

Australian Cystic Fibrosis Data Registry

Data Dictionary

**Version 1
May 2023**

Data Dictionary Approval

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Contents

Data Dictionary Approval	1
List of Abbreviations	8
Preface	9
Australian Cystic Fibrosis Data Registry Overview	9
Data Collection Obligation	9
Australian Cystic Fibrosis Data Registry Executive and Steering Committee	10
Access to ACFDR Data	11
Data Dictionary sub-headings guide	12
Registration Form Items	14
1. Unique Participant Identifier	15
2. Registration Type.....	16
3. Hospital Transfer	17
4. Consent to Identified Data Collection	19
5. Family Name.....	20
6. Given Name.....	21
7. Family Name Initial	22
8. Given Name Initial	23
9. Street Address	24
10. Suburb.....	25
11. Address State	26
12. Address	27
13. Mobile Number	28
14. Email Address.....	29
15. Biological Sex	30
16. Date of Birth.....	31
17. Participation Consent Status.....	32
18. Participation Consent Date	33
19. Opt Out Reason.....	34
20. Opt Out Reason Continued.....	35
21. Opt Out Date.....	36
22. Re-Consent Date	37
23. ACFDR Identification Number	38
24. Unique identifier across all ACFDR collection locations	39
25. Transferred or Shared Status.....	40
26. Rejection Reason	41
27. Data Collection Start Year.....	42
28. Data Collection Stop Year.....	43
29. Data Access Group.....	44
Demographics Form Items	45
30. Perceived Gender	46
31. Aboriginal and Torres Strait Islander status	47
32. Country of birth	48
33. Patient Status	55
34. Deceased Status	56

35. Date of death	57
36. Cause of death	58
37. Cause of Death CF Related	59
38. Cause of Death NOT CF Related.....	60
Initial Diagnosis Form Items	61
39. Date of Death via Data Linkage	62
40. Date of CF Diagnosis Known	63
41. Date of CF Diagnosis.....	64
42. Diagnosise Date Accuracy	65
43. Diagnosis Date Estimate Reason.....	66
44. Diagnosis Date Unknown Reason.....	67
45. Age at Diagnosis.....	68
46. Diagnosis Suggestion Entity	69
47. Clinical Symptoms for Diagnosis.....	70
48. Other Signs of CF	71
49. Sweat Test.....	72
50. Sweat Test No Reason	73
51. Sweat Test Date	74
52. Sweat test No Date.....	75
53. Sweat Chloride Value	76
54. Pancreatic Status.....	77
55. Pancreatic Status Basis	78
56. Faecal Elastase Date.....	79
57. Faecal Elastase No Date	80
58. Faecal Value.....	81
59. Genotyping	82
60. Genotyping Result Not Avaialble.....	83
61. Genotyping Date.....	84
62. Genotyping not Collected.....	85
63. Genetic Mutation 1.....	86
64. Poly T Status for Variant R117H	87
65. Other Mutation 1	88
66. Geneticc Mutation 2.....	89
67. Poly T Status for Variant R117H	90
68. Other Mutation 2	91
69. Genetic Mutation 3.....	92
70. Poly T Status for Variant R117H	93
71. Other Mutation 3	94
72. Birth Weight	95
73. Birth Weight Unknown	96
74. Birth length	97
75. Birth Length Unknown.....	98
76. Gestation length.....	99
Post Diagnosis Form Items.....	101
77. Date of Sweat Chloride Test Date.....	102
78. Sweat Chloride Value (mmol/L).....	103
79. Date of genotype test.....	104
80. Genetic mutation 1 (post diagnosis).....	105
81. Poly T form in cis with R117H	106
82. Other genetic mutation 1 (post diagnosis).....	107
83. Genetic mutation 2 (post diagnosis).....	108
84. Poly T form in cis with R117H	109

85. Other genetic mutation 2 (post diagnosis).....	110
86. Genetic mutation 3 (post diagnosis).....	111
87. Poly T form in cis with R117H.....	112
88. Other genetic mutation 3 (post diagnosis).....	113
89. Pancreatic insufficiency status.....	114
90. Date of pancreatic status assessment.....	115
91. Estimate date (only year correct).....	116
92. Pancreatic insufficiency status assessment based on:.....	117
93. Faecal elastase value (ug/g).....	118
Clinical Measures Form Items.....	119
94. Date clinical measure taken.....	120
95. Where was the clinical measurement captured?.....	121
96. Who performed/recorded the measurement?.....	122
97. Weight (kg).....	123
98. Height (cm).....	124
99. FVC (litres).....	125
100. FEV1 (litres).....	126
101. FEF25-75.....	127
102. Calculated age.....	128
103. FEV1pp (GLI).....	129
104. BMI.....	130
105. BMI Percentile.....	131
106. BMI z score.....	132
107. Weight z score.....	133
108. Weight percentile.....	134
109. Height z score.....	135
110. Height Percentile.....	136
111. IWT (infant weight for length).....	137
112. IWT (Infant length for weight) z score.....	138
113. Event.....	139
114. Hospitalisation Admission Type.....	140
115. Type of clinic visit.....	141
116. Date of clinic visit.....	142
117. Patient refused clinical measures (lung function and height/weight) to be taken at this visit.....	143
118. Hospital admission date.....	144
119. Hospital discharge date.....	145
120. Primary reason for hospitalisation.....	146
121. Specific respiratory related reason.....	147
122. GI related hospitalisation.....	148
123. Other primary reasons for hospitalisation.....	149
124. Procedure undertaken during hospitalisation.....	150
125. Other reason for hospitalisation.....	151
126. Other Reasons for Hospitalisation.....	152
127. Were hospital IV antibiotics administered during this admission?.....	153
128. Hospital IV antibiotic start date.....	154
129. Hospital IV antibiotic therapy end date.....	155
130. Home IV antibiotic therapy start date.....	156
131. Home IV antibiotic therapy end date.....	157
132. Were IV antibiotics given for respiratory indications?.....	158
Microbiology Form Items.....	159
133. Microbiology test date.....	160

134. Microbiology sample type.....	161
135. Upper airway sample type.....	162
136. Results for:.....	163
137. COVID-19 Test Outcome.....	164
138. Achromobacter species.....	165
139. Achromobacter species.....	166
140. Burkholderia species.....	167
141. Burkholderia species type.....	168
142. Burkholderia cepacia complex type.....	169
143. Burkholderia (non- cepacia complex) species.....	171
144. Burkholderia non cepacia complex other.....	172
145. Haemophilus influenzae.....	173
146. Pseudomonas.....	174
147. Pseudomonas aeruginosa status.....	175
148. Pseudomonas aeruginosa phenotype.....	176
149. Non-aeruginosa pseudomonas species, specify.....	177
150. Staphylococcus aureus.....	178
151. Staphylococcus aureus methicillin resistance status.....	179
152. Staphylococcus aureus multidrug resistance status.....	180
153. Stenotrophomonas species.....	181
154. Stenotrophomonas species type.....	182
155. Other bacteria.....	183
156. Normal respiratory flora grown.....	184
157. Sample was not processed (e.g. sample unlabeled, arrived outside transport times).....	185
158. No bacterial growth/sterile sample.....	186
159. Bacteria other.....	187
160. Pandoraea species type.....	189
161. Pandoraea species other.....	190
162. Ralstonia species type.....	191
163. Other bacteria not listed.....	192
164. Fungal results.....	193
165. Fungi, other specify:.....	194
166. Was the specimen for NTM/Mycobacterium testing smear positive?.....	195
167. Was NTM or other mycobacteria cultured from the specimen?.....	196
168. Reason why there were no results for NTM or other mycobacterial growth?.....	197
169. Mycobacterium cultured.....	198
170. NTM organism cultured.....	199
171. Other NTM organism.....	200
Quarterly Signoff Form Items.....	201
172. Please confirm if the number of clinical measures entered for this quarter is correct (this may include zero clinical measures for this quarter).....	202
173. Please confirm that the number of microbiology tests entered for this quarter is correct (this may include zero microbiology for this quarter).....	203
174. Please confirm that the number of clinic visits entered for this quarter is correct (this may include zero clinic visits for this quarter).....	204
175. Please confirm that the number of hospitalisations entered for this quarter is correct (this may include zero hospitalisations for this quarter).....	205
176. Please confirm the number of combined hospital/Home IV antibiotic events for this quarter (this may include zero events for this quarter).....	206
177. Please confirm the number of home IV antibiotic events entered for this quarter (this may include zero events for this quarter).....	207

178. Survey Year	208
Complications and Treatment Form Items	209
179. Cystic Fibrosis Lung Disease	210
180. Treatment for CF related lung disease during this calendar year	211
181. Mucolytics type	212
182. Oral corticosteroids	213
183. Macrolide type	214
184. Inhaled antibiotic type	215
185. Other inhaled antibiotic	216
186. Tobramycin use	217
187. Colistin use	218
188. Antifungal triazole type.....	219
189. Allergic bronchopulmonary aspergillus (ABPA)	220
190. Pneumothorax	221
191. Haemoptysis	222
192. Did any haemoptysis event this calendar year lead to embolization	223
193. Did the patient undergo surgery for nasal polyps or sinusitis during this calendar year?	224
194. Was long term oxygen used during the calendar year?	225
195. Long term oxygen therapy use during the current annual year.....	226
196. Was non-invasive ventilation used during this annual year (e.g. assisted breathing, BiPAP, CPAP)	227
197. Non-invasive ventilation use during the current annual year (assisted breathing, BiPap, CPAP etc)	228
198. Was invasive mechanical ventilation used during this calendar year?	229
199. Did the patient have an influenza vaccine during this calendar year?	230
200. Did the patient have a pneumococcal vaccination during this calendar year?	231
201. Did the patient have a Covid 19 vaccination during this calendar year?	232
202. Which dose has been administered	233
203. Did the patient receive vitamins, enzymes or salt replacement therapy during this calendar year?	234
204. Vitamins, enzymes or salt replacement used	235
205. Was a nutritional intervention (e.g. TPN, tube) required during the current calendar year?.....	236
206. Nutritional intervention type.....	237
207. Gastric oesophageal reflux (GOR)	238
208. Treatment for GOR during this calendar year?.....	239
209. Gastric oesophageal reflux treatment type	240
210. Pancreatitis	241
211. Diabetes/impaired glucose tolerance during the calendar year?	242
212. Diabetes treatment type	243
213. Insulin use	244
214. Secondary complications to diabetes during this calendar year	245
215. Hepatobiliary dysfunction during this calendar year?	246
216. Hepatobiliary/liver disease	247
217. Was a DEXA scan performed during this calendar year?	248
218. Date of most recent DEXA scan.....	249
219. Bone mineral density status	250
220. Treatment or prophylaxis for low bone mineral density (BMD)	251
221. Did the patient have a fracture during this calendar year?.....	252
222. Has a mental health screen using GAD-7 and PHQ-9 been performed during this calendar year?.....	253

223. Was a high score received for either questionnaire?	254
224. Has the patient engaged with a mental health service provider during this calendar year?.....	255
225. Did the patient receive a physiotherapy review during this calendar year?.....	256
226. Did the patient receive a social work review during the last calendar year?	257
227. Did the patient receive a gastroenterologist review during the last calendar year?	258
228. Did the patient receive an endocrine review during the last calendar year?	259
229. Did the patient receive a dietician review during this last calendar year?	260
230. Was a histologically confirmed cancer diagnosed during the current calendar year?	261
231. Cancer (histology proven) diagnosed during this calendar year	262
232. Other cancer	263
233. Was the patient involved in a research study during this calendar year?.....	264
234. Research therapeutic approach	265
235. Is the CFTR modulator trial an open label drug access study?.....	266
CFTR Modulators Form Items	267
236. CFTR modulator	268
237. Tricafort/Trikafta dose	269
238. Ivacaftor (KALYDECO) dose.....	270
239. Other Ivacaftor (KALYDECO) dose (mg).....	271
240. Ivacaftor/lumacaftor (ORKAMBI) dose (mg).....	272
241. Other lumacaftor daily dose (ORKAMBI combination) mg.....	273
242. Other Ivacaftor daily dose (ORKAMBI combination) mg.....	274
243. Tezecaftor/Ivacaftor (SYMDEKO) dose.....	275
244. Other Tezecaftor dose (SYMDEKO combination) mg	276
245. Other Ivacaftor dose (SYMDEKO combination) mg.....	277
246. Frequency of dose (SYMDEKO)	278
247. Reason for dose	279
248. Other reason for dose	280
249. CFTR start date (for this dose).....	281
250. Treatment on this dose is ongoing	282
251. Date ongoing status was updated	283
252. CFTR end date (for this dose).....	284
253. Reason the CFTR dose has ceased	285
254. Other reason for dosage ceasing	286
255. Outcome of Ivacaftor dose cessation	287
256. Outcome of the Orkambi dose cessation	288
257. Outcome of Symdeko cessation.....	289
258. Date drug regime was recommenced.....	290
Transplant Form Items	291
259. Date of transplant.....	292
260. Transplant type	293
261. Other transplant, specify	294
262. Was this a repeat transplant procedure?.....	295
263. Transplant centre	296
264. Other transplant centre	297
265. Was this the only transplant the patient underwent within the same calendar year?	298
Annual General update and Signoff Form Items	299
266. Age at the survey year	300
267. Additional Tests This Calendar Year?	301

268. Which tests have been undertaken?	302
269. Did the patient undergo treatment with CFTR modulators during this calendar year?	303
270. Has this patient been evaluated or re-evaluated for transplant during this calendar year?.....	304
271. Wait list status.....	305
272. The number of transplants that the patient underwent during the calendar year	306
273. Did the patient undergo IVF or fertility treatment during this calendar year?.....	307
274. Was the patient pregnant during this calendar year?	308
275. Pregnancy outcome	309
276. Did the patient have treatment for male infertility during this calendar year?	310
277. Did male infertility treatment result in a live birth this calendar year?.....	311
278. How many biological children does the patient have in total as of this calendar year?	312
279. Highest qualification attained to date	313
280. Employment status (for most of the time during the year)	314
281. Relationship status.....	315
282. Postcode.....	316
283. Postcode not known.....	317
284. Patient status	318
APPENDIX A: Full list of selectable genetic mutations.....	319

List of Abbreviations

ABPA	Allergic Bronchopulmonary Aspergillus
ACFDR	Australian Cystic Fibrosis Data Registry
ACT	Australian Capital Territory (Australian State)
BiPAP	Bilevel Positive Airway Pressure
BMD	Bone Mineral Density
BMI	Body Mass Index
CF	Cystic Fibrosis
CFA	Cystic Fibrosis Australia
CFTR	Cystic Fibrosis Transmembrane Conductance Regulator
cm	Centimetre(s)
COVID-19	Corona Virus Disease Variation 19
CPAP	Continuous Positive Airway Pressure
DARPC	Data Access and Research Publishing Committee
DEXA	Dual Energy X-ray Absorptiometry
FEF25-75	Forced mid-Expiratory Flow
FEV1	Forced Expiratory Volume
FVC	Forced Vital capacity
GAD-7	Generalised Anxiety Disorder Assessment
GLI	Global Lung-function Initiative
GOR	Gastric oesophageal reflux
IVF	In Vitro Fertilization
IWL	Infant Weight for Length
Kg	Kilogram(s)
METeOR	Metadata online Registry
mg	Milligram(s)
MRSA	Methicillin-Resistant Staphylococcus Aureus
NSW	New South Wale (Australian State)
NTM	Non-tuberculosis Mycobacteria
PHQ-9	Patient health Questionnaire depression module (module 9)
PRN	Pro Re Nata (unscheduled medication administration)
QLD	Queensland (Australian State)
REDCap	REDCap Database Software
SA	South Australia (Australian State)
SFTP	Solitary Fibrous Tumour of the Pleura
TAS	Tasmania (Australian State)
TPN	Total Perinatal Nutrition
ug	Microgram(s)
VIC	Victoria (Australian State)
WA	Western Australia (Australian State)

Preface

This data dictionary has been created to facilitate improved understanding of the information collected by the Australian Cystic Fibrosis Data Registry (ACFDR) by users, clinicians, researchers potential partners. The data dictionary identifies all variables collected and generated by the ACFDR during registry data collection activities, provides definitions for each variable, and gives qualifying and instructive information for data entry and clarity of interpretation.

Australian Cystic Fibrosis Data Registry Overview

The ACFDR has been collecting data since 1998 and includes data from an estimated 95% of Australia's Cystic Fibrosis (CF) population. CF is a recessive genetic condition which causes damage to the respiratory and digestive systems due to a variant in the Cystic Fibrosis Transmembrane Conductance Regulator (CFTR) gene. Variants in the CFTR gene cause disruption to the CFTR protein within the cells of lungs and other parts of the body causing a build-up of thick mucus, which can lead to infections, pancreatic distress, and a variety of other health complications.

The ACFDR dataset reports data in a manner generally consistent with other CF registries in Europe, Canada, the United Kingdom and the United States, including the 284 discrete variables detailed within this document. Australians newly diagnosed with CF are invited to participate in the registry through their treating CF centre. The ACFDR is managed by Monash University, under a shared data custodianship arrangement with Cystic Fibrosis Australia. The registry is supported by a multidisciplinary Steering Committee with consumer representation, which leads strategic direction, data and published outputs.

Data Collection Obligation

All of the variables included within this data dictionary are to be submitted by contributing sites to the greatest degree of certainty possible. However, there are variables which are not always required, or required conditionally, only once a variable requiring further clarification is supplied. Should you have a query related to reporting requirement of a given variable, see 'collection'.

Australian Cystic Fibrosis Data Registry Executive and Steering Committee 2023

Members	Role/specialisation	Institution/Association
Professor Susannah Ahern	Coordinating Investigator / Academic Lead	Monash University, VIC
Ms Jo Armstrong	CEO	Cystic Fibrosis Australia
Dr Andre Schultz	Clinical Lead ACFDR / CF Physician – Paediatrics	Perth Children’s Hospital, WA
Professor Peter Wark	Clinical Lead ACFDR / CF Physician – Adults	John Hunter Hospital, NSW
A/Professor Tom Kotsimbos	CF Physician – Adults	Alfred Health, VIC
Dr Katherine Frayman	CF Physician – Paediatrics	The Royal Children's Hospital, VIC
Dr Siobhain Mulrennan	CF Physician – Adults	Sir Charles Gairdner Hospital, WA
Dr Tonia Douglas	CF Physician – Paediatrics	Queensland Children’s Hospital, QLD
Dr Rasa Ruseckaite	Data Manager – ACFDR	Monash University, VIC
Dr Nathan Ward	Physiotherapist	Royal Adelaide Hospital, SA
Sue Morey	Nurse Practitioner	Sir Charles Gairdner Hospital, WA
Pia Sappl	Consumer Representative	NSW
Chloe Arthur	Consumer Representative	QLD
Honor Rose	Consumer Representative	VIC

Access to ACFDR Data

The ACFDR is managed on a secure Monash University platform, that has been reviewed by the Monash Cyber Security team. The Monash REDCap is hosted on-prem securely at a Monash Data Centre in Australia and uses multi-factor authentication for application access. The platform is continuously uplifting its security requirements in line with Monash University's cyber security advice.

Monash Registry Databases are housed and managed in an ISO 27001 certified environment. The ISO 27001 certification incorporates the Privacy Act (1988) and Health Records Act (2001) within its Applicability Statement. Data transfer is via Secure File Transfer Protocol (SFTP)/ Safe Haven. Data collected through REDCap is directly and permanently stored on infrastructure located in Australia and managed by Helix. Data stored on this infrastructure is backed up daily, and all traffic between the data collector's personal device, the web servers, the database servers, and the file servers are encrypted.

Only authorised personnel at the ACFDR (the Data Manager and the Registry Coordinator), will have access to the database for data verification purposes. Site personnel will be only able to review data from their own centre; they will not be able to view data from other centres. Access to the database is password protected. Privacy is paramount within the structure of the database, identifiers are known only to their immediate carers and authorised Monash University employees.

Data access is subject to the approval by the Data Access and Research Publishing Committee (DARPC), the representative sub-committee of the ACFDR Steering Committee. Its purpose is to facilitate the provision of appropriate access to data collected by or information provided by the ACFDR in line with the ACFDR Data Access Policy and protocol, and ethics requirements. The DARPC is expected to receive approximately a dozen or so requests for data access/information per annum. For information and forms required to apply for data access, please see the [Australian Cystic Fibrosis Registry Data Access Policy](#). When data is to be provided to external researchers as part of the data request process, raw data is not released. The dataset provided to the external researcher is de-identified

Data Dictionary sub-headings guide

Identifying and definitional attributes

Page heading in BLUE	Title of item or prompt in REDCap database.
Definition	A concise statement expressing the essential nature of a collected variable.
Purpose	The reason for collecting the variable.
Permissible Codes and Values	The set of possible values for the data field. These can include a code set, acceptable range, description of the possible values, text response, or defined set of response options.
Standard Source	The definition source and identifier/code for data linkage where applicable.
Guidance	Explanations or examples to assist with data entry of variables where definition, data type, format or collection may require further clarification.
Variable Name	The name of the variable within database and subsequent extractions.
Representation class	Describes the form of data to be recorded for a variable.
Data Type	The grouping type of data for a variable specified by combination of possible values, intended use, and data format.
Data Format	The specific format for entries to be reported as (e.g. date as: DDMMYYYY).
Collection	The method or reporting/generation responsibility of data entry into the database.
Logic	Programming rules for entry or generation, reporting, or automated use of the variable within the database. Clarifies logic when the field is enabled based on the values entered for related variables.

Data Dictionary Definitions

Registration Form Items

1. Unique Participant Identifier

Definition: Unique number assigned to each patient included in the registry dataset. Removes need for identifiable data such as names during processing and analysis. Determined by ascending numerical order of entry into registry.

Purpose: To enable patient identification, contact and data linkage.

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form: Registration

Guidance: This is an auto-generated field. No data is required to be entered by the participating site.

