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 (DateDRC_fzd)

	Immed. Cause of Death *(check only one)*	Contrib. Cause(s) of Death	Condition(s) Present but not Contributing to Death	Underlying C.O.D. *(check only one)*
8. Homicide:	ICD9immediate (CENSORED)	ICD9contribute (CENSORED)	ICD9present (CENSORED)	ICD9underlie (CENSORED)
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)	variable names same as page 1			
a. Tuberculosis:	___	(CENSORED)	___	___
b. Atypical tuberculosis:	___	___	___	___
(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. ___	___	___	___	___

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)
24. Other Malignancy:	Variable names Same as page 1			
a. Primary Site: _____	___	-CENSORED-	___	___
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

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:

COMM1_1 (CENSORED)

COMM1_2 (CENSORED)

Physician Signature: never entered

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

PWO 1871

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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:

Question	Variable Name	Format	Description
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)

Variable Name	Format	Description
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)

Variable Name	Format	Description
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.