		<u>HIBPSNUM</u>	1 (D3) <u>HIBPBRO</u>	2 -8 (D3)		<u>HIBPBNUM</u>
D3. Diabetes?	1 <u>DIABMOM</u>	2 -8		1 <u>DIABDAD</u>	2 -8		1 (D3e) <u>DIABSIS</u>	2 -8 (D3e)		<u>DIABSNUM</u>	1 (D4) <u>DIABBRO</u>	2 -8 (D4)		<u>DIABBNUM</u>
D4. Stroke?	1 <u>STRKMOM</u>	2 -8		1 <u>STRKDAD</u>	2 -8		1 (D4e) <u>STRKSIS</u>	2 -8 (D4e)		<u>STRKSNUM</u>	1 (D5) <u>STRKBRO</u>	2 -8 (D5)		<u>STRKBNUM</u>
D5. Hip fracture?	1 <u>HIPMOM</u>	2 -8		1 <u>HIPDAD</u>	2 -8		1 (D5e) <u>HIPSIS</u>	2 -8 (D5e)		<u>HIPSNUM</u>	1 (D6) <u>HIPBRO</u>	2 -8 (D6)		<u>HIPBNUM</u>
D6. Osteoporosis (brittle bones)?	1 <u>OSTEOMOM</u>	2 -8		1 <u>OSTEODAD</u>	2 -8		1 (D6e) <u>OSTEOSIS</u>	2 -8 (D6e)		<u>OSTEOSNUM</u>	1 (D7) <u>OSTEOBRO</u>	2 -8 (D7)		<u>OSTEOBNUM</u>
D7. Spine fractures?	1 <u>SPINEMOM</u>	2 -8		1 <u>SPINEDAD</u>	2 -8		1 (D7e) <u>SPINESIS</u>	2 -8 (D7e)		<u>SPINESNUM</u>	1 (D8) <u>SPINEBRO</u>	2 -8 (D8)		<u>SPINEBNUM</u>
D8. Dowager's (spine) hump?	1 <u>HUMPMOM</u>	2 -8		1 <u>HUMPDAD</u>	2 -8		1 (D8e) <u>HUMPSIS</u>	2 -8 (D8e)		<u>HUMPSNUM</u>	1 (D9) <u>HUMPBRO</u>	2 -8 (D9)		<u>HUMPBNUM</u>
D9. Colon cancer?	1 <u>COLONMOM</u>	2 -8		1 <u>COLONDAD</u>	2 -8		1 (D9e) <u>COLONSIS</u>	2 -8 (D9e)		<u>COLONSNUM</u>	1 (D10) <u>COLONBRO</u>	2 -8 (D10)		<u>COLONBNUM</u>
D10. Depression lasting longer than 4 weeks?	1 <u>DEPRMOM</u>	2 -8		1 <u>DEPRDAD</u>	2 -8		1 (D10e) <u>DEPRSIS</u>	2 -8 (D10e)		<u>DEPRSNUM</u>	1 (E1) <u>DEPRBRO</u>	2 -8 (E1)		<u>DEPRBNUM</u>

SECTION E. Have any of the following blood relatives had breast cancer? Please tell us even if you told us about this a few years ago.

	NO	YES	NOT APPLICABLE	DON'T KNOW	a. How old was she when her breast cancer was first diagnosed? (If you don't know the exact age, please guess as closely as you can.)
E1. Mother? BCMOM	1 (E2)	2		-8 (E2)	BCDIAMO years
E2. Sister(s)? BCSIS	1 (E3)	2		-8 (E3)	b. Is/was she a full or half sister? FULL HALF BCDIAS1 years 1 BCSISFH1 2 BCDIAS2 years 1 BCSISFH2 2 BCDIAS3 years 1 BCSISFH3 2
E2.1. How many sisters had breast cancer? _____(E2a)					
E3. Maternal Grandmother (your mother's mother)? BCMGR	1 (E4)	2		-8 (E4)	BCDIAMG years
E4. Paternal Grandmother (your father's mother)? BCPGR	1 (E5)	2		-8 (E5)	BCDIAPG years
E5. Maternal Aunt (s) (your mother's sisters)? BCMAU	1 (E6)	2	-1 (E6)	-8 (E6)	 BCDIAM1 years BCDIAM2 years BCDIAM3 years
E5.1. How many maternal aunts had breast cancer? _____(E5a) BCNUMMAU					
E6. Paternal Aunt (s) (your father's sisters)? BCPAU	1 (E7)	2	-1 (E7)	-8 (E7)	 BCDIAP1 years BCDIAP2 years BCDIAP3 years
E6.1. How many paternal aunts had breast cancer? _____(E6a) BCNUMPAU					
E7. Other blood relatives? BCOTH	1	2		-8	BCDIAOT1 – BCDIAOT10
E7.1 If yes please specify					______ years
a. BCOTH1					
b. BCOTH2					
BCOTH3 – BCOTH10					

SECTION F.

F1. DID THE RESPONDENT PREVIOUSLY COMPLETE A FAMILY MEDICAL HISTORY INTERVIEW? #PREVFAHX

NO	1
YES	2 (END OF INTERVIEW)

Next, we are interested in learning more about your mother's menstrual history. We realize that you may not know some of the answers.

F2. Do you know at about what age your biological mother stopped menstruating? **AGESTOP**

<30.....	1
30-34	2
35-39	3
40-44	4
45-49	5
50-54	6
55+.....	7
STILL MENSTRUATING WHEN SHE DIED	8 (GO TO F5)
UNCERTAIN IF STILL MENSTRUATING WHEN SHE DIED	9 (GO TO F5)
STILL MENSTRUATING DUE TO TAKING HORMONES	10 (GO TO F5)
DON'T KNOW	-8

F3. Did she stop menstruating naturally or did she stop due to surgery, medication or radiation treatments?
(CIRCLE ONLY ONE) **STOPMEN**

NATURAL.....	1
SURGERY.....	2
MEDICATION OR RADIATION	3
DON'T KNOW	-8

F4. Did your biological mother have any symptoms such as hot flashes, irregular or heavy periods, sleep problems or mood changes or problems associated with stopping her menstruation? SYMPTOM

- NO 1 (**GO TO F5**)
YES 2
DON'T KNOW -8 (**GO TO F5**)

F4a. Which of the following did she have?

	NO	YES	DON'T KNOW
1. Hot flashes?	1	2	-8 HOTFLAS
2. Irregular or heavy periods?	1	2	-8 HEVYPER
3. Sleep problems?	1	2	-8 SLEEPRO
4. Mood changes or problems?	1	2	-8 PSYPROB
5. Other?	1	2	-8 OTHRPROB

SPECIFY _____ **#OTHRPRS**

Now, we would like to ask you a few questions about the woman who raised you. This might be, for example, your biological mother, a step-mother, an aunt, or a grandmother.

F5. How much did the woman who raised you discuss her menopause with you? HERMENO

- Not at all 1
In some detail 2
In great detail 3
NOT APPLICABLE -1 (**END OF INTERVIEW**)

F6. How often did she discuss menopause in general with you? GENMENO

- Never 1
Occasionally or rarely 2
Sometimes 3
Often 4

F7. Which of the following best describes her overall attitudes or perceptions about menopause? ATTIMEN

- Neutral 1
Positive 2
Negative 3
DON'T KNOW -8

END OF INTERVIEW.

Thank you