

**ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
CAUSE OF DEATH REVIEW**

Form Completion Instructions:

This form is only for use by the Death Review Committee.

A member of the Death Review Committee will complete this form upon review of the information available from the Death Certificate and autopsy report. This determination will allow for cause-specific mortality analysis. A consensus form will also be completed with final results.

ALPHA 1-ANTITRYPSIN DEFICIENCY REGISTRY
Death Classification Form

1. Date form completed: F07Q01-fzd (fuzzed) _____ / _____ / _____
month day year
2. Form Type: F07Q02 _____ (1) Individual Reader _____ (2) Draft Consensus _____ (3) Final Consensus
- Patient name: Never entered
3. Patient Registry ID: newID (scrambled)
4. Patient Name code: namecode (censored)
5. Clinical Center code: clinic (censored)
6. Date of death: F07Q06-fzd (fuzzed) _____ / _____ / _____
month day year

7. Information available:
- a. Death Certificate: F07Q07A _____ (1) Yes _____ (2) No
- b. Autopsy Report: F07Q07B _____ (1) Yes _____ (2) No
1. Preliminary (anatomic): F07Q07B1 _____ (1) Yes _____ (2) No
2. Final (including microscopic): F07Q07B2 _____ (1) Yes _____ (2) No
- c. Complete Hospital Records (progress notes, labs, etc.): F07Q07C (1) Yes _____ (2) No
- d. Hospital Discharge Summaries: F07Q07D _____ (1) Yes _____ (2) No
- e. Other documents (1) yes (2) No F07Q07E

EVALUATION OF CAUSE(S) OF DEATH (C.O.D.) AND CONDITIONS PRESENT AT TIME OF DEATH.

| Date Review by Death Committee (Date DRC-fzd) | Immed. Cause of Death (check only one) | Contrib. Cause(s) of Death | Condition(s) Present but not Contributing to Death | Under- lying C.O.D. (check only one) |
|--|--|-------------------------------------|--|--|
| 8. Homicide: <u>ICD immediate (CENSORED)</u> | <u>ICD immediate (CENSORED)</u> | <u>ICD contribute (CENSORED)</u> | <u>ICD present (CENSORED)</u> | <u>ICD underlie (CENSORED)</u> |
| 9. Suicide: _____ | _____ | _____ | _____ | _____ |
| 10. Trauma/Accident: _____ | _____ | _____ | _____ | _____ |
| 11. Emphysema: _____ | _____ | _____ | _____ | _____ |
| 12. Chronic Obstructive Bronchitis: _____ | _____ | _____ | _____ | _____ |
| 13. Bronchiectasis: _____ | _____ | _____ | _____ | _____ |
| 14. Asthma: _____ | _____ | _____ | _____ | _____ |
| 15. Diffuse Pulmonary Fibrosis: _____ | _____ | _____ | _____ | _____ |
| 16. Pulmonary Embolism: _____ | _____ | _____ | _____ | _____ |
| 17. Pneumothorax: _____ | _____ | _____ | _____ | _____ |
| 18. Pleural Effusion: _____ | _____ | _____ | _____ | _____ |

White/Yellow: Clinical Coordinating Center, Pink: Physician Reader

Patient Registry ID: _____

| | Immed. Cause of Death (check only one) | Contrib. Cause(s) of Death | Condition(s) Present but not Contributing to Death | Under- lying C.O.D. (check only one) |
|--------------------------------------|--|-------------------------------------|--|--|
| 19. Pulmonary Infections (Pneumonia) | | | | |
| a. Tuberculosis:..... | | | | |
| <i>variable names same as page 1</i> | | | | |
| b. Atypical tuberculosis:..... | | | | |
| <i>(CENSORED)</i> | | | | |
| (list organism if known): | _____ | _____ | _____ | _____ |
| c. Bacterial:..... | | | | |
| (list organism if known): | _____ | _____ | _____ | _____ |
| d. Fungal:..... | | | | |
| (list organism if known): | _____ | _____ | _____ | _____ |
| e. Viral:..... | | | | |
| (list organism if known): | _____ | _____ | _____ | _____ |
| f. Pleural Infection (Empyema):..... | | | | |
| (list organism if known): | _____ | _____ | _____ | _____ |
| 20. Anaphylactic reaction:..... | | | | |
| Cause known? List: | _____ | _____ | _____ | _____ |
| 21. Drug toxicity or reaction:..... | | | | |
| Explain: | _____ | _____ | _____ | _____ |
| 22. Malignancy: | | | | |
| a. Lung Cancer:..... | | | | |
| (List cell type): | _____ | _____ | _____ | _____ |
| Metastases To (list sites): | _____ | _____ | _____ | _____ |
| 1. Brain:..... | | | | |
| 2. Bone:..... | | | | |
| 3. Liver:..... | | | | |
| 4. Adrenal:..... | | | | |
| 5. Other(s)..... | | | | |
| (Specify): | _____ | _____ | _____ | _____ |
| 23. Other Malignancy: | | | | |
| a. Primary Site:..... | | | | |
| b. Metastases To (list sites): | | | | |
| 1. _____ | | | | |
| 2. _____ | | | | |
| 3. _____ | | | | |

