



## INSTRUCTIONS FOR ANX DEMOGRAPHICS FORM (DEMx)

### I. General Instructions

The DEMx form is an updated version of the ACHIEVE Demographics Form (Screen and Baseline). The DEMx updates demographic information about the de novo participant only. The DEMx form is built in a way to ensure that DEM, DEMR, and DEMx align as closely as possible. To achieve this, some items will be marked as “no longer used”.

### II. Detailed instructions for each item

0a. Enter the date the form was completed.

0b. Enter staff ID of the person who administered the form

1. Hand response card 1 to the participant and read each category aloud. Read question 1 aloud, emphasizing the underlined word, and check the box which corresponds to the participant’s response.

- If the response to Q1 is a: Skip to question 4
- If the response to Q1 is b, c, d, or e: Skip to question 3
- If the response to Q1 is f or g: Proceed to question 2

2. Read the question aloud and record the participant’s response

- If the response to Q2 is a: Skip to item 4
- If the response to Q2 is b: Skip to item 4

3. Hand response card 2 to the participant and read aloud (if necessary). Read question 3 aloud, emphasizing the underlined word, and check the box which corresponds to the participant’s response. If the participant cannot decide, clarify their answer so they come to a single response that best describes their current or most recent occupation.

4. Hand response card 3 to the participant and read aloud (if necessary). Read question 4 aloud and check the box which corresponds to the participant’s response.

5. This question asks about the number of people living in the participants house in the past year. Read the question aloud and record the participants response.

6a-b. No longer used.

7. This question asks for the participant's first name. Record their name in the space provided. If you are unsure of the correct spelling, please ask the participant to spell their name for you.

8. This question asks for the participant's last name. Record their name in the space provided. If you are unsure of the correct spelling, please ask the participant to spell their name for you.

9. Read the question aloud then record the participant's date of birth in Month/Day/Year format.

10. Record the participant's sex as female (F) or male (M). It is not necessary to read this question aloud if the answer is already known to you.

11. No longer used.

12a-c. No longer used.

13. This question asks about a participant's primary language. Read the question aloud and check the box that corresponds to the participants answer.

14. This question asks about a participant's education. Read the question aloud and check the box that corresponds to the participants answer.

15. This question asks about a participant's marital status. Read the question aloud and check the box that corresponds to the participants answer.

16a-e: These questions ask about a participant's address. Read each question aloud and then record the response. If you are unsure of the correct spelling, please ask the participant to spell their address for you.

- a. Record the first line of the street address
- b. Record the second line of the street address (if applicable)
- c. Record the city
- d. Record the state
- e. Record the zip code

17: Read the question aloud and record the participant's response. If the participant does not have a home phone number leave the response boxes blank.

18. Read the question aloud and record the participant's response. If the participant does not have a cell phone number leave the response boxes blank.

19. Read the question aloud and record the participant's response. If the participant does not have an email address leave the response blank.

20. This question asks about the best way to contact the participant. Read the question aloud and record the participant's response.

21a-i: This question records contact information of someone who is most likely to provide data for the participant if needed (i.e., serve as an informant). This question serves two purposes:

- Provides contact information of a person who can act as a proxy and provide information about the participant.
- Provides secondary contact information if the field site cannot get hold of the participant.

As such, staff should emphasize the phrase **“someone who would be able to provide study data on your behalf”** so that the most appropriate person is identified.

- a. Record the first name in the space provided. If you are unsure of the correct spelling, please ask the participant to spell the name for you.
- b. Record the last name in the space provided. If you are unsure of the correct spelling, please ask the participant to spell the name for you.
- c. Record the street address
- d. Record the city
- e. Record the state
- f. Record the zip code
- g. Record the primary telephone number. If the number is unknown leave the response boxes blank.
- h. Record the alternate telephone number. If the number is unknown leave the response boxes blank.
- i. Record the email address. If there is no email address or the person does not have an email address leave the response blank.

22a-b: These questions ask about the participant's physician. Read each question aloud and then record the response. If you are unsure of the correct spelling, please ask the participant to spell their responses for you.

- a. Record the physician's first name.

- b. Record the physician's last name.

23a-f: These questions ask about the participant's physician's address. Read each question aloud and then record the response. If you are unsure of the correct spelling, please ask the participant to spell their responses for you.

- a. Record the clinic and/or building name
- b. Record the first line of the street address
- c. Record the second line of the street address (if applicable)
- d. Record the city
- e. Record the state
- f. Record the zip code

24a-i: This question records contact information of someone who is a legally authorized representative for the participant or research agent if needed. This person may or may not be the same person identified in question 21. This question serves two purposes:

- Provides contact information of a person who can act as a LAR and provide consent for the participant to continue taking part in the research study.
- Provides secondary contact information if the field site cannot get hold of the participant.

As such, staff should emphasize the phrase **“someone who would be able to provide consent to participate in the research study data on your behalf”** so that the most appropriate person is identified.

- a. Record the first name in the space provided. If you are unsure of the correct spelling, please ask the participant to spell the name for you.
- b. Record the last name in the space provided. If you are unsure of the correct spelling, please ask the participant to spell the name for you.
- c. Record the street address
- d. Record the city
- e. Record the state
- f. Record the zip code
- g. Record the primary telephone number. If the number is unknown leave the response boxes blank.
- h. Record the alternate telephone number. If the number is unknown leave the response boxes blank.
- i. Record the email address. If there is no email address or the person does not have an email address leave the response blank.

**Response card 1**

- a. Homemaking, not working outside the home
- b. Employed at a job for pay, either full or part-time
- c. Employed, but temporarily away from my regular work
- d. Unemployed, looking for work
- e. Unemployed, not looking for work
- f. Retired from my usual occupation and not working
- g. Retired from my usual occupation, but working for pay

**Response card 2**

- A. Homemaker
- B. Technician, sales, or clerical
- C. Mechanic, repairman, construction worker or craftsman
- D. Service: hairdresser, domestic, restaurant, security
- E. Management, professional
- F. Farming, forestry, fishing
- G. Driver, machine operator, sanitation, laborer
- H. Unknown

**Response card 3**

- A. Under \$5,000
- B. \$5,000 - \$7,999
- C. \$8,000 - \$11,999
- D. \$12,000 - \$15,999
- E. \$16,000 - \$24,999
- F. \$25,000 - \$34,999
- G. \$35,000 - \$49,999
- H. \$50,000 - \$74,999
- I. \$75,000 - \$99,999
- J. \$100,000 and over