

# Cystic Fibrosis strength in numbers

## UK CF Registry

[Print](#)

### 1. Patient information

#### CONSENT

- 1.1. Has a **valid** UK CF Registry consent form been signed and dated for this patient?  Yes  Consent withdrawn  Not known
- 1.2. Upload a scanned copy of the consent form (optional)  No file chosen  
  Not available

#### PATIENT INFORMATION

##### Basic information

- 1.3. Surname of patient
- a. Surname of patient at birth (if different)
- 1.4. Forename of patient
- 1.5. Middle name of patient   Not known
- 1.6. Gender of patient  Male  Female

##### Age

- 1.7. Enter DOB
- a. Age  (yrs)  (months)
- 1.8. Ethnicity of patient
- White (British)  Asian (Other)
- White (Irish)  Mixed (White and Black Caribbean)
- White (Other)  Mixed (White and Black African)
- Black (Caribbean)  Mixed (White and Asian)

Clinical ALL

- Black (African)     Mixed (Other)  
 Black (Other)     Other (Chinese)  
 Asian (Indian)     Other (Any other ethnic group)  
 Asian (Pakistani)     Prefer not to say  
 Asian (Bangladeshi)     Not known

i. If ethnicity is 'Other', please specify

### ID Numbers

- 1.9. NHS number of patient   Not known or not applicable
- 1.10. CHI number   Not known or not applicable

### Address Details

- 1.11. Postcode of patient
- 1.12. Was the patient born in the UK  Yes  No
- a. County of birth
- b. Birth country
- Not known

### GP Information

- 1.13. GP postcode    Not known

## 2. Genotyping

### GENOTYPING

2. Has the patient been genotyped?  Yes  No
- 2.1. Date genotyping sample taken   Not known
- 2.2. How many mutations have been identified?
- 2.3. Genetic mutation 1 (*Legacy/Protein/cDNA*)
- a. Genetic mutation 1 specify
- Mutation 1 Poly-T tract
- 5T     7T     9T     Not known/Not applicable

- 2.4. Genetic mutation 2 (*Legacy/Protein/cDNA*)
- a. Genetic mutation 2 specify
- Mutation 2 Poly-T tract
- 5T     7T     9T     Not known/Not applicable
- 2.5. Genetic mutation 3 (*Legacy/Protein/cDNA*)
- a. Genetic mutation 3 specify
- Mutation 3 Poly-T tract
- 5T     7T     9T     Not known/Not applicable

## 3. Diagnosis

### DIAGNOSIS

- 3.1 Date of Diagnosis
- a. Date diagnosis of CF was confirmed with the patient or parent
- b. Indicate if diagnosis date is accurate or estimated  Estimated  Exact
- 3.2 How did the patient present with CF?  
*Check all applicable*
- Family history     Genotype
- Newborn screening     Prenatal / antenatal
- Not known     Other
- a. Other CF associated complications / signs  
*Check all applicable*
- Persistent or acute respiratory infection
- Oedema
- Electrolyte imbalance
- Failure to thrive/malnutrition
- Bronchiectasis
- Pancreatitis
- Fertility investigations
- Liver disease
- Meconium Ileus
- How was Meconium Ileus complication managed?
- Surgically
- Medically
- Not known
- Nasal polyps
- Rectal prolapse

Steatorrhea/abnormal stools/malabsorbtion

If 'Other', please specify

**Diagnostic chloride sweat test**

3.3. How many diagnostic chloride sweat tests have been done?

	<b>Date</b>		<b>Value</b>
Test 1	<input type="text"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 2	<input type="text"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 3	<input type="text"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 4	<input type="text"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 5	<input type="text"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known

**New born screening**

3.4. NBS undertaken?

Yes  No

a. If no, why not?

- Born before NBS started
- Born outside UK
- NBS declined
- Appropriate sample not obtained before 8 weeks
- Not known

a. NBS Result

- Carrier
- Equivocal
- Suspected
- Not suspected
- Not known

i. Suspected - IRT?

ii. Carrier - IRT?

iii. Equivocal - IRT?

iv. Not Suspected - IRT?

b. NBS IRT results

i. Date 1st IRT sample taken

  Not known

a. IRT result  (mg/L - mean value)

ii. Date 2nd IRT sample taken   Not known  Not taken

a. IRT result  (mg/L - mean value)

c. Laboratory Details

i. Which laboratory was the sample sent to?

Not known

a. if other,

ii. Date sample sent to Lab

3.5 Referral Details

a. Date patient referred to regional CF team   Not known

b. Date patient seen by regional CF centre   Not known

c. Date patient seen by local CF centre   Not known  
 N/A (not shared care)

**Faecal elastase**

3.6. Was a diagnostic faecal elastase sample taken?  Yes  No

a. Date of sample   Not known

b. Result  (mcg/ml)  Not known

**OUTCOME**

**Death**

3.7. Has the patient died?  Yes  No

a. Date of death

i. Is date of death an estimate?  Yes  No

b. Cause of Death

If 'Cancer', please specify

- Bowel
- Breast
- Brain
- Cervical
- Liver
- Lung
- Lymphoma
- Oesophageal
- Ovarian
- Pancreatic

- Skin
- Testicular
- Other

Other

**Diagnosis reversal**

3.8. Diagnosis reversed?

- Yes
- No

a. Diagnosis reversal date

b. Reason for reversal of diagnosis?

i. If 'Other', please specify

Not known