Agricultural Health Study Health Follow Up

Attachment 26.4: Agricultural Health Study Phase IV Health Follow-Up Proxy Paper & Pen Survey

<Insert Proxy-appropriate intro text here>

Instructions:

- Please use dark blue or black ballpoint pen.
- Based on your answers, some questions will be skipped. If there's an arrow next to the answer you chose, please follow it for skip instructions.
- When we ask for dates or ages, if you can't remember the exact year or how old the study participant was when something happened, please give us your best guess.
- When we ask how many years the study participant did something, please round to the nearest whole number.

Fill in the bubbles COMPLETELY for each of the questions in this form.

Like this: • Yes

Not like this:

37863601

Collection of this information is authorized by The Public Health Service Act (42 USC 2851). Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private to the extent provided by law. Names and other identifiers will not appear in any report of the study. Information provided will be combined for all study participants and reported as summaries. You are being contacted by mail to complete this health follow-up survey because as a member of the Agricultural Health Study your continued involvement can help us learn more about how agricultural and environmental factors may affect the health of farmers and their families.

Public reporting burden for this collection of information is estimated to average 10 to 15 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing the collection of information. **An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0406). Do not return the completed form to this address.

Before you get started, we need you to confirm the information located on the label on the front cover of this survey. Please look at the label that indicates the name and date of birth of the person that this survey is for and about.

- **A.** Which of the following statements is true about the name on the label?
 - 1. This name is correct
 - 2. This name was correct, but it has since changed
 - \Box 3. This name is incorrect \rightarrow

Stop! Please call our Study Line at 1–855– 443–2692. If asked to leave a message, please leave us your name, phone number (including area code), and the best time of day to reach you. We apologize for the inconvenience.

- **B.** Which of the following statements is true about the date of birth on the label?
 - 1. The date of birth is correct
 - □ 2. The date of birth is incorrect → Stop! Please call our Study Line at 1–

Stop! Please call our Study Line at 1– 855–443–2692. If asked to leave a message, please leave us your name, phone number (including area code), and the best time of day to reach you. We apologize for the inconvenience.

Tobacco and Alcohol

1. Did he/she smoke a total of 100 cigarettes or more during his/her lifetime?



2. How old was he/she when he/she first started smoking cigarettes?

|__|_ Age

3. How old was he/she when he/she last smoked cigarettes?



4. Thinking about all the years that he/she smoked, about how many cigarettes per day did he/she usually smoke on days when he/she smoked?

|__|_ Cigarettes per day

5. The following questions ask about drinking alcoholic beverages including beer or ale, wine, wine coolers, champagne, mixed drinks, and liquor.

When you are asked about a "drink," think about a 12-ounce bottle or can of beer, a 5ounce glass of wine or champagne, one wine cooler, one shot of liquor, or one mixed drink or cocktail.

Did he/she ever drink any type of alcoholic beverage?

☐ Yes
☐ No → Skip to 7 (General Health)

6. How old was he/she when he/she last consumed an alcoholic beverage?

|__|_ Age

General Health

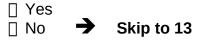
7. About how tall was he/she? Please answer in feet and inches, and round to the nearest inch.

|_| Feet |_| Inches

8. About how much did he/she weigh?

|__| Pounds

- **9.** Has anyone in his/her immediate family related **by blood** (his/her mother, father, sisters, brothers, or children) ever been diagnosed with asthma?
 - YesNo
- **10.** Has anyone in his/her immediate family related **by blood** (his/her mother, father, sisters, brothers, or children) ever been diagnosed with Parkinson's Disease?
 - YesNo
- **11.** Has anyone in his/her immediate family related **by blood** (his/her mother, father, sisters, brothers, or children) ever had cancer?



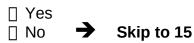
- **12.** What type(s) of cancer? Mark all that apply.
 - Bladder
 - □ Bone
 - □ Brain
 - ☐ Breast
 - Cervical
 - \square Colon or rectal
 - Esophagus
 - ☐ Kidney

 - Liver

 - 🛛 Lung

- Lymphoma
- 🛛 Melanoma
- Multiple myeloma
- 🛛 Ovarian
- Pancreatic
- \square Prostate
- ☐ Stomach
- Thyroid
- Uterine or endometrial
- Other type of cancer
- Don't know type

13. Was the study participant himself/herself ever diagnosed with or had cancer?



- **14.** What type(s) of cancer? Mark all that apply.
 - □ Bladder
 - Bone
 - 🛛 Brain
 - Breast
 - Cervical
 - \Box Colon or rectal
 - Esophagus
 - ☐ Kidney
 - Leukemia
 - Liver
 - 🛛 Lung

- Lymphoma
- 🛛 Melanoma
- Multiple myeloma
- 🛛 Ovarian
- Pancreatic
- Prostate
- Stomach
- 🛛 Thyroid
- Uterine or endometrial
- ☐ Other type of cancer
- Don't know type

Health Conditions

15. These questions are about medical conditions. Please only report conditions that were diagnosed by a doctor or other health professional. We are interested in what age he/she was diagnosed with a specific condition. If you do not know the exact age, please give us your best guess.

