AI/AN Flu Case-Control
Interview Questionnaire: PROXY for DECEASED PATIENT

I. Information available ahead of the interview (to be filled out by the interviewer).
DO NOT read section I to the respondent

Study ID # _____ Patient Name: _____

Specimen collection date: mm / dd / yyyy Status: ☐ **Case**
(Questions below will be in reference to this date) ☐ **Outpatient Control**
☐ **Hospitalized Control**

Interviewer: _____ Interview date: _____

Information Source: ☐ Patient ☐ **Proxy, Name: _____**

Use proxy (household member aged ≥18, preferably the parent or guardian) only if patient died or if he/she is age <18 years old or if there is an indication that patients are mentally or physically incapacitated to the point of not being able to respond for themselves.

Age of patient at the time of the death: _____

II. Introduction

START READING TO THE RESPONDENT with paragraph below, but do NOT read words in parentheses or in bold RED.

Hello, my name is _____ and I am calling on behalf of the_____ state health department and the Centers for Disease Control and Prevention. We are calling people to learn about their experiences with the pandemic H1N1 flu last year – I understand that you lost a loved one to the flu and I am so sorry for your loss. We are trying to learn more about why the pandemic flu made some people so sick. Hopefully this information will help us better protect people against the flu in the future. I have some questions about **[Patient Name].** Your answers are confidential and you don't have to answer any questions that you don't want to. Before we start do you have any questions for me? I will also give you a phone number in case you have follow-up questions.

There are approximately 35 questions; this should take an average of 20 minutes. Would you like to go on? ☐ Yes ☐ No

If not, what would be a better time to call back? _____ AM or PM

I've reached you at this phone number (refer to log sheet), is this the best number to reach you at? ☐ Yes ☐ No

If **"No"**, what is a better phone number: (__ __ __) __ __ __ - __ __ __ __

May I get your name?_____ (**Name of proxy**)

And what was your relationship with **[Patient Name]**? _____

Did you live with **[Patient Name]** at the time of **[his/her]** illness?
☐ Yes ☐ No

We are hoping to talk to the person who knows best about **[Patient Name]'s** health and living situation prior to their influenza illness last year. Would that be you? ☐ Yes ☐ No
If **"No",** who would be a better person to talk to?

Name_____ Relationship _____

Telephone #: (__ __ __) __ __ __ - __ __ __ __

****THANK RESPONDENT AND END INTERVIEW IF ANOTHER NAME IS GIVEN.**

These questions are only being asked of residents of XX (state). So, before we begin, at the time of **[Patient Name]'s** flu illness, what was **[his/her]** town or community, state, and zip code of residence?

Town/Community _____

State: _____

ZIP code: _____

****END INTERVIEW IF STATE OF RESIDENCE IS NOT AS EXPECTED.**

Ok, let's get started. The first couple questions are going to be about **[Patient Name]'s** use of health care and medical facilities.

(III. Healthcare use and Access)

1. At the time of **[Patient Name]'s** illness with H1N1, did **[he/she]** have one person **[he/she]** thought of as **[his/her]** personal doctor or health care provider?
   - ☐ Yes→q1a
   - ☐ No→q2
   - ☐ Don't know→q2
   - ☐ Refused→q2

   1a. If **"Yes",** what was that person's background/training? **(Check all that apply)**
   - ☐ Physician (MD, DO)
   - ☐ Traditional healer
   - ☐ Nurse Practitioner/Physician Assistant
   - ☐ Naturopath
   - ☐ Chiropractor
   - ☐ Other (specify) _____
   - ☐ Don't know
   - ☐ Refused

2. In the 12 months before **[Patient Name]** was diagnosed with H1N1 flu, did **[he/she]** see a doctor, nurse or other health professional to get any kind of care? This would have been from mm 2008 through mm 2009. **(Select only one answer)**
   - ☐ Yes→q2a
   - ☐ No, even though **[he/she]** needed to get care→q3
   - ☐ No, I/the patient was healthy. There was no need to get care→q3
   - ☐ Don't know→q3
   - ☐ Refused→q3

   2a. What was the name of the healthcare provider or clinic: _____

3. Was there a time in the 12 months before **[Patient Name]** was diagnosed with H1N1 flu, when **[Patient Name]** needed to see a health care provider but could not because of cost? This would have been from mm 2008 through mm 2009.
   - ☐ Yes
   - ☐ No
   - ☐ Don't know
   - ☐ Refused

