

**ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY  
PARTICIPANT SURVEY FORM**

**Form Completion Instructions:**

This form was created after the end of the enrollment period, during the follow-up period. It was designed to collect additional socioeconomic information on each Registry subject.

Questions 4-7 (employment status, occupation, income, health coverage) refer to the patient's employment status, etc. at baseline, i.e., at the time they enrolled in the Registry.

For patients who never have received augmentation therapy, the form also collects more detailed information on the reason why the patient did not receive augmentation therapy.

NO PUBLIC DATASET

Alpha 1-Antitrypsin Deficiency Registry  
PARTICIPANT SURVEY FORM

The information in this form is needed to complete the Registry data base and will remain confidential without release to anyone or any organization. DATA SET CENSORED

- 1. Patient Registry ID ..... ID .....
- 2. Patient Name Code ..... namecode .....
- 3. Clinical Center code number ..... clinic .....

Part I. The following questions refer to you at your first visit for the Registry:

JOB

- 4. At your first visit, what was your employment status? F21Q04 .....
- |                                     |                         |
|-------------------------------------|-------------------------|
| 1 = Employed Full-Time              | 5 = Retired (Medical)   |
| 2 = Employed Part-Time              | 6 = Retired (Age)       |
| 3 = Unemployed (Medical Reasons)    | 7 = Full-Time Homemaker |
| 4 = Unemployed (Other Reasons)      | 8 = Unknown             |
| 9 = Other (Specify) <u>F21Q04OT</u> |                         |

- 5. At your first visit, what had been your usual occupation or job -- the one you had worked at the longest?  
F21Q05 (see next page with occupation codes) .....

INCOME

- 6. At your first visit, what was your gross annual household income? F21Q06 .....
- |                       |                           |
|-----------------------|---------------------------|
| 1 = less than \$7,500 | 5 = \$40,000 - 49,999     |
| 2 = \$7,500 - 14,999  | 6 = \$50,000 - 74,999     |
| 3 = \$15,000 - 24,999 | 7 = greater than \$75,000 |
| 4 = \$25,000 - 39,999 | 9 = unknown               |

HEALTH COVERAGE

- 7. At your first visit, who was covering your health expenses? F21Q07 .....
- |   |                                  |
|---|----------------------------------|
| 1 = Insurance by Employer (through your job or your spouse) | 4 = Medicare (no supplemental)   |
| 2 = Insurance by Medicaid                                   | 5 = Medicare (with supplemental) |
| 3 = Self-insured  | 6 = No coverage                  |

Part II. The following refers to Prolastin Augmentation Therapy

- 8. Have you ever received Prolastin Augmentation Therapy since entry into the Registry? F21Q08  
1 = yes, 2 = no

- 8A. If No, why? F21Q08A .....

- Medical reason:**
- 1 = Not recommended by physician, because lung function is normal or only slightly below normal
  - 2 = Not recommended by physician, because lung function is too far below normal
  - 3 = Not recommended by physician because you smoke
  - 4 = You received lung transplant
  - 5 = Medical reasons other than transplant

- Financial reason:**
- 6 = No insurance
  - 7 = Insurance does not cover cost

None of the above: 8 = Other F21Q08OT

- 9. Who completed this form? F21Q09 Participant (1) \_\_\_\_\_ Study Coordinator (2) \_\_\_\_\_ Participant's Doctor (3) \_\_\_\_\_  
\_\_\_\_\_ Spouse/Others (4) \_\_\_\_\_ Others (5) (relationship) F21Q09OT

- 10. Type of communication: F21Q10 In person (1) \_\_\_\_\_ By Phone (2) \_\_\_\_\_ By letter/Fax (3) \_\_\_\_\_  
Other (4) F21Q10OT

Signature of Clinical Center Personnel never entered

**Notes on Coding:**

**Question 5. Occupation, coded at the CCC.**

Codes used:

- 1 Professional, technical, and kindred workers
- 2 Managers and administrators, except farm
- 3 Sales workers
- 4 Clerical and kindred workers
- 5 Craftsmen and kindred workers
- 6 Operatives, except transport
- 7 Transport equipment operatives
- 8 Laborers, except farm
- 9 Farmers and farm managers
- 10 Farm laborers and farm foremen
- 11 Service workers, except private household
- 12 Private household workers
- 13 Unknown - Not in work force
- 14 Unknown - retired