Data Element Attributes

Variable Name:	record_id	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

2. Registration Type

Definition:	Descriptor of patient data set's circumstance of entry into registry
Purpose:	To enable patient identification, contact and data linkage
Permissible Codes and Values:	1, New patient to the registry 2, Patient transfer (existing registry patient moving from another participating hospital) 3, Shared patient (existing registry patient with ongoing care at more than one participating hospital)
Standard Source:	-
Data Collection Form	Registration
Guidance:	Patients are considered 1 New to the registry, if they have never been entered into the ACFDR at any other location since the time of diagnosis

Data Element Attributes

Variable Name:	reg_type	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [reg_is_imported] <> '1'		

3. Hospital Transfer

Definition: The name identifying current hospital of primary care when a patient's primary care is transferred from one hospital to another

Purpose: To enable patient identification, contact and data linkage

Permissible Codes and Values:

- 202, Sydney Children's Hospital
- 203, Royal Prince Alfred Hospital
- 204, The Children's Hospital, Westmead
- 205, Westmead Hospital
- 206, Gosford Hospital
- 207, John Hunter Hospital - Adults
- 208, John Hunter Children's Hospital
- 301, Royal Children's Hospital, Victoria
- 302, The Alfred Hospital
- 303, Monash Medical Centre
- 403, The Prince Charles Hospital, Brisbane
- 405, Mater Hospital - Adults
- 406, Gold Coast University Hospital
- 414, Queensland Children's Hospital
- 501, Royal Adelaide Hospital
- 502, Women's and Children's Hospital
- 601, Perth Children's Hospital
- 602, Sir Charles Gairdner Hospital
- 701, Royal Hobart Hospital
- 702, Launceston General Hospital
- 703, North West Regional Hospital, Burnie
- 704, Tasmanian Adult CF Service
- 801, The Canberra Hospital - Children
- 802, The Canberra Hospital - Adults

Standard Source: -

Data Collection Form: Registration

Guidance: -

Data Element Attributes

Variable Name:	trans_share_hosp	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [reg_type] = '2' or [reg_type] = '3'		

4. Consent to Identified Data Collection

Definition:	Whether or not consent to be included within identified data sets was provided by patient
Purpose:	To verify permission to collect data
Permissible Codes and Values:	1, Yes 2, No
Standard Source:	-
Data Collection Form	Registration
Guidance:	New participants consent via the updated PICF, existing participants are required to verbally consent to the use of identified data

Data Element Attributes

Variable Name:	id_data	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [record-dag-name] = 'royal_prince_alfre' or [record-dag-name] = 'royal_childrens_hob' or [record-dag-name] = 'monash_medical_cen' or [record-dag-name] = 'john_hunter_hospit' or [record-dag-name] = 'westmead_hospital' or [record-dag-name] = 'john_hunter_childr' (more CF centres will be added to as Identified Data consent has been approved through ethics and governance)		

5. Family Name

Definition: The name a person has in common with some other members of their family, as represented by text

Purpose: To enable patient identification, contact and data linkage

Permissible Codes and Values: Text

Standard Source: METeOR: 613331

Data Collection Form: Registration

Guidance: -

Data Element Attributes

Variable Name:	surname_full	Representation Class:	Text
Data Type:	String	Data Format:	A[A(39)]
Collection:	Mandatory		
Logic:	text		
	This field is enabled if [id_data]='1'		

6. Given Name

Definition: First name; Forename; Christian name; Middle name; Second name; Other given name

Purpose: To enable patient identification, contact and data linkage

Permissible Codes and Values: Text

Standard Source: METeOR: 613340

Data Collection Form: Registration

Guidance: -

Data Element Attributes

Variable Name:	first_name_full	Representation Class:	Text
Data Type:	String	Data Format:	A[A(39)]
Collection:	Mandatory		
Logic:	text This field is enabled if [id_data]='1'		

7. Family Name Initial

Definition:	Person's family name initial
Purpose:	To enable patient identification, contact and data linkage
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	Registration
Guidance:	-

Data Element Attributes

Variable Name:	surname_initial	Representation Class:	Text
Data Type:	String	Data Format:	A[A(2)]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

8. Given Name Initial

Definition:	Person's given name name initial
Purpose:	To enable patient identification, contact and data linkage
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	Registration
Guidance:	-

Data Element Attributes

Variable Name:	first_name_initial	Representation Class:	Text
Data Type:	String	Data Format:	A[A(2)]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

9. Street Address

Definition: A composite of one or more standard address components that describes a low level of geographical/physical description of a location, as represented by text. Used in conjunction with the other high-level address components (i.e. Suburb/town/locality, Postcode) to describe residential geographical position. When addressing an Australian location, the following are the standard address data elements that may be concatenated in the street address:

- Building/property name (e.g., name of residential aged care facility, retirement village, supported accommodation, apartment/complex)
- Building/complex sub-unit
- House/property number/lot number
- Street name and type

Purpose: To enable patient identification, contact and data linkage

Permissible Codes and Values: Text

Standard Source: METeOR: 286620

Data Collection Form: Registration

Guidance: -

Data Element Attributes

Variable Name: add **Representation Class:** Text

Data Type: String **Data Format:** -

Collection: Mandatory

Logic: This field is enabled if
[id_data]='1'

10. Suburb

Definition: The name of the locality/suburb of the address, as represented by text

Purpose: To enable patient identification, contact and data linkage

Permissible Codes and Values: Text

Standard Source: METeOR: 761502

Data Collection Form: Registration

Guidance: -

Data Element Attributes

Variable Name: sub **Representation Class:** Text

Data Type: String **Data Format:** A[A(39)]

Collection: Mandatory

Logic: This field is enabled if
[id_data]='1'

11. Address State

Definition: An identifier of the state or territory of an address, as represented by a code

Purpose: To enable patient identification, contact and data linkage

Permissible Codes and Values:

- 1, ACT
- 2, NSW
- 3, QLD
- 4, SA
- 5, TAS
- 6, VIC
- 7, NT
- 8, WA

Standard Source: METeOR: 722751

Data Collection Form: Registration

Guidance: -

Data Element Attributes

Variable Name: state **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic:

This field is enabled if
[id_data]='1'

12. Address

Definition: The Australian numeric descriptor for a postal delivery area for an address

Purpose: To enable patient identification, contact and data linkage

Permissible Codes and Values: Text

Standard Source: METeOR: 429894

Data Collection Form: Registration

Guidance: -

Data Element Attributes

Variable Name:	postc	Representation Class:	Text
Data Type:	String	Data Format:	A[A(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [id_data]='1'		

13. Mobile Number

Definition:	Best Mobile Phone number to contact patient by
Purpose:	To enable patient identification, contact and data linkage
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	Registration
Guidance:	-

Data Element Attributes

Variable Name:	phone	Representation Class:	Text
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [id_data]='1'		

14. Email Address

Definition: A unique combination of characters used as to send an email for the purpose of contacting a person, as represented by text

Purpose: To enable patient identification, contact and data linkage

Permissible Codes and Values: Text

Standard Source: METeOR: 522692

Data Collection Form Registration

Guidance: -

Data Element Attributes

Variable Name:	email	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [id_data]='1'		

15. Biological Sex

Definition:	A person's sex is based upon their sex characteristics, such as their chromosomes, hormones and reproductive organs. While typically based upon the sex characteristics observed and recorded at birth or infancy, a person's reported sex can change over the course of their lifetime and may differ from their sex recorded at birth.
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data.
Permissible Codes and Values:	1, Male 2, Female
Standard Source:	METeOR: 602450
Data Collection Form:	Registration
Guidance:	This is the biological sex, that was recorded at the patient's birth. There is an additional field in the demographics page where the patient can list their perceived gender/gender reconfiguration.

Data Element Attributes

Variable Name:	sex	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

16. Date of Birth

Definition:	Date patient was born
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Date
Standard Source:	METeOR: 287007
Data Collection Form	Registration
Guidance:	-

Data Element Attributes

Variable Name:	dob	Representation Class:	Text
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This is enabled for all participants		

17. Participation Consent Status

Definition: Whether or not patient has consented to registry participation and collection of their data

Purpose: To verify permission to collect data

Permissible Codes and Values:
1, Consented
2, Waiver of consent (death)
3, Withdrawn/opted out
4, PBS drug recipient only

Standard Source: -

Data Collection Form Registration

Guidance: For registry purposes the patient has 1 Consented - when they have signed the PICF for 'opt-in' model of consent or have received the explanatory statement for those centres who participate in an 'opt-out' model of consent centres 2 Waiver of consent - the participant has been entered into the registry retrospectively 3 The participant has chosen to withdraw from being included in the registry 4 Pharmaceutical Benefits Scheme (PBS) drug recipient - CFTR modulators accessed via the PBS is conditional to being registered on the ACFDR, limited data entry is only required

Data Element Attributes

Variable Name: consent **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

18. Participation Consent Date

Definition: Date consent for data collection and registry participation was given

Purpose: To verify permission to collect data

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form Registration

Guidance: The date should be recorded when the participant signs the consent form for those centres who participate in the 'Opt-in' model of consent. Alternatively the date is recorded when participants are supplied with the Explanatory statement, for those centres who participate in the 'Opt-out' model of consent.

Data Element Attributes

Variable Name:	consent_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [consent]=1 or [consent]= 3		

19. Opt Out Reason

Definition: The reason a pateint has requested to be removed from further registry participation

Purpose: To verify permission to collect data

Permissible Codes and Values:
1, Privacy
2, Not interested
3, Other,specify
-1, Not stated

Standard Source: -

Data Collection Form Registration

Guidance: If 'Other, specify' is selected, then it is optional to record an opt out reason that is not included in the above list

Data Element Attributes

Variable Name: reas_opt_out **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if
[consent]=3

20. Opt Out Reason Continued

Definition:	Further reasons a pateint has requested to be removed from further registry participation
Purpose:	To verify permission to collect data
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	Registration
Guidance:	If the variable 'Other' has been selected for 'Opt out reason' please free text response

Data Element Attributes

Variable Name:	oth_optout	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [reas_opt_out]= 3		

21. Opt Out Date

Definition: Date consent for data collection and registry participation was withdrawn

Purpose: To verify permission to collect data

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form Registration

Guidance: -

Data Element Attributes

Variable Name:	opt_out_dt	Representation Class:	Text
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [consent]= 3		

22. Re-Consent Date

Definition: Date consent for data collection and registry participation was provided, after previously being withdrawn

Purpose: To verify permission to collect data

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form Registration

Guidance: There is a possibility the participant may be consented to the project more than once, this may be due to an updated PICF or additional verbal consent for the inclusion of identified data. You may input the date of additional consent here.

Data Element Attributes

Variable Name:	consent_dt2	Representation Class:	Text
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [consent]=1 or [consent]= 3		

23. ACFDR Identification Number

Definition:	Location and name based identifier for tracking of patient's data entries at specific locations
Purpose:	To enable patient identification, contact and data linkage
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	Registration
Guidance:	This is an auto-generated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	acfd_r_id	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

24. Unique identifier across all ACFDR collection locations

Definition: Unique alphanumeric combination assigned to each patient within ACFDR, used to group data which may be spread across sites and entry time points

Purpose: To enable patient identification, contact and data linkage

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form Registration

Guidance: This is an auto-generated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	ident	Representation Class:	Text
Data Type:	String	Data Format:	A[A(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

25. Transferred or Shared Status

Definition: Current state of approval for patients transferring primary care hospitals

Purpose: To facilitate registry data management and administration

Permissible Codes and Values:
1, Pending
2, Approved
3, Rejected

Standard Source: -

Data Collection Form Registration

Guidance: When a patient's information has been requested to be transferred from another centre, this variable will document the transferred status from the requesting centre

Data Element Attributes

Variable Name: trans_share_status **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if
[reg_type] = '2' or [reg_type] = '3'

26. Rejection Reason

Definition: If transfer is rejected, reason for rejection of primary care hospital transfer

Purpose: To facilitate registry data management and administration

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form: Registration

Guidance: -

Data Element Attributes

Variable Name:	reas_rej	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if[trans_share_status] = '3'		

27. Data Collection Start Year

Definition:	Year that a given patients data began to be entered in the registry
Purpose:	To facilitate registry data management and adiministration
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	Registration
Guidance:	Record the year the participant began attending your site and you iput data into the registry

Data Element Attributes

Variable Name:	dashboard_start_year	Representation Class:	Number
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

28. Data Collection Stop Year

Definition: Year that a given patients data ceased to be entered in the registry

Purpose: To facilitate registry data management and adiministration

Permissible Codes and Values: Number

Standard Source: -

Data Collection Form Registration

Guidance: When the participant no longer attends your site for management, please enter the last year the participant was present

Data Element Attributes

Variable Name: dashboard_stop_year **Representation Class:** Number

Data Type: Number **Data Format:** N[N]

Collection:

Logic:

29. Data Access Group

Definition: Method of assigning permissions for data access and editing within the registry database

Purpose: To facilitate registry data management and administration

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form Registration

Guidance: This is an auto-generated field. No data is required to be entered by the participating site. The data access group is also referred to as a dag, and is a unique code used for each CF centre site.

Data Element Attributes

Variable Name:	user_dag	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Auto-Generated		
Logic:	This is enabled for all participants '[user-dag-name]'		

Demographics Form Items

30. Perceived Gender

Definition:	Gender is a social and cultural concept. It is about social and cultural differences in identity, expression and experience as a man, woman or non-binary person. Non-binary is an umbrella term describing gender identities that are not exclusively male or female.
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data.
Permissible Codes and Values:	1, Male 2, Female 3, Other
Standard Source:	METeOR: 635994
Data Collection Form	demographics
Guidance:	This data item is to be used where a person has identified as a gender that does not align with their biological sex.

Data Element Attributes

Variable Name:	perc_gender	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

31. Aboriginal and Torres Strait Islander status

Definition:	Whether a person identifies as being of Aboriginal or Torres Strait Islander origin, as represented by a code
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	1, Aboriginal but not Torres Strait Islander origin 2, Torres Strait Islander but not Aboriginal origin 3, Both Aboriginal and Torres Strait Islander origin 4, Neither Aboriginal nor Torres Strait Islander origin -1, Not stated/inadequately described
Standard Source:	METeOR: 602543
Data Collection Form	demographics
Guidance:	-

Data Element Attributes

Variable Name:	atsi	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

32. Country of birth

Definition:	The country in which the person was born, as represented by a code
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	1101, Australia 1201, New Zealand -1, Not known 1102, Norfolk Island 1301, New Caledonia 1302, Papua New Guinea 1303, Solomon Islands 1304, Vanuatu 1401, Guam 1402, Kiribati 1403, Marshall Islands 1404, Micronesia, Federated States of 1405, Nauru 1406, Northern Mariana Islands 1407, Palau 1501, Cook Islands 1502, Fiji 1503, French Polynesia 1504, Niue 1505, Samoa 1506, Samoa, American 1507, Tokelau 1508, Tonga 1511, Tuvalu 1512, Wallis and Futuna 1513, Pitcairn Islands 1601, Adelie Land (France) 1602, Argentinian Antarctic Territory 1603, Australian Antarctic Territory 1604, British Antarctic Territory 1605, Chilean Antarctic Territory 1606, Queen Maud Land (Norway) 1607, Ross Dependency (New Zealand) 2102, England

2103, Isle of Man
2104, Northern Ireland
2105, Scotland
2106, Wales
2107, Guernsey
2108, Jersey
2201, Ireland
2301, Austria
2302, Belgium
2303, France
2304, Germany
2305, Liechtenstein
2306, Luxembourg
2307, Monaco
2308, Netherlands
2311, Switzerland
2401, Denmark
2402, Faroe Islands
2403, Finland
2404, Greenland
2405, Iceland
2406, Norway
2407, Sweden
2408, Aland Islands
3101, Andorra
3102, Gibraltar
3103, Holy See
3104, Italy
3105, Malta
3106, Portugal
3107, San Marino
3108, Spain
3201, Albania
3202, Bosnia and Herzegovina
3203, Bulgaria
3204, Croatia
3205, Cyprus
3206, The former Yugoslav Republic of Macedonia
3207, Greece

3208, Moldova
3211, Romania
3212, Slovenia
3214, Montenegro
3215, Serbia
3216, Kosovo
3301, Belarus
3302, Czechia
3303, Estonia
3304, Hungary
3305, Latvia
3306, Lithuania
3307, Poland
3308, Russian Federation
3311, Slovakia
3312, Ukraine
4101, Algeria
4102, Egypt
4103, Libya
4104, Morocco
4105, Sudan
4106, Tunisia
4107, Western Sahara
4108, Spanish North Africa
4111, South Sudan
4201, Bahrain
4202, Gaza Strip and West Bank
4203, Iran
4204, Iraq
4205, Israel
4206, Jordan
4207, Kuwait
4208, Lebanon
4211, Oman
4212, Qatar
4213, Saudi Arabia
4214, Syria
4215, Turkey
4216, United Arab Emirates

4217, Yemen
5101, Myanmar
5102, Cambodia
5103, Laos
5104, Thailand
5105, Vietnam
5201, Brunei Darussalam
5202, Indonesia
5203, Malaysia
5204, Philippines
5205, Singapore
5206, Timor-Leste
6101, China (excludes SARs and Taiwan)
6102, Hong Kong (SAR of China)
6103, Macau (SAR of China)
6104, Mongolia
6105, Taiwan
6201, Japan
6202, Korea, Democratic People's Republic of (North)
6203, Korea, Republic of (South)
7101, Bangladesh
7102, Bhutan
7103, India
7104, Maldives
7105, Nepal
7106, Pakistan
7107, Sri Lanka
7201, Afghanistan
7202, Armenia
7203, Azerbaijan
7204, Georgia
7205, Kazakhstan
7206, Kyrgyzstan
7207, Tajikistan
7208, Turkmenistan
7211, Uzbekistan
8101, Bermuda
8102, Canada
8103, St Pierre and Miquelon

8104, United States of America
8201, Argentina
8202, Bolivia
8203, Brazil
8204, Chile
8205, Colombia
8206, Ecuador
8207, Falkland Islands
8208, French Guiana
8211, Guyana
8212, Paraguay
8213, Peru
8214, Suriname
8215, Uruguay
8216, Venezuela
8301, Belize
8302, Costa Rica
8303, El Salvador
8304, Guatemala
8305, Honduras
8306, Mexico
8307, Nicaragua
8308, Panama
8401, Anguilla
8402, Antigua and Barbuda
8403, Aruba
8404, Bahamas
8405, Barbados
8406, Cayman Islands
8407, Cuba
8408, Dominica
8411, Dominican Republic
8412, Grenada
8413, Guadeloupe
8414, Haiti
8415, Jamaica
8416, Martinique
8417, Montserrat
8421, Puerto Rico

8422, St Kitts and Nevis
8423, St Lucia
8424, St Vincent and the Grenadines
8425, Trinidad and Tobago
8426, Turks and Caicos Islands
8427, Virgin Islands, British
8428, Virgin Islands, United States
8431, St Barthelemy
8432, St Martin (French part)
8433, Bonaire, Sint Eustatius and Saba
8434, Curacao
8435, Sint Maarten (Dutch part)
9101, Benin | 9102, Burkina Faso
9103, Cameroon | 9104, Cabo Verde
9105, Central African Republic
9106, Chad
9107, Congo, Republic of
9108, Congo, Democratic Republic of
9111, Cote d'Ivoire
9112, Equatorial Guinea
9113, Gabon
9114, Gambia
9115, Ghana
9116, Guinea
9117, Guinea-Bissau
9118, Liberia
9121, Mali
9122, Mauritania
9123, Niger
9124, Nigeria
9125, Sao Tome and Principe
9126, Senegal
9127, Sierra Leone
9128, Togo
9201, Angola
9202, Botswana
9203, Burundi
9204, Comoros
9205, Djibouti

9206, Eritrea
 9207, Ethiopia
 9208, Kenya
 9211, Lesotho
 9212, Madagascar
 9213, Malawi
 9214, Mauritius
 9215, Mayotte
 9216, Mozambique
 9217, Namibia
 9218, Reunion
 9221, Rwanda
 9222, St Helena
 9223, Seychelles
 9224, Somalia
 9225, South Africa
 9226, Eswatini
 9227, Tanzania
 9228, Uganda
 9231, Zambia
 9232, Zimbabwe

Standard Source: METeOR: 459973

Data Collection Form: demographics

Guidance: -

Data Element Attributes

Variable Name:	birth_country	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

33. Patient Status

Definition:	The current registry data collection status of a patient
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Text
Standard Source:	METeOR: 659454
Data Collection Form	annual_general_update_and_sign_off/demographics
Guidance:	This is an auto generated field - No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	pat_stat1	Representation Class:	Text
Data Type:	Number	Data Format:	N[N]
Collection:	Auto- Generated		
Logic:	Patient status is an auto - generated field detrived from [annual_data_arm_1][pat_status][last-instance]		

34. Deceased Status

Definition:	Whether or not a patient is currently deceased
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	annual_general_update_and_sign_off/demographics
Guidance:	This is an auto generated field - No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	pat_is_dead	Representation Class:	Text
Data Type:	String	Data Format:	A[A[39]]
Collection:	Mandatory		
Logic:	This field is enabled if [pat_status)=9		

35. Date of death

Definition:	The date upon which a person ceases to live
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	text (date_dmy) Show the field ONLY if: [pat_is_dead] <> " and [pat_is_dead] > 0
Standard Source:	METeOR: 646025
Data Collection Form	demographics
Guidance:	The actual (or approximate if actual is unknown) date of death of the participant

Data Element Attributes

Variable Name:	dth_dte	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [pat_is_dead] <> " and [pat_is_dead] > 0		

36. Cause of death

Definition: The disease or injury which initiated the train of morbid events leading directly to a person's death or the circumstances of the accident or violence which produced the fatal injury

Purpose: To enable patient identification, contact, data linkage, and provide demographic data

Permissible Codes and Values:

- 1, Cystic Fibrosis with pulmonary manifestations
- 2, Cystic fibrosis with Intestinal manifestations
- 3, Cystic Fibrosis related -liver failure
- 4, Cystic Fibrosis related- post transplant complications
- 5, Cystic Fibrosis related-other
- 6, Cystic Fibrosis related-unspecified
- 7, Death unrelated to CF-Trauma
- 8, Death Unrelated to CF-suicide
- 9, Death Unrelated to CF-other
- 1, Cause of death not known

Standard Source: METeOR: 307862

Data Collection Form demographics

Guidance: If 'Death Unrelated to CF - other' is selected, then it is optional to record a cause of death reason that is not included in the above list

Data Element Attributes

Variable Name:	cod	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [dth_dte] <> "		

37. Cause of Death CF Related

Definition:	Confirms a death WAS caused by CF related factors
Purpose:	To provide knowledge of CF outcomes
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	demographics
Guidance:	If the variable 'Cystic Fibrosis related - other' has been selected for 'Cause of death' please free text response

Data Element Attributes

Variable Name:	cod_oth_cf	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [cod]=5		

38. Cause of Death NOT CF Related

Definition:	Confirms a death WAS NOT caused by CF related factors
Purpose:	To provide knowledge of CF outcomes
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	demographics
Guidance:	If the variable 'Death Unrelated to CF - other' has been selected for 'Cause of death' please free text response

Data Element Attributes

Variable Name:	cod_oth_notcf	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [cod]=9		

Initial Diagnosis Form Items

39. Date of Death via Data Linkage

Definition: Date of death per data provided through Deaths Registry Linkage

Purpose: To provide knowledge of diagnostic practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form demographics

Guidance: This field is not a data entry field and is for death linkage studies only

Data Element Attributes

Variable Name: dth_dt_linkage **Representation Class:** Date

Data Type: Date **Data Format:** DDMMYYYY

Collection:

Logic: This is enabled for all participants

40. Date of CF Diagnosis Known

Definition: Whether the date a patient was diagnosed with CF if known via recall or records

Purpose: To provide knowledge of diagnostic practice

Permissible Codes and Values: 1, Yes
2, No

Standard Source: -

Data Collection Form initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name: diag_dtkn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

