

## 1. Patient personal details

Insurance number:.....  
Name:.....  
Date of Birth:.....  
Gender: female / male  
Race: Asian/Indian / White / Black / N/A  
Date of visit: .....  
Year of follow-up:.....  
Date of last visit:.....  
Diagnosis of CF (year):.....

CF centre:  
Doctor code:  
Blood sample code:  
Date of blood sampling:  
Stool sample code:  
Date of stool sampling:

## 2. Social background

### Any changes from the last annual visit?

yes / no / no data

Family members living together with the patient

Siblings

Social services input

yes / no / no data

Kindergarten/School/other

Adherence good

yes / no / no data

## 3. Medical history

### Any changes from the last annual visit?

yes / no / no data

### A) General information about the medical history

#### Alcohol consumption:

yes / no / no data

if yes:

frequency:

occasionally / monthly / weekly / daily

amount (g/occasion):.....

duration (years):.....

total alcohol consumption in the last 2 weeks: .....

if not: Alcohol consumption earlier

yes / no / no data

if yes:

frequency:

occasionally / monthly / weekly / daily

amount (g/occasion):.....



duration (years).....  
How long ago did you stop drinking alcohol?.....

Guide for estimation of the amount:  
1 dl beer (4.5 vol. %) = ~3.5 g alcohol  
1 dl wine (12.5 vol. %) = ~10 g alcohol  
1 dl hard drink (50 vol. %) = ~40 g alcohol

**Smoking:** yes / no/ no data

if yes: amount (cigarettes/day):.....  
duration (years).....

if not: Smoking earlier yes / no/ no data

if yes: amount (cigarettes/day):.....  
duration (years).....  
How long ago did you stop smoking? .....

do parents smoking? yes / no/ no data  
if yes: inside/outside/no data

do other household members smoking? yes / no/ no data  
if yes: inside/outside/no data

**Drug abuse:** yes / no / no data

*Prescribed medication should not be included here.*

if yes: name of drug:..... dose:.....  
duration (years).....

**Heart disease:** yes / no / no data

**Renal disease:** yes / no / no data

**Liver disease:** yes / no / no data

**Diabetes mellitus:** yes / no / no data  
if yes: type: Type I. / Type II. / Type III. c / MODY/undetermined

date of diagnosis (year):.....

**GI problems:** yes / no / no data

**Disease of the pancreas:** yes / no / no data

if yes: acute pancreatitis / chronic pancreatitis / autoimmune pancreatitis / pancreatic cancer / congenital anatomical malformation / other

if other: please describe:.....

If acute pancreatitis:

Number of acute episodes before current:.....

Date of first episode (year):.....

If chronic / autoimmune pancreatitis:

Date of diagnosis:.....

Date of first episode (year):.....  
 Number of acute episodes before current:.....

If pancreatic cancer:

Date of diagnosis:.....  
 Diagnosed with chronic pancreatitis?                      yes / no / no data  
 If yes, date of diagnosis:.....

Number of acute episodes before current:.....  
 Date of first episode (year):.....

If congenital anatomical malformation:

Date of diagnosis:.....  
 Date of first episode (year):.....  
 Number of acute episodes before current:.....

If cystic lesions/malformation:

Date of diagnosis: .....  
 Number of cysts: .....  
 Diameters of cysts: .....  
 Other:.....

**Porthacath:**                                      yes / no / no data  
 if yes, please describe type:.....

**Gastrostomy:**                                      yes / no / no data  
 if yes, please describe type:.....

**Malignancies:**                                      yes / no / no data  
 if yes, please describe type:.....

**Allergies:**    yes / no / no data  
 if yes, please describe type:.....

**Transplantation**

Did the patient have a transplantation surgery?                      yes / no/ no data  
     liver transplant                                      yes / no/ no data                      year of latest:.....  
     lung transplant                                      yes / no/ no data                      year of latest:.....  
     other, please specify:.....                      yes / no/ no data                      year of latest:.....

referred awaiting assessment                                      yes / no/ no data  
 date:.....

assessed awaiting decision                                      yes / no/ no data  
 date:.....

Decision on suitability for listing                                      yes / no/ no data  
 date:.....



## B) Exacerbation history

Has the patient had exacerbation from the last annual visit?

yes / no / no data

### Oral antibiotics taken

name:.....	start date:.....	stop date:.....
name:.....	start date:.....	stop date:.....
name:.....	start date:.....	stop date:.....

### Inhaled antibiotics

name:.....	start date:.....	stop date:.....
name:.....	start date:.....	stop date:.....
name:.....	start date:.....	stop date:.....

### Intravenous antibiotics

name:.....	start date:.....	stop date:.....
name:.....	start date:.....	stop date:.....
name:.....	start date:.....	stop date:.....

### Hospitalisations:

date:.....	reason:.....
date:.....	reason:.....
date:.....	reason:.....

## C) Microbiology (Have these organisms been isolated from the last annual visit?)

Mucoid Pseudomonas aeruginosa yes / no/no data  
Sample Type oropharyngeal swab / sputum / bronchoalveolar lavage /Unknown  
Sample Date:.....