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|--------------------------------------|--|-------------------------------------|--|--|
| 24. Other Malignancy: | | | | |
| a. Primary Site: _____ | | _____ | _____ | _____ |
| <i>Variable names same as page 1</i> | | | | |
| <i>- C E N S O R E D -</i> | | | | |
| b. Metastases To (list sites): | | | | |
| 1. _____ | | _____ | _____ | _____ |
| 2. _____ | | _____ | _____ | _____ |
| 3. _____ | | _____ | _____ | _____ |
| 25. Hypertension:..... | _____ | _____ | _____ | _____ |
| 26. Coronary Artery Disease:..... | _____ | _____ | _____ | _____ |
| 27. Myocardial Infarction:..... | _____ | _____ | _____ | _____ |
| 28. Cor Pulmonale:..... | _____ | _____ | _____ | _____ |
| 29. Arrhythmia:..... | _____ | _____ | _____ | _____ |
| 30. Cardiogenic Shock:..... | _____ | _____ | _____ | _____ |
| 31. Valvular Heart Disease:..... | _____ | _____ | _____ | _____ |
| a. List valve abnormalities: | | | | |
| 1. _____ | | _____ | _____ | _____ |
| 2. _____ | | _____ | _____ | _____ |
| 3. _____ | | _____ | _____ | _____ |
| 4. _____ | | _____ | _____ | _____ |
| 32. Pancreatitis:..... | _____ | _____ | _____ | _____ |
| 33. Hepatitis:..... | _____ | _____ | _____ | _____ |
| 34. Portal Fibrosis:..... | _____ | _____ | _____ | _____ |
| 35. Cirrhosis:..... | _____ | _____ | _____ | _____ |
| 36. Esophageal Varices:..... | _____ | _____ | _____ | _____ |
| 37. Ascites:..... | _____ | _____ | _____ | _____ |
| 38. Hepatic Encephalopathy:..... | _____ | _____ | _____ | _____ |
| 39. Rheumatoid Arthritis:..... | _____ | _____ | _____ | _____ |

White/Yellow: Clinical Coordinating Center, Pink: Physician Reader

PWO 1871

Patient Registry ID: _____

| | Immed. Cause of Death (check only one) | Contrib. Cause(s) of Death | Condition(s) Present but not Contributing to Death | Under- lying C.O.D. (check only one) |
|---|--|-------------------------------------|--|--|
| 40. Weber-Christian Disease (Necrotizing Panniculitis):..... | _____ | _____ | _____ | _____ |
| Variable names same as page 1 (CENSORED) | | | | |
| 41. Sepsis/Infection (Other than Respiratory System):..... | _____ | _____ | _____ | _____ |
| a. Primary Location (list): _____ | | | | |
| b. If organism identified (list): _____ | | | | |
| 42. Diabetes: | _____ | _____ | _____ | _____ |
| 43. Renovascular Disease:..... | _____ | _____ | _____ | _____ |
| 44. Azotemia:..... | _____ | _____ | _____ | _____ |
| 45. Nephritis:..... | _____ | _____ | _____ | _____ |
| 46. Renal Stones:..... | _____ | _____ | _____ | _____ |
| 47. Stroke (hemorrhagic):..... | _____ | _____ | _____ | _____ |
| 48. Stroke (ischemic):..... | _____ | _____ | _____ | _____ |
| 49. Stroke (embolic):..... | _____ | _____ | _____ | _____ |
| 50. Subarachnoid Hemorrhage:..... | _____ | _____ | _____ | _____ |
| 51. Other conditions not listed: | | | | |
| 1. _____ | _____ | _____ | _____ | _____ |
| 2. _____ | _____ | _____ | _____ | _____ |
| 3. _____ | _____ | _____ | _____ | _____ |
| 4. _____ | _____ | _____ | _____ | _____ |

52. Comments:

 COMM-1 (CENSORED)

 COMM-2 (CENSORED)

Physician Signature: never entered

Notes on Coding:

Form 7 information is contained in three SAS files, named FORM07, F7CCOD, and F7PCOD.

1) FORM07

Contains selected information from Form 7, and the single underlying and immediate causes of death. There is one record per patient.

Variable Names and Formats:

| <u>Question</u> | <u>Variable Name</u> | <u>Format</u> | <u>Description</u> |
|-----------------|----------------------|---------------|--|
| 1 | FORMDATE | MMDDYY6. | Date form completed |
| 3 | ID | Num 8 | Patient Registry ID number |
| 7c | HR | Num 8 | Hospital records available (1=Y, 2=N) |
| 7d | DS | Num 8 | Discharge summaries available (1=Y, 2=N) |
| -- | OD | Num 8 | Other documents available (1=Y, 2=N) |
| -- | UCOD | Char 6 | Underlying COD (ICD-9 code) |
| -- | ICOD | Char 6 | Immediate COD (ICD-9 code) |

2) F7CCOD

Contains causes of death that were classified as contributing, with one cause of death per record (multiple records per patient)

| <u>Variable Name</u> | <u>Format</u> | <u>Description</u> |
|----------------------|---------------|--|
| ID | Num 8 | Patient ID |
| CCOD | Char 6 | Contributing cause of death (ICD-9 code) |

3) F7PCOD

Contains causes of death that were classified as present but not contributing, with one cause of death per record (multiple records per patient)

| <u>Variable Name</u> | <u>Format</u> | <u>Description</u> |
|----------------------|---------------|--|
| ID | Num 8 | Patient ID |
| PCOD | Char 6 | Present but not contributing cause of death (ICD-9 code) |
| Type | Num 8 | Condition occurred/was present in the past; not present currently (1=Y, 2=N) |

Descriptions of the ICD-9 codes used are provided on the following pages.