41. Date of CF Diagnosis

Definition:	The date a patient was diagnosed with CF
Purpose:	To provide knowledge of diagnostic practice
Permissible Codes and Values:	Date
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	The actual (or approximate if actual is unknown) date of CF diagnosis for the participant

Data Element Attributes

Variable Name:	diag_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [diag_dtkn] = 1		

42. Diagnose Date Accuracy

Definition: Wether the date given for CF diagnosis is exact, or estimated

Purpose: To provide knowelge of diagnostic practice

Permissible Codes and Values: 1, Accurate
2, Estimate
Show the field ONLY if:
[diag_dt] <> "

Standard Source: -

Data Collection Form initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name: date_acc **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [diag_dt] <>

44. Diagnosis Date Unknown Reason

Definition:	The reason a patient does not know thier diagnosis date
Purpose:	To provide knowelge of diagnostic practice
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	If the variable 'No' has been selected for 'Date of CF Diagnkosis Known' please free text response for the reason the date of CF diagnosis is unknown

Data Element Attributes

Variable Name:	reas_diagdt_uk	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [diag_dtkn]=2		

45. Age at Diagnosis

Definition:	The age of a patient at diagnosis of CF
Purpose:	To provide knowledge of clinical practice
Permissible Codes and Values:	Calculated Field
Standard Source:	-
Data Collection Form	initial_diagnosis/registrtion
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	age_diag	Representation Class:	Text
Data Type:	Number	Data Format:	Auto- Calculated
Collection:	Mandatory		
Logic:	This field is enabled if [diag_dt]<>"" Calculation: datediff([dob],[diag_dt],'y','dmy',true)		

46. Diagnosis Suggestion Entity

Definition:	The clinical event or reason for diagnosis of CF becoming clear
Purpose:	To provide knowledge of clinical practice
Permissible Codes and Values:	1, Prenatal screening 2, Newborn screening 3, Clinical signs/symptoms 4, Family History -1, Not known
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	Please select all that apply To display the list of clinical symptoms and signs at diagnosis, 'clinical signs/symptoms' must be selected

Data Element Attributes

Variable Name:	diag_sugby	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

47. Clinical Symptoms for Diagnosis

Definition: The symptoms identified which clinically indicate for diagnosis of CF, chosen from a list

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values:

- 1, Abnormal respiratory imaging consistent with CF (e g bronchiectasis)
- 2, Persistent respiratory colonisation/infection with a typical CF pathogen(s), (e g pseudomonas aeruginosa)
- 3, Pulmonary NTM (non-tuberculosis mycobacteria infection)
- 4, Respiratory signs and symptoms not specified
- 5, Electrolyte imbalance
- 6, Liver abnormalities
- 7, Pancreatitis
- 8, Meconium ileus/other intestinal obstruction
- 9, Steatorrhea/abnormal stools/malabsorption
- 10, Failure to thrive/malnutrition
- 11, Nasal polyps/sinus disease
- 12, Rectal prolapse
- 13, Digital clubbing
- 14, Infertility/e g CBAVD/GU abnormalities
- 15, GI symptoms not specified
- 16, Minor manifestations, not specified
- 17, Other, specify

Show the field ONLY if:
[diag_sugby(3)]='1'

Standard Source: -

Data Collection Form: initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name: diag_signs **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [diag_sugby(3)]='1'

48. Other Signs of CF

Definition: The symptoms identified which clinically indicate for diagnosis of CF, which are not available on the registry diagnosis symptoms list

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form initial_diagnosis

Guidance: If the variable 'Other, specify' has been selected for 'Clicial Symptoms of Diagnosis' please free text response for the other signs of CF

Data Element Attributes

Variable Name:	other_signcf	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [diag_signs(17)] ="1"		

49. Sweat Test

Definition: Whether a sweat chloride test was undertaken to assist with diagnosis

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name: chloryn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

50. Sweat Test No Reason

Definition:	The reason no sweat chloride test was undertaken to assist with diagnosis
Purpose:	To provide knowledge of clinical practice
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	chlorn	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [chloryn] = '2' or [chloryn] = '-1'		

51. Sweat Test Date

Definition: The date a sweat chloride test was undertaken to assist with diagnosis

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form: initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	chlor_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [chloryn]=1 and [chlor_dtmiss] = 0		

52. Sweat test No Date

Definition:	Confirmation that no sweat chloride test was undertaken to assist with diagnosis
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	This is an auto-generated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	chlor_dtmiss	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

53. Sweat Chloride Value

Definition:	The result of any sweat chloride test undertaken to assist with diagnosis, recorded in mmol/L
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	chlor_val	Representation Class:	Number
Data Type:	String	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [chloryn]=1		

54. Pancreatic Status

Definition:	Whether or not a patient's pancreas currently functions at the clinically determined level to maintain general health
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, Sufficient 2 Insufficient -1, Not known
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	panc_status	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

55. Pancreatic Status Basis

Definition:	The method of pancreatic status assessment
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, Faecal elastase 2, Clinical 3, Other, not stated -1, Not known
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	paninsuff_test	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [panc_status]='1' or [panc_status]='2'		

56. Faecal Elastase Date

Definition:	The date faecal elastase test was undertaken to assist with diagnosis
Purpose:	To provide knowledge of clinical practice
Permissible Codes and Values:	Date
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	faec_elast_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [paninsuff_test]=1 and [faec_elast_dtmiss]=0		

57. Faecal Elastase No Date

Definition:	Confirmation that no faecal elastase test date has been provided
Purpose:	To provide knowledge of clinical practice
Permissible Codes and Values:	1, Yes
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	This is an auto-generated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	faec_elast_dtmiss	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Auto- Generated		
Logic:	This field is enabled if [faec_elast_dt] = "" and [paninsuff_test]=1		

58. Faecal Value

Definition: The result of any faecal elastase test undertaken to assist with diagnosis, recorded in ug/g

Purpose: To provide knowledge of CF pathology and trajectory of symptoms and markers

Permissible Codes and Values: Number

Standard Source: -

Data Collection Form initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name: faec_elast_val **Representation Class:** Number

Data Type: Number **Data Format:** N[N(39)]

Collection: Mandatory

Logic: This field is enabled if [paninsuff_test]=1

59. Genotyping

Definition: Whether or not genotyping was undertaken to assist with diagnosis

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name: genoyn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

60. Genotyping Result Not Available

Definition: The reason no genotyping test was undertaken to assist with diagnosis

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	gent_nk	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [genoyrn]= "2" or [genoyrn]= "-1"		

61. Genotyping Date

Definition: The date genotyping was undertaken to assist with diagnosis

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	geno_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [genoy]=1 and [geno_dtmiss]=0		

62. Genotyping not Collected

Definition: Confirmation that no genotyping test date has been provided

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: 1, Yes

Standard Source: -

Data Collection Form initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name: geno_dtmiss **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Auto- Generated

Logic: This field is enabled if [genoyrn]=1 and [geno_dt]=""

63. Genetic Mutation 1

Definition: The first molecular genetic mutation detected during testing.
Molecular pathology is the study and diagnosis of disease through the examination of genetic and molecular abnormalities. It endeavours to explain why a given genetic change results in particular clinical phenotype.

Molecular pathology testing is performed on a patient's tissue sample and includes techniques such as, for example, oligonucleotide array sequence analysis of gene expression patterns in disease states and the detection of mutations with polymerase chain reaction.

Purpose: To provide knowledge of CF pathology and trajectory of symptoms and markers

Permissible Codes and Values: Please refer to [Appendix A](#) for a full list of genetic mutations

Standard Source: METeOR: 523059

Data Collection Form: initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name: mut1 **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [genoyr]=1

64. Poly T Status for Variant R117H

Definition:	The first variant of Poly T detected
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, 5T 2, 7T 3, 9T 4, 5T/9T 5, 7T/9T 6, TG12/5/T 7, 7T/5T -1, Not known
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	polyt_incis1	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [mut1] = '0006 9'		

65. Other Mutation 1

Definition:	The first detected mutation variant, if not included in database list
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	othermut1	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [mut1] = '9995'		

66. Geneticc Mutation 2

Definition: The first molecular genetic mutation detected during testing.
Molecular pathology is the study and diagnosis of disease through the examination of genetic and molecular abnormalities. It endeavours to explain why a given genetic change results in particular clinical phenotype.

Molecular pathology testing is performed on a patient's tissue sample and includes techniques such as, for example, oligonucleotide array sequence analysis of gene expression patterns in disease states and the detection of mutations with polymerase chain reaction

Purpose: To provide knoweldge of CF pathology and trajectory of symptoms and markers

Permissible Codes and Values: Please refer to [Appendix A](#) for a full list of genetic mutations

Standard Source: METeOR: 523059

Data Collection Form initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	mut2	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [genoyN]=1		

67. Poly T Status for Variant R117H

Definition:	The second variant of Poly T detected
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, 5T 2, 7T 3, 9T 4, 5T/9T 5, 7T/9T 6, TG12/5/T 7, 7T/5T -1, Not known
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	polyt_incis2	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [mut2] = '0006 9'		

68. Other Mutation 2

Definition:	The second detected mutation variant, if not included in database list
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	othermut2	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [mut2] = '9995'		

69. Genetic Mutation 3

Definition: The first molecular genetic mutation detected during testing.

Molecular pathology is the study and diagnosis of disease through the examination of genetic and molecular abnormalities. It endeavours to explain why a given genetic change results in particular clinical phenotype.

Molecular pathology testing is performed on a patient's tissue sample and includes techniques such as, for example, oligonucleotide array sequence analysis of gene expression patterns in disease states and the detection of mutations with polymerase chain reaction

Purpose: To provide knowledge of CF pathology and trajectory of symptoms and markers

Permissible Codes and Values: Please refer to [Appendix A](#) for a full list of genetic mutations

Standard Source: METeOR: 523059

Data Collection Form: initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	mut3	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [genoyr]=1		

70. Poly T Status for Variant R117H

Definition:	The second variant of Poly T detected
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, 5T 2, 7T 3, 9T 4, 5T/9T 5, 7T/9T 6, TG12/5/T 7, 7T/5T -1, Not known
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	polyt_incis3	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [mut3] = '0006 9'		

71. Other Mutation 3

Definition:	The second detected mutation variant, if not included in database list
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	othermut3	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [mut3]='9995'		

72. Birth Weight

Definition:	The first weight of the live born or stillborn baby obtained after birth, or the weight of the neonate or infant on the date admitted if this is different from the date of birth
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	METeOR: 269455
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	birthwt	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [birthwtuk]=0 Acceptable range: Min: 1 0, Max: 6 0)		

73. Birth Weight Unknown

Definition: Confirmation that the birth weight of a patient is unknown

Purpose: To confirm missing value

Permissible Codes and Values: 1, Yes

Standard Source: -

Data Collection Form initial_diagnosis

Guidance:

Data Element Attributes

Variable Name: birthwtuk **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [birthwt]=""

74. Birth length

Definition:	The first length of the live born or stillborn baby obtained after birth, or the length of the neonate or infant on the date admitted if this is different from the date of birth
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	Acceptable range for the birth length is between 20 cm and 70 cm

Data Element Attributes

Variable Name:	birthlgth	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [birthlgthuk]=0 Acceptable range Min: 20, Max: 70)		

75. Birth Length Unknown

Definition:	Confirmation that the birth length of a patient is unknown
Purpose:	To confirm missing value
Permissible Codes and Values:	1, Yes
Standard Source:	-
Data Collection Form	initial_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	birthlghuk	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [birthlgh]=""		

76. Gestation length

Definition:	The period of time between conception and birth of the patient
Purpose:	To provide knowledge of potential CF identifiers, risk factors, or co-variables
Permissible Codes and Values:	40, = or > 40 weeks 39, 39 weeks 38, 38 weeks 37, 37 weeks 36, 36 weeks 35, 35 weeks 34, 34 weeks 33, 33 weeks 32, 32 weeks 31, 31 weeks 30, 30 weeks 29, 29 weeks 28, 28 weeks 27, 27 weeks 26, 26 weeks 25, 25 weeks 24, 24 weeks 23, 23 weeks 22, 22 weeks 21, 21 weeks 20, 20 weeks 2, < 20 weeks 3, < 32 weeks(for old data only) 4, >32 weeks(for old data only) -1, Not known

Standard Source: -

Data Collection Form: initial_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	gestation	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]

Collection: Mandatory

Logic: This is enabled for all participants

Post Diagnosis Form Items

77. Date of Sweat Chloride Test Date

Definition: The date a sweat chloride test was undertaken to assist with diagnosis

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form sweat_tests_post_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	chlor_dt2	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This is enabled for all participants		

78. Sweat Chloride Value (mmol/L)

Definition:	The result of any sweat chloride test undertaken to assist with diagnosis, recorded in mmol/L
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	sweat_tests_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	chlor_val2	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [chlor_dt2] <>"" Acceptable range: Min: 10, Max: 140		

79. Date of genotype test

Definition: The date a genotype test was undertaken to assist with diagnosis

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form genetic_mutation_results_post_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	geno_dt2	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This is enabled for all participants This field is enabled if		

80. Genetic mutation 1 (post diagnosis)

Definition: The first molecular genetic mutation detected during testing post diagnosis.

Molecular pathology is the study and diagnosis of disease through the examination of genetic and molecular abnormalities. It endeavours to explain why a given genetic change results in particular clinical phenotype.

Molecular pathology testing is performed on a patient's tissue sample and includes techniques such as, for example, oligonucleotide array sequence analysis of gene expression patterns in disease states and the detection of mutations with polymerase chain reaction

Purpose: To provide knowledge of CF pathology and trajectory of symptoms and markers

Permissible Codes and Values: Please refer to [Appendix A](#) for a full list of genetic mutations

Standard Source: METeOR: 523059

Data Collection Form genetic_mutation_results_post_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	mut1_pd	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [geno_dt2]<>""		

81. Poly T form in cis with R117H

Definition:	The first variant of Poly T detected if detected post diagnosis
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, 5T 2, 7T 3, 9T 4, 5T/9T 5, 7T/9T 6, TG12/5/T 7, 7T/5T -1, Not known
Standard Source:	-
Data Collection Form	genetic_mutation_results_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	polt_incis4	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [mut1_pd] = '0006 9'		

82. Other genetic mutation 1 (post diagnosis)

Definition:	The first detected mutation variant, if not included in database list, and if detected post diagnosis
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	genetic_mutation_results_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	othermut1_pd	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [mut1_pd] = '9995'		

83. Genetic mutation 2 (post diagnosis)

Definition:	<p>The first molecular genetic mutation detected during testing post diagnosis.</p> <p>Molecular pathology is the study and diagnosis of disease through the examination of genetic and molecular abnormalities. It endeavours to explain why a given genetic change results in particular clinical phenotype.</p> <p>Molecular pathology testing is performed on a patient's tissue sample and includes techniques such as, for example, oligonucleotide array sequence analysis of gene expression patterns in disease states and the detection of mutations with polymerase chain reaction</p>
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Please refer to Appendix A for a full list of genetic mutations
Standard Source:	METeOR: 523059
Data Collection Form	genetic_mutation_results_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	mut2_pd	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [geno_dt2]<>""		

84. Poly T form in cis with R117H

Definition:	The second variant of Poly T detected, if detected post diagnosis
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, 5T 2, 7T 3, 9T 4, 5T/9T 5, 7T/9T 6, TG12/5/T 7, 7T/5T -1, Not known
Standard Source:	-
Data Collection Form	genetic_mutation_results_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	polyt_incis5	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [mut2_pd] = '0006 9'		

85. Other genetic mutation 2 (post diagnosis)

Definition:	The second detected mutation variant, if not included in database list, and if detected post diagnosis
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	genetic_mutation_results_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	othermut2_pd	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [mut2_pd] = '9995'		

86. Genetic mutation 3 (post diagnosis)

Definition: The first molecular genetic mutation detected during testing post diagnosis.

Molecular pathology is the study and diagnosis of disease through the examination of genetic and molecular abnormalities. It endeavours to explain why a given genetic change results in particular clinical phenotype.

Molecular pathology testing is performed on a patient's tissue sample and includes techniques such as, for example, oligonucleotide array sequence analysis of gene expression patterns in disease states and the detection of mutations with polymerase chain reaction

Purpose: To provide knowledge of CF pathology and trajectory of symptoms and markers

Permissible Codes and Values: Please refer to [Appendix A](#) for a full list of genetic mutations

Standard Source: METeOR: 523059

Data Collection Form: genetic_mutation_results_post_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	mut3_pd	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [geno_dt2]<>"		

87. Poly T form in cis with R117H

Definition:	The third variant of Poly T detected, if detected post diagnosis
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, 5T 2, 7T 3, 9T 4, 5T/9T 7, 7T/5T 5, 7T/9T 6, TG12/5/T -1, Not known
Standard Source:	-
Data Collection Form	genetic_mutation_results_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	polyt_incis6	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [mut3_pd] = '0006 9'		

88. Other genetic mutation 3 (post diagnosis)

Definition:	The third detected mutation variant, if not included in database list
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	genetic_mutation_results_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	othermut3_pd	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [mut3_pd] = '9995'		

89. Pancreatic insufficiency status

Definition:	Whether pancreatic enzym activity is sufficient for normal digestive function
Purpose:	To provide knoweldge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, Sufficient 2, Insufficient
Standard Source:	-
Data Collection Form	pancreatic_insufficiency_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	panc_status2	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

90. Date of pancreatic status assessment

Definition: The date of pancreatic status assessment

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form pancreatic_insufficiency_post_diagnosis

Guidance: -

Data Element Attributes

Variable Name:	panc_dt2	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This is enabled for all participants		

91. Estimate date (only year correct)

Definition: Confirmation that the specific date of pancreatic status assessment is unknown, but year is correct

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: 1, Yes
0, No

Standard Source: -

Data Collection Form pancreatic_insufficiency_post_diagnosis

Guidance: This is an auto-generated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name: panc_dt_est **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Auto- Generated

Logic: This is enabled for all participants

92. Pancreatic insufficiency status assessment based on:

Definition: The type of measure used to determine pancreatic insufficiency status

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: 1, Faecal elastase
2, Clinical
3, Other
-1, Not known

Standard Source: -

Data Collection Form pancreatic_insufficiency_post_diagnosis

Guidance: -

Data Element Attributes

Variable Name: paninsuff_test2 **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [panc_status2]='1' or [panc_status2]='2'

93. Faecal elastase value (ug/g)

Definition:	The numerical result of faecal elastase test measured in ug/g
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	pancreatic_insufficiency_post_diagnosis
Guidance:	-

Data Element Attributes

Variable Name:	faec_elast_val2	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

Clinical Measures Form Items

94. Date clinical measure taken

Definition: The date of major clinical measures assesment including height, weight, Forced Vital Capacity

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: text (date_dmy)

Standard Source: -

Data Collection Form clinical_measures

Guidance: -

Data Element Attributes

Variable Name:	clin_meas_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This is enabled for all participants		

95. Where was the clinical measurement captured?

Definition: The type of location where clinical measures were taken

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: 1, In patient's home
2, In clinic/hospital
3, Unknown

Standard Source: -

Data Collection Form clinical_measures

Guidance: -

Data Element Attributes

Variable Name: where_clin_meas **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

96. Who performed/recorded the measurement?

Definition: Whether the patient, another, or unknown source provided clinical measurements

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values:
1, The patient with their own equipment
2, Clinician/Technician with their own equipment
3, Unknown

Standard Source: -

Data Collection Form: clinical_measures

Guidance: -

Data Element Attributes

Variable Name: who_record_meas **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [where_clin_meas] = '1'

97. Weight (kg)

Definition:	The weight (body mass) of a person measured in kilograms
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Number
Standard Source:	METeOR: 702085
Data Collection Form	clinical_measures
Guidance:	-

Data Element Attributes

Variable Name:	wt	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	Acceptable range Min: 1, Max: 115)		

98. Height (cm)

Definition:	The standing height or recumbent length of a body
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Number
Standard Source:	METeOR: 269299
Data Collection Form	clinical_measures
Guidance:	-

Data Element Attributes

Variable Name:	ht	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	Acceptable range Min: 25, Max: 198)		

99. FVC (litres)

Definition:	Result of Forced Vital Capacity Test, recorded in Litres
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures
Guidance:	-

Data Element Attributes

Variable Name:	fvc	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	Acceptable range Min: 0.4, Max: 8.0)		

100. FEV1 (litres)

Definition:	Result for Forced Expiratory Volume, recorded in Litres
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures
Guidance:	-

Data Element Attributes

Variable Name:	fev1	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	Acceptable range Min: 0.2, Max: 8.0)		

101. FEF25-75

Definition:	Result for Forced mid-Expiratory Flow
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures
Guidance:	-

Data Element Attributes

Variable Name:	fef25_75	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

102. Calculated age

Definition:	The age of the person in (completed) years at a specific point in time
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	METeOR: 303794
Data Collection Form	clinical_measures/registration
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	ageclin	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

103. FEV1pp (GLI)

Definition: Result for Forced Expiratory Volume, recorded in Litres, as collected by the Global Lung Function initiative

Purpose: To provide knowledge of CF pathology and trajectory of symptoms and markers

Permissible Codes and Values: Number

Standard Source: -

Data Collection Form clinical_measures/registration

Guidance: This is an auto-calculated field No data is required to be entered by the participating site
This field will be calculated if age is >6 years

Data Element Attributes

Variable Name: fev1pp_gli **Representation Class:** Number

Data Type: Number **Data Format:** N[N(39)]

Collection: Auto- Generated

Logic: This is enabled for all participants

104. BMI

Definition:	A measure of an adult's weight (body mass) relative to height used to assess the extent of weight deficit or excess where height and weight have been measured
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	METeOR: 270084
Data Collection Form	clinical_measures/registration
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site BMI will be calculated for ages greater than two years of age at the time of this clinical measure

Data Element Attributes

Variable Name:	bmi	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

105. BMI Percentile

Definition:	The percentile of Australian population a patient's BMI result equates to
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures/registration
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site This field will only populate if the participant is between 2 and 20 years of age at the date the clinical measure was taken

Data Element Attributes

Variable Name:	bmi_perc	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

106. BMI z score

Definition:	The numerical difference between population mean and a patient's BMI result
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures/registration
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	bmiz	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

107. Weight z score

Definition:	The numerical difference between population mean and a patient's weight result
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures/registration
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	wtz	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

108. Weight percentile

Definition:	The percentile of Australian population a patient's weight result equates to
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures/registration
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	wt_perc	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

109. Height z score

Definition:	The numerical difference between population mean and a patient's height result
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures/registration
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	htz	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

110. Height Percentile

Definition:	The percentile of Australian population a patient's height result equates to
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures/registration
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	ht_perc	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

111. IWT (infant weight for length)

Definition: Infant Weight for Length result, calculated for patient's which data collected prior to age 2

Purpose: To enable patient identification, contact, data linkage, and provide demographic data

