

Section 3. CF Cases At or Above the IRT Cut Off Value

IMPORTANT NOTE: Please answer all questions referring only to the time period starting with the date in Question 8 and ending on 12/31/12.

For questions 47-74, provide the number of CF cases at or above the IRT cut-off value in each category. If your state does not collect the requested data item, enter "DC" in the "Unknown" field.

47. Total CF Cases at or above IRT cut off (*see instructions for Section 3 for definition*) _____
48. Child's sex Male _____ Female _____ Unknown _____
49. Child's race: White Yes _____ No _____ Unknown _____
50. Child's race: Black Yes _____ No _____ Unknown _____
51. Child's race: Other Yes _____ No _____ Unknown _____
52. Child's ethnicity Hispanic _____ Non-Hispanic _____ Unknown _____
53. Hospital of Birth (*Complete all but last column in Worksheet 1 with the number of CF Cases at or above the IRT cut-off in each hospital.*)
54. Day of week birth occurred
Sun _____ Mon _____ Tue _____ Wed _____
Thu _____ Fri _____ Sat _____ Unknown _____
55. Gestational age at birth (completed weeks)
<34 _____ 35-36 _____ 37-41 _____ >41 _____ Unknown _____
56. Birth weight (grams) <1500 _____ 1500-2499 _____ 2500+ _____ Unknown _____
57. Meconium ileus Yes _____ No _____ Unknown _____
58. CFTR mutations
Not genotyped _____
Genotyped (*provide count of each genotype on Worksheet 2*) _____
Unknown if genotyped _____
59. Age at CF diagnosis (days)
<29 _____ 29-56 _____ 57-84 _____ 85-112 _____ 113-130 _____
131-158 _____ >158 _____ Unknown _____
60. CF diagnosis suggested by newborn screening Yes _____ No _____ Unknown _____
61. CF diagnosis suggested by family history Yes _____ No _____ Unknown _____
62. CF diagnosis suggested by symptoms Yes _____ No _____ Unknown _____
63. CF diagnosis suggested by
CF prenatal/carrier screening Yes _____ No _____ Unknown _____

For states using a 2-specimen IRT-IRT or IRT-IRT-DNA screening model, Questions 62-75 should be answered for both specimens, as specified in the table. Provide information only for the specimen(s) used to make the CF NBS interpretation.

	<u>Specimen 1</u>	<u>Specimen 2</u>
64. Median age of children at specimen collection	_____ hours	_____ hours
65. Median age of children at time of IRT analysis	_____ days	_____ days
66. Month of specimen collection		
Specimen 1:	Jan _____ Feb _____ Mar _____ Apr _____ May _____ June _____	
	July _____ Aug _____ Sep _____ Oct _____ Nov _____ Dec _____	
Specimen 2:	Jan _____ Feb _____ Mar _____ Apr _____ May _____ June _____	
	July _____ Aug _____ Sep _____ Oct _____ Nov _____ Dec _____	

	<u>Specimen 1</u>	<u>Specimen 2</u>
67. Median IRT value	_____ ng/mL	_____ ng/mL
68. IRT value cut point used (provide median, if multiple cut points used)	_____ ng/mL	_____ ng/mL
69. Median IRT percentile	_____	_____
70. IRT percentile cut point used (provide median, if multiple cut points used)	_____	_____

Questions 71-74 refer to the period from birth to the time of specimen collection:

71. Infant Feedings	_____ Breast only _____ Formula only _____ Breast and formula _____ Unknown	_____ Breast only _____ Formula only _____ Breast and formula _____ Unknown
72. Red Blood Cell Transfusion	_____ Yes _____ No _____ Unknown	_____ Yes _____ No _____ Unknown
73. Intravenous Nutrition	_____ Yes _____ No _____ Unknown	_____ Yes _____ No _____ Unknown
74. Neonatal Intensive Care Unit	_____ Yes _____ No _____ Unknown	_____ Yes _____ No _____ Unknown