Was he/she ever diagnosed with Parkinson's disease?

🛛 Yes	_	
🛛 No	\rightarrow	Skip to 20

16. How old was he/she when first diagnosed with Parkinson's disease?

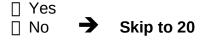


17. Was the diagnosis made or confirmed by a neurologist or movement disorder specialist?

YesNo

18. Did he/she ever take any prescribed medicines for Parkinson's disease? Examples include:

Carbidopa or levodopa (brand names such as Sinemet, Stalevo, or Parcopa); Mirapex or Pramipexole; Requip or Ropinirole; Permax or Pergolide



19. Did his/her symptoms ever improve after taking any of these medicines?

Ves
No

20. Was he/she ever diagnosed with a heart attack (or myocardial infarction)?

🛛 Yes	_	
🛛 No	→	Skip to 22

21. How old was he/she when first diagnosed with a heart attack (or myocardial infarction)?

|__|_| Age

22. Was he/she ever diagnosed with depression?

	 ☐ Yes ☐ No → Skip to 24
23.	How old was he/she when first diagnosed with depression?
	Age
24.	Was he/she ever diagnosed with high blood pressure or hypertension?
	☐ Yes ☐ No → Skip to 26
25.	How old was he/she when first diagnosed with high blood pressure or hypertension?
	Age
26.	Was he/she ever diagnosed with heart failure ?
	☐ Yes ☐ No → Skip to 28
27.	How old was he/she when first diagnosed with heart failure?
	Age
28.	Was he/she ever diagnosed with a stroke ? Do not include TIAs or mini-strokes.
	 ☐ Yes ☐ No → Skip to 30
29.	How old was he/she when first diagnosed with a stroke?
	Age
30.	Was he/she ever diagnosed with asthma?
	 ☐ Yes ☐ No → Skip to 32
31.	How old was he/she when first diagnosed with asthma?
	Age
32.	Was he/she ever diagnosed with Farmer's Lung ?

	🛛 No 🔿 Skip to 34
33.	How old was he/she when first diagnosed with Farmer's Lung?
34.	Was he/she ever diagnosed with idiopathic pulmonary fibrosis ? ☐ Yes ☐ No → Skip to 36
35.	How old was he/she when first diagnosed with idiopathic pulmonary fibrosis?
36.	Was he/she ever diagnosed with emphysema ? ☐ Yes ☐ No → Skip to 38
37.	How old was he/she when first diagnosed with emphysema?
38.	Was he/she ever diagnosed with chronic bronchitis ? ☐ Yes ☐ No → Skip to 40
39.	How old was he/she when first diagnosed with chronic bronchitis?
40.	Was he/she ever diagnosed with chronic obstructive pulmonary disease (COPD)? ☐ Yes ☐ No → Skip to 42
41.	How old was he/she when first diagnosed with chronic obstructive pulmonary disease (COPD)?

|__|__| Age

42. Was he/she ever diagnosed with diabetes?

🛛 Yes		
🗌 No	\rightarrow	Skip to 46

43. How old was he/she when first diagnosed with diabetes?



- 44. Did he/she ever take any prescribed medicines for diabetes?
 - ☐ Yes
 ☐ No → Skip to 46
- 45. Did he/she ever take insulin?
 - □ Yes □ No
- 46. Was he/she ever diagnosed with thyroid disease or thyroid problems?
 - ☐ Yes
 ☐ No → Skip to 53
- 47. Was he/she ever diagnosed with an overactive thyroid (hyperthyroidism)?
 - ☐ Yes
 ☐ No → Skip to 50
- 48. How old was he/she when first diagnosed with an overactive thyroid?

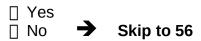


- **49.** Was this **Graves' disease** or some other type of thyroid condition that caused the overactive thyroid gland?
 - Graves' disease
 - Other overactive thyroid condition
 - Don't know
- 50. Was he/she ever diagnosed with an underactive thyroid (hypothyroidism)?
 - ☐ Yes
 ☐ No → Skip to 53

51. How old was he/she when first diagnosed with an underactive thyroid (hypothyroidism)?

|__|_ Age

- **52.** Was this **thyroiditis**, sometimes called Hashimoto's thyroiditis, or was this some other type of thyroid condition that caused the underactive thyroid gland?
 - Thyroiditis (also called Hashimoto's thyroiditis)
 - Other underactive thyroid condition
 - Don't know
- 53. Was he/she ever diagnosed with kidney stones?



54. How old was he/she when first diagnosed with kidney stones?

|__|_ Age

55. How many times has he/she had kidney stones?

|__| Times

56.	Was he/she ever diagnosed with kidn	ey disease? Do not include kidney stones.

Yes		
No	\rightarrow	Skip to 60

57. How old was he/she when first diagnosed with kidney disease?



58. Was he/she ever treated with dialysis?

🛛 Yes		
□ No ▪	→	Skip to 60

59. How old was he/she when first treated with dialysis?



- **60.** Was he/she ever diagnosed with **rheumatoid arthritis** (an autoimmune disease)? Do not include osteoarthritis (the most common type of arthritis).
 - ☐ Yes
 ☐ No → Skip to 64
- 61. How old was he/she when first diagnosed with rheumatoid arthritis?