Permissible Codes and Values: Number

Standard Source: -

Data Collection Form clinical_measures/registration

Guidance: This is an auto-calculated field No data is required to be entered by the participating site For children less than 2 years of age at the time clinical measures were taken, IWT (infant weight for length) will be calculated in this field

Data Element Attributes

Variable Name: iwt **Representation Class:** Number

Data Type: Number **Data Format:** N[N(39)]

Collection: Auto- Generated

Logic: This is enabled for all participants

112. IWT (Infant length for weight) z score

Definition:	The numerical difference between population mean and a patient's Infant Weight for Length result
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	clinical_measures/registration
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site For infants between 0 and 2 years of age

Data Element Attributes

Variable Name:	lwtz	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

113. Event

Definition: The type of treatment or consultation event occurring when data was captured

Purpose: To differentiate data entry points, and contextualise data

Permissible Codes and Values: 1, Clinic visit
2, Hospitalisation
3, IV Home Therapy
4, Both IV hospitalisation and IV Home

Standard Source: -

Data Collection Form hospitalclinic_visits_home_iv_ab_events

Guidance: -

Data Element Attributes

Variable Name: event **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

114. Hospitalisation Admission Type

Definition:	Area of hospital patient was admitted to on a given visit
Purpose:	To differentiate data entry points, and contextualise data
Permissible Codes and Values:	1, General Ward Admission 2, ICU/Critical Care Admission 3, Other
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	hosp_adms_type	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants [event] = '2'		

116. Date of clinic visit

Definition:	The date of clinic visit when data was captured
Purpose:	To differentiate data entry points, and contextualise data
Permissible Codes and Values:	Date
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	clin_vis_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [event]= 1		

117. Patient refused clinical measures (lung function and height/weight) to be taken at this visit

Definition:	Confirmation that a patient declined to have standard clinical measures taken during a time where data were usually collected
Purpose:	To provide knowledge of clinical practice
Permissible Codes and Values:	1, Yes
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	clinmeas_none	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [clin_vis_type]=1 or [clin_vis_type]=2		

118. Hospital admission date

Definition:	Date of patient admission to hospital for a given event
Purpose:	To differentiate data entry points, and contextualise data
Permissible Codes and Values:	Date
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	hosp_adm_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [event] ='2' or [event] = '4'		

119. Hospital discharge date

Definition: Date of patient discharge from hospital for a given event

Purpose: To differentiate data entry points, and contextualise data

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form hospitalclinic_visits_home_iv_ab_events

Guidance: -

Data Element Attributes

Variable Name:	hosp_dis_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [event] ='2' or [event] = '4'		

120. Primary reason for hospitalisation

Definition:	The reason for hospitalisation
Purpose:	To differentiate data entry points, and contextualise data
Permissible Codes and Values:	1, Respiratory related 2, Gastro-Intestinal related 3, Other reason (incl non-transplant surgery) -1, Reason unknown
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	prim_reas_hosp	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [event]= 2 or [event] = 4		

121. Specific respiratory related reason

Definition:	The reason medical care was sought if respiratory related
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, Respiratory infection- bacterial/fungal related 2, Respiratory infection,- viral 3, Respiratory infection, not specified 4, Asthma 5, ABPA flair 6, Haemoptysis 7, Pneumothorax 8, COVID-19 -1, Respiratory -not specified
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	resp_hosp	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [prim_reas_hosp]=1		

122. GI related hospitalisation

Definition:	The reason medical care was sought if gastro-intestinal related
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	11, Diabetes 12, Liver 15, Pancreatitis 16, DIOS 21, Nutrition related/malnutrition -1, GI related - not specified
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	gi_rel_hosp	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [prim_reas_hosp]=2		

124. Procedure undertaken during hospitalisation

Definition: The type of intervention applied

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values:

- 1, Permanent IV access device insertion
- 2, Gallbladder disease
- 3, Gastrostomy
- 4, Intestinal obstruction (CF related)
- 5, Nasal polyp surgery
- 6, Sinus surgery
- 7, Therapeutic embolization of bronchial artery
- 1, Other, not specified/not known

Standard Source: -

Data Collection Form hospitalclinic_visits_home_iv_ab_events

Guidance: -

Data Element Attributes

Variable Name:	proc_hosp	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [oth_primhosp]="3" or [oth_hosp_reas(18)] = 1		

125. Other reason for hospitalisation

Definition:	Reason for hospitalisation if not related to pre-fill options
Purpose:	To provide knoweldge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	other_prim_reas	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [oth_primhosp]=6		

126. Other Reasons for Hospitalisation

Definition: Other reasons related to hospitalisation other than the primary reason already recorded

Purpose: To provide knowledge of CF pathology and trajectory of symptoms and markers

Permissible Codes and Values:

- 1, Respiratory not specified
- 2, Respiratory infection- bacterial/fungal related
- 3, Respiratory infection- viral
- 4, Respiratory infection, not specified
- 5, Asthma
- 6, ABPA flair
- 7, Haemoptysis
- 8, Pneumothorax
- 9, GI related unknown*
- 10, Dehydration
- 21, Nutrition related/malnutrition
- 11, Diabetes
- 12, Liver disease
- 13, Transplant related
- 14, Sinus infection
- 15, Pancreatitis
- 16, DIOS
- 17, CFTR medication administration
- 18, NON-transplant surgery (includes outpatient surgeries)
- 19, Secondary reason not specified or not evident

Standard Source: -

Data Collection Form: hospitalclinic_visits_home_iv_ab_events

Guidance: -

Data Element Attributes

Variable Name: oth_hosp_reas **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [event] =2 or [event] =4

128. Hospital IV antibiotic start date

Definition: That date intra-veinous anti-biotics began to be administered this hospital stay

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form hospitalclinic_visits_home_iv_ab_events

Guidance: -

Data Element Attributes

Variable Name:	hosp_ivab_st_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [ivab_hospyn]=1		

129 Hospital IV antibiotic therapy end date

Definition: That date intra-veinous anti-biotics ceased to be administered this hospital stay

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form hospitalclinic_visits_home_iv_ab_events

Guidance: -

Data Element Attributes

Variable Name:	hosp_ivab_end_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [ivab_hospyn]=1		

130. Home IV antibiotic therapy start date

Definition:	That date intra-veinous anti-biotics began to be administered at the patient's home
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	Date
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	homeivab_st_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [event]= 3 or [event] =4		

131. Home IV antibiotic therapy end date

Definition:	That date intra-veinous anti-biotics ceased to be administered at the patient's home
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	Date
Standard Source:	-
Data Collection Form	hospitalclinic_visits_home_iv_ab_events
Guidance:	-

Data Element Attributes

Variable Name:	homeivab_end_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This field is enabled if [event] = 3 or [event] =4		

132. Were IV antibiotics given for respiratory indications?

Definition: Whether intra-veinous anti-biotics were administered for respiratory related clinical indications

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form hospitalclinic_visits_home_iv_ab_events

Guidance: -

Data Element Attributes

Variable Name: ivab_respyn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [ivab_hospyn]=1 or [event]=3 or [homeivab_st_dt] <>""

Microbiology Form Items

133. Microbiology test date

Definition: The Date of microbilology tests related to the present medical event or consultation

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: micro_dt	Representation Class: Date
Data Type: Date	Data Format: DDMMYYYY
Collection: Mandatory	
Logic: This is enabled for all participants	

136. Results for:

Definition:	The specific type and result for any microbiology test has been undertaken
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	1, Bacteria (excluding NTM and other mycobacteria) 2, Fungi 3, NTM and other mycobacteria 4, COVID-19
Standard Source:	-
Data Collection Form	microbiology
Guidance:	To understand what tests were ordered and the outcome i.e. positive growth, no growth, sampling error or just not ordered, we have separated the microbiology tests into these broad groups. Not all tests are ordered each time, sometimes only NTM or bacteria might be ordered, sometimes all three

Data Element Attributes

Variable Name:	cult_for	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

137. COVID-19 Test Outcome

Definition: The result of any COVID-19 test undertaken

Purpose: To provide further respiratory health context

Permissible Codes and Values: 1, Positive
2, Negative

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: covid_test_outcome **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cult_for(4)] = '1'

138. Achromobacter species

Definition: Whether Achromobacter species were detected

Purpose: To provide further respiratory health context

Permissible Codes and Values: 1, Yes

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: achromo **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cult_for(1)]=1

139. Achromobacter species

Definition: When Achromobacter species were detected, which specific species was found

Purpose: To provide further respiratory health context

Permissible Codes and Values:

- 1, Achromobacter aegrifaciens
- 2, Achromobacter agilis
- 3, Achromobacter animicus
- 4, A anxifer
- 5, A deleyi
- 6, A denitrificans
- 7, A dolens
- 8, A insolitus
- 9, A insuavis
- 10, A kerstersii
- 11, A marplatensis
- 12, A mucicolens
- 13, A pestifer
- 14, A piechaudii
- 15, A pulmonis
- 16, A ruhlandii
- 17, A spanius
- 18, A xylosoxidans
- 19, Achromobacter species - other/indeterminate
- 20, Achromobacter species - not specified

Standard Source: -

Data Collection Form: microbiology

Guidance: -

Data Element Attributes

Variable Name: achromo_spec_type **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [achromo] = 'I'

140. Burkholderia species

Definition:	Whether Burkholderia species were detected
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	1, Yes
Standard Source:	-
Data Collection Form	microbiology
Guidance:	-

Data Element Attributes

Variable Name:	burkhold	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [cult_for(1)]=1		

141. Burkholderia species type

Definition: When Burkholderia species were detected, which specific species was found

Purpose: To provide further respiratory health context

Permissible Codes and Values: 1, Burkholderia cepacia complex
2, Burkholderia (non cepacia) species

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: burk_type **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [burkhold]=1

142. Burkholderia cepacia complex type

Definition: When Burkholderia cepacia complex species were detected, which specific species was found

Purpose: To provide further respiratory health context

Permissible Codes and Values:

- 1, Burkholderia ambifaria
- 2, Burkholderia anthina
- 3, Burkholderia arboris
- 4, Burkholderia cenocepacia
- 5, Burkholderia cepacia
- 6, Burkholderia contaminans
- 7, Burkholderia diffusa
- 8, Burkholderia dolosa
- 9, Burkholderia lata
- 10, Burkholderia latens
- 11, Burkholderia metallica
- 12, Burkholderia multivorans
- 13, Burkholderia puraquae
- 14, Burkholderia pseudomultivorans
- 15, Burkholderia pyrrocinia
- 16, Burkholderia seminalis
- 17, Burkholderia stabilis
- 18, Burkholderia stagnalis
- 19, Burkholderia territorii
- 20, Burkholderia ubonensis
- 21, Burkholderia vietnamiensis
- 22, Burkholderia cepacia species, other/indeterminate
- 23, Burkholderia cepacia complex -species not specified

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: burk_cep_type **Representation Class:** Code Set - Checkbox

Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [burk_type(1)]=1		

143. Burkholderia (non- cepacia complex) species

Definition: When Burkholderia (non cepacia) species were detected, which specific species was found

Purpose: To provide further respiratory health context

Permissible Codes and Values:
1, Burkholderia gladioli
2, Burkholderia pseudomallei
3, Other Burkholderia species

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: burk_noncep_typ **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [burk_type(2)]=1

144. Burkholderia non cepacia complex other

Definition: The specific species found, when Burkholderia (non cepacia) species were detected are the species is not listed in the database's current options

Purpose: To provide further respiratory health context

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: burk_noncep_notspec **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This field is enabled if [burk_noncep_typ(3)] = '1'

147. Pseudomonas aeruginosa status

Definition: Indicator of Pseudomonas aeruginosa status, and type

Purpose: To provide further respiratory health context

Permissible Codes and Values: 1, Pseudomonas aeruginosa
2, Pseudomonas other (non-aeruginosa)

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: pseud_aerug_stat **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [pseudomonas] = '1'

148. Pseudomonas aeruginosa phenotype

Definition: The phenotype of pseudomonas aeruginosa, when detected

Purpose: To provide further respiratory health context

Permissible Codes and Values:
1, Mucoid
2, Rough/non-mucoid
3, Phenotype unknown

Standard Source: -

Data Collection Form: microbiology

Guidance: -

Data Element Attributes

Variable Name: pseud_aerug_phen **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [pseud_aerug_stat(1)] = '1'

149. Non-aeruginosa pseudomonas species, specify

Definition:	The species of pseudomonas aeruginosa, when the species is not listed in the database options
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	microbiology
Guidance:	-

Data Element Attributes

Variable Name:	pseud_nonaerug	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [pseud_aerug_stat(2)] = '1		

151. Staphylococcus aureus methicillin resistance status

Definition: Whether the patient has resistance to staphylococcus aureus methicillin, and the level of resistance

Purpose: To provide further respiratory health context

Permissible Codes and Values: 1, Methicillin sensitive SA (MSSA)
2, Methicillin resistant SA (MRSA)
-1, Not stated/not known

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name:	sa_meth_stat	Representation Class:	Code Set - Radio Button
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Data Type:	Number	Data Format:	N[N]
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Collection: Mandatory

Logic: This field is enabled if [staph_aur]=1

152. Staphylococcus aureus multidrug resistance status

Definition:	Whether the patient has resistance to staphylococcus aureus multidrug, and the level of resistance
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	1, Multi-drug resistant to all tested antibiotics 2, Not multi-drug resistant (methicillin resistant but sensitive to other tested antibiotics) -1, Not stated/Not known
Standard Source:	-
Data Collection Form	microbiology
Guidance:	-

Data Element Attributes

Variable Name:	multi_drug_sa	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [sa_meth_stat]=2		

153. Stenotrophomonas species

Definition: Whether stenotrophomonas aureus was detected

Purpose: To provide further respiratory health context

Permissible Codes and Values: 1, Yes

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: stenot_y **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cult_for(1)]=1

154. Stenotrophomonas species type

Definition: The type of stenotrophomonas aureus detected

Purpose: To provide further respiratory health context

Permissible Codes and Values: 1, Stenotrophomonas maltophilia
2, Stenotrophomonas, other

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: sten_type **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [stenot_y]=1

155. Other bacteria

Definition: Whether another bacteria not included in the database lists was detected

Purpose: To provide further respiratory health context

Permissible Codes and Values: 1, Yes

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: oth_bacy **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cult_for(1)]=1

156. Normal respiratory flora grown

Definition:	Whether normal levels of normal respiratory flora grows in the patient
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	1, Yes
Standard Source:	-
Data Collection Form	microbiology
Guidance:	-

Data Element Attributes

Variable Name:	bac_normgrwth	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [cult_for(1)]=1		

159. Bacteria other

Definition:	Whether another bacteria not yet included in the data entry for the patient was detected, and the name of the bacteria, represented by a numerical identifier
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	<ol style="list-style-type: none">1, Acinetobacter baumannii2, Acinetobacter species - other*3, Agrobacterium species4, Bordetella pertussis5, Bordetella parapertussis6, Bordetella bronchiseptica7, Brevundimonas species8, Chryseobacterium species9, Cupriavidus basilensis10, Cupriavidus gilardii11, Cupriavidus metallidurans12, Cupriavidus necator13, Cupriavidus pauculus14, Cupriavidus respiraculi15, Delftia acidivordans16, Delftia species - other*17, Enterobacter species18, Exophilia dermatitidis19, Herbaspirillum frisingense20, Herbaspirillum putei21, Herbaspirillum seropedicae22, Inquilinus limosus23, Nocardia species24, Streptococcus anginosus25, Streptococcus constellatus26, Streptococcus intermedius27, Escherichia Coli (E coli)28, Klebsiella species29, Serratia marcescens30, Pandoraea species31, Ralstonia species32, Streptococcus pneumoniae33, Streptococcus pyogenes

160. Pandoraea species type

Definition: The specific species of pandoraea, if detected

Purpose: To provide further respiratory health context

Permissible Codes and Values:

- 1, Pandoraea apista
- 2, Pandoraea norimbergensis
- 3, Pandoraea pnomenusa
- 4, Pandoraea pulmonicola
- 5, Pandoraea sputorum
- 6, Pandoraea terrae
- 7, Pandoraea species - other*

Standard Source: -

Data Collection Form: microbiology

Guidance: -

Data Element Attributes

Variable Name: pandorea_typ **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [bact_oth(30)]=1

161. Pandoraea species other

Definition:	The specific species of pandoraea detected, if not found in the database list
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	microbiology
Guidance:	-

Data Element Attributes

Variable Name:	pand_spec_oth	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [pandorea_typ(7)] = '1'		

162. Ralstonia species type

Definition: The specific species of ralstonia species, if detected

Purpose: To provide further respiratory health context

Permissible Codes and Values:

- 1, Ralstonia insidiosa
- 2, Ralstonia mannitolilytica
- 3, Ralstonia pickettii
- 4, Ralstonia pseudosolanacearum
- 5, Ralstonia solanacearum
- 6, Ralstonia syzygii
- 7, Ralstonia species, not specified

Standard Source: -

Data Collection Form: microbiology

Guidance: -

Data Element Attributes

Variable Name: ralstonia_type **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [bact_oth(31)]=1

163. Other bacteria not listed

Definition: Whether any other bacteria were detected if not yet reported

Purpose: To provide further respiratory health context

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name:	bacteria_notlist	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [bact_oth(38)]=1		

164. Fungal results

Definition:	The result or type of fungus detected, if fungal testing was undertaken
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	1, Aspergillus (any) 2, Candida 3, Scedosporium 4, Exophiala (Wangiella) 5, Other fungus 6, No growth/sterile sample 7, Not processed (e.g. sample unlabeled, arrived outside window timeframe)

Standard Source: -

Data Collection Form: microbiology

Guidance: -

Data Element Attributes

Variable Name:	posfung_typ	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [cult_for(2)]=1		

165. Fungi, other specify:

Definition: The type of fungus detected, if not included in the database list

Purpose: To provide further respiratory health context

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name:	posfun_oth	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [posfung_typ(5)]=1		

167. Was NTM or other mycobacteria cultured from the specimen?

Definition: Whether Nontuberculous Mycobacteria or other mycobacteria were cultured from the specimen

Purpose: To provide further respiratory health context

Permissible Codes and Values: 1, Yes
2, No
3, Results pending

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: ntm_procynt **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cult_for(3)] = '1'

168. Reason why there were no results for NTM or other mycobacterial growth?

Definition:	The reason, if there was not result for Nontuberculous Mycobacteria or other mycobacterial growth
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	1, No growth 2, Overgrowth of specimen 5, Insufficient growth of specimen 6, Not processed adequately (e g sample not labeled, outside window timeframe) -1, Reason not known
Standard Source:	-
Data Collection Form	microbiology
Guidance:	-

Data Element Attributes

Variable Name:	reas_nontm	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [ntm_procyn]=2		

169. Mycobacterium cultured

Definition:	The type of Mycobacterium cultured
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	1, Mycobacterium tuberculosis 2, Non-tuberculosis mycobacterium(NTM)
Standard Source:	-
Data Collection Form	microbiology
Guidance:	-

Data Element Attributes

Variable Name:	ntm_yn	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [ntm_procyn]=1		

170. NTM organism cultured

Definition:	The type of Nontuberculous Mycobacteria cultured
Purpose:	To provide further respiratory health context
Permissible Codes and Values:	<ol style="list-style-type: none"> 1, Mycobacterium avium 2, Mycobacterium intracellulare 3, Mycobacterium kansasii 4, Mycobacterium species (not specified) 5, Mycobacterium abscessus- (not sub speciated) 6, Mycobacterium abscessus sub species abscessus 7, Mycobacterium abscessus sub species massiliense 8, Mycobacterium abscessus sub species bolletti 9, Mycobacterium fortuitum 10, Mycobacterium fortuitum complex 11, Mycobacterium chelonae 12, Mycobacterium gordonae 13, Mycobacterium peregrinum 14, Mycobacterium scrofulaceum 15, Mycobacterium terrae 16, Mycobacterium triplex 17, Mycobacterium lentiflavum 18, Mycobacterium interjectum 19, Mycobacterium species (rapid grower) not further speciated x 20, Mycobacterium species (slow grower) not further speciated 21, Other NTM organism (specify)
Standard Source:	-
Data Collection Form	microbiology
Guidance:	-

Data Element Attributes

Variable Name:	ntm_org	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [ntm_yn(2)]=1		

171. Other NTM organism

Definition: The type of Nontuberculous Mycobacteria cultured, if the result does not appear in the database list

Purpose: To provide further respiratory health context

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form microbiology

Guidance: -

Data Element Attributes

Variable Name: ntm_oth **Representation Class:** Text

Data Type: String **Data Format:** X[X(39)]

Collection: Mandatory

Logic: This field is enabled if [ntm_org(21)] = '1'

Quarterly Signoff Form Items

172. Please confirm if the number of clinical measures entered for this quarter is correct (this may include zero clinical measures for this quarter)

Definition:	Confirmation of the number of clinical measures entered for this quarter is correct
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	1, Correct 2, Incorrect
Standard Source:	-
Data Collection Form	quarterly_sign_off
Guidance:	Please confirm if the number of clinical measures entered for this quarter is correct (this may include zero clinical measures for this quarter)

Data Element Attributes

Variable Name:	clinmeas_coryn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

173. Please confirm that the number of microbiology tests entered for this quarter is correct (this may include zero microbiology for this quarter)

Definition:	Confirmation of the number of microbiology tests entered for this quarter is correct
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	1, Correct 2, Incorrect
Standard Source:	-
Data Collection Form	quarterly_sign_off
Guidance:	Please confirm that the number of microbiology tests entered for this quarter is correct (this may include zero microbiology for this quarter)

Data Element Attributes

Variable Name:	micro_coryn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

174. Please confirm that the number of clinic visits entered for this quarter is correct (this may include zero clinic visits for this quarter)

Definition:	Confirmation of the number of clinic visits entered for this quarter is correct
Purpose:	To provide knowledge of clinical practice
Permissible Codes and Values:	1, Correct 2, Incorrect
Standard Source:	-
Data Collection Form	quarterly_sign_off
Guidance:	Please confirm that the number of clinic visits entered for this quarter is correct (this may include zero clinic visits for this quarter)

Data Element Attributes

Variable Name:	clinvis_coryn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

175. Please confirm that the number of hospitalisations entered for this quarter is correct (this may include zero hospitalisations for this quarter)

Definition: Confirmation of the number of hospital visits entered for this quarter is correct

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: 1, Correct
2, Incorrect

Standard Source: -

Data Collection Form quarterly_sign_off

Guidance: Please confirm that the number of hospitalisations entered for this quarter is correct (this may include zero hospitalisations for this quarter)

Data Element Attributes

Variable Name:	hospviz_coryn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

176. Please confirm the number of combined hospital/Home IV antibiotic events for this quarter (this may include zero events for this quarter)

Definition: Confirmation of the number of combined hospital/Home IV antibiotic events entered for this quarter is correct

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: 1, Correct
2, Incorrect

Standard Source: -

Data Collection Form quarterly_sign_off

Guidance: Please confirm the number of combined hospital/Home IV antibiotic events for this quarter (this may include zero events for this quarter)