4. Was there a time in the 12 months before **[Patient Name]** was diagnosed with H1N1 flu, when **[Patient Name]** needed to see a health care provider but could not because of how far it was to travel to a healthcare facility or because it was hard to get a ride? This would have been from mm 2008 through mm 2009.
   - ☐ Yes
   - ☐ No
   - ☐ Don't know
   - ☐ Refused

5. About how many miles was **[Patient Name]** home from the place **[he/she]** went for healthcare when **[he/she]** was sick? **(Select only one answer)**
   - ☐ 0-10 miles
   - ☐ 11-30 miles
   - ☐ 31-50 miles
   - ☐ More than 50 miles
   - ☐ Don't know
   - ☐ Refused

6. What type of health care facility was it? **(Check all that apply)**
   - ☐ Private clinic
   - ☐ Tribal clinic
   - ☐ Urban Indian clinic
   - ☐ Indian Health Service Facility
   - ☐ Other public clinic
   - ☐ Hospital emergency department
   - ☐ Other (specify) _____
   - ☐ Don't know
   - ☐ Refused

7. At the time **[Patient Name]** was sick, did **[Patient Name]** have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare, including IHS benefits?
   - ☐ Yes→q7a
   - ☐ No→q8
   - ☐ Don't know→q8
   - ☐ Refused→q8

7a. If **"Yes",** what type of health coverage did **[Patient Name]** use to cover costs of medical care? Was it coverage through: **(Check all that apply)**

- ☐ **[His/her]** employer
- ☐ A family member's employer
- ☐ A plan that **[he/she]** or someone else bought on his or her own
- ☐ Medicare
- ☐ Medicaid or Medical assistance
- ☐ The military, CHAMPUS, TriCare, or the VA
- ☐ Indian Health Service or tribal benefits
- ☐ Other (specify) _____
- ☐ Don't know
- ☐ Refused

SKIP Q8 IF DOING A CASE PROXY INTERVIEW.

8. Was **[Patient Name]** hospitalized for influenza illness in the 30 days after **[he/she]** tested positive for H1N1 in 2009?
   - ☐ Yes→q8a
   - ☐ No→q9

Comment [I1]: Can this be greyed out; how often would we be doing a proxy for a deceased control?

8a. If **"Yes"**, what was the name and location of the hospital(s)? _____

_____

8b. If **"Yes"**, what was the date(s) of hospitalization? _____

(IV. Vaccines)

Now I will ask you questions about vaccines. There were two different flu vaccines available last flu season – the seasonal flu, and the 2009 H1N1 flu. I will first ask about vaccination for H1N1 flu, which is sometimes called swine flu or pandemic flu, and then about vaccination for seasonal flu.

SKIP Q9-10 IF THE SPECIMEN COLLECTION DATE WAS BEFORE SEPT 2009.

9. There are two ways to get the H1N1 flu vaccination. One is a shot in the arm and the other is a spray, mist or drop in the nose. In the Fall of 2009, was **[Patient Name]** vaccinated to prevent H1N1 flu?
   - ☐ Yes→q9a IF PATIENT WAS LESS THAN 9 YEARS OF AGE; if >9 years→q10
   - ☐ No→q10
   - ☐ Don't know→q10
   - ☐ Refused→q10

9a. (**ONLY FOR THOSE 9 YEARS AND YOUNGER)** How many doses of this vaccine did [**Patient Name]** get?

- ☐ One
- ☐ Two
- ☐ Don't know
- ☐ Refused
- ☐ Other_____

10. There are two ways to get the seasonal flu vaccine. One is a shot in the arm and the other is a spray, mist or drop in the nose. In the Fall of 2009, was **[Patient Name]** vaccinated to prevent seasonal flu?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Refused

11 Was **[Patient Name]** vaccinated to prevent seasonal flu during the 2008 – 2009 flu season? This would have been sometime from September 2008 through March 2009?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Refused

12. **(FOR PERSONS 2 YEARS AND OLDER)** Pneumococcal vaccines come in two types. One kind is given to older adults and some children who have chronic illnesses, have weakened immune systems, or are at increased risk of getting pneumococcal disease. This type of pneumococcal vaccine is sometimes called the pneumonia shot. Did **[Patient Name]** ever receive a pneumonia shot (brand name: Pneumovax)?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Refused

13. **(FOR PERSONS < 15 YEARS OLD)** The other kind of pneumococcal vaccine, called Prevnar, is routinely given to infants and children, usually as a series of 4 shots. Did **[Patient Name]** ever receive the Prevnar vaccine?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Refused

(V. Medical History/Risk Factors)

The next few questions are going to be about the living environment when **[Patient Name]** got sick. These interviews are being done in five different states and so some of the questions I will be asking may not seem appropriate but please try and answer as best you can.