- **62.** Did he/she see a rheumatologist (a physician who specializes in bone, joint, and skin diseases) for rheumatoid arthritis?
 - YesNo
- 63. Did he/she ever take any of the following medicines for rheumatoid arthritis?

Mark an answer for each row below:		No	Don't know
a. Hydroxychloroquine or chloroquine (Plaquenil), Methotrexate (Rheumatrex or Trexall)			
b. Leflunomide (Arava), Sulfasalazine (Azulfidine)			
 Biologics, given by infusion or injection, such as infliximab (Remicade), adalimumab (Humira), etanercept (Enbrel), rituximab (Rituxan). Do not include steroid injections in the joints. 			

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64. Was he/she ever diagnosed with **lupus**?

🛛 Yes	_	
🛛 No	\rightarrow	Skip to 68

65. How old was he/she when first diagnosed with lupus?

	Age
--	-----

- **66.** Did he/she see a rheumatologist (a physician who specializes in bone, joint, and skin diseases) for lupus?
 - YesNo
- 67. Did he/she ever take any of the following medicines for lupus?

Mark an answer for each row below:	Yes	No	Don't know
a. Hydroxychloroquine or chloroquine (Plaquenil), Methotrexate (Rheumatrex or Trexall)			
b. Azathioprine (Imuran), Cellcept, Cytoxan, or Cyclosporine			
c. Biologics, given by infusion or injection, such as belimumab (Benlysta). Do not include steroid injections in the joints or skin.			

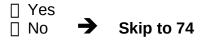
- 68. Was he/she ever diagnosed with Sjögren's disease?
 - ☐ Yes
 ☐ No → Skip to 72
- 69. How old was he/she when first diagnosed with Sjögren's disease?

	Age
--	-----

- **70.** Did he/she see a rheumatologist (a physician who specializes in bone, joint, and skin diseases) or ear, nose and throat specialist for Sjögren's disease?
 - YesNo
- 71. Did he/she ever take any of the following medicines for Sjögren's disease?

Mark an answer for each row below:	Yes	No	Don't know
a. Hydroxychloroquine or chloroquine (Plaquenil), or Methotrexate (Rheumatrex or Trexall)			
b. Pilocarpine (Salagen) or Cevimeline (Evoxac), or Cyclosporine Ophthalmic (Restasis)			
c. Biologics, given by infusion or injection, such as Rituximab (Rituxan)			

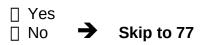
72. Was he/she ever diagnosed with sarcoidosis?



73. How old was he/she when first diagnosed with sarcoidosis?



74. Was he/she ever diagnosed with pesticide poisoning?



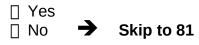
75. How old was he/she when first diagnosed with pesticide poisoning?

____ Age

76. How many times was he/she poisoned by pesticides?

| | | Times

77. Did he/she ever have a head injury requiring medical attention?



- **78.** Did he/she ever have a head injury that resulted in loss of consciousness (got knocked out)?
 - ☐ Yes
 ☐ No → Skip to 81

79. How old was he/she the first time he/she lost consciousness from a head injury?

|__|_ Age

80. How many times did he/she have a head injury with loss of consciousness?

	Times

- **81.** Did he/she ever have hay fever, seasonal allergies or allergic rhinitis, **whether or not it was diagnosed** by a doctor?
 - YesNo
- **82.** Date this form was completed:

	/		/		
Month		Day		Year	

83. Thank you for completing the AHS Health Follow-up! Can we contact you again in the future?

☐ Yes → Please go to next page to fill out the contact information sheet.
 ☐ No

Contact Information

We would like to make sure that our records include your accurate contact information should we need to contact you in the future.

1a. Please record your phone number(s) in the spaces provided below.

Phone Numbers:
HOME: () _ - _
WORK: () _ - _
CELL: () _ -
OTHER:(_) _ - _
What is the best number to reach you? \Box Home \Box Work \Box Cell \Box Other
1b. If you have an E-mail address or multiple E-mail addresses, then please write them in the space below.
E-mail Address: _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _
E-mail Address:
E-mail Address: _ _ _ _ _ _ _ _
1c. What is your preferred method of contact? \Box Phone \Box Email \Box Mail
2. Please record your mailing address in the space provided below.
Address 1
City State Zip Code

Finally, we have just a two more questions we need answered that will help us better understand the responses you gave us about the Agricultural Health Study participant.

- **3.** What is your relationship to the person whose name is printed on the cover of this questionnaire?
 - 1. Spouse
 - 2. Sibling
 - 3. Child
 - 4. Grandchild
 - 5. Parent
 - ☐ 6. Other relative
 - 7. Guardian
 - 8. Friend
 - 9. Other
- **4.** How long have you known the person whose name is printed on the cover of this questionnaire?

[____] # Years