Data Element Attributes

Variable Name:	hosp_homiv_coryn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

177. Please confirm the number of home IV antibiotic events entered for this quarter (this may include zero events for this quarter)

Definition:	Confirmation of the number of home IV antibiotic events entered for this quarter is correct
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	1, Correct 2, Incorrect
Standard Source:	-
Data Collection Form	quarterly_sign_off
Guidance:	Please confirm the number of home IV antibiotic events entered for this quarter (this may include zero events for this quarter)

Data Element Attributes

Variable Name:	homivab_coryn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

178. Survey Year

Definition:	Confirmation of the year the survey was completed
Purpose:	To differentiate data entry points, and contextualise data
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	This is an auto-calculated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	survey_year_comp	Representation Class:	Number
Data Type:	Number	Data Format:	YYYY
Collection:	Auto- Generated		
Logic:	This is enabled for all participants		

Complications and Treatment Form Items

179. Cystic Fibrosis Lung Disease

Definition:	Whether Cystic Fibrosis Lung Disease is present in the patient
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, Yes 2, No
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	cf_lungyn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

180. Treatment for CF related lung disease during this calendar year

Definition: The type of treatment for Cystic Fibrosis Lung Disease implemented for th patient

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values:

- 1, Bronchodilators
- 2, Mucolytics
- 3, Inhaled corticosteroids
- 4, Oral corticosteroids
- 5, Macrolides
- 6, Inhaled antibiotics
- 7, Acetylcysteine
- 8, Antifungal triazoles
- 9, Regular oral antibiotic use
- 0, No treatment during the calendar year
- 1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: Select all that apply

Data Element Attributes

Variable Name: cflungtxt **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cf_lungyn]=1

182. Oral corticosteroids

Definition: The Oral corticosteroids type used in CF treatment for a patient

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: 1, Short term oral corticosteroids (< 3months)
2, Long term oral corticosteroids (> 3 months)
-1, Oral corticosteroid use, duration not specified

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: Select all that apply

Data Element Attributes

Variable Name: oral_cort_lth **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cflungtxt(4)]=1

183. Macrolide type

Definition: The Macrolide type used in CF treatment for a patient

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:
1, Azithromycin
2, Clarithromycin
3, Erythromycin
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: Select all that apply

Data Element Attributes

Variable Name: macro_typ **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cflungtxt(5)]=1

184. Inhaled antibiotic type

Definition: The inhaled antibiotic type used in CF treatment for a patient

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:
1, Tobramycin
2, Colistin
3, Other inhaled antibiotic, specify
-1, Inhaled antibiotic not specified

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: Select all that apply

Data Element Attributes

Variable Name: inhal_ab_typ **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cflungtxt(6)]= '1'

185. Other inhaled antibiotic

Definition: The type of inhaled antibiotic used in CF treatment for a patient, if not included in the database lists

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: oth_inh_ab **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This field is enabled if [inhal_ab_typ(3)]=1

186. Tobramycin use

Definition: The Tobramycin type used in CF treatment for a patient

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:
1, Continuous
2, Interrupted (e g month on/off)
3, Short term (e g exacerbations)
4, Pseudomonas eradication
-2, Not specified

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: Select all that apply

Data Element Attributes

Variable Name: tob_use **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [inhal_ab_typ(1)]="1"

187. Colistin use

Definition: The Colistin type used in CF treatment for a patient

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:
1, Continuous
2, Interrupted (e g month on/off)
3, short term (e g exacerbations)
4, Pseudomonas eradication -1, Not specified

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: Select all that apply

Data Element Attributes

Variable Name: col_use **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [inhal_ab_typ(2)]="1"

188. Antifungal triazole type

Definition: The Antifungal triazole type used in CF treatment for a patient

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:
1, Intraconazole
2, Voriconazole
3, Posaconazole
4, Fluconazole
-1, Triazole, not specified

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: Select all that apply

Data Element Attributes

Variable Name: azole_type **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [cflungtxt(8)]=1

189. Allergic bronchopulmonary aspergillus (ABPA)

Definition: Whether allergic bronchopulmonary aspergillus is present in the patient

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: abpa **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

190. Pneumothorax

Definition: Whether pneumothorax is present in the patient

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: pneumoth **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

191. Haemoptysis

Definition: Whether haemoptysis is present in the patient

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: haemoptyn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

192. Did any haemoptysis event this calendar year lead to embolization

Definition: Whether the patient was embolized as a result of haemoptysis during the present calendar year

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: haem_txt **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [haemoptyn]=1

193. Did the patient undergo surgery for nasal polyps or sinusitis during this calendar year?

Definition:	Whether the patient underwent surgery for nasal polyps or sinusitis during this calendar year
Purpose:	To provide knowledge of CF treatments
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	nas_sinsurg	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

196. Was non-invasive ventilation used during this annual year (e.g. assisted breathing, BiPAP, CPAP)

Definition: Whether the patient utilised non-invasive ventilation used during the present calendar year

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: noninvas_yn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

197. Non-invasive ventilation use during the current annual year (assisted breathing, BiPap, CPAP etc)

Definition: The type of non-invasive ventilation used during the present calendar year

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: 1, Continuous
2, Nocturnal
3, Intermittent (e g severe exacerbation)
4, With physiotherapy (ACT etc)
-1, Non invasive ventilation used, but not specified

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: non_invas_o2 **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [noninvas_yn]=1

201. Did the patient have a Covid 19 vaccination during this calendar year?

Definition:	Whether the patient had a Covid 19 vaccination vaccine during the present calendar year
Purpose:	To provide further health context
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	covid	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

202. Which dose has been administered

Definition: The number of COVID-19 Doses the patient has received

Purpose: To provide further health context

Permissible Codes and Values:
1, 1st dose
2, 2nd dose
3, 3rd dose
4, 4th dose
5, 5th dose

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name:	dose	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [covid]=1		

203. Did the patient receive vitamins, enzymes or salt replacement therapy during this calendar year?

Definition: Whether the patient underwent vitamins, enzymes or salt replacement therapy during the present calendar year

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: nutrit_yn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

204. Vitamins, enzymes or salt replacement used

Definition:	The type of vitamins, enzymes or salt replacement therapy utilised
Purpose:	To provide knowledge of CF treatments
Permissible Codes and Values:	1, Pancreatic enzymes 2, Vitamins A, D, E, K 3, Salt replacement (salt tablets, prescribed salt replacement drinks)
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	nutsup_opt	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [nutrit_yn]=1		

206. Nutritional intervention type

Definition: The type of nutritional intervention therapy utilised

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values: 1, Gastrostomy tube
2, Nasogastric tube
3, Oral
4, Jejunostomy tube
5, TPN
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: nut_int_type **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [nut_intyn]=1

207. Gastric oesophageal reflux (GOR)

Definition:	Whether the patient exhibited gastric oesophageal reflux during the present calendar year
Purpose:	To provide knoweldge of CF treatments
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	gor	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

209. Gastric oesophageal reflux treatment type

Definition: The type of gastric oesophageal reflux treatment utilised

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values: 1, Gastric acid secretion reducers
2, Proton pump inhibitors
3, Prokinetics
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: gor_txt **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [txt_goryn]=1

210. Pancreatitis

Definition:	Whether the patient has ever exhibited pancreatitis, and if yes, the type of recurrence
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, No history of pancreatitis 2, Acute (first pancreatitis event this current year) 3, Recurrent pancreatitis (history of more than one event of pancreatitis) 4, Pancreatitis, not specified -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	panc_stat	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

211. Diabetes/impaired glucose tolerance during the calendar year?

Definition:	Whether the patient has exhibited diabetes/impaired glucose tolerance during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Normal, (no diabetes or impaired glucose tolerance) 2, Impaired glucose tolerance 3, Diabetes -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	diabetes	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

212. Diabetes treatment type

Definition:	The type of diabetes treatment utilised
Purpose:	To provide further health context, and identify potential CF risk factors and co-variables
Permissible Codes and Values:	1, Insulin 2, Hypoglycaemics 3, Insulin and hypoglycaemics 4, Diet/lifestyle management only 5, No treatment for diabetes
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	diab_txttyp	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [diabetes] =3		

213. Insulin use

Definition:	The regularity of insulin treatment utilised
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Chronic insulin use 2, Intermittent insulin use 3, Insulin use, duration unknown
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	If both chronic and intermittent use of insulin occurred, please select the type of use that was mostly used during this calendar year

Data Element Attributes

Variable Name:	insulin	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [diab_txttyp] ="1" or [diab_txttyp]= "3"		

214. Secondary complications to diabetes during this calendar year

Definition:	Whether the patient exhibited Secondary complications to diabetes during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, No secondary complications 2, Retinopathy 3, Microalbuminuria 4, Diabetic nephropathy (diabetes related renal disease) 5, Peripheral neuropathy -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	Select all that apply

Data Element Attributes

Variable Name:	sec_comp_diab	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [diabetes]=3		

215. Hepatobiliary dysfunction during this calendar year?

Definition:	Whether the patient exhibited hepatobiliary dysfunction during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	hepatyn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

216. Hepatobiliary/liver disease

Definition:	The type of epatobiliary/liver disease exhibited
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	2, Liver disease, non-cirrhosis (includes viral hepatitis, fatty liver) 3, Liver disease, cirrhosis (image confirmed) 4, Liver disease, cirrhosis with portal hypertension 6, Gall stones, requiring surgery/procedure -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	hepatic_dysfunction	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [hepatyn]=1		

217. Was a DEXA scan performed during this calendar year?

Definition: Whether the patient underwent a DEXA scan during the present year

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: 1, Yes
2, No
3, Not known

Standard Source: -

Data Collection Form complications_and_treatment

Guidance: -

Data Element Attributes

Variable Name: dexa **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

218. Date of most recent DEXA scan

Definition:	The date of the most recent DEXA scan
Purpose:	To provide knowledge of clinical practice
Permissible Codes and Values:	Date
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	dexa_dt	Representation Class:	Text
Data Type:		Data Format:	
Collection:			
Logic:	This field is enabled if [dexa] = "1"		

219. Bone mineral density status

Definition:	The bone mineral density status of the patient
Purpose:	To provide knowledge of CF pathology and trajectory of symptoms and markers
Permissible Codes and Values:	1, Normal (>-1SD) 2, Osteopenia (< -1to - 2 5 SD for hip/spine) 3, Osteoporosis (< -2 5 SD and/or fracture for hip/spine) -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	bmdstat	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [dexa] = "1"		

221. Did the patient have a fracture during this calendar year?

Definition:	Whether the patient fractured any bones during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	fracture	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants This field is enabled if		

222. Has a mental health screen using GAD-7 and PHQ-9 been performed during this calendar year?

Definition: Whether the patient underwent mental health screen using GAD-7 and PHQ-9 during the present year

Purpose: To provide further health context, and identify potential CF risk factors and co-variates

Permissible Codes and Values:
1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form complications_and_treatment/registration

Guidance: This question is enabled when the participant is 12 years and above

Data Element Attributes

Variable Name: menthealth_scrn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if
`datediff([core_data_arm_1][dob],[survey_year_date_comp],'y','dmy',true) >= 12`

223 Was a high score received for either questionnaire?

Definition:	Whether a GAD-7 and PHQ-9 'high score' of over 10 was exhibited by the patient this calendar year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	Definition of a high score equals >10

Data Element Attributes

Variable Name:	menthealth_score	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

224. Has the patient engaged with a mental health service provider during this calendar year?

Definition:	Whether the patient engaged with a mental health service provider during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	menthealth_pract	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

225. Did the patient receive a physiotherapy review during this calendar year?

Definition:	Whether the patient underwent a physiotherapy review during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variables
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	physio	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

226. Did the patient receive a social work review during the last calendar year?

Definition:	Whether the patient received a social work review during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	social_work	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

227. Did the patient receive a gastroenterologist review during the last calendar year?

Definition:	Whether the patient received a gastroenterologist review during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	gastro	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

228. Did the patient receive an endocrine review during the last calendar year?

Definition:	Whether the patient received an endocrine review during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	endo	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

229. Did the patient receive a dietician review during this last calendar year?

Definition:	Whether the patient received a dietician review during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	diet	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

230. Was a histologically confirmed cancer diagnosed during the current calendar year?

Definition:	Whether the patient received a histologically confirmed cancer diagnosed during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	canceryn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

231. Cancer (histology proven) diagnosed during this calendar year

Definition:	The type of histologically confirmed cancer diagnosis during the present year		
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates		
Permissible Codes and Values:	1, Biliary tract 2, Bladder 3, Brain 4, Breast 5, Bone (sarcoma) 6, Bowel (colorectal) 7, Endocrine (thyroid) 8, Gastric 9, Kidney 10, Liver 11, Lung 12, Melanoma (skin) 13, Oesophageal 14, Pancreatic 15, Prostate 16, Small intestine 17, Testes 18, Cancer- site not specified 19, Other, cancer (describe)		
Standard Source:	-		
Data Collection Form	complications_and_treatment		
Guidance:	Select all that apply		

Data Element Attributes

Variable Name:	cancer	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [canceryn] = '1'		

232. Other cancer

Definition:	The type of histologically confirmed cancer diagnosis during the present year, if not listed in the database options
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	cancer_oth	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [cancer(19)]= "1"		

233. Was the patient involved in a research study during this calendar year?

Definition:	Whether the patient was involved in a research study outside of ACFDR in the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	ACFDR is a clinical quality registry and is not considered a research project for the purpose of this response

Data Element Attributes

Variable Name:	research	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		

234. Research therapeutic approach

Definition:	The type of therapeutic approach investigated by the research project outside of ACFDR
Purpose:	To provide further health context, and identify potential CF risk factors and co-variables
Permissible Codes and Values:	1, Restore CFTR function 2, Anti-infective 3, Anti-inflammatory 4, Mucociliary clearance 5, Nutritional-GI 6, Behavioural 7, Observational 8, Other -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	res_type	Representation Class:	Code Set - Checkbox
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [research]=1		

235. Is the CFTR modulator trial an open label drug access study?

Definition:	Whether or not any cystic fibrosis transmembrane conductance regulator trial participated in was an open label drug access study
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	complications_and_treatment
Guidance:	-

Data Element Attributes

Variable Name:	open_label	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [res_type(1)]=1'		

CFTR Modulators Form Items

236. CFTR modulator

Definition: The type of cystic fibrosis transmembrane conductance regulator used

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:
1, Ivacaftor (Kalydeco)
2, Lumacaftor/Ivacaftor (Orkambi)
3, Tezacaftor/Ivacaftor (Symdeko)
4, Tricafort/Trikafta

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: cftrmod **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants
This field is enabled if

237. Tricaftor/Trikafta dose

Definition:	If applicable, the dose of Tricaftor/Trikafta prescribed
Purpose:	To provide knowledge of CF treatments
Permissible Codes and Values:	<p>1, Elexacaftor 100mg +tezacaftor 50mg+ivacaftor 75mg X2 tabs in AM; Ivacaftor 150mg in PM</p> <p>2, Non standard dose is Elexacaftor 100mg +tezacaftor 50mg+ivacaftor 75mg X2 tabs in AM twice weekly</p> <p>3, Non standard dose elexacaftor 50mg/tezacaftor 25mg/ivacaftor 37 5mg per tablet - 2 tabs AM & ivacaftor 75mg per tablet - 1 tab PM</p> <p>4, Non standard dose is Elexacaftor 100mg + tezacaftor 50mg + ivacaftor 75mg x2 tabs in AM on alternate days and Ivacaftor 150mg x1 tab in AM on other alternate days</p> <p>5, Non standard dose Elexacaftor 100mg + Tezacaftor 50mg + Ivacaftor 75mg in AM daily</p> <p>6, Non standard dose Elexacaftor 100mg + Tezacaftor 50mg + Ivacaftor 75mg AM + Ivacaftor 150 mg PM</p> <p>7, Non standard dose Elexacaftor 100mg + Tezacaftor 50mg + Ivacaftor 75mg - 2 tablets AM + Ivacaftor 150mg PM on alternate days with nothing on the intervening days</p> <p>8, Non standard dose Elexacaftor 100mg + Tezacaftor 50mg + Ivacaftor 75mg x2 tabs AM on alternate days and Elexacaftor 100mg + Tezacaftor 50mg + Ivacaftor 75mg x1 tab AM on other alternate days</p> <p>9, Desensitisation Regime</p> <p>10, Non standard dose Elexacaftor 100mg + Tezacaftor 50mg + Ivacaftor 75mg x2 AM daily</p>
Standard Source:	-
Data Collection Form	cftr_modulators
Guidance:	-

Data Element Attributes

Variable Name:	tricaftor_dose	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants		
	This field is enabled if		

238. Ivacaftor (KALYDECO) dose

Definition:	If applicable, the dose of Tricafort/Trikafta prescribed
Purpose:	To provide knowledge of CF treatments
Permissible Codes and Values:	1, 50mg ivacaftor twice daily /(age >2, and < 14kg) = 100mg total daily dose 2, 75mg Ivacaftor twice daily (age >2, and < 25 kg), = 150mg total daily dose 3, 150mg ivacaftor twice daily (age >2, and > 25kg), = 300 mg total daily dose 4, 150mg ivacaftor twice daily? (age >2 and >25mg), twice weekly = ?? total daily dose 5, Non-standard dose
Standard Source:	-
Data Collection Form	cftr_modulators
Guidance:	-

Data Element Attributes

Variable Name:	ivac_dse_kal	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants This field is enabled if		

239. Other Ivacaftor (KALYDECO) dose (mg)

Definition: If applicable, the dose of Ivacaftor (KALYDECO) prescribed

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:

Standard Source: -

Data Collection Form: cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: other_ivac_dse **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This is enabled for all participants
This field is enabled if

240. Ivacaftor/lumacaftor (ORKAMBI) dose (mg)

Definition:	If applicable, the dose of Ivacaftor/lumacaftor prescribed
Purpose:	To provide knowledge of CF treatments
Permissible Codes and Values:	1, 400mg Lumacaftor/250mg Ivacaftor twice daily (>12 yrs), Max daily dose = 800 luma/500 Iva 2, 200mg Lumacaftor/250mg Ivacaftor twice daily (bw 6 and 11 yrs) Max daily dose = 400 luma/500 iva 3, Non-standard dose 4, 100mg Lumacaftor/125mg Ivacaftor twice daily (6-11 years old) 5, Granule: 1 packet containing lumacaftor 100mg/ivacaftor 125 mg BD (< 6 years; < 14kg) 6, Granule: 1 packet containing lumacaftor 150mg/ivacaftor 188 mg BD (< 6 years; ≥14 kg)

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name:	lum_iva_dse	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants This field is enabled if		

241. Other lumacaftor daily dose (ORKAMBI combination) mg

Definition: If applicable, the other lumacaftor daily dose (ORKAMBI combination) prescribed, if not available in the database list

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:

Standard Source: -

Data Collection Form: cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: oth_ivac_dse_ork **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This is enabled for all participants
This field is enabled if

242. Other Ivacaftor daily dose (ORKAMBI combination) mg

Definition: If applicable, the other Ivacaftor daily dose (ORKAMBI combination) prescribed, if not available in the database list

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:

Standard Source: -

Data Collection Form: cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: lum_oth_dse_ork **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This is enabled for all participants
This field is enabled if

243. Tezacaftor/Ivacaftor (SYMDEKO) dose

Definition:	If applicable, the dose of Tezacaftor/Ivacaftor (SYMDEKO) prescribed
Purpose:	To provide knowledge of CF treatments
Permissible Codes and Values:	1, 100mg tezacaftor/150mg ivacaftor- am, 150mg ivacaftor pm (>12 years of age) 2, Non-standard dose
Standard Source:	-
Data Collection Form	cftr_modulators
Guidance:	-

Data Element Attributes

Variable Name:	sym_dse	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants This field is enabled if		

244. Other Tezecaftor dose (SYMDEKO combination) mg

Definition: If applicable, the dose of other Tezecaftor (SYMDEKO combination) prescribed, if not available in the database list

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values:

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: tez_dose_sym **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This is enabled for all participants
This field is enabled if

245. Other Ivacaftor dose (SYMDEKO combination) mg

Definition: If applicable, the dose of other Ivacaftor (SYMDEKO combination) prescribed, if not available in the database list

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values:

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: iva_dose_sym **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This is enabled for all participants
This field is enabled if

246. Frequency of dose (SYMDEKO)

Definition: If applicable, the dose of Tricafort/Trikafta prescribed

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: 1, Daily
2, Twice weekly
3, Other

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: sym_freq **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants
This field is enabled if

247. Reason for dose

Definition: The reason for doses of cystic fibrosis transmembrane conductance regulator prescribed

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:

- 1, Low lung function
- 2, Hepatic dysfunction
- 3, Concomitant medication (e g CYP3 inhibitors)
- 4, Other reason

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: reas_dse **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants
This field is enabled if

248. Other reason for dose

Definition: The reason for doses of cystic fibrosis transmembrane conductance regulator prescribed, if not an option in the database list

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form: cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: oth_reas_dse **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This is enabled for all participants
This field is enabled if

250. Treatment on this dose is ongoing

Definition:	Confirmation that cystic fibrosis transmembrane conductance regulator treatment is ongoing
Purpose:	To provide knoweldge of CF treatments
Permissible Codes and Values:	1, Yes
Standard Source:	-
Data Collection Form	cftr_modulators
Guidance:	-

Data Element Attributes

Variable Name:	ongoing	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants This field is enabled if		

251. Date ongoing status was updated

Definition: The date patient's cystic fibrosis transmembrane conductance regulator prescription was last updated

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form: cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: ongoing_dt **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This is enabled for all participants
This field is enabled if

252. CFTR end date (for this dose)

Definition: The date patient ended cystic fibrosis transmembrane conductance regulator prescription

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form: cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: cftr_end_dt **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This is enabled for all participants
This field is enabled if

253. Reason the CFTR dose has ceased

Definition: The reason patient ended cystic fibrosis transmembrane conductance regulator prescription

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values:

- 1, Pulmonary side effect/intolerance
- 2, Liver impairment/intolerance
- 3, Other intolerance/adverse event
- 4, Pregnancy
- 5, Concomitant drug interaction
- 7, Switch to other CFTR modulator
- 6, Other reason

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: dose_change_reas **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants
This field is enabled if

254. Other reason for dosage ceasing

Definition: The reason patient ended cystic fibrosis transmembrane conductance regulator prescription, if not an option in the database list

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: Text

Standard Source: -

Data Collection Form: cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: other_dose_change_reas **Representation Class:** Text

Data Type: **Data Format:**

Collection:

Logic: This is enabled for all participants
This field is enabled if

255. Outcome of Ivacaftor dose cessation

Definition: The outcome of Ivacaftor treatment upon prescription ending

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:
1, Change in dose of ivacaftor
2, Temporary cessation of Ivacaftor
3, Permanent cessation of Ivacafto

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: ivac_ceas **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants
This field is enabled if

