

<AHS Logo>

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: ☐

41666201

Collection of this information is authorized by The Public Health Service Act (42 USC 285I). 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
- 3. This name is incorrect → **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 1-855-443-2692. 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?

Yes

No → **Skip to 5**

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?

|_|_|_| Age

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 5-ounce 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?

Yes

No

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?

Yes

No

11. Has anyone in his/her immediate family related **by blood** (his/her mother, father, sisters, brothers, or children) ever had cancer?

Yes

No → **Skip to 13**

12. What type(s) of cancer? Mark all that apply.

Bladder

Bone

Brain

Breast

Cervical

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

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

Yes

No → **Skip to 15**

14. What type(s) of cancer? Mark all that apply.

Bladder

Bone

Brain

Breast

Cervical

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 → **Skip to 20**

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

|_|_|_| Age

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

- Yes
 No

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

- Yes
 No → **Skip to 20**

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

- Yes
 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**?

- Yes

No → **Skip to 34**

33. How old was he/she when first diagnosed with Farmer's Lung?

|_|_|_| Age

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?

|_|_|_| Age

36. Was he/she ever diagnosed with **emphysema**?

Yes

No → **Skip to 38**

37. How old was he/she when first diagnosed with emphysema?

|_|_|_| Age

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?

|_|_|_| Age

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 → **Skip to 46**

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

|_|_|_| Age

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?

|_|_|_| Age

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**?

Yes

No → **Skip to 56**

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 **kidney disease**? Do not include kidney stones.

- Yes
- No → **Skip to 60**

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

____ Age

58. Was he/she ever treated with dialysis?

- Yes
- No → **Skip to 60**

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

____ Age

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?

____ Age

62. Did he/she see a rheumatologist (a physician who specializes in bone, joint, and skin diseases) for rheumatoid arthritis?

- Yes
- No

63. Did he/she **ever** take any of the following medicines for rheumatoid arthritis?

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

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

- Yes
- No → **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?

- Yes
- No

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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Azathioprine (Imuran), Cellcept, Cytoxan, or Cyclosporine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Biologics, given by infusion or injection, such as belimumab (Benlysta). Do not include steroid injections in the joints or skin.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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?

- Yes
- No

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)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Pilocarpine (Salagen) or Cevimeline (Evoxac), or Cyclosporine Ophthalmic (Restasis)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Biologics, given by infusion or injection, such as Rituximab (Rituxan)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

72. Was he/she ever diagnosed with **sarcoidosis**?

- Yes
 No → **Skip to 74**

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

|_|_|_| Age

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

- Yes
 No → **Skip to 77**

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**?

- Yes
 No → **Skip to 81**

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?

Yes

No

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

No

➔ Please go to next page to fill out the contact information sheet.

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