Non-mucoid Pseudomonas aeruginosa yes / no/no data  
Sample Type oropharyngeal swab / sputum / bronchoalveolar lavage /Unknown  
Sample Date:.....

Staphylococcus Aureus yes / no/ no data  
Sample Type oropharyngeal swab / sputum / bronchoalveolar lavage /Unknown  
Sample Date:.....

Methicillin-Resistant Staphylococcus aureus yes / no/ no data  
Sample Type oropharyngeal swab / sputum / bronchoalveolar lavage /Unknown  
Sample Date:.....

Burkholderia cepacia complex yes / no/ no data  
Sample Type oropharyngeal swab / sputum / bronchoalveolar lavage /Unknown  
Sample Date:.....

Non-tuberculous Mycobacteria	no / MAC / abscessus / other/ no data
Sample Type	oropharyngeal swab / sputum / bronchoalveolar lavage /Unknown
Sample Date:.....	
Stenotrophomonas maltophilia	yes / no/ no data
Sample Type	oropharyngeal swab / sputum / bronchoalveolar lavage /Unknown
Sample Date:.....	
Achromobacter species	yes / no/ no data
Sample Type	oropharyngeal swab / sputum / bronchoalveolar lavage /Unknown
Sample Date:.....	
Haemophilus influenzae	yes / no/ no data
Sample Type	oropharyngeal swab / sputum / bronchoalveolar lavage /Unknown
Sample Date:.....	

### D) Complications (Have these complications been occurred since the last annual visit?)

Allergic bronchopulmonary aspergillosis (ABPA)	yes / no/ no data
Distal intestinal obstruction syndrome (DIOS)	yes / no/ no data
Pneumothorax requiring chest drain	yes / no/ no data
Liver disease	yes / no/ no data
Haemoptysis more than 250ml	yes / no/ no data
Malignancy diagnosed	yes / no/ no data
Sinusitis	yes / no/ no data
Osteoporosis	yes / no/ no data
Osteopenia	yes / no/ no data
Gastroesophageal reflux	yes / no/ no data

### 5. Diseases have been diagnosed in the family since the last annual visit

**yes/no/no data**

**Cystic fibrosis in family history:** yes / no / no data  
if yes, please describe type:..... relationship to patient:.....

**Diabetes mellitus in family history:** yes / no / no data  
if yes, please describe type:..... relationship to patient:.....

**Pancreas disorders in family history:** yes / no / no data

acute pancreatitis:	yes / no	if yes: relationship to patient:.....
chronic pancreatitis:	yes / no	if yes: relationship to patient:.....
autoimmune pancreatitis:	yes / no	if yes: relationship to patient:.....
pancreatic cancer:	yes / no	if yes: relationship to patient:.....
congenital anatomical malformation:	yes / no	if yes: relationship to patient:.....
other (please describe):.....		if yes: relationship to patient:.....

**Other GI disease in family history:** yes / no / no data  
if yes, please describe type:..... relationship to patient:.....

**Heart disease in family history:** yes / no / no data  
if yes, please describe type:..... relationship to patient:.....

**Renal disease in family history:** yes / no / no data  
if yes, please describe type:..... relationship to patient:.....

**Liver disease in family history:** yes / no / no data  
if yes, please describe type:..... relationship to patient:.....

**Any other disease in the family history:** .....

.....

## 6. Current Medications

### Any changes in medication since the last annual visit?

yes/no/no data

**Maintenance antibiotic therapy:** yes / no/ no data  
if yes, please specify:

Nebulised Tobramycin no / continuous / alternating monthly / unknown

Nebulised Colomycin no / continuous / alternating monthly / unknown

Nebulised Aztreonam no / continuous / alternating monthly / unknown

Tobramycin Dry Powder Inhaler no / continuous / alternating monthly / unknown

Colomycin Dry Powder Inhaler no / continuous / alternating monthly / unknown

Azithromycin Maint. Therapy no / continuous / alternating monthly / unknown

Anti Staphyloccocal Maint. Therapy no / continuous / alternating monthly / unknown

Name of other nebulised / dry powder antibiotic:.....

**Respiratory therapy:** yes / no/no data  
if yes, please specify:

Use of rhDNase yes / no / no data  
if yes, please specify name:.....dose:.....

Use of Hypertonic Saline - Percent yes / no / no data  
if yes, please specify name:.....dose:.....

Inhaled Short Acting Bronchodilators yes / no / no data  
if yes, please specify name:.....dose:.....

Inhaled Long Acting Bronchodilators yes / no / no data  
if yes, please specify name:.....dose:.....

Inhaled Steroid Alone yes / no / no data  
if yes, please specify name:.....dose:.....



Inhaled Steroid with Long-acting Muscarinic Antagonist (LAMA) yes / no / no data  
if yes, please specify name:.....dose:.....

Inhaled Long-acting Beta-agonist (LABA) yes / no / no data  
if yes, please specify name:.....dose:.....