256. Outcome of the Orkambi dose cessation

Definition: The outcome of Orkambi treatment upon prescription ending

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values:
1, Change in dose of Orkambi
2, Temporary cessation of Orkambi
3, Permanent cessation of Orkambi

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: ork_ceas **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants
This field is enabled if

257. Outcome of Symdeko cessation

Definition: The outcome of Symdeko treatment upon prescription ending

Purpose: To provide knoweldge of CF treatments

Permissible Codes and Values:
1, Change in dose of Symdeko
2, Temporary cessation of Symdeko
3, Permanent cessation of Symdeko

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name: symd_ceas **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants
This field is enabled if

258. Date drug regime was recommenced

Definition: The date patient's cystic fibrosis transmembrane conductance regulator prescription was recommenced

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values: Date

Standard Source: -

Data Collection Form cftr_modulators

Guidance: -

Data Element Attributes

Variable Name:	drug_cess_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This is enabled for all participants This field is enabled if		

Transplant Form Items

259. Date of transplant

Definition:	The date of any transplant received
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	Date
Standard Source:	-
Data Collection Form	transplants
Guidance:	-

Data Element Attributes

Variable Name:	transplant_dt	Representation Class:	Date
Data Type:	Date	Data Format:	DDMMYYYY
Collection:	Mandatory		
Logic:	This is enabled for all participants		

260. Transplant type

Definition: The type of transplant, if a transplant was received

Purpose: To provide knoweldge of clinical practice

Permissible Codes and Values:

- 1, Bilateral lung
- 2, Liver
- 3, Heart-Lung
- 4, Liver and bilateral lung
- 5, Heart, bilateral lung and liver
- 6, Kidney
- 7, Kidney and bilateral lung
- 8, Pancreas
- 9, Bilateral lung, liver, pancreas
- 10, Other, specify

Standard Source: -

Data Collection Form transplants

Guidance: -

Data Element Attributes

Variable Name: transplant_type **Representation Class:** Code Set - Dropdown

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

261. Other transplant, specify

Definition:	The type of transplant, if a transplant was received, if it does not appear in the database list
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	transplants
Guidance:	-

Data Element Attributes

Variable Name:	transplant_other	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [transplant_type]= 10		

262. Was this a repeat transplant procedure?

Definition: Whether the transplant was a repeat of previous transplant

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form transplants

Guidance: -

Data Element Attributes

Variable Name: redo_trans **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants
This field is enabled if

263. Transplant centre

Definition:	The location of transplant procedure
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	1, The Alfred Hospital VIC 2, Royal Perth Hospital , WA 3, Fiona Stanley Hospital, WA 4, The Prince Charles Hospital, QLD 5, St Vincents Hospital NSW 6, Other transplant centre
Standard Source:	-
Data Collection Form	transplants
Guidance:	-

Data Element Attributes

Variable Name:	trans_centre	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants This field is enabled if		

264. Other transplant centre

Definition:	The location of transplant procedure, if it does not appear in the database list
Purpose:	To provide knoweldge of clinical practice
Permissible Codes and Values:	Text
Standard Source:	-
Data Collection Form	transplants
Guidance:	-

Data Element Attributes

Variable Name:	oth_txt_cent	Representation Class:	Text
Data Type:	String	Data Format:	X[X(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [trans_centre]=6		

Annual General update and Signoff Form Items

266. Age at the survey year

Definition: The age of the person in (completed) years at a specific point in time

Purpose:

Permissible Codes and Values: Number

Standard Source: METeOR: 303794

Data Collection Form: annual_general_update_and_sign_off

Guidance: This is an auto-calculated field No data is required to be entered by the participating site

Data Element Attributes

Variable Name:	age_at_survey_year	Representation Class:	Number
Data Type:	Number	Data Format:	Auto- Calculated
Collection:	Mandatory		
Logic:	Calculation: datediff([core_data_arm_1][dob],[survey_year_date],'y','dmy',true) This field is enabled if		

267. Additional Tests This Calendar Year?

Definition: Whether the patient underwent additional sweat chloride, pancreatic insufficiency or genetic mutation tests during this calendar year?

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form annual_general_update_and_sign_off

Guidance: -

Data Element Attributes

Variable Name: add_testyn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Auto- Generated

Logic: This field is enabled if Calculation:
datediff([core_data_arm_1][dob],[survey_year_date],'y','dmy',true)

268. Which tests have been undertaken?

Definition: If additional tests were undertaken in the present year, which tests?

Purpose: To provide knowledge of clinical practice

Permissible Codes and Values:
1, Sweat chloride
2, Genotyping
3, Pancreatic status

Standard Source: -

Data Collection Form annual_general_update_and_sign_off

Guidance: Please add the results of any of these tests under the relevant post diagnostic result form; Sweat tests (post diagnosis), Genetic mutation results (post diagnosis) or Pancreatic insufficiency (post diagnosis) form

Data Element Attributes

Variable Name: update_test_type **Representation Class:** Code Set - Checkbox

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This field is enabled if [add_testyn]= "1"

269. Did the patient undergo treatment with CFTR modulators during this calendar year?

Definition: Whether or not any cystic fibrosis transmembrane conductance regulator trial participated in was an open label drug access study

Purpose: To provide knowledge of CF treatments

Permissible Codes and Values: 1, Yes
2, No
-1, Not known

Standard Source: -

Data Collection Form annual_general_update_and_sign_off

Guidance: If the response is 'Yes' please complete or updated the CFTR modulator form

Data Element Attributes

Variable Name: cftr_yn **Representation Class:** Code Set - Radio Button

Data Type: Number **Data Format:** N[N]

Collection: Mandatory

Logic: This is enabled for all participants

271. Wait list status

Definition:	The waitlist status of patient if applicable
Purpose:	To provide knoweldge of CF treatments
Permissible Codes and Values:	1, On or still on active wait list this year 2, Deferred waiting list this year 3, Pending wait list status (subject to further review) 3, Withdrawn from waiting list this year (clinical decision) 4, Withdrew from wait list this year (patient decision) 5, Withdrawn from waiting list year (patient deceased) 6, Patient transplanted 7, Not accepted to wait list (rejected for transplant) following assessment 8, Not accepted to wait list (rejected for transplant)-no formal assessment

Standard Source: -

Data Collection Form annual_general_update_and_sign_off

Guidance: If the participant had a transplant this year, please complete in the transplant form tansplant form under core data If the patient was withdrawn from the wait list due to death, please update the patient status on this form and complete death details in the demographics form under the core data in the patient record

Data Element Attributes

Variable Name:	wait_status	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [trans_evalyn]=1		

274. Was the patient pregnant during this calendar year?

Definition:	Whether the patient was pregnant during the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	annual_general_update_and_sign_off
Guidance:	This question is enabled if the participants are 13 years and above

Data Element Attributes

Variable Name:	preg_yn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [core_data_arm_1][sex]="2" and [age_at_survey_year][current-instance] >= 13		

275. Pregnancy outcome

Definition:	The outcome of prgnancy if applicable
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Still pregnant at the end of the year 2, Live birth 3, Miscarriage or stillbirth 4, Termination -1, Not known
Standard Source:	-
Data Collection Form	annual_general_update_and_sign_off
Guidance:	

Data Element Attributes

Variable Name:	preg_outcome	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [preg_yn]=1		

276. Did the patient have treatment for male infertility during this calendar year?

Definition:	Whether the patient underwent male infertility treatment in the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	annual_general_update_and_sign_off
Guidance:	This question is enabled if the participants are 18 years and above

Data Element Attributes

Variable Name:	infert_male_yn	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [core_data_arm_1][sex]=1 and [age_at_survey_year][current-instance] >= 18		

277. Did male infertility treatment result in a live birth this calendar year?

Definition:	Whether male infertility treatment resulted in a live birth in the present year
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	1, Yes 2, No -1, Not known
Standard Source:	-
Data Collection Form	annual_general_update_and_sign_off
Guidance:	-

Data Element Attributes

Variable Name:	male_infert_bth	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [infert_male_yn]=1		

278. How many biological children does the patient have in total as of this calendar year?

Definition:	The number of biological children the patient has sired
Purpose:	To provide further health context, and identify potential CF risk factors and co-variates
Permissible Codes and Values:	Number
Standard Source:	-
Data Collection Form	annual_general_update_and_sign_off
Guidance:	This question is enabled if the participants are 13 years and above

Data Element Attributes

Variable Name:	child_num	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [age_at_survey_year][current-instance] >= 13		

279. Highest qualification attained to date

Definition:	The highest level of qualification achieved by a patient at an educational institutions
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	1, Left school prior to completing year 10 2, Junior secondary school (year 10) 3, Senior secondary school (year 12) 4, Tertiary certificate or Diploma 5, University degree 6, Masters or doctoral degree 7, Not known
Standard Source:	METeOR: 321069
Data Collection Form	annual_general_update_and_sign_off
Guidance:	This question is enabled if the participants are 16 years and above

Data Element Attributes

Variable Name:	educ_stat	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [age_at_survey_year][current-instance] >= 16		

280. Employment status (for most of the time during the year)

Definition:	The employment status of a pateint for the majority of the present calendar year
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	1, Employed full time 2, Part time 3, Full time homemaker 5, Disability support/Pensioner 7, Retired 8, Student 9, Unemployed -1, Not known
Standard Source:	Similar to 'Current employment status'; METeOR: 621450
Data Collection Form	annual_general_update_and_sign_off
Guidance:	This question is enabled if the participants are 16 years and above

Data Element Attributes

Variable Name:	activity_stat	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [age_at_survey_year][current-instance] >= 16		

281. Relationship status

Definition:	The relationship status of the patient
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	1, Married (includes defacto) 2, Not married (single/divorced/separated) -1, Not known
Standard Source:	-
Data Collection Form	annual_general_update_and_sign_off
Guidance:	This question is enabled if the participants are 17 years and above

Data Element Attributes

Variable Name:	relat_stat	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [age_at_survey_year][current-instance] >= 17		

282. Postcode

Definition:	The Australian numeric descriptor for a postal delivery area for an address
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	Number
Standard Source:	METeOR: 429894
Data Collection Form	annual_general_update_and_sign_off
Guidance:	-

Data Element Attributes

Variable Name:	pcode	Representation Class:	Number
Data Type:	Number	Data Format:	N[N(39)]
Collection:	Mandatory		
Logic:	This field is enabled if [pcode_nk]=0		

283. Postcode not known

Definition:	Confirmation tha the patient's postcode is unknown
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	1, Yes
Standard Source:	-
Data Collection Form	annual_general_update_and_sign_off
Guidance:	-

Data Element Attributes

Variable Name:	pcode_nk	Representation Class:	Code Set - Radio Button
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This field is enabled if [pcode]=""		

284. Patient status

Definition:	Patient's follow-up status as related to ACFDR data collection
Purpose:	To enable patient identification, contact, data linkage, and provide demographic data
Permissible Codes and Values:	<ol style="list-style-type: none">1, Patient was seen this year and remains a current patient2, Current patient seen this year and is also being followed up at a transplant centre3, Current patient who was not seen this year, reason not transplant related4, Current patient who was not seen this year, reason is transplant related5, Transferred to another centre6, Transferred to private care7, Lost to follow up (not seen for three or more years)8, Patient is no longer current at this centre, reason is transplant related9, Died10, Patient withdrawn consent11, No longer considered to have CF

Standard Source: -

Data Collection Form: annual_general_update_and_sign_off

Guidance: If patient has died, please complete date of death and cause of death under demographics

Data Element Attributes

Variable Name:	pat_status	Representation Class:	Code Set - Dropdown
Data Type:	Number	Data Format:	N[N]
Collection:	Mandatory		
Logic:	This is enabled for all participants This field is enabled if		

APPENDIX A: Full list of selectable genetic mutations

Data Code	Sequence
0001	F508del--- p Phe508del--- c 1521_1523delCTT
0002	G542X ---p Gly542X ---- c 1624G>T
0003	G551D--- p Gly551Asp --- c 1652G>A
0004	N1303K--- p Asn1303Lys --- c 3909C>G
0005	W1282X--- p Trp1282X --- c 3846G>A---
0006.1	R117H;5T--- p Arg117His;None(5T) --- c [350G>A;1210-12[5]]
0006.2	R117H;7T--- p Arg117His;None(7T) --- c [350G>A;1210-12[7]]
0006.9	R117H--- p Arg117His --- c 350G>A
0007	R553X ---p Arg553X --- c 1657C>T
0008	1717-1G->A--- None --- c 1585-1G>A
0009	621+1G->T--- None ---c 489+1G>T
0010	2789+5G->A--- None --- c 2657+5G>A
0011	3849+10kbC->T--- None--- c 3718-2477C>T
0012	R1162X--- p Arg1162X --- c 3484C>T
0013	2183AA->G or 2183delAA->G--- p Lys684SerfsX38 --- c 2051_2052delAAinsG
0014	CFTRdele2,3 ---p Ser18ArgfsX16 ----c 54-5940_273+10250del21kb
0015	G85E--- p Gly85Glu ---- c 254G>A
0016	3120+1G->A--- None--- c 2988+1G>A
0017	I507del ---p Ile507del --- c 1519_1521delATC
0018	1898+1G->A ---None--- c 1766+1G>A
0019	3659delC--- p Lys1177SerfsX15 --- c 3528delC
0020	R347P ---p Arg347Pro --- c 1040G>C
0021	D1152H ---p Asp1152His --- c 3454G>C
0022	R560T ---p Arg560Thr --- c 1679G>C
0023	3272-26A->G ---None ---c 3140-26A>G
0024	Q493X ---p Gln493X --- c 1477C>T
0025	E60X--- p Glu60X --- c 178G>T
0026	R334W ---p Arg334Trp ---c 1000C>T
0027	394delTT--- p Leu88IlefsX22 --- c 262_263delTT
0028	2184insA--- p Gln685ThrfsX4 --- c 2052dup
0029.1	5T;TG11--- None--- c 1210-7_1210-6del
0029.2	5T;TG12--- None ---c 1210-11T>G
0029.3	5T;TG13 ---None--- c 1210-11delinsGTG
0029.9	5T;TG not specified--- None--- c 1210-12T[5]
0030	3905insT--- p Leu1258PhefsX7 --- c 3773dupT
0031.1	Y1092X--- p Tyr1092X --- c 3276C>A
0031.2	Y1092X ---p Tyr1092X --- c 3276C>G
0031.9	Y1092X--- p Tyr1092X --- cDNA variant not specified
0032	A455E--- p Ala455Glu --- c 1364C>A
0033	2184delA--- p Lys684AsnfsX38 --- c 2052delA
0034	R1066C--- p Arg1066Cys --- c 3196C>T
0035	1078delT--- p Phe316LeufsX12 --- c 948delT
0036	1154insTC--- p Phe342HisfsX28 --- c 1021_1022dupTC
0037	R1158X--- p Arg1158X ---c 3472C>T

0038 R347H --- p Arg347His --- c 1040G>A
 0039 S1251N --- p Ser1251Asn --- c 3752G>A
 0040 L206W--- p Leu206Trp --- c 617T>G
 0041 S549N--- p Ser549Asn --- c 1646G>A
 0042 M1101K--- p Met1101Lys --- c 3302T>A
 0043 711+1G->T--- None---- c 579+1G>T
 0044 Y122X--- p Tyr122X --- c 366T>A
 0045 2143delT--- p Leu671X--- c 2012delT
 0046 S945L--- p Ser945Leu --- c 2834C>T
 0047 I148T--- p Ile148Thr --- c 443T>C
 0048 R117C--- p Arg117Cys --- c 349C>T
 0049 V520F ---p Val520Phe --- c 1558G>T
 0050 S1235R --- p Ser1235Arg --- c 3705T>G
 0051 T338I--- p Thr338Ile --- c 1013C>T
 0052 P67L--- p Pro67Leu --- c 200C>T
 0053 G1244E ---p Gly1244Glu ---c 3731G>A
 0054 G178R--- p Gly178Arg --- c 532G>A
 0055 1677delTA --- p Tyr515X --- c 1545_1546delTA
 0056 R352Q --- p Arg352Gln --- c 1055G>A
 0057 711+5G->A --- None --- c 579+5G>A
 0058 R668C --- p Arg668Cys --- c 2002C>T
 0059.1 S549R --- p Ser549Arg --- c 1645A>C
 0059.2 S549R ---p Ser549Arg --- c 1647T>G
 0059.9 S549R ---p Ser549Arg ---cDNA variant not specified
 0060 A559T--- p Ala559Thr --- c 1675G>A
 0061 L1077P--- p Leu1077Pro ---c 3230T>C
 0062 W1089X--- p Trp1089X --- c 3266G>A
 0063 I1027T--- p Ile1027Thr --- c 3080T>C
 0064 G576A ---p Gly576Ala --- c 1727G>C
 0065 M470V ---p Met470Val --- c 1408A>G
 0066 3120G->A--- None --- c 2988G>A
 0067 R75X --- p Arg75X --- c 223C>T
 0068 W846X --- p Trp846X --- c 2537G>A
 0069 E585X --- p Glu585X --- c 1753G>T
 0070 1811+1634A->G --- None --- c 1679+1 6kbA>G
 0071 3876delA--- p Lys1250ArgfsX9 --- c 3744delA
 0072 D1270N --- p Asp1270Asn ---c 3808G>A
 0073 Q220X ---p Gln220X ---c 658C>T
 0074 2307insA--- p Glu726ArgfsX4 --- c 2175dupA
 0075 D110H ---p Asp110His --- c 328G>C
 0076 4016insT--- p Ser1297PhefsX5 --- c 3889dupT
 0077 4382delA--- p Glu1418ArgfsX14 --- c 4251delA
 0078 I336K ---p Ile336Lys ---c 1007T>A
 0079 R1066H--- p Arg1066His --- c 3197G>A
 0080 2347delG--- p Val739TyrfsX16 --- c 2215delG
 0081 L997F ---p Leu997Phe --- c 2991G>C
 0082 K710X--- p Lys710X --- c 2128A>T
 0083 E822X ---p Glu822X --- c 2464G>T

0084 L1065P ---p Leu1065Pro --- c 3194T>C
 0085 Q552X ---p Gln552X ---c 1654C>T
 0086 R74W--- p Arg74Trp --- c 220C>T
 0087 2622+1G->A--- None --- c 2490+1G>A
 0088 2789+2insA--- None--- c 2657+2_2657+3insA
 0089 E92X--- p Glu92X --- c 274G>T
 0090 Q39X--- p Gln39X --- c 115C>T
 0091 R75Q--- p Arg75Gln --- c 224G>A
 0092 D579G--- p Asp579Gly --- c 1736A>G
 0093 E831X--- p Glu831X --- c 2491G>T
 0094 3007delG --- p Ala959HisfsX9 --- c 2875delG
 0095 405+1G->A --- None ---c 273+1G>A
 0096 406-1G->A--- None ---c 274-1G>A
 0097 711+3A->G--- None--- c 579+3A>G
 0098 Q1313X--- p Gln1313X --- c 3937C>T
 0099 R709X--- p Arg709X --- c 2125C>T
 0100 2711delT--- p Phe861LeufsX3 --- c 2583delT
 0101 4005+1G->A--- None --- c 3873+1G>A
 0102 574delA--- p Ile148LeufsX5 --- c 442delA
 0103 1525-1G->A--- None--- c 1393-1G>A
 0104 1812-1G->A--- None--- c 1680-1G>A
 0105 I1234V ---p Ile1234Val --- c 3700A>G
 0106 R1070Q--- p Arg1070Gln--- c 3209G>A
 0107.1 S466X ---p Ser466X --- c 1397C>A
 0107.2 S466X--- p Ser466X --- c 1397C>G
 0107.9 S466X--- p Ser466X --- cDNA variant not specified
 0108 S489X--- p Ser489X --- c 1466C>A
 0109 L467P--- p Leu467Pro --- c 1400T>C
 0110 S492F--- p Ser492Phe --- c 1475C>T
 0111 3791delC--- p Thr1220LysfsX8 --- c 3659delC
 0112 L927P--- p Leu927Pro --- c 2780T>C
 0113 712-1G->T--- None--- c 580-1G>T
 0114 E92K--- p Glu92Lys --- c 274G>A
 0115 Q359K/T360K--- p [Gln359Lys;Thr360Lys] --- c [1075C>A;1079C>A]
 0116 Q890X ---p Gln890X --- c 2668C>T
 0117 R764X ---p Arg764X --- c 2290C>T
 0118 S1196X ---p Ser1196X --- c 3587C>G
 0119.1 W401X--- p Trp401X --- c 1202G>A
 0119.2 W401X ---p Trp401X --- c 1203G>A
 0119.3 W401X ---p Trp401X --- cDNA variant not specified
 0120 1248+1G->A--- None--- c 1116+1G>A
 0121 L732X--- p Leu732X ---c 2195T>G
 0122 Q98X--- p Gln98X --- c 292C>T
 0123 R1070W--- p Arg1070Trp--- c 3208C>T
 0124 R31C--- p Arg31Cys --- c 91C>T
 0125 R851X ---p Arg851X ---c 2551C>T
 0126 W1204X--- p Trp1204X --- c 3611G>A
 0126 W1204X--- p Trp1204X --- c 3612G>A

0127 W1204X--- p Trp1204X --- cDNA variant not specified
 0127 663delT--- p Ile177MetfsX12 --- c 531delT
 0128 F1052V--- p Phe1052Val--- c 3154T>G
 0129 G330X ---p Gly330X --- c 988G>T
 0130 P205S--- p Pro205Ser --- c 613C>T
 0131 1259insA--- p Gln378AlafsX4 --- c 1130dupA
 0132 2585delT--- p Leu818TrpfsX3 --- c 2453delT
 0133 852del22--- p Gly241GlufsX13 --- c 722_743delGGAGAATGATGATGAAGTACAG
 0134 E1104X ---p Glu1104X --- c 3310G>T
 0135 H199Y ---p His199Tyr --- c 595C>T
 0136 Q525X ---p Gln525X --- c 1573C>T
 0137 1461ins4--- p Ile444ArgfsX3 --- c 1329_1330insAGAT
 0138 1898+3A->G--- None--- c 1766+3A>G
 0139 7T--- None--- c 1210-12[7]
 0140 CFTRdela22,23 ---None ---c 3964-78_4242+577del
 0141 D614G--- p Asp614Gly --- c 1841A>G
 0142 L227R--- p Leu227Arg ---c 680T>G
 0143 L558S--- p Leu558Ser --- c 1673T>C
 0144 1213delT--- p Trp361GlyfsX8 --- c 1081delT
 0145 1341+1G->A--- None--- c 1209+1G>A
 0146 1548delG--- p Gly473GlufsX54 --- c 1418delG
 0147 1717-8G->A--- None--- c 1585-8G>A
 0148 3121-1G->A--- None--- c 2989-1G>A
 0149 4209TGTT->AA--- None--- c 4077_4080delTGTTinsAA
 0150 457TAT->G--- p Tyr109GlyfsX4 --- c 325_327delTATinsG
 0151 G1069R ---p Gly1069Arg --- c 3205G>A
 0152 G970R--- p Gly970Arg--- c 2908G>C
 0153 M1V--- p Met1Val --- c 1A>G
 0154 R1162L--- p Arg1162Leu --- c 3485G>T
 0155 R560K--- p Arg560Lys --- c 1679G>A
 0156 S341P--- p Ser341Pro --- c 1021T>C
 0157 S977F--- p Ser977Phe --- c 2930C>T
 0158 V754M ---p Val754Met--- c 2260G>A
 0159 Y569D ---p Tyr569Asp ---c 1705T>G
 0160 2594delGT ---p Ser821ArgfsX4 --- c 2462_2463delGT
 0161 4374+1G->T--- None--- c 4242+1G>T
 0162 R785X--- p Arg785X --- c 2353C>T
 0163 2055del9->A--- p Ser641ArgfsX5--- c 1923_1931del9insA
 0164 2105-2117del13insAGAAA--- p Arg658LysfsX4--- c 1973_1985del13insAGAAA
 0165 G551S--- p Gly551Ser --- c 1651G>A
 0166 A561E--- p Ala561Glu --- c 1682C>A
 0167 H1054D--- p His1054Asp --- c 3160C>G
 0168 1288insTA--- p Asn386IlefsX3 --- c 1155_1156dupTA
 0169 1471delA--- p Lys447ArgfsX2 --- c 1340delA
 0170 444delA--- p Ile105SerfsX2--- c 313delA
 0171 3667ins4--- p Thr1179IlefsX17 --- c 3532_3535dupTCAA
 0172 3821delT--- p Ser1231ProfsX4 --- c 3691delT
 0173 4326delTC--- p Cys1400X --- c 4196_4197delTC