14. When **[Patient Name]** got sick, in what type of housing was **[he/she]** living? **(Check only one option)**
    - ☐ House, apartment, or trailer→q15
    - ☐ Residential facility, specify if long-term care facility, school dorms, military barracks, jail, other setting: _____→q22
    - ☐ Homeless→q22
    - ☐ Refused→q22

15. What was the number of rooms in **[Patient Name]'s** house/apartment, excluding bathrooms and closets, at the time **[he/she]** was sick? _____

16. How many people age 18 years or older lived in **[Patient Name]'s** household at the time **[he/she]** was sick? _____

17. How many people younger than age 18 years lived in **[Patient Name]'s** household at the time **[he/she]** was sick? _____

18. When **[Patient Name]** got sick, did the household use a wood-burning stove or fireplace to cook or help heat the house?
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Refused

19. When **[Patient Name]** got sick, was there running (plumbed) water in the house?
    - ☐ Yes→q20
    - ☐ No→q22
    - ☐ Don't know→q22
    - ☐ Refused→q22

20. In what rooms did **[Patient Name]** have working sinks for washing up? And how many sinks in total were in those types of rooms? **(Check all that apply and write down numbers in each of the types of rooms)**
    - ☐ Bathrooms, how many_____?
    - ☐ Kitchen, how many_____?
    - ☐ Laundry room, how many_____?
    - ☐ Other, how many_____?
    - ☐ None
    - ☐ Don't know
    - ☐ Refused

21. When **[Patient Name]** got sick, did **[he/she]** have working flush toilets in the house/apartment? If there's a honeybucket or outhouse, answer "No".
    - ☐ Yes
    - ☐ No
    - ☐ Don't know
    - ☐ Refused

The next few questions are about health behaviors that might make someone more vulnerable to the flu.

22. **(ONLY FOR PATIENTS OLDER THAN 7 YEARS OF AGE)** Did **[Patient name]** smoke at least 100 cigarettes in **[his/her]** entire life? **READ TO RESPONDENT: "5 packs = 100 cigarettes"**
    - ☐ Yes→q23
    - ☐ No→q24
    - ☐ Don't know→q24
    - ☐ Refused→q24

23. **(ONLY FOR PATIENTS OLDER THAN 7 YEARS OF AGE)** When **[Patient Name]** got sick, did **[he/she]** smoke cigarettes every day, some days, or not at all?
    - ☐ Every day
    - ☐ Some days
    - ☐ Not at all
    - ☐ Don't know
    - ☐ Refused

24. When **[Patient Name]** got sick, in a typical week, was **[he/she]** exposed to secondhand tobacco smoke at home?
- ☐ Yes→q24a
- ☐ No→q25
- ☐ Don't know→q25
- ☐ Refused→q25

24a. If **"Yes"**, how often:
- ☐ Every day
- ☐ Some days
- ☐ Not at all
- ☐ Don't know
- ☐ Refused

25. **(ONLY IF PATIENT WAS AN ADULT)** When **[Patient Name]** got sick, in a typical week, was **[he/she]** exposed to secondhand tobacco smoke at work?
- ☐ Yes→q25a
- ☐ No→q26
- ☐ Don't know→q26
- ☐ Refused→q26

25a. If **"Yes"**, how often:
- ☐ Every day
- ☐ Some days
- ☐ Not at all
- ☐ Don't know
- ☐ Refused

26 **(ONLY FOR PATIENTS OLDER THAN 7 YEARS OF AGE)** During the 30 days before the flu illness, did **[Patient Name]** have at least one drink of any alcoholic beverage such as beer, wine, a malt beverage or liquor?
- ☐ Yes→q26a
- ☐ No→q27
- ☐ Don't know→q27
- ☐ Refused→q27

26a. If yes, how many days per week or per month did **[he/she]** have at least one drink of any alcoholic beverage**? (Check box and give number)**
- ☐ _____Days per week
- ☐ ___ Days in past 30 days
- ☐ Don't know / Not sure
- ☐ Refused

26b. During the 30 days before **[Patient Name]** got sick, on the days when **[Patient Name]** drank, about how many drinks did **[he/she]** drink on average? One drink is equivalent to a 12-ounce beer, a 5-ounce glass of wine, or a drink with one shot of liquor.

