



# UK CF Registry

## Demographics

Encounters are locked annually by the Registry team as part of the reporting cycle. If you require a record to be edited please contact [registry@cysticfibrosis.org.uk](mailto:registry@cysticfibrosis.org.uk)

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Site: Aberdeen Royal Infirmary. Case ID: 220402

[Comments](#) █ Complete █ Incomplete █ Errors █ Not saved

1. Patient information	2. Genotyping	3. Diagnosis
<b>CONSENT</b>		
1.1. Has a <b>valid</b> UK CF Registry consent form been signed and dated for this patient?	<input checked="" type="radio"/> Yes <input type="radio"/> Consent withdrawn <input type="radio"/> Not known	<a href="#">?</a>
1.2. Upload a scanned copy of the consent form (optional)	<input type="button" value="Choose File"/> No file chosen <input type="button" value="Upload"/> <input type="checkbox"/> Not available	<a href="#">?</a>
<b>PATIENT INFORMATION</b>		
<b>Basic information</b>		
1.3. Surname of patient	<input type="text"/>	<a href="#">?</a>
a. Surname of patient at birth (if different)	<input type="text"/>	
1.4. Forename of patient	<input type="text"/>	<a href="#">?</a>
1.5. Middle name of patient	<input type="text"/> <input type="checkbox"/> Not known	<a href="#">?</a>
1.6. Gender of patient	<input type="radio"/> Male <input type="radio"/> Female	<a href="#">?</a>
<b>Age</b>		
1.7. Enter DOB	<input type="text" value="DD/MM/YYYY"/>	<a href="#">?</a>
1.8. Ethnicity of patient	<input type="radio"/> White (British) <input type="radio"/> Asian (Other) <input type="radio"/> White (Irish) <input type="radio"/> Mixed (White and Black Caribbean) <input type="radio"/> White (Other) <input type="radio"/> Mixed (White and Black African) <input type="radio"/> Black (Caribbean) <input type="radio"/> Mixed (White and Asian) <input type="radio"/> Black (African) <input type="radio"/> Mixed (Other) <input type="radio"/> Black (Other) <input type="radio"/> Other (Chinese) <input type="radio"/> Asian (Indian) <input type="radio"/> Other (Any other ethnic group)	<a href="#">?</a>

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

Registry Team alerted to duplicate NHS/CHI number?  Email sent  Email not sent

**Address Details**

1.11. Postcode of patient

1.12. Was the patient born in the UK  Yes  No

a. County of birth

Select...

i. Other details, please specify

b. Birth country

Select...

i. Other details, please specify

**GP Information**

1.13. GP postcode    Not known

**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

Exit

**BIRTHWEIGHT**

3.0. Birthweight

(kg)  Not known

?

**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
  - Surgically
  - Medically
  - Not known
- Nasal polyps
- Rectal prolapse
- Steatorrhea/abnormal stools/malabsorbtion

How was Meconium Ileus complication managed?

If 'Other', please specify

**Diagnostic chloride sweat test**

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

Select... ▼

?

	Date		Value
Test 1	<input type="text" value="January 0001"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 2	<input type="text" value="January 0001"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 3	<input type="text" value="January 0001"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known
Test 4	<input type="text" value="January 0001"/>	<input type="checkbox"/> Not known	<input type="text"/> (mmol/litre) <input type="checkbox"/> Not known

Test 5   Not known

(mmol/litre)  
 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?

Select...

ii. Carrier - IRT?

Select...

iii. Equivocal - IRT?

Select...

iv. Not Suspected - IRT?

Select...

b. NBS IRT results

i. Date 1st IRT sample taken

Not known

a. IRT result

(ng/ml or µg/l - mean value)

ii. Date 2nd IRT sample taken

Not known  Not taken

a. IRT result

(ng/ml or µg/l - mean value)

c. Laboratory Details

i. Which laboratory was the sample sent to?

Select...  
 Not known

a. if other,

ii. Date sample sent to Lab

Not known

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

DD/MM/YYYY

i. Is date of death an estimate?

Yes  No

b. Cause of Death

Select...

If 'Cancer', please specify

- Bowel
- Breast
- Brain
- Cervical
- Liver
- Lung
- Lymphoma
- Oesophageal
- Ovarian
- Pancreatic
- Skin
- Testicular
- Other

Other

c. ONS Date of Death

01/01/0001 00:00:00

d. ONS Primary cause of death

**Diagnosis reversal**

3.8. Diagnosis reversed?

Yes  No



a. Diagnosis reversal date

DD/MM/YYYY

b. Reason for reversal of diagnosis?

Select...

i. If 'Other', please specify

Not known