0174 R792X--- p Arg792X --- c 2374C>T
 0175 S912X--- p Ser912X --- c 2735C>A
 0176 C276X ---p Cys276X --- c 828C>A
 0177 1811+1G->C--- None--- c 1679+1G>C
 0178 3850-1G->A ---None ---c 3718-1G>A
 0179 306insA ---p Arg59LysfsX10 --- c 175dupA
 0180 A46D ---p Ala46Asp --- c 137C>A
 0181 1782delA--- p Gly551ValfsX8 --- c 1650delA
 0182 2118del4--- p Thr663ArgfsX8 --- c 1986_1989delAACT
 0183 2869insG--- p Tyr913X --- c 2737_2738insG
 0184 2896insAG--- p Val922GluX2 --- c 2763_2764dupAG
 0185 3132delTG--- p Val1001AspfsX45 --- c 3002_3003delTG
 0186 3737delA--- p Asp1202AlafsX9 --- c 3605delA
 0187 Q414X--- p Gln414X --- c 1240C>T
 0188 S1255X--- p Ser1255X --- c 3764C>A
 0189 E56K--- p Glu56Lys ---c 166G>A
 0190 G1061R--- p Gly1061Arg--- c 3181G>C
 0191 F1074L ---p Phe1074Leu --- c 3222T>A
 0192 G1349D--- p Gly1349Asp --- c 4046G>A
 0193 4428insGA--- p Ser1435GlyfsX14 --- c 4300_4301dup
 0194 Y849X--- p Tyr849X --- c 2547C>A
 0195 E1371X ---p Glu1371X--- c 4111G>T
 0196 1898+1G->C--- None ---c 1766+1G>C
 0197 2790-1G->C--- None--- c 2658-1G>C
 0198 297-1G->A--- None--- c 165-1G>A
 0199 1824delA--- p Asp565MetfsX7 --- c 1692delA
 0200 2556insAT--- p Ser809IlefsX13 --- c 2424_2425dupAT
 0201 3121-977_3499+248del2515--- None--- c 2989-977_3367+248del
 0202 4015delA--- p Ile1295PhefsX33--- c 3883delA
 0203 675del4--- p Leu183PhefsX5 --- c 543_546delTAGT
 0204 Y913X--- p Tyr913X --- c 2739T>A
 0205 Q1412X--- p Gln1412X --- c 4234C>T
 0206 S1255P--- p Ser1255Pro --- c 3763T>C
 0207 CFTRdele17a-18--- None--- c (2988+1_2989-1)_(3468+1_3469-1)del
 0208 CFTRdele2--- None--- c (53+1_54-1)_(164+1_165-1)del
 0209 CFTRdele22-24 ---None--- c (3963+1_3964-1)_(?1_?)del
 0210 L1254X ---p Leu1254X--- c 3761T>G
 0211 1138insG--- p Ile336SerfsX28--- c 1006_1007insG
 0212 935delA--- p Asn268IlefsX17--- c 803delA
 0213 1161delC--- p Cys343X--- c 1029delC
 0214 1609delCA ---p Gln493ValfsX10--- c 1477_1478delCA
 0215 CFTRdele14b-17b--- None ---c (2619+1_2620-1)_(3367+1_3368-1)del
 0216 CFTRdele17a,17b--- None--- c (2988+1_2989-1)_(3367+1_3368-1)del
 0217 E193X ---p Glu193X--- c 577G>T
 0218 CFTRdup6b-10--- None--- c (743+1_744-1)_(1584+1_1585-1)dup
 0219 4016insT --- p Ser1297PhefsX5--- c 3889dupT
 0220 S4X--- p Ser4X --- c 11C>A
 0221 3500-2A->G--- None--- c 3368-2A>G

0222 CFTRdele16-17b--- None--- c (2908+1_2909-1)_(3367+1_3368-1)del
 0223 991del5--- p Asn287LysfsX19--- c 861_865delCTTAA
 0224 G673X ---p Gly673X--- c 2017G>T
 0225 G27X ---p Gly27X--- c 79G>T
 0226 2991del32--- p Leu953PhefsX11--- c
 2859_2890delACATTCTGTTCTTCAAGCACCTATGTCAACCC
 0227 541delC--- p Leu137SerfsX16--- c 409delC
 0228 4010del4--- p Ile1295PhefsX32--- c 3882_3885delTATT
 0229 3878delG--- p Lys1250ArgfsX9--- c 3747delG
 0230 W1098X--- p Trp1098X--- c 3293G>A or c 3294G>A
 0231 182delT ---p Phe17SerfsX8--- c 50delT
 0232 4040delA--- p Asn1303ThrfsX25--- c 3908delA
 0233 CFTRdele19--- None ---c (3468+1_3469-1)_(3717+1_3718-1)del
 0234 C524X--- p Cys524X--- c 1572C>A
 0235 2942insT--- p Val938GlyfsX37--- c 2810dupT
 0236 1525-2A->G--- None ---c 1393-2A>G
 0237 185+1G->T--- None ---c 53+1G>T
 0238 2957delT--- p Ile942ThrfsX26--- c 2825delT
 0239 3121-2A->G--- None --- c 2989-2A>G
 0240 2721del11--- p Ile864SerfsX28--- c 2589_2599delAATTTGGTGCT
 0241 1924del7--- p Lys598GlyfsX11--- c 1792_1798delAAAACTA
 0242 G550X ---p Gly550X ---c 1648G>T
 0243 1249-1G->A ---None--- c 1117-1G>A
 0244 W57X ---p Trp57X--- c 170G>A or c 171G>A
 0245 124del23bp ---None ---c -9_14del23
 0246 Q1411X ---p Gln1411X ---c 4231C>T
 0247 CFTRdele1--- None ---c (?_1)_(53+1_54-1)del
 0248 1497delGG--- p Val456CysfsX25--- c 1365_1366delGG
 0249 Q1382X--- p Gln1382X--- c 4144C>T
 0250 R1102X ---p Arg1102X--- c 3304A>T
 0251 CFTRdele4-7 ---None--- c (273+1_274-1)_(1116+1_1117-1)del
 0252 CFTR50kdel--- None--- c (273+1_274-1)_(1116+1_1117-1)del(1584+1_1585-1)_(3468+1_3469-1)del
 0253 4218insT--- p Lys1363X--- c 4086dupT
 0254 3171delC--- p Tyr1014ThrfsX9--- c 3039delC
 0255 2732insA--- p Val868SerfsX28--- c 2601dupA
 0256 4279insA--- p Ile1383AsnfsX3--- c 4147dupA
 0257 442delA--- p Arg104GlufsX3--- c 310delA
 0258 CFTRdele11--- None--- c (1584+1_1585-1)_(1679+1_1680-1)del
 0259 CFTRdele2-4--- None--- c (53+1_54-1)_(489+1_490-1)del
 0260 2185insC--- p Gln685ProfsX84--- c 2053dupC
 0261 365-366insT--- p Trp79LeufsX32--- c 233dupT
 0262 CFTRdele13,14a ---None ---c (1766+1_1767-1)_(2619+1_2620-1)del
 0263 Q685X ---p Gln685X--- c 2053C>T
 0264 3028delA ---p Thr966ArgfsX2 ---c 2896delA
 0265 296+1G->A--- None--- c 164+1G>A
 0266 1119delA--- p Gly330GlufsX39--- c 987delA
 0267 3849+4A->G--- None--- c 3717+4A>G

0268 405+3A->C--- None--- c 273+3A>C
 0269 621+3A->G--- None--- c 489+3A>G
 0270 2752-26A->G--- None--- c 2620-26A>G
 0271 3850-3T->G--- None--- c 3718-3T>G
 0272 Q98R---p Gln98Arg--c 293A>G
 0273 T1246I --- p Thr1246Ile --- c 3737C>T
 0274 S1159F --- p Ser1159Phe --- c 3476C>T
 0275 I502T--- p Ile502Thr --- c 1505T>C
 0276 R117L --- p Arg117Leu --- c 350G>T
 0277 V456A --- p Val456Ala --- c 1367T>C
 0278 1898+1G->T--- None--- c 1766+1G>T
 0279 R751L ---p Arg751Leu ---c 2776_2777del
 0280 2907delTT ---p Leu926AlafsX48 ---c 2775_2776delTT
 0281 4022insT ---p Gly1298TrpfsX4 --- c 3891dupT
 0282 977insA ---p Met284AsnfsX3 ---c 850dupA
 0283 1461ins4 --- p Ile444ArgfsX3 --- c 1327_1330dup
 0284 1717-2A->G ---None---c 1585-2A>G
 0285 Y563N ---p Tyr563Asn---c 1687T>A
 0286 F575Y ---p Phe575Tyr---c 1724T>A
 0287 W679X ---p Trp679X---c 2036G>A
 0288 P750L ---p Pro750Leu---c 2249C>T
 0289 I807M ---p Ile807Met---c 2421A>G
 0290 F834L ---p Phe834Leu---c 2502T>G
 0291 5UTR-274C->A---None---c -274C>A
 0292 I1023T---p Ile1023Thr---c 3068T>C
 0293 W1098C---p Trp1098Cys--- c 3294G>C or c 3294G>T
 0294 3499+2T->C---None---c 3367+2T>C
 0295 Q1144X---p Gln1144X---c 3430C>T
 0296 I1269N---p Ile1269Asn---c 3806T>A
 0297 Q1291H---p Gln1291His---c 3873G>C
 0298 L1335P---p Leu1335Pro---c 4004T>C
 0299 579+A>G---p Glu193Glu or p Glu193= ---c 579A>G
 0300 875+1G->C---None---c 743+1G>C
 0301 1001+3A>T---None---c 869+3A>T
 0302 D110E---p Asp110Glu---c 330C>A
 0303 CFTRdele22,23 ---None---c (3963+1_3964-1)_(4242+1_4243-1)del
 0304 I601F---p Ile601Phe---c 1801A>T
 0305 L218X---p Leu218X---c 653T>A
 0306 3967delTT ---p Leu1279AlafsX22---c 3835_3836del
 0307 M952T---p Met952Thr---c 2855T>C
 0308 N186K---p Asn186Lys---c 558C>A
 0309 G27R---p Gly27Arg---c 79G>A
 0310 P5L---p Pro5Leu---c 14C>T
 0311 F508C---p Phe508Cys---c 1523T>G
 0312 Q1291R---p Gln1291Arg---c 3872A>G
 0313 Q1476X---p Gln1476X---c 4426C>T
 0314 R170H---p Arg170His---c 509G>A
 0315 S1118F---p Ser1118Phe---c 3353C>T

0316 S902R---p Ser902Arg---c 2706C>G
 0317 125G/C--None--c -8G>C
 0318 CFTRdele1--c 3469-1G>C--c (?_1)_(53+1_54-1)del
 0319 Q2X--p Gln2X--c 4C>T
 0320 Q2X;R3W--p [Gln2X;Arg3Trp]--c [4C>T;7A>T]
 0321 S13F--p Ser13Phe--c 38C>T
 0322 L15P--p Leu15Pro--c 44T>C
 0323 IVSI-5842_IVS4+401del--None--c 54-5842_489+401del
 0324 W19X--p Trp19X--c 57G>A
 0325 Q30X--p Gln30X--c 88C>T
 0326 R31L--p Arg31Leu--c 92G>T
 0327 296+1G->T--None--c 164+1G>T
 0328 CFTRdele3-10,14b-16--None--c (164+1_165-1)_(1584_+1_1585-1)del(2619+1_2620-1)_(2988+1_2989-1)del
 0329 296+28A->G--None--c 164+28A>G
 0330 296+2T->C--None--c 164+2T>C
 0331 296+3insT--None--c 164+4dupT
 0332 297-3C->T--None--c 165-3C>T
 0333 300delA--p Glu56AspfsX35--c 168delA
 0334 W57G--p Trp57Gly--c 169T>G
 0335 306delTAGA--p Asp58GlufsX32--c 174_177delTAGA
 0336 E60K--p Glu60Lys--c 178G>A
 0337 L88X--p Leu88X--c 263T>A or c 263T>G
 0338 G91R--p Gly91Arg--c 271G>A
 0339 CFTRdele4-10--None--c (273+1_274-1)_(1584+1_1585-1)del
 0340 CFTRdele4-11--None--c (273+1_274-1)_(1679+1_1680-1)del
 0341 406-2A->G--None--c 274-2A>G
 0342 P99L--p Pro99Leu--c 296C>T
 0343 L102R--p Leu102Arg--c 305T>G
 0344 E116K--p Glu116Lys--c 346G>A
 0345 R117G--p Arg117Gly--c 349C>G
 0346 R117P--p Arg117Pro--c 350G>C
 0347 A120T--p Ala120Thr--c 358G>A
 0348 G126D--p Gly126D--c 377G>A
 0349 L138ins--p Leu138dup--c 413_415dupTAC
 0350 H139R--p His139Arg--c 416A>G
 0351 556delA--p Ile142PhefsX11--c 424delA
 0352 557delT--p Phe143LeufsX10--c 429delT
 0353 602del14--p Phe157X--c 470_483delTTAGTTTGATTTAT
 0354 Y161D--p Tyr161Asp--c 481T>G
 0355 L165S--p Leu165Ser--c 494T>C
 0356 R170H--p Arg170His--c 509G>A
 0357 F191V--p Phe191Val--c 571T>G
 0358 D192G--p Asp192Gly--c 575A>G
 0359 E193K--p Glu193Lys--c 577G>A
 0360 712-2A->G--None--c 580-2A>G
 0361 G194R--p Gly194Arg--c 580G>A
 0362 G194V--p Gly194Val--c 581G>T

0363 V201M--p Val201Met--c 601G>A
 0364 W216X--p Trp216X--c 647G>A
 0365 V232D--p Val232Asp--c 695T>A
 0366 Q237E--p Gln237Glu--c 709C>G
 0367 849delG--p Leu240X--c 717delG
 0368 876-2A->G--None--c 744-2A>G
 0369 892delA--p Lys254ArgfsX7--c 761delA
 0370 R258G--p Arg258Gly--c 772A>G
 0371 M265R--p Met265Arg--c 794T>G
 0372 Y275X--p Tyr275X--c 825C>G
 0373 F311L--p Phe311Leu--c 933C>G or c 933C>A
 0374 F312del--p Phe312del--c 935_937delTCT
 0375 G314E--p Gly314Glu--c 941G>A
 0376 L320V--p Leu320Val--c 958T>G
 0377 R334Q--p Arg334Gln--c 1001G>A
 0378 R334L--p Arg334Leu--c 1001G>T
 0379 L346P--p Leu346Pro--c 1037T>C
 0380 A349V--p Ala349Val--c 1046C>T
 0381 R352W--p Arg352Trp--c 1054C>T
 0382 Q359R--p Gln359Arg--c 1076A>G
 0383 E379X--p Glu379X--c 1135G>T
 0384 9T--None--c 1210-12T[9]
 0385 1342-2A->C--None--c 1210-2A>C
 0386 1343delG--p Gly404AspfsX38--c 1211delG
 0387 S434X--p Ser434X--c 1301C>A or c 1301C>G
 0388 1429del7--p Ser434LeufsX6--c 1301_1307delCACTTCT
 0389 D443Y--p Asp443Tyr--c 1327G>T
 0390 1460delAT--p Ile444X--c 1330_1331delAT
 0391 L453S--p Leu453Ser--c 1358T>C
 0392 1504delG--p Gly458AspfsX11--c 1373delG
 0393 S466X;R1070Q--p [Ser466X;Arg1070Gln]--c [1397C>G;3209G>A]
 0394 E474K--p Glu474Lys--c 1420G>A
 0395 W496X--p Trp496X--c 1487G>A
 0396 F508del;11027T--p [Phe508del;Ile1027Thr]--c [1521_1523delCTT;3080T>C]
 0397 F508C;S1251N--p [Phe508Cys;Ser1251Asn]--c [1523T>G;3752G>A]
 0398 D513G--p Asp513Gly--c 1538A>G
 0399 1716G/A--p Glu528Glu--c 1584G>A
 0400 1716+1G->A--None--c 1584+1G>A
 0401 1802delC--p Ser557PhefsX2--c 1670delC
 0402 1802delC--p Ser557PhefsX2--c 1670delC
 0403 1811+1G->A--None--c 1679+1G>A
 0404 1811+1634A->G or 1811+1 6kbA->G--None--c 1680-886A>G
 0405 1811+1643G->T--None--c 1680-877G>T
 0406 R560S--p Arg560Ser--c 1680A>C
 0407 V562I--p Val562Ile--c 1684G>A
 0408 Y563D--p Tyr563Asp--c 1687T>G
 0409 1833delT--p Leu568CysfsX4--c 1703delT
 0410 P574H--p Pro574His--c 1721C>A

0411 E588V--p Glu588Val--c 1763A>T
 0412 1898+5G->T--None--c 1766+5G>T
 0413 1949del84--p Met607_Gln634del--c 1820_1903del84
 0414 H609R--p His609Arg--c 1826A>G
 0415 A613T--p Ala613Thr--c 1837G>A
 0416 I618T--p Ile618Thr--c 1853T>C
 0417 G622D--p Gly622Asp--c 1865G>A
 0418 G628R--p Gly628Arg--c 1882G>C or c 1882G>A
 0419 2043delG--p Gln637HisfsX26--c 1911delG
 0420 2075delA--p Asp648ValfsX15--c 1943delA
 0421 E656X--p Glu656X--c 1966G>T
 0422 E664X--p Glu664X--c 1990G>T
 0423 Q715X--p Gln715X--c 2143C>T
 0424 Q720X--p Gln720X--c 2158C>T
 0425 G745X--p Gly745X--c 2233G>T
 0426 2372del8--p Ile748SerfsX28--c 2241_2248delGATACTGC
 0427 2634insT--p Asp835X--c 2502dupT
 0428 D836Y--p Asp836Tyr--c 2506G>T
 0429 T854T--p Thr854Thr--c 2562T>C or c 2562T>G or c 2562T>A
 0430 W882X--p Trp882X--c 2645G>A
 0431 S912L--p Ser912Leu--c 2735C>T
 0432 D924N--p Asp924Asn--c 2770G>A
 0433 R933G--p Arg933Gly--c 2797A>G
 0434 2954delT--p Leu941GlnfsX27--c 2822delT
 0435 L967S--p Leu967Ser--c 2900T>C
 0436 G970D--p Gly970Asp--c 2909G>A
 0437 D979V--p Asp979Val--c 2936A>T
 0438 A1006E--p Ala1006Glu--c 3017C>A
 0439 3143del9--p Ala1004_Ala1006del--c 3011_3019delCTATAGCAG or c
 3009_3017delAGCTATAGC
 0440 3171insC--p Tyr1014LeufsX33--c 3039dupC
 0441 Y1014C--p Tyr1014Cys--c 3041A>G
 0442 F1016S--p Phe1016Ser--c 3047T>C
 0443 I1027T--p Ile1027Thr--c 3080T>C
 0444 Y1032C--p Tyr1032Cys--c 3095A>G
 0445 Q1035X--p Gln1035X--c 3103C>T
 0446 T1036N--p Thr1036Asn--c 3107C>A
 0447 Q1042X--p Gln1042X--c 3124C>T
 0448 3271delGG--p Gly1047GlnfsX28--c 3139_3139+1delGG
 0449 T1053I--p Thr1053Ile--c 3158C>T
 0450 3349insT--p Tyr1073LeufsX3--c 3217dupT
 0451 W1098R--p Trp1098Arg--c 3292T>C
 0452 F1099L--p Phe1099Leu--c 3297C>A
 0453 M1101R--p Met1101Arg--c 3302T>G
 0454 CFTRdele18--None--c (3367+1+3368-1)_(3468+1_3469-1)del
 0455 R1128X--p Arg1128X--c 3382A>T
 0456 W1145X--p Trp1145X--c 3435G>A
 0457 V1153E--p Val1153Glu--c 3458T>A