Inhaled nasal steroid yes / no / no data  
if yes, please specify name:.....dose:.....

Oral steroid yes / no / no data  
if yes, please specify name:.....dose:.....

Oxygen Therapy yes / no / no data

Non-invasive positive pressure ventilation yes / no / no data

**Nutrition / GI therapy:**

Pancreatic enzyme replacement yes / no / no data  
if yes, please specify name:.....dose:.....

Ursodeoxycholic Acid yes / no / no data  
if yes, please specify name:.....dose:.....

Proton Pump Inhibitors yes / no / no data  
if yes, please specify name:.....dose:.....

Enteral Feeding yes / no / no data  
if yes, please specify name:.....dose:.....

Vitamin A Supplements yes / no / no data  
if yes, please specify name:.....dose:.....

Vitamin E Supplements yes / no / no data  
if yes, please specify name:.....dose:.....

Vitamin D Supplements yes / no / no data  
if yes, please specify name:.....dose:.....

Vitamin K Supplements yes / no / no data  
if yes, please specify name:.....dose:.....

**Endocrine therapy:**

Hormonal contraception yes / no / no data  
if yes, please specify name:.....dose:.....

Calcium supplementation yes / no / no data  
if yes, please specify name:.....dose:.....

Bisphosphonate yes / no / no data  
if yes, please specify name:.....dose:.....

Insulin yes / no / no data  
if yes, please specify name:.....dose:.....

**Other therapy:**

CFTR modifier therapy yes / no / no data

Ivacaftor yes / no / no data

Lumacaftor yes / no / no data  
if other, please specify name:.....dose:.....

**7. General state at the annual visit**

**A) Status**

Heart rate (/minute)	
Blood pressure (Hgmm)	
Respiratory rate (/minute)	
Oxygen saturation (%) on air	
Weight (kg)	
Height (cm)	
Height and weight Z-score	
BMI	
BMI age percentile	
BMI Z-score	
Body temperature (°C) axillary	

**B) Respiratory function tests**

	Value	%
FEV1		
FVC		
FEV1/FVC		
TLC		
FRC		
RV		
TLCO		
KCO		

**Appetite:** good / retained / bad/ no data

**Weight loss:** yes / no / no data  
if yes: duration (weeks):.....  
amount (kg):.....





**Stool:** normal / diarrhea / constipation / fatty / putrid / undigested food / bloody / mucus

## 8. Laboratory parameters at the annual visit

### A) Biochemistry

Sodium (mmol/l)	
Potassium (mmol/l)	
Calcium (mmol/l)	
Iron (umol/l)	
Transferrin (ug/l)	
Ferritin (mg/dl)	
Total protein (g/l)	
Albumin (g/l)	
Cholesterol (mmol/l) fasting	
Triglyceride (mmol/l) fasting	
ASAT/GOT (U/l)	
ALAT/GPT (U/l)	
Gamma GT (U/l)	
Total bilirubin (umol/l)	
Direct/Conjugated bilirubin (umol/l)	
Alkaline phosphatase (U/l)	
Lactate dehydrogenase (U/l)	
Cholinesterase (U/l)	
Blood urea nitrogen (mmol/l)	
Creatinine (umol/l)	
C-reactive protein (mg/l)	
Amylase (U/l)	
Lipase (U/l)	

### B) Hematology

White blood cell (WBC) count (G/l)	
Red blood cell (RBC) count (T/l)	
Hemoglobin (g/l)	
Hematocrit (%)	
Thrombocyte (G/l)	

### C) Blood gas on air

arterial/capillary/venous

pH	
pO2	
pCO2	
BXS	
HCO3	
Sat	

**D) Carbohydrate metabolism**

serum glucose 0' (mmol/l)	
serum glucose 30' (mmol/l)	
serum glucose 60' (mmol/l)	
serum glucose 90' (mmol/l)	
serum glucose 120' (mmol/l)	
insulin 0' (pmol/l)	
insulin 60' (pmol/l)	
insulin 120' (pmol/l)	
Hemoglobin A1C (%)	
C-peptide	
Glutamic Acid Decarboxylase Autoantibodies	

**E) Immunology and gluten sensitivite**

IgA (g/l)	
IgM (g/l)	
IgG (g/l)	
EmA	
tTGA	

**F) Virology**

HIV	
CMV	
EBV	
Hepatitis A	
Hepatitis B	
Hepatitis C	

**G) Others**

faecal elastase	
sweat chloride (mmol/l)	

**H) Additional Microbiology**

## 9. Imaging examinations at the annual visit

yes / no/no

data

### Abdominal ultrasonography:

yes / no/ no data

Description:

.....  
.....

### Chest X-ray:

yes / no/no data

Description:

.....  
.....

## 10. Vital status

Has the patient died since the last annual registration?

yes / no/ no data

if yes:

date of death:.....

cause of death:.....

## 11. Final report

Consent form is filled

I declare that the patient received the necessary information and signed the consent form.

Notes:.....

