

S1. Monitoring protocol after positive newborn screening for CF

(months of age)	0	1	2	3	4	5	6	7	8	9	10	11	12	15	18	21	24	27	30	33	36	39	42	45	48	51	54	57	60
1. Informed consent	x																												
2. Demographic History	x																												
3. DNA	x																												
4. Sweattest	x																												
5. Out-patient clinic visits/contacts	x	x	x	x	x	x	x		x		x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
a. Pediatric pulmonologist/CF nurse	x	x	x	x	x	x	x		x		x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
b. Gastro-enterologist/dietician		x	x°	x			x				x°		x°				x°				x°				x°				x°
6. Medical history/review symptoms	x	x	x	x	x	x	x		x		x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
7. Physical examination	x	x	x	x	x	x	x		x		x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
8. Length, weight, head circumference	x	x	x	x	x	x	x		x		x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
9. Symptom diary	x	x	x	x	x	x	x		x		x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
10. Throat swab/sputum culture, nasopharyngeal swab	x	x	x	x	x	x	x		x		x		x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
11. Faecal elastase	x												x#				x#				x#				x#				x#
12. Faecal fat balance																									x				x
13. Blood				x									x				x				x				x				x
14. Urine				x*									x*																
15. Bronchoscopy and BAL													x								x								x
16. Chest X-ray				x													x								x				
17. Chest CT scan													x								x								x
18. Infant lungfunction¥													x																
19. Spirometry																									x	x	x	x	x
20. CFQ-R																													x
21. ICM													x																x^

* for Na, creatinine

only in pancreatic sufficient patients

° both GI specialist and dietician, other months only dietician

^ in case of rest activity measured at 12 months

¥ only applicable for Rotterdam patients