0458 3600G->A--None--c 3468G>A
 0459 CFTRdele19-21--None--c (3468+1_3469-1)_(3963+1_3964-1)del
 0460 3600+2insT--None--c 3468+2dupT
 0461 3600+5G->A--None--c 3468+5G>A
 0462 S1159P--p Ser1159Pro--c 3475T>C
 0463 3732delA--p Asp1201MetfsX10--c 3600delA
 0464 3849G->A--None--c 3717G>A
 0465 3849+5G->A--None--c 3717+5G>A
 0466 3849+40A->G--None--c 3717+40A>G
 0467 V1240G--p Val1240Gly--c 3719T>G
 0468 G1249R--p Gly1249Arg--c 3745G>A
 0469 W1274X--p Trp1274X--c 3822G>A
 0470 W1282X;R1283M--p [Trp1282X;Arg1283Met]--c [3846G>A;3848G>T]
 0471 R1283M--p Arg1283Met--c 3848G>T
 0472 CFTRdele21--None--c (3873+1_3874-1)_(3963+1_3964-1)del
 0473 4005+2T->C--None--c 3873+2T>C
 0474 W1310X--p Trp1310X--c 3929G>A
 0475 L1324P--p Leu1324Pro--c 3971T>C
 0476 Q1330X--p Gln1330X--c 3988C>T
 0477 4168delCTAAGCC--p Leu1346MetfsX6--c 4036_4042del
 0478 I1366N--p Ile1366Asn--c 4097T>A
 0479 H1375P--p His1375Pro--c 4124A>C
 0480 4259del5--p Leu1376SerfsX8--c 4127_4131delITGGAT
 0481 4374+1G->A--None--c 4242+1G>A
 0482 S1455X--p Ser1455X--c 4364C>G
 0483 L1480P--p Leu1480Pro--c 4439T>C
 0484 CFTRdelePr-1--No protein name--c (?_-1270)_(53+1_54-1)del
 0485 175insT--p Ser18GlnfsX27--c 50dupT
 0486 K68X--p Lys68X--c 202A>T
 0487 Y109X--p Tyr109X--c 327T>A
 0488 663insT--p Gly178TrpfsX5--c 531dupT
 0489 G194X--p Gly194X--c 580G>T
 0490 C225X--p Cys225X--c 675T>A
 0491 Q290X--p Gln290X--c 868C>T
 0492 Q353X--p Gln353X--c 1057C>T
 0493 CFTRdele10--No protein name--c (1392+1_1393-1)_(1584+1_1585-1)del
 0494 1717-2A->G--No protein name--c 1585-2A>G
 0495 Y563X--p Tyr563X--c 1689C>A
 0496 Y577X--p Tyr577X--c 1731C>A
 0497 1898+2T->A--No protein name--c 1766+2T>A
 0498 2053insTA--p Ser641IlefsX23--c 1920_1921dupTA
 0499 3130delA--p Ile1000LeufsX2--c 2998delA
 0500 CFTRdele17b--No protein name--c (3139+1_3140-1)_(3367+1_3368-1)del
 0501 3497delC--p Thr1122LysfsX12--c 3365delC
 0502 3940delG--p Asp1270MetfsX8--c 3808delG
 0503 V470M--p Val470Met--c 1408G>A
 0504 R516G--p Arg516Gly--c 1546A>G
 0505 G149R--p Gly149Arg--c 445G>A

0506 875+1G->A--p ?--c 743+1G>A
 0507 3129del4--p Ile1000X--c 2997_3000del
 0508 3601-2A->G--p ?--c 3469-2A>G
 0509 S1206X--p Ser1206X--c 3617C>G
 0510 875+1G->C--p ?--c 743+1G>C
 0511 V456F--p Val456Phe--c 1366G>T
 0512 G103X--p Gly103X--c 307G>T
 0513 3359delCT--p Leu1077ValfsX78--c 3229_3230del
 0514 H1085P--p His1085Pro--c 3254A>C
 0515 593insT--p Ala155SerfsX4--c 461dup
 0516 1112delT--p Leu327GlnfsX42--c 980del
 0517 1540del10--p Val470GlufsX54--c 1409_1418del
 0518 1601delTC--p Phe490LeufsX13--c 1470_1471del
 0519 295ins8--p Arg55AsnfsX39--c 156_163dup
 0520 1716+2T->C--p ?--c 1584+2T>C
 0521 1774delCT--p Leu548GlufsX19--c 1642_1643del
 0522 S962X--p Ser962X--c 2885C> / c 2885C>G
 0523 3662delA--p Lys1177SerfsX15--c 3530del
 0524 Y1182X--p Tyr1182X--c 3546C>G
 0525 4006-1G->A--p ?--c 3874-1G>A
 0526 Q1390X--p Gln1390X--c 4168C>T
 0527 1199delG--p Ala357LeufsX12--c 1069del
 0528 1215delG--p Trp361CysfsX8--c 1083del
 0529 Y362X--p Tyr362X--c 1086T>A | c 1086T>G
 0530 1221delCT--p Leu365TrpfsX16--c 1093_1094del
 0531 1366delG--p Ala412GlnfsX30--c 1234del
 0532 1434delA--p Leu435PhefsX7--c 1302del
 0533 c 1375_1385del--p Ser459ArgfsX19--c 1375_1385del
 0534 1524+1G->A--p ?--c 1392+1G>A
 0535 1576insT--p Lys483X--c 1446dup
 0536 1717-1G->T--p ?--c 1585-1G>T
 0537 297-2A->G--p ?--c 165-2A>G
 0538 1811+2T->C--p ?--c 1679+2T>C
 0539 L568X--p Leu568X--c 1703T>A
 0540 1898+2T->C--p ?--c 1766+2T>C
 0541 1918delGC--p Ala596X--c 1786_1787del
 0542 G646X--p Gly646X--c 1936G>T
 0543 Q652X--p Gln652X--c 1954C>T
 0544 2113delA--p Ile661SerfsX2--c 1981del
 0545 M1L--p Met1?--c 1A>C
 0546 K688X--p Lys688X--c 2062A>T
 0547 2221insA--p Arg697LysfsX33--c 2089dup
 0548 L719X--p Leu719X--c 2156T>A
 0549 E730X--p Glu730X--c 2188G>T
 0550 2335delA--p Arg735GlyfsX4--c 2203del
 0551 c 2261delT--p Val754GlyfsX17--c 2261del
 0552 Q767X--p Gln767X--c 2299C>T
 0553 Q779X--p Gln779X--c 2335C>T

0554 Q781X--p Gln781X--c 2341C>T
 0555 c 234delC--p Trp79GlyfsX12--c 234del
 0556 W79X--p Trp79X--c 236G>A
 0557 2522insC--p Gln799SerfsX6--c 2393dup
 0558 Q814X--p Gln814X--c 2440C>T
 0559 E815X--p Glu815X--c 2443G>T
 0560 K830X--p Lys830X--c 2488A>T
 0561 2708del13--p Leu859X--c 2576_2588del
 0562 2751+2T->C--p ?--c 2619+2T>C
 0563 2777insTG--p Trp882CysfsX25--c 2644_2645dup
 0564 405+2T->G--p ?--c 273+2T>G
 0565 406-1G->C--p ?--c 274-1G>C
 0566 3041delG--p Gly970ValfsX11--c 2909del
 0567 3056delGA--p Arg975IlefsX10--c 2924_2925del
 0568 K978X--p Lys978X--c 2932A>T
 0569 3095insT--p Leu989SerfsX5--c 2964dup
 0570 G1003X--p Gly1003X--c 3007G>T
 0571 3139delG--p Gly1003GlufsX3--c 3008del
 0572 3143delC--p Ala1004ValfsX2--c 3011del
 0573 3154delG--p Val1008SerfsX15--c 3022del
 0574 3238delA--p Thr1036ProfsX24--c 3106del
 0575 3293delA--p His1054LeufsX6--c 3161del
 0576 W1063X--p Trp1063X--c 3189G>A
 0577 3396delC--p Trp1089GlyfsX13--c 3264del
 0578 3407_3422del16--p Tyr1092SerfsX5--c 3275_3290del
 0579 3528delC--p Leu1133X--c 3397del
 0580 3532AC->GTA--p Thr1134ValfsX22--c 3400_3401delinsGTA
 0581 c 3407_3422del16--p Ala1136ValfsX7--c 3407_3422del
 0582 3667del4--p Thr1179AsnfsX12--c 3536_3539del
 0583 489delC--p Ile119MetfsX5--c 357del
 0584 3730A->TCT--p Lys1200SerfsX12--c 3598delinsTCT
 0585 3747delC--p Ser1206GlnfsX5--c 3615del
 0586 3750delAG--p Gly1208ProfsX56--c 3618_3619del
 0587 Q1281X--p Gln1281X--c 3841C>T
 0588 K1302X--p Lys1302X--c 3904A>T
 0589 Y1307X--p Tyr1307X--c 3921T>A
 0590 525delT--p Phe131LeufsX3--c 393del
 0591 W1316X--p Trp1316X--c 3947G>A
 0592 4108delT--p Ser1326LeufsX2--c 3976del
 0593 4160insG--p Cys1344LeufsX15--c 4028dup
 0594 541del4--p Leu137TyrfsX15--c 409_412del
 0595 542del7--p Leu137ProfsX14--c 410_416del
 0596 621+1G->A--p ?--c 489+1G>A
 0597 621+2T->C--p ?--c 489+2T>C
 0598 181_182dup--p Trp19AlafsX7--c 49_50dup
 0599 630delG--p Lys166AsnfsX7--c 498del
 0600 654del5--p Ile175TyrfsX6--c 522_526del
 0601 186-1G->A--p ?--c 54-1G>A

0602 675del14--p Ser182GlnfsX6--c 543_556del
 0603 680delT--p Leu183ProfsX6--c 548del
 0604 681delC--p Leu184PhefsX5--c 550del
 0605 710_711+5del7--p ?--c 578_579+5del
 0606 713delGA--p Gly194AlafsX63--c 581_582del
 0607 733delG--p Val201CysfsX14--c 601del
 0608 840insT--p Gln237SerfsX21--c 708dup
 0609 896delT--p Ile255ThrfsX6--c 764del
 0610 982delA--p Met284X--c 850del
 0611 1006_1007delGA--p Glu292ThrfsX15--c 874_875del
 0612 1157insTA--p Cys343ThrfsX27--c 1025_1026insTA
 0613 1185delTC--p Arg352AlafsX11--c 1053_1054del
 0614 W356X--p Trp356X--c 1068G>A
 0615 W361X--p Trp361X--c 1082G>A|c 1083G>A
 0616 1248insATCAA--p ?--c 1116_1116+1insATCAA
 0617 1249insA--p Asp373GlufsX9--c 1118dup
 0618 241delAT--p Tyr38ProfsX6--c 112_113del
 0619 1262delA--p Lys377SerfsX11--c 1130del
 0620 Q378X--p Gln378X--c 1132C>T
 0621 1288insA--p Asn386LysfsX25--c 1157dup
 0622 1291delTT--p Leu387AsnfsX23--c 1159_1160del
 0623 T388X--p Thr388X--c 1162_1163delinsTA
 0624 1294del7--p Thr388GlnfsX3--c 1162_1168del
 0625 1341+1G->C--p ?--c 1209+1G>C
 0626 1341+1G->T--p ?--c 1209+1G>T
 0627 1341+2T->G--p ?--c 1209+2T>G
 0628 1342-1G->C--p ?--c 1210-1G>C
 0629 1342-1G->T--p ?--c 1210-1G>T
 0630 1353delA--p Glu407AspfsX35--c 1221del
 0631 1367del5--p Asn415X--c 1243_1247del
 0632 1380insT--p Asn417X--c 1248dup
 0633 1419delC--p Phe430SerfsX12--c 1287del
 0634 K442X--p Lys442X--c 1324A>T
 0635 1491-1500del--p Leu454AlafsX6--c 1360_1387del
 0636 1498delG--p Val456LeufsX13--c 1366del
 0637 1524+1delG--p ?--c 1392+1del
 0638 c 142_145delAATC--p Asn48TyrfsX42--c 142_145del
 0639 1556delT--p Leu475ArgfsX52--c 1424del
 0640 1571delG--p Gly480ValfsX47--c 1439del
 0641 E504X--p Glu504X--c 1510G>T
 0642 E514X--p Glu514X--c 1540G>T
 0643 K52X--p Lys52X--c 154A>T
 0644 Y517X--p Tyr517X--c 1551C>A|c 1551C>G
 0645 284delA--p Lys52AsnfsX39--c 156del
 0646 E528X--p Glu528X--c 1582G>T
 0647 1749insTA--p Val540X--c 1616_1617dup
 0648 296+1G->C--p ?--c 164+1G>C
 0649 296+2T->G--p ?--c 164+2T>G

0650 1806delA--p Ala559GlnfsX13--c 1674del
 0651 IVS11-1G->C--p ?--c 1680-1G>C
 0652 1812-2A->C--p ?--c 1680-2A>C
 0653 1813insC--p Val562SerfsX6--c 1682dup
 0654 1874_1875insTT--p Leu581PhefsX2--c 1741_1742dup
 0655 1874insT--p Leu581PhefsX8--c 1742dup
 0656 1898+2delT--p ?--c 1766+2del
 0657 308insA--p Glu60ArgfsX9--c 177dup
 0658 K598X--p Lys598X--c 1792A>T
 0659 1932delG--p Ile601PhefsX10--c 1800del
 0660 c 1807delG--p Val603SerfsX8--c 1807del
 0661 1942del17--p Thr604PhefsX5--c 1810_1826del
 0662 1978delA--p Ile616TyrfsX2--c 1846del
 0663 1978dupA--p Ile616AsnfsX6--c 1846dup
 0664 317insC--p Ser63PhefsX6--c 185dup
 0665 2005delTA--p Tyr625PhefsX16--c 1874_1875del
 0666 Q634X--p Gln634X--c 1900C>T
 0667 2104insA--p Arg658LysfsX7--c 1972dup
 0668 2108delA--p Asn659IlefsX4--c 1976del
 0669 2109-2118del10--p Asn659LysfsX10--c 1977_1986del
 0670 2118del14--p Thr663ProfsX21--c 1987_2000del
 0671 2132delAC--p His667ProfsX21--c 2000_2001del
 0672 W679X--p Trp679X--c 2036G>A
 0673 2175insA--p Thr682AsnfsX7--c 2044dup
 0674 2176insC--p Gln685ThrfsX4--c 2045dup
 0675 2183delAA--p Lys684ThrfsX4--c 2051_2052del
 0676 2189CT->A--p Ser686TyrfsX36--c 2057_2058delinsA
 0677 E692X--p Glu692X--c 2074G>T
 0678 2215delG--p Glu695LysfsX27--c 2083del
 0679 2222delG--p Lys698ArgfsX24--c 2091del
 0680 K716X--p Lys716X--c 2145_2146delinsGT
 0681 c 2148delG--p Thr717LeufsX5--c 2148del
 0682 2409delC--p Thr760ArgfsX11--c 2277del
 0683 2435insC--p Val769CysfsX10--c 2303dup
 0684 2456delAC--p His775LeufsX3--c 2324_2325del
 0685 2481-2482insT--p His784SerfsX21--c 2349dup
 0686 2512delG--p Val794CysfsX9--c 2380del
 0687 2557delT--p Ser809GlnfsX12--c 2425del
 0688 2586-2687insT--p Glu819X--c 2454_2455insT
 0689 c 2489_2490insA--p Glu831GlyfsX5--c 2489dup
 0690 2623-2A->G--p ?--c 2491-2A>G
 0691 2634delT--p Phe834LeufsX10--c 2502del
 0692 2640delT--p Asp836GlufsX8--c 2508del
 0693 2655del26--p Ala842SerfsX45--c 2523_2548del
 0694 2694delT--p Val855SerfsX5--c 2562del
 0695 2723delTT--p Ile864MetfsX31--c 2592_2593del
 0696 156insG--p Ala9GlyfsX36--c 25dup
 0697 2747delC--p Ala872GlufsX34--c 2615del

0698 2751+2T->A--p ?--c 2619+2T>A
 0699 2752-1G->T--p ?--c 2620-1G>T
 0700 2752-2A->G--p ?--c 2620-2A>G
 0701 2787del16--p Asn886ThrfsX15--c 2655_2670del
 0702 2790-2A->G--p ?--c 2658-2A>G
 0703 2837delG--p Ser902ThrfsX4--c 2705del
 0704 c 2732_2733insA--p Ser911ArgfsX64--c 2732_2733insA
 0705 c 2733insA--p Ser912IlefsX63--c 2733_2734insA
 0706 406-2A->C--p ?--c 274-2A>C
 0707 2907delTT--p Leu926AlafsX48--c 2776_2777del
 0708 2909delT--p Leu926CysfsX16--c 2777del
 0709 2935del11--p Leu935AlafsX36--c 2803_2813del
 0710 2937_2942delinsTCAGA--p Pro936_Leu937del--c 2805_2810del
 0711 2948delA--p His939LeufsX3--c 2816del
 0712 2951insA--p Leu941SerfsX34--c 2819_2820insA
 0713 2949del5--p Thr940AsnfsX33--c 2819_2823del
 0714 K946X--p Lys946X--c 2836A>T
 0715 415insA--p Ala96SerfsX15--c 285dup
 0716 3011delC--p Pro960LeufsX8--c 2879del
 0717 3015_3018dupGTCA--p Thr963ValfsX13--c 2883_2886dup
 0718 3029delC--p Thr966SerfsX2--c 2897del
 0719 3031-3032delinsA--p Leu967ArgfsX14--c 2899_2900delinsA
 0720 3040+1G->A--p ?--c 2908+1G>A
 0721 c 2982_2988+2delCATCCAGGT--p ?--c 2982_2988+2del
 0722 Q996X--p Gln996X--c 2986C>T
 0723 3121-1G->T--p ?--c 2989-1G>T
 0724 3121-2A->C--p ?--c 2989-2A>C
 0725 3121-2A->T--p ?--c 2989-2A>T
 0726 M1K--p Met1?--c 2T>A
 0727 c 3033dup--p Gln1012ThrfsX35--c 3033dup
 0728 435insA--p Leu102ThrfsX9--c 303dup
 0729 3213-3214insT--p Met1028TyrfsX19--c 3081dup
 0730 E1046X--p Glu1046X--c 3136G>T
 0731 3271+2T->C--p ?--c 3139+2T>C
 0732 3272-1G->A--p ?--c 3140-1G>A
 0733 L1059X--p Leu1059X--c 3176T>G
 0734 3359delCTCTG--p Thr1076IlefsX78--c 3227_3231del
 0735 3422del16--p Arg1097GlnfsX2--c 3290_3305del
 0736 3425delG--p Trp1098CysfsX4--c 3294del
 0737 3447delG--p Met1105IlefsX16--c 3315del
 0738 3456delC--p Ile1109SerfsX12--c 3324del
 0739 464delC--p Pro1111ArgfsX13--c 332del
 0740 3499+1G->T--p ?--c 3367+1G>T
 0741 3499+2T->C--p ?--c 3367+2T>C
 0742 3500-1G->A--p ?--c 3368-1G>A
 0743 3516del5--p Val1129TyrfsX25--c 3384_3388del
 0744 3521del14--p Gly1130ValfsX21--c 3389_3402del
 0745 K114X--p Lys114X--c 340A>T

0746 3556insAGTA--p Thr1142LysfsX15--c 3421_3424dup
 0747 Q1144X--p Gln1144X--c 3430C>T
 0748 3600+1G->A--p ?--c 3468+1G>A
 0749 3600+1G->T--p ?--c 3468+1G>T
 0750 3601-1G->A--p ?--c 3469-1G>A
 0751 3622insT--p Lys1165X--c 3492dup
 0752 K1165X--p Lys1165X--c 3493A>T
 0753 3629delT--p Phe1166SerfsX26--c 3497del
 0754 S1178X--p Ser1178X--c 3533C>A|c 3533C>G
 0755 c 3539_3554del--p Lys1180ThrfsX7--c 3539_3554del
 0756 Q1186X--p Gln1186X--c 3556C>T
 0757 3724delG--p Val1198X--c 3592del
 0758 3731-3732AA->G--p Lys1200ArgfsX11--c 3599_3600delinsG
 0759 3755dupG--p Gln1209ProfsX56--c 3623dup
 0760 3789insA--p Thr1220AsnfsX45--c 3658dup
 0761 499dupC--p Leu123ProfsX36--c 367dup
 0762 3840delT--p Gly1237AlafsX22--c 3708del
 0763 3856delC--p Leu1242SerfsX17--c 3724del
 0764 S1248X--p Ser1248X--c 3743C>A|c 3743C>G
 0765 3886insA--p Thr1252AsnfsX13--c 3754dup
 0766 3889dupT--p Leu1253PhefsX12--c 3758dup
 0767 3898insC--p Leu1258PhefsX7--c 3767dup
 0768 3905delT--p Leu1258X--c 3773del
 0769 E1266X--p Glu1266X--c 3796G>T
 0770 3944delGT--p Ser1273LeufsX28--c 3816_3817del
 0771 3959delC--p Ser1276X--c 3827del
 0772 3960-3961delA--p Ile1277X--c 3829del
 0773 Q1280X--p Gln1280X--c 3838C>T
 0774 4006delA--p Val1293TyrfsX35--c 3876del
 0775 519delT--p Leu130SerfsX4--c 387del
 0776 4048insCC--p Tyr1307ProfsX22--c 3917_3918dup
 0777 Q1309X--p Gln1309X--c 3925C>T
 0778 4064-4065delinsAATATG--p Ser1311LysfsX12--c 3932_3933delinsAATATG
 0779 4089delA--p Asp1320MetfsX8--c 3957del
 0780 4095+1G->A--p ?--c 3963+1G>A
 0781 4095+1G->C--p ?--c 3963+1G>C
 0782 4165delGT--p Val1345ProfsX13--c 4033_4034del
 0783 p S1347PfsX13--p Ser1347ProfsX13--c 4035_4038dup
 0784 4172delGC--p Ser1347ThrfsX11--c 4040_4041del
 0785 4177delG--p Gly1349AlafsX5--c 4046del
 0786 K1351X--p Lys1351X--c 4051A>T
 0787 4197_4198delCT--p Leu1356GlyfsX2--c 4065_4066del
 0788 4203TAG->AA--p Arg1358AsnfsX22--c 4071_4073delinsAA
 0789 4222delG--p Ala1364ArgfsX16--c 4090del
 0790 4271delC--p Thr1380AsnfsX4--c 4139del
 0791 4301delA--p Ala1391HisfsX7--c 4170del
 0792 582insG--p Gln151AlafsX8--c 450dup
 0793 605insT--p Leu159PhefsX4--c 476dup

0794 L159X--p Leu159X--c 476T>A
 0795 621+2T->G--p ?--c 489+2T>G
 0796 c 49_50delTT--p Phe17GlnfsX27--c 49_50del
 0797 622-2A->C--p ?--c 490-2A>C
 0798 185+2T->C--p ?--c 53+2T>C
 0799 185+2T->G--p ?--c 53+2T>G
 0800 186-2A->G--p ?--c 54-2A>G
 0801 c 551_555delTTTCC--p Leu184GlnfsX7--c 551_555del
 0802 710del4--p ?--c 579_579+3del
 0803 c 604_605delTG--p Trp202AspfsX55--c 604_605del
 0804 W202X--p Trp202X--c 606G>A
 0805 746insC--p Leu206PhefsX52--c 614dup
 0806 749delT--p Leu206CysfsX9--c 617del
 0807 Q207X--p Gln207X--c 619C>T
 0808 875+2T->C--p ?--c 743+2T>C
 0809 Q250X--p Gln250X--c 748C>T
 0810 905delG--p Arg258AsnfsX3--c 773del
 0811 909delT--p Val260X--c 777del
 0812 936delTA--p Ile269ProfsX4--c 805_806del
 0813 W277X--p Trp277X--c 830G>A
 0814 R289X--p Arg289X--c 865A>T
 0815 1001+1G->C--p ?--c 869+1G>C
 0816 218insA--p Gln30ThrfsX15--c 87dup
 0817 1037insA--p Arg303GlufsX5--c 905_906insA
 0818 1040del4--p Arg303ThrfsX24--c 908_911del
 0819 1058delC--p Phe310SerfsX18--c 927del
 0820 L320X--p Leu320X--c 959T>A
 0821 c 982delA--p Ile328SerfsX41--c 982del
 9995 Other--- Other--- Other
 -1 Not known ---Not known--- Not known