☐ ___ Number of drinks
☐ Don't know / Not sure
☐ Refused

27. When **[Patient Name]** got sick, about how much did **[he/she]** weigh without shoes? __ __ __ **(lbs, kg – Circle one)**

☐ Don't know
☐ Refused

28. When **[Patient Name]** got sick, about how tall was **[he/she]** without shoes? __ __/__ __ **(feet/inches, meters/centimeters – Circle one)]**

☐ Don't know
☐ Refused

(VI. Demographics)

The final questions I will be asking are about things like **[Patient Name]'s** race, occupation and education, which sometimes are related to certain health conditions. We are trying to understand how these things may have affected pandemic flu illness severity.

29. Was **[Patient Name]** Hispanic or Latino?

☐ Yes
☐ No
☐ Don't know / Not sure
☐ Refused

30. **(MAY NEED TO MODIFY IF PATIENT WAS VERY YOUNG)** What race or races did **[Patient Name]** consider **[him/herself]**? (**Select all that apply)**

- ☐ White→q31 if MORE THAN ONE race is selected; if not, then q32
- ☐ Asian→q31 if MORE THAN ONE race is selected; if not, then q32
- ☐ Black or African American→q31 if MORE THAN ONE race is selected; if not, then q32
- ☐ Native Hawaiian/Other Pacific Islander→q31 if MORE THAN ONE race is selected; if not, then q32
- ☐ American Indian or Alaska Native→q30a
- ☐ Other, please specify: _____→q31 if MORE THAN ONE race is selected; if not, then q32
- ☐ Don't know / Not sure→q32
- ☐ Refused→q32

30a. If American Indian/Alaska Native, what was **[his/her]** tribe/Native Health Corporation? _____

IF ONLY ONE RACE IS SELECTED, SKIP Q31.

31. **(MAY NEED TO MODIFY IF PATIENT WAS VERY YOUNG)** What did **[Patient Name]** consider **[his/her]** primary race if selecting only one? **(Select only one option)**

- ☐ White
- ☐ Asian
- ☐ Black or African American
- ☐ Native Hawaiian/Other Pacific Islander
- ☐ American Indian or Alaska Native
- ☐ Other, please specify: _____
- ☐ Don't know / Not sure
- ☐ Refused

32. **(ONLY IF PATIENT WAS AN ADULT)** What was **[Patient Name]'s** occupation at the time that **[he/she]** was sick? (**Specify**) _____

33. **(MAY NEED TO MODIFY IF PATIENT WAS VERY YOUNG)** What was the highest grade or year of school **[Patient Name]** completed? **(Select only one option)**
    - ☐ Never attended school or only attended kindergarten
    - ☐ Grades 1 through 8 (elementary)
    - ☐ Grades 9-11 (some high school)
    - ☐ Grade 12 or GED (high school graduate)
    - ☐ Attended college but did not graduate
    - ☐ Graduated from college
    - ☐ Post-graduate training
    - ☐ Don't know / Not sure
    - ☐ Refused

34. In 2009, what was **[Patient Name]'s** annual household income from all sources? **(Select only one option).**
    - ☐ <$10,000
    - ☐ $10,000 < $15,000
    - ☐ $15,000 < $20,000
    - ☐ $20,000 < $25,000
    - ☐ $25,000 < $30,000
    - ☐ $30,000 < $35,000
    - ☐ $35,000 < $40,000
    - ☐ $40,000 < $45,000
    - ☐ $45,000 < $50,000
    - ☐ $50,000 < $55,000
    - ☐ $55,000 < $60,000
    - ☐ $60,000 < $100,000
    - ☐ $100,000 < $150,000
    - ☐ > $150,000

    DO NOT READ TO RESPONDENT:
    - ☐ Don't know / Not sure
    - ☐ Refused

Thank you very much for your time. If you have any follow-up questions, please call us at _____